Examining Patient Reported Outcome Measures in First-Episode Psychosis: An Equity-Based Review of Reviews and Cross-Cultural Analysis

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Contribution of Authors

As first author of all three manuscripts, I (**Neha Nair)** took primary responsibility for and made significant contributions to the conceptualization, design, data analysis, interpretation of results, and writing of this thesis, and each of the three manuscripts included in it.

Dr. Srividya Iyer provided overall supervision and guidance on the conceptualization, design, interpretation of results and revisions of all three manuscripts and this thesis in its entirety.

Dr. Navdeep Kaur and **Maria-Abou Farhat** contributed significantly to the data collection, interpretation of results and writing for the first manuscript.

Jill Boruff contributed significantly to the search strategy and data collection for the first manuscript.

Dr. Aarati Taksal contributed significantly to the data analysis, interpretation of results and writing for the second manuscript.

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Abstract

Background: The rise of patient-oriented care has led to a shift towards valuing patient-reported outcome measures (PROMs) in psychosis. Concerns have, however, been raised about the extent to which PROMs have been developed and used in diverse contexts, particularly low- and middle-income countries, and about attention to equity and involvement of lived experience in this field. Our study addresses these concerns through an equity-focused synthesis of extant knowledge, and an examination of two widely used single-item PROMs, Self-Rated Health (SRH) and Self-Rated Mental Health (SRMH) in two distinct geo-cultural contexts: Chennai, India and Montréal, Canada.

Methods: For Study I, we searched three electronic databases (MEDLINE, Embase and PsycINFO) for published reviews on patient-reported measures in populations with psychosis. Using a combination of Cochrane's PROGRESS-plus and the Social Sciences and Humanities Research Council's criteria, reviews were examined for population and geographical diversity, cross-cultural validity, and inclusion of lived experience. Studies II and III was part of a larger comparative study of outcomes of early intervention in Chennai (N=168) and Montréal (N=165). In Study II, test-retest reliability and criterion validity were estimated for both sites and in French, Tamil, and English. Study III investigated how responses to these two measures vary from entry to two years after treatment in these two contexts. Ordinal logistic regressions examined the effects of time, site, and other sociodemographic and clinical covariates.

Results: In Study I, eight reviews were included in the review of reviews. Of these, only one extracted age and gender distributions, two considered the availability of translations, and one evaluated cross-cultural validity. Only one review team involved service users and evaluated service user involvement in developing PROMs. In Study II, SRH and SRMH showed good to excellent test-retest reliability at both sites and in English and Tamil. In Montréal and Chennai, SRH and clinician-reported functioning were associated, indicative of criterion validity. In Montréal, SRH was also associated with clinician-reported positive symptoms and patient-reported quality of life. In Chennai, clinician-rated positive symptoms and functioning were associated with SRMH. Study III revealed that SRH (but not SRMH) scores were different between the sites at baseline, with Chennai patients reporting poorer health. Chennai patients reported greater improvements in their health and mental health. At both sites, anxiety and duration of untreated psychosis significantly predicted SRH and SRMH, while negative symptoms were associated with only SRH. Women in Chennai (but not Montréal) had lower mental health than men.

Discussion: Our findings indicate that single-item patient-reported measures may be feasibly integrated into early intervention. However, these measures should first be examined across various languages and contexts to account for the cultural nuances embedded in perceptions of and responses to these questions, as well as in illness experiences. If PROMs are to bring patient perspectives into a clinician-dominated field, a diverse range of patients must be involved in their design and evaluation. Reporting on such inclusion and involvement is also urgently needed to identify and redress equity gaps.

Résumé

Contexte: La croissance des soins centrés sur le patient a entraîné une évolution vers la valorisation des mesures des résultats rapportés par les patients (PROM) dans le domaine de la psychose. Des inquiétudes ont été soulevées quant à l'utilisation des PROMs dans différents contextes, en particulier dans les pays à revenus faibles et moyens, et à l'attention portée à l'équité et à l'implication de l'expérience vécue. Notre étude aborde ces questions par une synthèse axée sur l'équité des connaissances existantes et une étude de deux PROMs à item unique, le Self-Rated Health (SRH) et le Self-Rated Mental Health (SRMH), dans deux contextes géoculturels distincts: Chennai (Inde) et Montréal (Canada).

Méthodes: Pour l'étude I, nous avons recherché dans trois bases de données électroniques (MEDLINE, Embase et PsycINFO) les revues publiées sur les PROMs dans les populations atteintes de psychose. Les revues ont été examinées selon les critères PROGRESS-plus de Cochrane et du Conseil de recherches en sciences humaines, en tenant compte de la diversité démographique et géographique, de la validité interculturelle et de l'inclusion de l'expérience vécue. Les études II et III faisaient partie d'une étude comparative plus large sur l'intervention précoce à Chennai (N=168) et à Montréal (N=165). Dans l'étude II, la fiabilité test-retest et la validité de critère ont été évaluées dans les deux sites et en français, tamoul et anglais. L'étude III a examiné les variations des réponses à ces mesures entre le début et deux ans après le traitement dans ces deux contextes. Des régressions logistiques ordinales ont analysé les effets du temps, du site et d'autres covariables sociodémographiques et cliniques.

Résultats: Dans l'étude I, huit revues ont été examinées, une seule incluant les répartitions par âge et par sexe. Deux revues ont pris en compte les traductions disponibles et une revue a évalué la validité interculturelle. Seule une équipe a impliqué des utilisateurs de services et évalué leur participation aux PROMs. Dans l'étude II, le SRH et le SRMH ont démontré une bonne à excellente fiabilité test-retest sur les deux sites et en anglais et en tamoul. À Montréal et à Chennai, le SRH était associé au fonctionnement rapporté par le clinicien, indiquant une validité de critère. À Montréal, le SRH était également associé aux symptômes positifs rapportés par le clinicien et à la qualité de vie rapportée par le patient. À Chennai, les symptômes positifs et le fonctionnement évalués par le clinicien étaient associés au SRMH. L'étude III a révélé des différences initiales dans les scores de SRH entre les sites, les patients de Chennai signalant une moins bonne santé. Les patients de Chennai ont indiqué une plus grande amélioration de leur santé mentale. L'anxiété et la durée de la psychose non traitée ont significativement prédit le SRH et le SRMH dans les deux sites, tandis que les symptômes négatifs étaient liés uniquement au SRH. Les femmes de Chennai avaient une moins bonne santé mentale que les hommes, contrairement à Montréal.

Discussion: Nos résultats suggèrent l'intégration possible de mesures à un seul item rapportées par les patients en intervention précoce. Cependant, ces mesures doivent être examinées dans diverses langues et contextes pour tenir compte des nuances culturelles dans les perceptions et réponses, ainsi que dans les expériences de la maladie. Pour que les PROMs reflètent le point de vue des patients dans un domaine dominé par les cliniciens, une participation diversifiée des patients dans leur conception et évaluation est essentielle. Il est urgent de rendre compte de cette inclusion et de cette participation pour identifier et combler les lacunes en matière d'équité.

Chapter 1: Introduction – Literature Review & Objectives

Psychosis refers to an array of symptoms that influence an individual's perception of reality, often changing the way in which they think, perceive, and/or behave (Arciniegas, 2015). Those living through an episode of psychosis may experience both positive symptoms (i.e., delusions, hallucinations, thought disorder, etc.) and/or negative symptoms (i.e., anhedonia, avolition, alogia, etc.). As a subgroup of mental illnesses that affect persons of varying social class, cultural background, migrant status, urbanicity and geographic region, psychosis (schizophrenia, bipolar affective disorder, and other psychotic disorders), as categorized by its diagnostic criteria, affects those across varied global contexts (Bhugra, 2005; Saha et al., 2005).

More importantly, psychosis incidence has been reported to vary substantially across countries and populations within countries (Anglin et al., 2021; Fett et al., 2019; Morgan et al., 2023). This variation in incidence has been shown to be associated with the differential distribution of social determinants of psychosis (from individual-level aspects of social disadvantage to larger issues pertaining to social, cultural, historical, and political contexts), as well as the ways in which this illness is experienced, manifested, and interpreted across cultural contexts (Castillejos et al., 2018; Jarvis et al., 2020).

In recent years, the recovery movement has attempted to shift psychiatry's reductionist approach of seeing individuals as having uncurable, embodied diagnoses to individuals who, given the appropriate resources, opportunities, and treatment, have the capacity for recovery in serious mental illnesses (Davidson, 2016; Frese et al., 2001; Jacobson & Greenley, 2001). By reconceptualizing recovery as incorporating a broader and more holistic set of outcomes that have been defined in collaboration with patients (Roberts & Wolfson, 2004), psychiatry has witnessed a shift in focus on many fronts – from 'recovery from psychosis' to 'recovery in psychosis' (Davidson & Roe, 2007), from the individual to their families and broader community, from 'patients' to 'service-users', from a limitation to a strengths-based model, and from psychiatric outcomes to other social, functional and occupational needs (Best et al., 2017). Moreover, the perceptions of and recommendations for recovery by service users experiencing psychosis are increasingly documented (O'Keeffe et al., 2018; Skar-Fröding et al., 2021).

While once thought of as impossible, the concept of recovery in psychosis – a process whose definition goes well beyond only symptom remission – has recently gained much more traction (Liberman & Kopelowicz, 2005; Vita & Barlati, 2018; Warner, 2009). Longitudinal explorations of this illness's trajectory have highlighted that, to improve the likelihood of recovery, it is important for those experiencing psychosis or psychosis-like symptoms to receive treatment as early as possible (Fusar-Poli et al., 2017). Meta-analyses highlighting the adverse effects of longer durations of untreated psychosis (DUP) have also provided an important foundation for the inception of early intervention (Penttilä et al., 2014; Perkins et al., 2005). Coupled with the growing attentional shift onto integrated recovery, the discovery and understanding of this pivotal period of untreated psychosis have launched the creation of several early intervention services for psychosis and the standardization of such a therapeutic approach for psychosis treatment (Marshall & Rathbone, 2011).

1.1. Early Intervention Services for Psychosis

Early intervention services for psychosis (EIS) have emerged from the "critical period hypothesis" which suggests that the earliest phases of psychosis – both the prodromal phase and the first episode of psychosis – are those in which many individuals experience the most intense deterioration/the quickest accumulation of psychotic symptoms. Thus, intervening as early as possible can stall the progression of psychosis and improve social, occupational, and interpersonal functioning (Birchwood & Macmillan, 1993; Birchwood et al., 1998). The aims of EIS involve: (1) reducing the duration of untreated psychosis by outreach/early case identification and rapid, simplified pathways to care, and (2) providing sustained care to those experiencing their first episode of psychosis with the intention of improving their chances of recovery (Marshall & Rathbone, 2011; McGorry et al., 2008). Such services aim to operate on EIS philosophy – one grounded in collaboration between stakeholders, family/caregiver engagement, service user autonomy, recovery, and hope (Singh & Fisher, 2005).

Not only is this approach to care for first-episode psychosis designed to intervene earlier in the illness trajectory, but also to match the specific needs of those experiencing this critical change/accumulation of symptoms (Malla et al., 2005). Treatment is often comprehensive and multi-modal, with a focus on recovery and reintegration, psychosocial support and education for both patients and their families, low-dosage antipsychotic medication, personalized case management, and phase-specific psychological interventions (Addington et al., 2013; Iyer et al., 2015; White et al., 2015).

With the implementation of many early intervention services globally, the short-term benefits of early intervention have been increasingly reviewed and documented (Bird et al., 2010; Norman et al., 2011). A recent meta-analysis comparing outcomes of early intervention and regular care demonstrated better clinical outcomes (i.e., improvements in the severity of psychopathology, decreased rates of relapse, increased service engagement, etc.), occupational outcomes (i.e., financial independence, ‘adequate role’ functioning, being in employment, education or training, etc.), social outcomes (i.e., maintenance of social relations, improvement in the different dimensions of community functioning, etc.), and quality of life outcomes in early intervention (Correll et al., 2018). Evidence indicates that longer DUP is associated with worse long-term clinical and functional outcomes (Marshall & Rathbone, 2011; Perkins et al., 2005), with a recent meta-analysis linking longer DUP to more severe symptomatology, lower remission, and poorer overall functioning (Howes et al., 2021). Also, DUP has been shown to be a "malleable" characteristic, with early intervention services for psychosis demonstrating their ability to reduce DUP through service design and outreach activities (Malla, 2022).

1.2. Patient-Oriented Care: A Measurement-Based Approach

Through the rise of the recovery movement, a patient-centred approach to both clinical care and research practice has become popular (Epstein & Street, 2011; Sacristán, 2013). Patient-oriented approaches seek to situate patients at the centre of their treatment, giving clinicians more insight into individuals’ illness experience and their specific needs for recovery (Stewart et al., 2000). Such an orientation allows for patients to be seen as experts on their own experience, leading to greater collaboration, and more trust between patients and clinicians/researchers (Cuperfain et al., 2021; Rathert et al., 2013; Stewart et al., 2000).

Measurement-based care is an evidence-based system of care – used in a variety of health-related contexts – that routinely uses both standardized and individualized assessment measures as a means to elicit information from patients, which will then determine the content and direction of care provided by clinicians to patients (Fortney et al., 2016; Lewis et al., 2019). Instruments that are prioritized are usually those that are low burden, cost effective, psychometrically suitable (i.e., reliable, valid, sensitive to change, etc.), easily implementable, easily accessible to patients, and have the potential to directly inform clinical care (Connors et al., 2021). Measurement-based care thus offers patients the opportunity to speak to their multi-faceted experience of illness which, in turn, may help guide the treatment they receive.

Categorized as either clinician-reported, patient-reported or family-reported, the measures used in measurement-based EIS seek to provide insight into the breadth and depth of the patients' experience of psychosis and bridge the perspectives between the various stakeholders implicated in an individual's treatment and progress (Scott & Lewis, 2015). However, despite their focus on trying to better understand the patient-experience and support patients and their families alike, early psychosis services using a measurement-based approach often fail to extract information directly from service users themselves (Roe et al., 2022). Indeed, a recent systematic scoping review indicated that EIS rarely consult patients and families when selecting and implementing the measures, and infrequently use patient-reported and family-reported measures as part of their protocol (Ferrari et al., 2022).

1.3. Patient-Reported Outcome/Experience Measures

Patient-reported measures, frequently known as self-reported measures, are assessment tools that seek to obtain information directly from patients themselves, without interference or bias from clinicians – with respect to both their reporting and interpretation (Nelson et al., 2015). Such measures greatly help in measuring and implementing patient-oriented care (Tzelepis et al., 2015) and usually fall into one of these two categories: patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs). Measures within the former category are either generic or diagnosis-specific and aim to extract information important to individuals' sense of recovery, while those in the latter attempt to gain perspective into the quality of the services the patient is receiving (Kingsley & Patel, 2017).

Assessment burden and long, complex questionnaires contribute to the lower uptake of PROMs and PREMs (Weldring & Smith, 2013). One way to address this burden is via the use of brief and/or single-item questionnaires (Aiyegbusi et al., 2022), including but not limited to the Self-Rated Health (Idler & Benyamini, 1997), the Self-Rated Mental Health (Mawani & Gilmour, 2010), the Global Rating of Change (Kamper et al., 2009), and the Short-Form 12 (Ware et al., 1996), which measures health-related quality of life.

Insight, a construct that attempts to bridge patient constructions of their own experience and clinician perspectives of the patients' illness experience (Marková & Berrios, 1992), has often been a limiting factor in valuing the patient voice in psychosis. Historically, patients experiencing psychosis have often been thought to lack the adequate insight into their own condition and to be able to appropriately report on their experience, arguably posing a challenge to the accurate completion of patient-reported measures (Amador et al., 1991; Cohen et al., 2008). However, recent studies have shown that poor insight does not actually affect the validity and utility of PROMs and PREMs within this population, and that patient-reported measures can still be beneficial for patients and clinicians alike (Bell et al., 2007; Lysaker et al., 2022). Especially with regards to the illness experience, patient-report measures can help to highlight the patient voice and bring much-needed attention to patients' own conceptualization and interpretation of their psychosis experience.

Various patient-reported measures (e.g., the 20-item version of Recovering Quality of Life, the 9-item Patient Health Questionnaire, the Glasgow Antipsychotic Side-Effect Scale, etc.) have been psychometrically evaluated and tested for their suitability for use with individuals experiencing psychosis (McKenzie et al., 2022). However, many patient-reported measures have been developed without directly involving service users and their perspectives in the process and incorporating/upholding patient values in the wording and significance of the measures themselves (Roe et al., 2022; Trujols et al., 2013). Moreover, these measures have been tested predominantly in Western, high-income countries (Hunter et al., 2009; Mauriño et al., 2011). Large research gaps still remain within the realm of examining how these measures perform cross-culturally and across linguistic translations.

1.4. Cultural Considerations for PROMs and PREMs

Considering that (1) a variety of sociodemographic and environmental factors (i.e., social isolation, discrimination, marginalization, social disadvantage, living in dense urban areas, etc.) influence the course of psychosis (van Os et al., 2010), (2) a majority of persons with psychosis live in low-and-middle income countries (LMICs) (Singh & Javed, 2020), and (3) high-income countries (HICs) often have multicultural societies and have to cater to patients from varied ethnic and cultural backgrounds, it becomes all the more imperative that PROMs and PREMs used in measurement-based care are attentive to this diversity. Previous studies have shown that persons from LMICs, women and other gender identities, and other non-Western, Educated, Industrialized, Rich, and Democratic (WEIRD) societies tend to be underrepresented in psychosis and schizophrenia research (Alliende et al., 2022; Burkhard et al., 2021). Given that patient-reported measures are beneficial only insofar as they create accessible spaces in which patients feel comfortable to share information about their experiences, it is crucial that they are designed and implemented with the diversity of individuals experiencing psychosis in mind.

1.5. Summary and Critical Evaluation of Literature

To be truly patient-oriented, patient-reported measures need to be: 1. created in conjunction with patients themselves; 2. accessible to individuals from diverse socioeconomic, cultural, linguistic, and geographical backgrounds; 3. assessed in a variety of populations and languages for their psychometric properties and suitability for use; and 4. tested cross-culturally to examine the nuances of each measure and explore the possible constructs they tap into. With growing literature on the patient-reported measures in psychosis, reviews are often used by services to determine which measures are the most psychometrically suitable, beneficial and easily implementable. The extent to which literature reviews of PROMs and PREMs have considered and evaluated equity, accessibility, and lived experience in the development and examination of patient-reported measures remains unknown.

In addition to this equity gap in the reviews, there is also a cross-cultural gap in the use and evaluation of patient-reported measures in early intervention services for psychosis. Few PROMs have been used in early psychosis services and research in LMICs (Ferrari et al., 2022) and there have been few, if any, investigations examining how context and culture precipitate differences in patient-reported outcomes.

1.6. Research Questions and Objectives

Aligned with these gaps in early psychosis research, this thesis focuses on the following two research questions: (1) How have equity, diversity, and inclusion (EDI) considerations been incorporated in reviews of patient-reported measures in psychosis? (2) To what extent does context matter when developing and implementing patient-reported measures within early intervention services for psychosis?

To answer these questions, we conducted three studies, each with a specific objective:

(1) The objective of Study I was to examine the extent to which previously peer-reviewed published reviews of patient-reported measures in psychosis and schizophrenia have considered and prioritized equity and patient input when evaluating measures for their suitability, by conducting a review of reviews.

(2) Studies II and III focused the scope to two single-item patient-reported outcome measures – Self-Rated Health (SRH) and Self-Rated Mental Health (SRMH) – and narrowed the context to similarly structured early intervention services for psychosis in two distinct geo-sociocultural contexts.

   a. The objective of Study II was to assess the psychometric properties (test-retest reliability, criterion validity, specificity) of the SRH and SRMH among persons experiencing a first episode of psychosis in a high-income context (Montréal, Canada) and a low-and-middle income context (Chennai, India), with the measures being tested in three languages (French, English, and Tamil).

   b. The objective of Study III was to examine differences in SRH and SRMH between persons receiving a similarly designed two-year course of early intervention for psychosis in Montréal and Chennai. The goal was to unpack both the individual and intersecting influences of time and context on these two PROMs.

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Chapter 2: First Manuscript

Title: Can we be patient-centred without integrating equity, diversity, and inclusion? A review of reviews of patient-reported outcome measures in schizophrenia and psychosis

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2.1. Abstract

Background: With the rise of the recovery movement and measurement-based care, there has been a shift toward valuing patient-reported measures, which have become the subject of several literature reviews in psychosis. However, the extent to which the evaluation of patient-reported measures has prioritised equity and lived experience remains unclear. To address this gap, we examined the ways in which published reviews of patient-reported measures in schizophrenia and psychosis considered equity, diversity, and inclusion (EDI).

Methodology: We searched three electronic databases (MEDLINE, Embase and PsycINFO) for reviews on patient-reported measures in populations with psychotic disorders/schizophrenia from inception until April 2022. Two reviewers independently screened reviews' titles, abstracts, and full texts, and descriptively synthesised and appraised the quality of included reviews. Reviews were evaluated on criteria selected *a priori* based on Cochrane's PROGRESS-plus and SSHRC's EDI frameworks, namely, population and geographical diversity, accessibility, cross-cultural validity, and inclusion of persons with lived experience.

Results: We included eight reviews (approximately 299 studies, 130 measures). Only one extracted age and gender distributions. Two reviews considered the availability of translations. While one review briefly commented on readability level, none commented on the literacy levels of the assessed populations. Only one review evaluated cross-cultural validity. Only one review was conducted by a team that included service users and evaluated service user involvement in developing patient-reported measures. None referenced EDI frameworks/approaches.

Conclusions: If patient-reported measures are to bring patient perspectives into a clinician-dominated field, studies and reviews of such measures must involve service users in their design and evaluation, and report on such involvement. Fuller, wider inclusion of patients across socio-demographics and geographies (and an evaluation of the nature of such inclusion) is also urgently needed to identify and redress equity gaps.

2.2. Introduction

Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) are thought to provide unique insights into health status and outcomes from the service user perspective, helping clinicians and caregivers to better understand patient experiences (Mejdahl et al., 2020).

Previously, individuals diagnosed with psychosis or schizophrenia were thought to lack insight into their condition and consequently, seen as incapable of reliably completing self-reports (Amador et al., 1991; Arango & Amador, 2011). More recently, however, it has been noted that poor insight need not affect the validity of self-report measures in populations with psychosis or schizophrenia (Bell et al., 2007; Lysaker et al., 2022). Furthermore, the rise of recovery and patient-oriented treatment movements have contributed to an epistemological shift toward valuing patient-reported measures and increasing their usage in clinical trials and measurement-based care systems in mental health (Mercieca-Bebber et al., 2018; Fortney et al., 2018).

Despite the benefits of patient-reported measures, it has been eloquently argued that PROMs and PREMs must be co-developed with service users and peer researchers. If their development, examination and use neglects to consider and incorporate patient perspectives and values, they may de facto differ little from traditional instruments and still reflect clinician, and not patient, priorities (Trujols et al., 2013; Roe et al, 2022).

When considering PROMs for use in different populations, it is important not to assume that a measure will automatically tap into similar construct(s) across cultures, languages, and geographical regions. Self-reported tools may be more or less valid and valuable depending on their readability; and, particularly in translated versions, their sensitivity and cultural relevance (Leidy & Vernon, 2008).

Because the populations availing healthcare are highly diverse across, as well as increasingly within, geographies, it is important that PROMs and PREMs be developed by, tested in, and validated for demographically, linguistically, geographically, and socioeconomically diverse communities and stakeholders. Moreover, failure to incorporate such diversity in research on patient-reported measures may exclude, and even harm, individuals in underserved groups, with low literacy levels, from ethnic minorities or from low- and middle-income countries (LMICs) (Calvert et al., 2022).

The extent to which equity, diversity, and inclusion of lived experience perspectives are considered in the creation and evaluation of PROMs and PREMS for use in psychosis has not been examined. Because reviews are often used by guideline developers, services, measurement-based systems of care and researchers to guide their selection of patient-reported measures (Al Sayah et al., 2021), they serve as an apt starting point to addressing this knowledge gap. Reviews are also often consulted first by stakeholders desiring to inform and update themselves about a topic (Palmatier et al., 2018; Paul & Criado, 2020). Reviews published thus far on PROMs and PREMs in psychosis not only focus on the development and psychometric properties of these measures, but also often advocate for their wide use (McKenzie et al., 2022; Buck et al., 2022).

We therefore conducted a review of existing reviews on patient-reported measures in psychosis and schizophrenia with the aim of examining the extent to which they had considered the tenets of equity, diversity, and inclusion. Specific questions we asked included: To what extent have reviews of PROMs and PREMs in psychosis reported or commented on the population groups targeted and socio-demographic contexts in which their included studies were conducted? How have reviews thus far used EDI frameworks to guide their methods and review processes? Have reviews evaluated the readability of measures? Have reviews commented on whether and how service users were involved in developing PROMs?

2.3. Methods

2.3.1. Study Design

We conducted a review of reviews of patient-reported measures in schizophrenia and psychosis. Reporting of the review of reviews was performed using PRISMA guidelines (Page et al., 2021).

2.3.2. Data Sources and Search Strategy

A health sciences librarian (JB) developed the search strategy for published reviews on patient-reported outcome and experience measures (and related terms) in schizophrenia and psychosis and performed the literature searches in MEDLINE (Ovid), PsycINFO (Ovid), and EMBASE (Ovid) on April 13, 2022. No date limit or language limit was applied. The MEDLINE strategy was developed with input from the project team and adapted for use in the other databases. Grey literature was not searched, as the review focused on peer-reviewed publications. The complete search strategy is available at https://doi.org/10.5683/SP3/GCP7IG (Boruff, 2023).

2.3.3. Eligibility Criteria

Reviews were included if they met the following criteria: 1) They included either studies focused on specific patient-reported (or self-reported measures) or studies that examined one or more outcomes assessed via PROMs, PREMs or other self-reported questionnaires; and 2) They only included studies that primarily focused on individuals with schizophrenia, psychosis, and/or other psychotic disorders.

Reviews were excluded if they focused on clinical high-risk populations or psychotic-like experiences in the general population. If the primary focus of a review was a psychiatric diagnosis other than a psychotic disorder or a broad category comprising multiple diagnoses (e.g., severe mental health problems), it was excluded. Reviews were excluded if they were only found as abstracts or conference submissions, rather than as full-text articles.

2.3.4. Equity, Diversity, and Inclusion Criteria

The EDI criteria for evaluating included reviews were informed by both Cochrane’s PROGRESS-Plus (O’Neill et al, 2014) and the Social Sciences and Humanities Research Council of Canada’s (SSHRC) sections on ‘EDI in research practice’ and ‘EDI in research design’ (SSHRC, 2021). As neither framework was judged to be sufficient to answer the study questions, we used a combination of the two to ensure that a more comprehensive equity lens was applied in our review of reviews.

Cochrane’s PROGRESS-Plus is an acronym that stands for Place of residence, Race/ethnicity/culture/language, Occupation, Gender/sex, Religion, Education, Socioeconomic status, and Social capital, while the Plus stands for other characteristics associated with discrimination or disadvantage (O’Neill et al., 2014). This framework was created to identify those socially stratifying factors associated with inequalities in healthcare outcomes and services. The SSHRC EDI guidelines pertain more specifically to research practice and design and are like EDI values of other frameworks like the Outcome Measures in Rheumatoid Arthritis Clinical Trials-equity extension (Beaton et al. 2019) and those from other agencies including the National Institute of Mental Health (NIMH, 2022), the National Institute for Health and Care Research (NIHR, 2022), and the World Health Organization (Solar, 2010). Both frameworks are described further in Table 1.

Using both PROGRESS-Plus and SSHRC guidelines, we identified and grouped an assortment of criteria into the following categories to guide our extraction process: 1. Population Diversity, 2. Study Population and Clinical Setting/Health System Context, 3. Measures of Accessibility, 4. Cross-cultural Validity, 5. Use of EDI Frameworks, 6. Service User Involvement, and 7. EDI within the Research Team. The selected reviews were then subjected to an in-depth examination of whether and how they addressed these criteria in their methodology, results (text, tables, and figures), and/or discussion sections.

2.3.4.1. Definitions of Evaluation Criteria

2.3.4.1.1. Population Diversity

Informed by PROGRESS-Plus, we examined whether the reviews commented on the place of residence or geographic settings of their included studies, including cities, countries, world-regions, and income levels. The reviews were also screened for whether they reported or commented on the age, gender, sexual orientation, race, ethnicity, culture, language, religion, occupation, education, socio-economic status, and social capital of the included studies' participants. We also examined whether the reviews identified, within the studies they searched, any other characteristics associated with discrimination/disadvantage or intersecting identities associated with disadvantage (e.g., Indigenous persons, immigrant homeless populations, etc.).

2.3.4.1.2. Study Population and Clinical Setting/Health System Context

We examined whether the review specified the clinical populations of their included studies – specifically, whether they commented on the diagnoses, the clinical setting of the studied population (i.e., early intervention, inpatient, outpatient, emergency, residential, etc.) and the health system context (i.e., public, private, NGO, etc.).

2.3.4.1.3. Measures of Accessibility

We considered whether the reviews extracted information about the length (number of items, time required) of the PROMs, the ease of administration as determined either by patients or the person administering, the reading level required by the measure, the literacy of the population that filled in the measure, and the languages in which the measure was translated.

2.3.4.1.4. Cross-cultural Validity

We considered whether the reviews examined their articles for psychometric validation for samples from various cultures and/or countries or languages (cross-cultural validation).

2.3.4.1.5. Use of EDI Frameworks

We examined the reviews to see if they used or referred to any frameworks with criteria pertinent to diversity (e.g., Consensus-based Standards for the Selection of Health Measurement Instruments (COSMIN)) or any EDI frameworks such as gender-based analysis plus (GBA+), intersectionality, anti-racist approaches etc. to guide their methodology of selecting, reviewing, and/or examining included studies.

2.3.4.1.6 Service User Involvement

We extracted information on whether and how reviews described and evaluated the involvement of service users (e.g., in developing, choosing, or evaluating measures; in designing, implementing, or writing the study, etc.) in included studies.

2.3.4.1.7. EDI within the Research Team

We also reported on EDI considerations within the research team that conducted the reviews. We focused on extrapolating the income-level and geographic setting of the countries reported being affiliated with, and looked at whether the research teams included any persons recruited for their lived experience of mental illnesses.

2.3.5. Study Selection Process

All citations were imported into the EndNote X9 software where duplicates were removed. A screening form was developed *a priori* for data extraction and study selection. We followed a three-step study selection process. First, two reviewers (NN, MA) independently screened titles and abstracts with the screening form. Second, full texts meeting the inclusion criteria were independently reviewed and relevant studies selected. Third, the same two independent reviewers (NN, MA) screened and extracted data from the full texts and a third reviewer (NK) resolved discrepancies between reviewers. NN and MA received guidance throughout from SI.

2.3.6. Data Charting and Synthesis

From each review, the following information was extracted: the kind of review conducted, the general aims of the review, the country in which the review was conducted, the number of measures or studies considered, the psychometric information extracted, and the language restrictions for the inclusion of studies in the review.

The main outcome of interest was whether and how the reviews considered EDI (as operationalized by the seven criteria above) when examining their selected studies and forming conclusions such as which patient-reported outcome measures should be used in psychosis and schizophrenia research and care and why.

Data were synthesised descriptively, and study characteristics were presented in a tabular form (Table 2). Review characteristics and findings corresponding to each of the examined criteria were formulated into structured summaries by both reviewers (NN, MA) with guidance from senior authors (NK, SI).

2.3.7. Quality Assessment

A quality appraisal was conducted to assess the overall quality of the included reviews, but not with the objective of eliminating any reviews given our focus on EDI. The included systematic reviews were appraised for their quality using the 11-question JBI Critical Appraisal Checklist for Systematic Reviews and Research Syntheses (Aromataris et al., 2020). This appraisal assessed the search strategy, the efforts adopted to minimise bias, and whether the reviews included recommendations for practice and future directions. Each question was answered with a ‘yes’, ‘no’, ‘unclear’, or ‘NA’.

Non-systematic reviews were appraised using the 6-question Scale for the Assessment of Narrative Review Articles (SANRA; Baethge et al., 2019). This tool assessed papers for their logical structuring and methodological strategy, and each question was rated on a scale of 0 to 2. Before conducting the appraisals, the reviewers (NN, MF) discussed and established what each evaluation criterion comprises. The appraisals were conducted independently by each reviewer and a consensus was reached with the help of a third reviewer (NK). Positive answers (‘yes’ for systematic reviews and a score of 2 for non-systematic reviews) were tallied, the results of which were tabularized (see Tables 3 and 4 in Appendix).

2.4. Results

2.4.1. Search Findings

Our search yielded 1,000 results, which was narrowed down to 658 reviews after duplicates were removed. After screening the full-text articles, the final phase of the search resulted in the selection of 8 reviews (Figure 1).

2.4.2. Main Findings

All the reviews had a strong focus on the psychometric properties of the measures they considered. Two reviews examined existing self-report measures of recovery in psychosis and focused on their measurement qualities, with the goal of helping services identify the best-suited patient-reported recovery measures (Cavelti et al. 2011; Law et al., 2012). One review focused on studies of the psychometric properties of patient-reported measures of schizophrenia symptoms (Buck et al., 2022), while another looked at those patient-reported measures that assessed the various features and gradations of delusional ideation (Martins et al., 2016). Three reviews were broader in their scope, and reported on not only psychometric properties, but also on more general concepts and constructs that the measures touched upon (McCabe et al., 2007; Millier et al., 2012; Reininghaus et al., 2012). One review solely focused on four quality-of-life patient-reported measures and documented their psychometric evidence across studies (Papaioannou et al., 2011).

Four of the eight reviews represented a total of 299 reviewed studies (range of 21-175 studies). The other four did not report the number of studies reviewed. Seven reviews represent 130 measures (range of 4-73 measures), with one review not reporting the number of measures represented. See Table 2 for a summary of included reviews.

2.4.2.1. Population Diversity

Two of the eight reviews (Millier et al., 2012; Reininghaus et al., 2012) neither retrieved nor commented on the size or characteristics of the populations in the studies they reviewed. The remaining six reviews commented on population characteristics at varying levels of detail. Three (Buck et al., 2022; Cavelti et al., 2012; Martins et al., 2016) only reported the sample size of the final studies reviewed, without mentioning any other demographic data. Two reviews, in addition to reporting on sample size, also reported the country in which the samples were taken from for validation studies (Law et al., 2012; Papaioannou et al., 2011). In both these reviews, the validation studies were mainly conducted in high-income countries, with the exception of two studies that took place in Ethiopia (Papaioannou et al., 2011). However, neither of the two reviews commented on this apparent lack of geographical and socio-economic diversity.

Only one review reported on the age and gender distributions of the samples considered; however, no insights were drawn about the proportions of various genders in the sample or how many studies viewed gender solely as a binary (Papaioannou et al., 2011). One review commented on whether age, gender, ethnicity, race, employment, and education level influenced levels of empowerment and self-esteem, as measured by the Empowerment Scale and the Rosenberg Self-Esteem Scale. This review did not comment on these characteristics in relation to any of the other examined self-report measures (McCabe et al., 2007). None of the reviews systematically extracted or commented on the language of the target populations of their selected studies, nor did they comment on the race/ethnicity/culture, occupation, religion, education, socio-economic status, or social capital of the populations, or the income level or world region in which their selected studies were conducted. Moreover, none of the reviews extracted information or commented on vulnerable populations or populations experiencing discrimination or intersecting disadvantages, except for one listing of an individual study focusing on "individuals experiencing or at risk for homelessness" (Buck et al., 2022).

2.4.2.2. Study Population and Clinical Setting/Health System Context

Three reviews systematically reported, for each included study, both the specific psychosis-related diagnoses of the studied populations and their clinical setting (Buck et al., 2022; Martins et al., 2016; Papaioannou et al., 2011). One review only partially reported on both the clinical diagnoses and context where the populations were recruited from in the validation studies it examined and occasionally left out these details completely (Cavelti et al., 2012). One review reported on neither of these criteria (Reininghaus et al., 2012). One review reported on the diagnoses of the clinical populations in each included study (Law et al., 2012). The remaining two reviews mentioned the target population for which the measures had been designed; however, they did not specify the diagnoses, or clinical setting of the populations examined within the selected studies (McCabe et al., 2007; Millier et al., 2012). None of the reviews extracted information about or commented on the health system context.

2.4.2.3. Measures of Accessibility

All eight reviews commented, at least partially, on the number of items included in the patient-reported measures they reported on. Four reviews considered the length of time required to complete a given self-report measure (Cavelti et al., 2012; Law et al., 2012; McCabe et al., 2007; Reininghaus et al., 2012). Four reviews extracted information on the response options/formats used by the measures (Buck et al., 2022; Cavelti et al., 2012; Martins et al., 2016; Reininghaus et al., 2012), while two reviews investigated issues regarding formatting (e.g., variations in answer formats for the same patient-reported measure) (Cavelti et al., 2012; Martins et al., 2016).

Four reviews reported on the ease and accessibility of administering and scoring measures (Buck et al., 2022; Cavelti et al., 2012; Law et al., 2012; Martins et al., 2016). However, only one study within these four reviews contacted actual service users to assess how simple the format was and how easy the scoring was to understand (Law et al., 2012). None of the reviews commented on the method used by studies to assess the ease/accessibility of responding to measures. The reviews themselves also assessed ‘ease’ with their own predetermined criteria. Two reviews examined the language of the patient-reported measures, specifically whether the questions were negatively formulated (Cavelti et al., 2012) and whether the language was positive and acceptable (Law et al., 2012).

None of the reviews commented on the literacy levels of the populations that the patient-reported measures were used in, and only one briefly mentioned that one of the patient-reported measures they focused on – the Conviction of Delusional Beliefs Scale – was written at a 5th grade reading level (Martins et al., 2016).

As for translations, only two reviews systematically extracted the languages into which the patient-reported measures had been either developed or translated (Cavelti et al., 2012; Millier et al., 2012). Only one review did not restrict its search by language and translated articles when necessary, and, hence, reviewed various patient-reported measures in twenty languages (Millier et al., 2012). They also found that the most translated PROM was the Schizophrenia Quality of Life Scale Revision 4 (SQLS-R4), which had been translated into 52 languages through standardised procedures, although the psychometric properties of these translations were not commented on (Millier et al., 2012).

Only one review systematically examined whether the psychometric suitability of the patient-reported measures had been established in the translated versions (Cavelti et al., 2012). Out of the thirteen self-reported scales it assessed, this review found only three [the Illness Management and Recovery Scale, the Recovery Assessment Scale, and the Self-Identified Stage of Recovery] had been translated into Hebrew (IMR) and Japanese (RAS and SISR), and that the psychometric properties of these translated versions had been evaluated. Of the remaining ten patient-reported measures in this review, seven had no translated versions and three had translated versions whose psychometric properties had not been assessed.

2.4.2.4. Cross-cultural Validity

Only one review extracted data on cross-cultural validity. It reported that only two included studies (focused on the EuroQOL-5D and the Client Assessment of Treatment scales) out of a total of 175 included studies assessed this property (Reininghaus et al., 2012). Another review briefly mentioned that six of its included studies had been undertaken across more than one country but did not comment on this further in terms of validity, adaptations, etc. (Papaioannou et al., 2011). Two reviews commented on how the translation of measures as per certain standardised methods, along with their linguistic and psychometric validation, could help to compare patient-reported measures across distinct cultures and languages (Cavelti et al., 2012;

Millier et al., 2012). Moreover, two reviews commented on cultural variations in the conceptualization of certain themes (i.e., recovery), but neither extracted information from their studies of recovery measures on cross-cultural variability or validity (Cavelti et al., 2012; Law et al., 2012).

2.4.2.5. Use of EDI Frameworks

While one review used the Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) framework (Reininghaus et al., 2012), none of the reviews made any reference to any EDI-focused frameworks or approaches to examining the studies in their reviews. Also, no reviews commented on or recommended the use of such frameworks in research on patient-reported measures.

2.4.2.6. Service User involvement

Only one review extracted information regarding the ‘level of service user input during [the] development of the measure’, considering factors such as the inclusion of service user researchers and service user feedback in the development of the measure (Law et al., 2012). This review identified six measures of recovery, and synthesised, in a tabular form, the ways in which each one incorporated service user input in its design. The service user input took various forms for each measure, including focus groups, feedback on content and wording, service users in the research team, pilot testing by service users or some combination of the aforementioned. None of the other seven reviews commented on service user involvement in the included studies, even when they considered factors such as user-friendliness or accessibility.

2.4.2.7. EDI within the Research Team

Authors of all but one of the reviews were affiliated only with institutions in high-income countries: the United States, Switzerland, the United Kingdom, Portugal, and France. The exception had two authors (out of 7 authors) associated with an institution in Tunisia (Millier et al., 2012). In the case of only one review (Law et al., 2012), the research team included service users/persons with lived experience as co-authors. This review included two service user consultants, who provided feedback about what the format and content criteria that were important in completing a self-report, and this feedback was presented in the review itself.

Notably, this was also the only review that extracted information regarding the extent of service user involvement in the included studies. None of the reviews make any reference to considerations of EDI within their own research team.

2.4.3. Quality Appraisal

The four systematic reviews fulfilled between 4 and 7 of the 11 criteria on the quality appraisal checklist, with many of the answers marked as “unclear” (Table 3). Out of these, three did not perform quality appraisals, while one carried out a quality appraisal but not with two or more reviewers (Papaioannou et al., 2011). None of the reviews that only considered English-language studies provided justifications for this inclusion criterion or listed it as a limitation of their study. Two of the reviews used appropriate methods to minimise bias (Buck et al., 2022; Millier et al., 2012), while one was unclear if it did (Papaioannou et al., 2011) and another review did not (Law et al., 2012). While all four systematic reviews provided suggestions for future research, only one provided clear recommendations for policy makers and practitioners (Buck et al., 2022). No clear associations were found between those systematic reviews that scored better on the JBI criteria and those that considered more EDI criteria.

The four non-systematic reviews scored between 9 and 12 (out a possible 12) on the quality appraisal checklist for non-systematic reviews, with two of the reviews receiving full scores (Cavelti et al., 2012; Martins et al., 2016) (Table 4). All four non-systematic reviews provided well-formulated aims, consistently backed up their claims with references, and appropriately presented their data. Two did not explicitly justify their importance for readership (McCabe et al., 2007; Reininghaus et al., 2012), while one did not present any kind of search strategy (McCabe et al., 2007). Those non-systematic reviews that scored all 12 points did a better job at considering targeted EDI criteria compared to those that scored fewer points on the SANRA.

2.5. Discussion

The eight examined reviews were written and published in English mainly by authors in high-income, Western countries, highlighting the lack of LMIC representation within the research teams reviewing patient-reported measures in schizophrenia and psychosis. The earliest review included in this review of reviews was published in 2007 (McCabe et al., 2007) and the latest in 2022 (Buck et al., 2022). Despite increasing expectations to incorporate EDI into psychiatric research practices and policy (Jackson & Gracia, 2014; Moreno & Chhatwal, 2020), even some of the latest reviews have not significantly considered these aspects or commented on how a lack of diversity or inclusion could be a limitation of their work or of the included studies.

Only one review included service users on its team. It was also the only one that extracted information about how service users were involved in developing patient-reported measures. This is disconcerting because it reflects an abandonment of the epistemological shift toward recognizing the validity of patient experience as an important form and source of knowledge that drove the uptake of patient-reported measures in the first place (Roe et al., 2022). How patient-oriented can patient-reported measures (and measurement) really be if we cannot even tell whether and how patients were included in their conception, design, and evaluation?

All reviews extracted psychometric information from the measures they evaluated, focusing on varying kinds of reliability and validity. In doing so, the reviews demonstrated the priority they accorded to using psychometric robustness as a central determinant of a PROM’s suitability. Nonetheless, even within these psychometric characteristics, cross-cultural validity - a more diversity-focused psychometric - was only considered once, emphasising how little importance is placed on understanding psychometric variability across different cultures and contexts. Although various guidelines have previously been created to both translate and culturally adapt patient-reported measures (Wild et al., 2005; Beaton et al., 2000), none of the reviews reported on whether these guidelines were followed.

When measures were reported to be validated in different countries, the countries were usually of high-income status, matching previous findings that high-income countries are overrepresented in schizophrenia research (Alliende et al., 2022). This predominance of high-income countries makes visible both the lack of global representation in the samples used to evaluate patient-reported measures and the concern that certain measures - while patient-reported - may not always be accessible, acceptable, valid, or even culturally safe for patients from distinct demographics, communities, and countries. Not even age and gender considerations have been included in all reviews, reflecting the gap in the representation of women and other gender identities from psychosis research (Alliende et al., 2022). Previously, ethno-culturally diverse individuals diagnosed with psychosis have been reassessed using cultural formulations, after which inaccuracies and mistakes in their diagnoses were found (Adeponle et al., 2012). Similarly, patient-reported measures that have not been vetted and may not be suitable across language/cultural groups may be erroneous and even harmful, particularly if they guide treatment decision-making as they are designed to do.

While the reviews mentioned the target population of the studies/measures they examined, they failed to consistently mention the diagnoses, settings, or health contexts of the studies examined. In terms of ease of use, the reviews mostly focused on quantitative criteria such as the number of items in a measure and the length of time required to complete it. While these characteristics are important, they are not enough to judge the readability and validity of measures.

Our analysis confirmed our concern that reviews of patient-reported measures in psychosis and schizophrenia demonstrate a clear lack of attention to EDI. Although patient-reported measures align themselves with patient-centred care and are increasingly used (or advocated for), they cannot be assumed to reflect a truly patient-centred approach unless they integrate a diverse and inclusive range of patient perspectives (Trujols et al., 2013).

Research on psychosis and schizophrenia has been found to be greatly focused on samples from Western, Educated, Industrialised, Rich, and Democratic (WEIRD) societies (Burkhard et al., 2021). Given that gender, urbanicity, immigration status, economic level and other social and environmental stressors have been shown to significantly affect the incidence and course of psychosis (Anglin et al., 2021; Castillejos et al., 2018), it is essential that patient-reported measures are suitable for a wide range of socio-demographics.

2.5.1. Strengths and Limitations

Our review is novel in its approach of compiling existing reviews to evaluate the ways in which they have prioritised EDI. Our study benefits from the inclusion of both a systematic quality appraisal of the included reviews and a comprehensive, holistic range of EDI criteria upon which the reviews were evaluated. Both these components were carried out by two reviewers, which helped reduce potential bias in the search, selection, and extraction processes.

In terms of limitations, although we did not restrict our search by language, we used three databases which may be better at picking English studies. Our review may have thus not picked up reviews in other languages. Our search was also limited to reviews published in larger peer-reviewed databases. Future reviews should consider accessing grey literature and a wider variety of databases. Another shortcoming of only reviewing reviews themselves is our limited ability to infer if lack of EDI consideration also extends to the design of each of the individual studies within the selected reviews.

2.5.2. Implications

If reviews aim to help clinical and research programs in psychosis to identify the patient-oriented measures best suited to their needs and demographics, they must extract and report information on EDI factors and comment on associated gaps. See Table 5 for our recommendations in this regard. Peer reviewers and journal editors must ensure that studies and reviews of patient-reported measures that do not report on setting and population characteristics (such as those in PROGESS-plus), and that do not involve service users in the design and evaluation of measures do not get published.

Our review holds up a mirror to the field. It shows us that while it is admirable that patient-reported measures are increasingly being used, if the hope is that they will bring patient perspectives to a hitherto clinician-dominated field, much more needs to be done. If the inclusion of patients is not the primary barometer by which the conception, design and performance of patient-reported measures is evaluated, these measures or their use may not have the desired effects. The fuller and wider inclusion of patients may also help redress some of the glaring equity gaps with respect to language, region, income, education level, etc. that still vex psychosis research (Burkhard et al., 2021). More fundamentally, a rights- and values-based case can and must be made for the deep involvement of service users in designing, choosing, and implementing PROMs, and in reviews and evaluations of such measures.

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2.7. Tables and Figures

Table 1: Cochrane PROGESS-plus and SSHRC Content on EDI in Research

Cochrane's PROGRESS-plus (O'Neill et al, 2014)	**PROGRESS** refers to: - **P**lace of residence - **R**ace/ethnicity/culture/language - **O**ccupation - **G**ender/sex - **R**eligion - **E**ducation - **S**ocioeconomic status - **S**ocial capital **Plus** refers to: - 1) Personal characteristics associated with discrimination (e.g., age, disability) - 2) Features of relationships (e.g., smoking parents, excluded from school) - 3) Time-dependent relationships (e.g., leaving the hospital, respite care, other instances where a person may be temporarily at a disadvantage)
SSHRC Guide to EDI (SSHRC, 2021)	**EDI in Research Practice (EDI-RP)** - Promoting diversity in team composition and trainee recruitment - Fostering an equitable, inclusive and accessible research work environment for team members and trainees - Highlighting diversity and equity in mentoring, training and access to development opportunities **EDI in Research Design (EDI-RD)** - Including EDI approaches such as intersectionality, gender-based analysis plus (GBA+), anti-racist approaches, and disaggregated data collection and analysis - Considers diversity and identity factors such as, but not limited to, age, culture, disability, education, ethnicity, gender expression and gender identity, immigration and newcomer status, Indigenous identity, language, neurodiversity, parental status/responsibility, place of origin, religion, race, sexual orientation, and socioeconomic status

Table 2: Overview of the Selected Reviews

	Aim of Review	Date of Search	Time Frame of Search	Type of Review	Country in which the corresponding author was based	Psychometric Information Extracted	Other Characteristics evaluated	Number of measures reviewed	Number of studies included in review	Language restrictions in inclusion criteria	Language of Studies in Review
Buck et al., 2022	To identify psychometric studies of patient-reported measures assessing ongoing symptoms	September 28th, 2020	No time restriction	Systematic search and critical review	United States of America	Internal consistency, test-retest reliability, convergent validity, criterion validity, group differences between clinical and non-clinical individuals, responsiveness to change	(1) Length, (2) symptom domains, (3) presence of assessment of suicidal ideation, (4) scoring methodology, (5) time frame assessed	11 measures	21 studies	Limited to English studies	English
Cavelti et al., 2012	To review existing self-report measures for assessing personal recovery	October 2009 to August 2010	No time restriction	Not specified; search strategy defined	Switzerland	Content validity, construct validity, internal consistency, test-retest reliability	Issues of application: (1) user-friendliness, (2) administrator friendliness, (3) translations	13 measures	Not specified	Limited to English studies	English

	Aim of Review	**Date of Search**	**Time Frame of Search**	**Type of Review**	**Country in which the corresponding author was based**	**Psychometric Information Extracted**	**Other Characteristics evaluated**	**Number of measures reviewed**	**Number of studies included in review**	**Language restrictions in inclusion criteria**	**Language of Studies in Review**
Law et al., 2012	To examine existing self-report measures of psychosis recovery	Not specified	1990 to present	Systematic review	United Kingdom	Internal consistency, convergent validity, content validity, test-retest reliability	Ease of administration (number of items, time to complete measure and ease of scoring), level of service-user input during measure development, service-user evaluation	6 measures	Not specified	Limited to English studies	English
Martins et al., 2016	To review existing self-report measures for assessing delusional activity	April 2016	No time restriction	Narrative review with systematic search	Portugal	Internal consistency, test-retest correlation, convergent validity, divergent validity	Issues regarding administration, instructions, number of items, response scale	4 measures	Not specified	Not specified	English

	Aim of Review	**Date of Search**	**Time Frame of Search**	**Type of Review**	**Country in which the corresponding author was based**	**Psychometric Information Extracted**	**Other Characteristics evaluated**	**Number of measures reviewed**	**Number of studies included in review**	**Language restrictions in inclusion criteria**	**Language of Studies in Review**
McCabe et al., 2007	To present an overview of patient-reported outcomes in schizophrenia	Not specified	Not specified	Necessary selective (non-systematic) review; search strategy not specified	United Kingdom	Reliability (test-retest, inter-rater consistency, internal consistency), validity (face, predictive, construct, convergent, criterion, discriminant)	Underlying constructs, corresponding scales and key empirical findings relating to these constructs	19 measures	Not specified	Not specified	Not specified
Millier et al., 2012	To identify all the patient-reported outcome questionnaires used in evaluating patients with schizophrenia	Not specified	Not specified	Systematic review	France	Internal consistency, reproducibility, content validity, construct validity, sensitivity to change	Target population (generic or specific), dimensions, languages in which developed or translated, number of items, whether article was dedicated	73 measures	70 studies	No language restrictions (translations were done when required)	Spanish, French, English, Japanese, Chinese, Finnish, Hebrew, Arabic, Danish, German, Greek, Irish, Italian, Dutch, Portuguese, Singapore (?), Swedish, Turkish, Korean

	Aim of Review	**Date of Search**	**Time Frame of Search**	**Type of Review**	**Country in which the corresponding author was based**	**Psychometric Information Extracted**	**Other Characteristics evaluated**	**Number of measures reviewed**	**Number of studies included in review**	**Language restrictions in inclusion criteria**	**Language of Studies in Review**
							to PRO validation or only mentioned validity				
Papaioannou et al., 2011	To investigate the psychometric properties of self-reported quality of life measures in schizophrenia	August 2009	No time restriction	Systematic review	United Kingdom	Type and method of validity assessment, type and method of responsiveness assessment, and validity and responsiveness data	Country of publication, type of disorder, study sample characteristics (numbers, age, gender), other measures used	4 measures	33 studies	Not specified	English

	Aim of Review	**Date of Search**	**Time Frame of Search**	**Type of Review**	**Country in which the corresponding author was based**	**Psychometric Information Extracted**	**Other Characteristics evaluated**	**Number of measures reviewed**	**Number of studies included in review**	**Language restrictions in inclusion criteria**	**Language of Studies in Review**
Reininghaus et al., 2012	To examine measures of four widely used patient-reported outcomes in the evaluation of care of people with psychosis	Not specified	Not specified	Conceptual and methodological review; Systematic search	United Kingdom	Internal consistency, reliability, scale information, content validity, construct validity (structural, convergent, discriminant, cross-cultural, concurrent, and predictive validity), responsiveness	Concept to be measured, number and content of domains, estimated completion time, response options and type	Not specified	175 studies	Not specified	Not specified

Table 3: Joanna Briggs Institute (JBI) Quality Appraisal for Systematic Reviews

	Buck et al., 2022	**Law et al., 2012**	**Millier et al., 2012**	**Papaioannou et al., 2011**
1. Is the review question clearly and explicitly stated?	Yes	Yes	Yes	Yes
2. Were the inclusion criteria appropriate for the review question?	Yes	Unclear	Unclear	Yes
3. Was the search strategy appropriate?	Unclear	Unclear	Yes	Unclear
4. Were the sources and resources used to search for studies adequate?	Yes	Yes	Yes	Yes
5. Were the criteria for appraising studies appropriate?	No	No	No	Yes
6. Was critical appraisal conducted by two or more reviewers independently?	No	No	No	No
7. Were there methods to minimise errors in data extraction?	Yes	No	Yes	Unclear
8. Were the methods used to combine studies appropriate?	Yes	Yes	Yes	Yes
9. Was the likelihood of publication bias assessed?	N/A	N/A	N/A	N/A
10. Were recommendations for policy and/or practice supported by the reported data?	Yes	Unclear	No	No
11. Were the specific directives for new research appropriate?	Yes	Yes	Yes	Yes

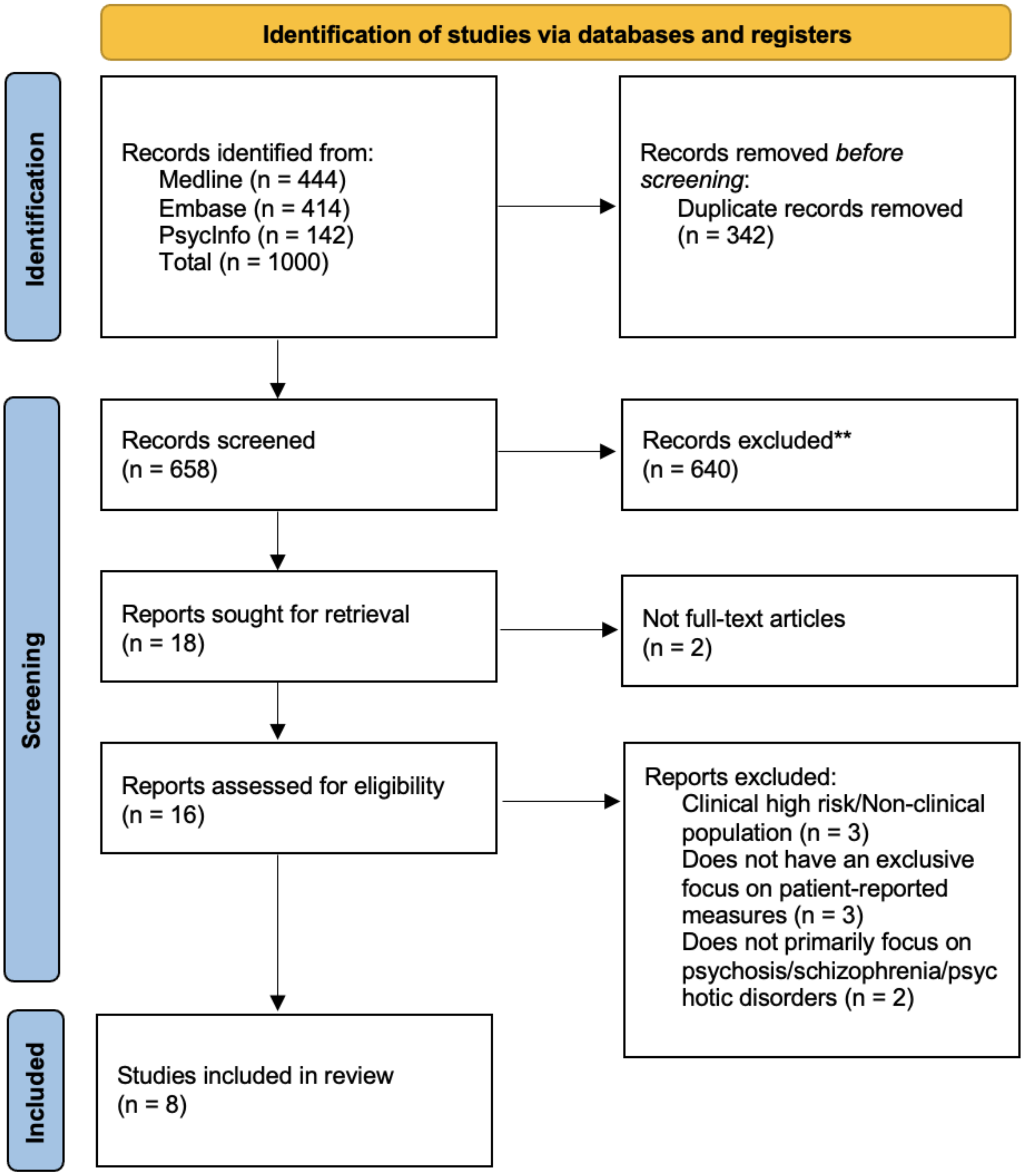
Table 4: Scale for the Assessment of Narrative Review Articles (SANRA): Quality Appraisal for Non-Systematic Reviews

	McCabe et al., 2007	**Martins et al., 2016**	**Cavelti et al., 2012**	**Reininghaus et al., 2012**
1. Justification of the article's importance for the readership	1	2	2	1
2. Statement of concrete aims or formulation of questions	2	2	2	2
3. Description of the literature search	0	2	2	2
4. Referencing	2	2	2	2
5. Scientific reasoning	2	2	2	2
6. Appropriate presentation of data	2	2	2	2

Table 5: EDI Guidelines for Future Reviews on Patient-Reported Outcome Measures

1. Population Diversity	➔ Extract and report socio-demographic information about the patients included in the studies (i.e., age, gender, sexual orientation, race, ethnicity, culture, language, religion, occupation, education, socio-economic status, and social capital, etc.) ➔ Extract and report information on the geographic and socio-economic context in which the study was conducted (i.e., city, country, world-region, income level (high or low-middle), etc.) ➔ Comment about gaps in population diversity in included studies
2. Study Population and Clinical Setting/Health System Context	➔ Report on the clinical setting (inpatient, outpatient, emergency, residential, etc.) and health system context (public, private, non-profit) from which the patients in each study were taken ➔ Specify the diagnoses of the patients included in the studies ➔ Comment about gaps in population (in terms of diagnoses) and clinical setting/health system context
3. Measures of Accessibility	➔ Extract and report information regarding the readability levels of PROMs, referring to tools used to assess and report readability such as the Flesch-Kincaid reading grade (Flesch, 1948; Kincaid et al., 1975) or the Simple Measure of Gobbledygook (McLaughlin, 1969). ➔ Extract and report information on the known literacy rates and reading levels of the population in which the tool was validated ➔ Systematically report the languages in which the PROMs have been translated and validated in ➔ Comment on gaps related to measures of accessibility
4. Between-Sample Comparisons	➔ Evaluate studies for whether they report on cross-cultural reliability and validity of their PROMS, either across different linguistic translations or across various cultural backgrounds
5. Use of Existing EDI Frameworks	➔ Refer to EDI frameworks and incorporate equity-oriented tools, such as but not limited to the PROGRESS-plus criteria (O'Neill et al, 2014) and/or the 8Quity tool (Kakoti et al., 2023) ➔ Comment on whether and how included studies/measures refer to EDI frameworks or frameworks with criteria aligned with diversity
6. Service user involvement	➔ Extract and report on whether and how studies include service users in developing and evaluating measures ➔ Comment on gaps in relation to service user involvement in included studies
7. EDI within the Research Team	➔ Thoughtfully include persons with lived experiences of mental ill-health/mental health services in research team and processes (Callard et al., 2012; Colder et al., 2023) ➔ Meaningfully integrate multiple perspectives and reflexivity statements from authors from diverse backgrounds (i.e., from WEIRD and non-WEIRD countries, with intersecting identities, different career stages, different backgrounds, etc.) (Colder et al., 2023; Jamieson et al., 2022)

Figure 1: Results of Database Search and Final Selection of Reviews



Chapter 3: Second Manuscript

Title: Patient-reported outcome measures in early psychosis: Evaluating the psychometric properties of the single-item Self-Reported Health and Self-Reported Mental Health measures in Chennai, India and Montréal, Canada

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Under review in Early Intervention for Psychiatry

3.1. Abstract

Aim: Patient-reported outcome measures (PROMs) provide valuable information and promote shared decision-making but are infrequently used in psychosis. Self-Rated Health (SRH) and Self-Rated Mental Health (SRMH) are single-item PROMs in which respondents rate their health and mental health from ‘poor’ to ‘excellent’. We examined the psychometric properties of the SRH and SRMH in early intervention for psychosis contexts in Chennai, India and Montréal, Canada.

Methods: Assessments were completed in Tamil/English in Chennai and French/English in Montréal. Test-retest reliability included data from 59 patients in Chennai and Montréal. Criterion validity was examined against clinician-rated measures of depression, anxiety, positive and negative symptoms, and a quality-of-life PROM for 261 patients in Chennai and Montréal.

Results: SRH and SRMH had good to excellent test-retest reliability (ICC>0.63) at both sites and in English and Tamil (but not French). Results for criterion validity were mixed. Whereas in Montréal, low SRH was associated with not being in positive symptom remission, and poorer functioning and quality of life, SRH was associated only with functioning in Chennai. No associations were found for SRMH in Montréal. In Chennai, however, low SRMH was associated with not being in positive symptom remission and poorer functioning.

Conclusions: Our work advances knowledge of more feasibly integrating single-item PROMs into clinical settings. Importantly, it highlights how PROMs may perform differently across languages and contexts. More critical work is needed to understand if discrepancies between PROMs and CROMs are indicative of poor validity of PROMs or “valid” differences between patient and clinician perceptions.

3.2. Introduction

Psychiatry relies heavily on clinician-reported outcome measures (CROMs) to evaluate patients' health status and treatment response (Powers et al., 2017). Patient perspectives concerning their health, symptoms, functioning, quality of life, and recovery are infrequently assessed (Weldring & Smith, 2013). As measurement-based care becomes increasingly relevant, patient-reported outcome measures (PROMs) are being deemed useful for monitoring progress, strengthening patient participation in their care, and improving patient-clinician communication (Mejdahl et al., 2020). Despite its patient-oriented philosophy, even early intervention for psychosis implements PROMs to a limited extent (Ferrari et al., 2022).

In population surveys, two single-item measures, the Self-Rated Health (SRH) and the Self-Rated Mental Health (SRMH), are extensively used and are known to distinguish better from worse health and mental health (Idler & Benyamini, 1997; Mavaddat et al., 2011; Mawani & Gilmour, 2010). The SRH is also part of the widely used 36-Item Short Form Health Survey (SF-36; Mavaddat et al.,2011).

The SRH and SRMH can be used as PROMs in early intervention because as single-item measures, they are simple and entail a lower burden of assessment. They have been tested for their reliability and validity in general population surveys in countries including India and Canada. The SRH predicted mortality, morbidity, and various health indicators, while the SRMH correlated with treatment adherence, severity of mental disorders, and need for care (Ahmad et al., 2014; Cullati et al., 2018). In persons with schizophrenia, the SRMH correlated with self-reported distress, depression, and anxiety (Maguire et al., 2016).

The SRH and SRMH have been closely associated with each other (Fleishman & Zuvekas, 2007; Maguire et al., 2016). Yet, they may tap into different domains, the SRH being more associated with physical health conditions and the SRMH with mental disorders (Levinson & Kaplan, 2014).

Despite their wide use, the SRH and SRMH have not been examined in first-episode psychosis and their use in schizophrenia has been limited to English-speaking, high-income contexts (Cohen et al., 2021; Maguire et al., 2016).

This study examined the reliability and validity of the SRH and SRMH in early intervention for psychosis in a low-and middle-income country (LMIC; Chennai, India) and a high-income country (HIC; Montréal, Canada), and in three languages (Tamil and English in Chennai; French and English in Montréal).

3.3. Methods

3.3.1. Setting

This study was part of a larger two-year prospective study of first-episode psychosis outcomes conducted at two similarly designed early intervention services in Chennai and Montréal (Iyer et al., 2020; Malla et al., 2020). The Chennai site was run by the Schizophrenia Research Foundation (SCARF), a mental health non-governmental organization. The Montréal site comprised two McGill University-affiliated programs called Prevention and Early Intervention Program for Psychosis (PEPP).

PEPP and SCARF maintain similar treatment protocols based on international guidelines (IRIS, 2012; Ministry of Health and Long-Term Care, 2011). At both sites, patients receive two years of assertive case management, lowest effective dosage of antipsychotic medication, and family psychoeducation (Iyer et al., 2015).

This study was approved by the relevant ethics boards in Chennai and Montréal. All adult participants provided informed consent, while those <18 years provided assent along with their parents'/guardians' consent.

3.3.2. Participants

Patients were eligible for the study if they were 16-35 years old, diagnosed with affective or non-affective psychosis based on the Structured Clinical Interview for the DSM IV-TR criteria (First et al., 2002), previously treated with antipsychotic medications for <30 days, and fluent in either

Tamil or English in Chennai and French or English in Montréal. Those with concurrent substance use were included, while patients with substance-induced psychosis, organic brain disorders, an IQ<70, or a pervasive developmental disorder were excluded. In Montréal, there were 248 clients who were eligible to participate in the study, of whom 167 clients consented to participate and two withdrew – leaving a final total of 165 in the Montréal cohort. In Chennai, 244 clients were eligible and 170 signed the project consent form. However, two clients were withdrawn from the study, leaving a total of 168 clients at the Chennai site.

This study is based on a standardization sample (29 Chennai patients, 30 Montréal patients); and a larger sample for examining criterion validity composed of the participants in the main comparative study who completed the measures of interest (N=165 in Montréal and N =168 in Chennai).

3.3.3. Assessments

Assessments were administered in Tamil/English in Chennai and in French/English in Montréal. At both sites, patients completed self-report measures and rating scales were administered by trained staff at baseline (program entry), Month 12, and Month 24.

Socio-demographic information was collected from all patients and the SCID (First et al., 2002) used to establish diagnoses. The Circumstances of Onset of Symptoms and Relapse Schedule (Malla et al., 2006) was used to determine age of onset and duration of untreated psychosis. As previously reported, intra- and inter-site reliability for these measures were satisfactory (Iyer et al., 2010).

3.3.3.1. PROMs

3.3.3.1.1. SRH and SRMH

The SRH and SRMH are single-item measures of general and mental health. They are phrased as, “Would you say that in general your health is…” (SRH) and “In the past four weeks, would you say that your mental health has been…” (SRMH). Each item is answered on a 5-point Likert-type scale, ranging from ‘poor’(1) to ‘fair’(2) to ‘good”(3) to ‘very good’(4) to ‘excellent’(5). Some studies use the entire range, while others categorize scores 1-2 as “low” and scores 3-5 as “high” levels of health and mental health (Cohen et al., 2021; Maguire et al., 2016; McAlpine et al., 2018).

3.3.3.1.2. Quality of Life

Using the General Satisfaction domain of the Wisconsin Quality of Life Index (WQLI), patients answered 11 questions about their satisfaction with various life aspects (e.g., leisure, physical health). Each item was rated from ‘very dissatisfied’(-3) to ‘very satisfied’(+3) (Diamond & Becker, 1999). An average of the responses and the score to the physical health item were categorized into ‘poor’(<0) and ‘fair’(≥0) quality of life and physical health, respectively.

3.3.3.2. CROMs

3.3.3.2.1. Psychosis

The severities of positive and negative symptoms were assessed with the Scale for the Assessment of Positive Symptoms (SAPS; Andreasen, 1984) and the Scale for the Assessment of Negative Symptoms (SANS; Andreasen, 1989). The SANS severity score excluded the items of ‘inappropriate affect’, ‘poverty of content of speech’, and ‘attention’, as previously recommended (Malla et al., 1993). Scores ≤2 on the global SAPS or global SANS indicate being in positive or negative symptom remission (Andreasen et al., 2005).

3.3.3.2.2. Depressive Symptoms

Depressive symptoms were assessed using the nine-item Calgary Depression Scale for Schizophrenia (CDSS; Addington et al., 1990), wherein items are rated on a 4-point Likert-type scale. Scores ≥7 indicate clinically significant depression (Addington et al., 1993).

3.3.3.2.3. Anxiety

Anxiety was assessed using the 14-item Hamilton Rating Scale for Anxiety (HAM-A; Hamilton, 1959). All items were scored on a 4-point Likert-type scale, with scores <17 indicating mild anxiety; between 18 and 24 indicating mild-to-moderate anxiety; and >25 indicating moderate-to-severe anxiety (Hamilton, 1959).

3.3.3.2.4. Functioning

Functioning was assessed with the Social and Occupational Functioning Assessment Scale (SOFAS; Goldman et al., 1992) on a scale of 0-100, with higher scores representing better functioning. Scores ≤60 indicate significantly impaired functioning, while ≥61 indicate adequate functioning (Goldman et al., 1992; Koivumaa-Honkanen et al., 2008).

3.3.4. Procedure

3.3.4.1. Test-Retest Reliability

To evaluate test-retest reliability, participants in the standardization sample (Chennai N = 29, Montréal N = 30) completed the SRH and SRMH twice, approximately two weeks apart.

3.3.4.2. Validity

3.3.4.2.1. Criterion Validity

Criterion validity was examined by using SRH and SRMH responses and scores on the SAPS, SANS, CDSS, HAM-A, and SOFAS (CROMs), and WQLI (PROM) at Months 12 or 24. For each patient, the SRH and SRMH score from either Month 12 or 24 and the same month's score on the CROM or WQLI were used. The choice of month depended on data availability, with Month 24 used when data for both timepoints were available. Data from those patients from the larger study sample that had completed both the SRH and SRMH (at either Month 12 or Month 24) and at least one of the CROMs or the PROM (WQLI) targeted for cross-cultural validity (Chennai N=159, Montréal N=102), were used for this analysis.

We examined the categories of "low" and "high" SRH and SRMH against the distributions of remitted and non-remitted (SANS, SAPS); depressed and non-depressed (CDSS); no anxiety, mild, moderate, and severe anxiety (HAM-A); low and high functioning (SOFAS); and poor and fair quality of life (WQLI). We also examined associations between low" and "high" SRH and physical health.

We expected that those reporting lower SRH and SRMH would be likelier to fall into the following categories: unremitted positive and negative symptoms, clinically significant depression, moderate-to-severe anxiety, impaired functioning, and poorer quality of life (and poorer physical health); and vice-versa for those reporting higher SRH and SRMH.

3.3.4.2.2. Sensitivity

We described how the SRH and SRMH scores of our first-episode psychosis sample compared to those of similarly aged community samples from Canada (sample aged 15-34; Canadian Community Health Survey; Statistics Canada, 2017/2018) and India (sample aged 16-35; WHO World Health Survey India; World Health Organization, 2003). We predicted that our sample would rate themselves as having poorer health and mental health than the general population. For this analysis, we used scores from patients at baseline (when they are generally "ill") as we were comparing these scores with those of "healthy" controls. Data was analysed from 163 Chennai patients and 87/86 Montréal patients (for SRH and SRMH, respectively) from the larger study sample who had completed the SRH and SRMH at baseline.

3.3.4.3. Frequencies

We examined the frequency distributions of SRH and SRMH scores to see if respondents used all or part of the possible range (1-5).

3.3.5. Data Analysis

All data were analysed using SPSS v.28 for Mac. SRH and SRMH data were checked for normality using Kolmogorov-Smirnov tests and were found to be not normally distributed. Descriptive statistics, such as means, standard deviations, medians, interquartile ranges, frequencies, and percentages, were used to represent the group data. Inferential statistics were used for group comparisons including independent samples *t*-tests and Pearson chi-square tests, and effect sizes were calculated.

Test-retest reliabilities of the SRH and the SRMH were computed using the intra-class correlation coefficient for a two-way random model with absolute agreement and single measure ($ICC_{2,1}$) at each site and for each language (French, Tamil, English). The calculated ICCs were interpreted as poor (<0.40), fair (0.40-0.59), good (0.60-0.74), and excellent (0.75-1.00) (Cicchetti, 1994; Koo & Li, 2016).

Pearson chi square (χ^2) and Cramer's V effect sizes were used to assess the association of 'low' and 'high' SRH and SRMH with distributions on the CROMS [remitted and non-remitted (SANS, SAPS); depressed and non-depressed (CDSS); no anxiety, mild, moderate, and severe anxiety (HAM-A); and low and high functioning (SOFAS)]; and WQLI (poor and fair quality of life and physical health).

We also tested associations between SRH and SRMH at each site and for each language.

p-values <0.05 were considered significant. For chi-square distributions in which any of the sample sizes was ≤5, Fisher's exact test was used. Cramer's V effect sizes were interpreted as small-medium (0.10-0.30) and medium-large (>0.30) for 1 degree of freedom (Cohen, 1988).

SRH and SRMH distributions from nationwide samples and their descriptive statistics were visually inspected using histograms and compared with our samples.

3.4. Results

3.4.1. Demographic Characteristics: Test-Retest Sample (Supplementary Table 1)

In the test-retest sample, Chennai (N=29) and Montréal (N=30) patients were comparable on age, gender, and education. Chennai had a significantly greater proportion of non-English (Tamil) to English speakers than Montréal (French).

3.4.2. Baseline Demographic and Clinical Characteristics: Validity Sample (Table 1)

As previously reported (Pawliuk et al., 2022), the two samples were comparable on DUP and education. The Montréal sample was younger, more likely to be single, and included more men (equal numbers of men and women in Chennai); had more English speakers (more non-English in Chennai) and more unemployed patients (more homemakers in Chennai). More Chennai patients lived with their family.

3.4.3. Test-Retest Reliability (Table 2)

The test-retest reliability ranged between good and excellent at both sites and in all three languages for the SRH. Test-retest reliability ranged between good and excellent at both sites and for the English and Tamil versions of the SRMH. However, test-retest reliability was inadequate for the French version of the SRMH.

3.4.4. Criterion Validity

3.4.4.1. Site (Table 3)

In Montréal, as expected, the distributions of low vs. high SRH were associated with worse versus better scores on the SAPS, SOFAS, and WQLI (small-medium effect sizes) and the physical health item (medium-large effect size). However, there was no association between the SRMH and any of the CROMs or the other PROM (WQLI).

In Chennai, as expected, the distributions of low vs. high SRH were associated worse versus better scores on the SOFAS (small-medium effect size). Low SRMH was associated with not being in positive symptom remission (SAPS) and worse functioning (SOFAS; small-medium effect sizes).

3.4.4.2. Language (Table 4)

In English, the distributions of low vs high SRH were associated with worse versus better scores on the SAPS, SOFAS, HAS and WQLI overall and physical health item (medium-large effect sizes) and with SANS (small-medium effect size). The SRMH however was not associated with any other measure.

In Tamil, the SRH was not associated with any measure. The distributions of low vs high SRMH were associated with worse vs better scores on SAPS, SANS, and SOFAS (small-medium effect sizes).

In French, the SRH was not associated with any measure. Although low vs high SRMH was associated with worse vs better SANS (medium-large effect size), this should be interpreted cautiously given that test-retest reliability was poor.

3.4.5. Frequencies and Associations

As shown in Supplementary Tables 2 and 3, scores fell in the entire possible range of 1 to 5 for SRH and SRMH, at both sites and in all three languages.

As Supplementary Table 4 shows, SRH and SRMH scores were significantly associated with each other at both sites and in all three languages, with effect sizes ranging from medium to large.

3.4.6. Sensitivity (Tables 5-6; Figures 1-2)

Descriptive statistics reveal higher SRH and SRMH averages in similarly aged general population samples than in the Chennai and Montréal first-episode psychosis samples. The histograms indicate that the similarly aged general population samples had higher percentages of ‘very good’ and ‘excellent’ scores and lower percentages of ‘poor’ and ‘fair’ scores than our samples at each site. These differences between “ill” and “healthy” populations are as theorized and indicate validity.

3.5. Discussion

The Chennai and Montréal early psychosis samples reported worse health and mental health than the general populations of their respective countries. This indicates that both measures are sensitive, i.e., can distinguish those with psychosis the from general population. That the entire possible range of scores was used highlights that the measures capture variations in patients’ perceptions of their health and mental health. Also, as expected (Levinson & Kaplan, 2014; Maguire et al., 2016), SRH and SRMH were significantly associated with each other.

The SRH and SRMH had good to excellent test-retest reliability in Chennai and Montréal, and in English and Tamil. Test-retest reliability could not be established for the SRMH’s French version. Although acceptable, test-retest reliability of the SRH French version was also lower than in English and Tamil.

That the French version of the SRMH, widely used in Canada in population surveys (Mawani & Gilmour, 2010), did not have test-retest reliability in our patient sample may be a function of our small sample size. Still, it indicates that even measures used in population surveys require testing when used in distinct sub-groups. Moreover, more SRMH studies have focused on validity, rather than test-retest reliability (Ahmad et al., 2014)

With validity, the picture was mixed. We found greater concord between SRH and CROMs and patient-reported quality of life and physical health in Montréal than in Chennai, and in English more than in French or Tamil. Conversely, we found greater concord between SRMH and CROMs in Chennai than in Montréal, and in Tamil more than in English or French. This suggests that Chennai patients may associate positive symptoms and functioning with their mental health. Conversely, Montréal patients seem to see symptoms and functioning as relating more to their general health.

Site differences in the associations between SRH/SRMH and CROMs and quality-of-life may indicate that the SRH and SRMH tap into different understandings of health and mental health within each context. Moreover, cultural and linguistic differences can shape how patients understand and rate such measures (Choi & Miyamoto, 2022; von dem Knesebeck & Geyer, 2007).

Our findings show that PROMs perform differently across languages and contexts, an area that has received limited attention in early psychosis. In the general population, studies have shown that reliability was worse for the SRH in individuals from disadvantaged sociodemographic backgrounds (Zajacova & Dowd, 2011) and that the extent to which the SRMH was associated with mental health service use and symptoms varied by ethnicity (Zuvekas & Fleishman, 2008).

Critical work is needed to understand if the lack of convergence between PROMs and CROMs is indicative of the poor validity of PROMs or of “valid” differences in patient and clinician perceptions of patients’ health and functioning. Patient constructions of their health may differ from and extend well beyond an evaluation of their symptoms, akin to their recovery perceptions. While there has been a strong push for PROMs, our results highlight that they cannot be simply translated and used across contexts.

PROMs may be affected by factors that are shaped by “context” such as the language and vocabulary around health and mental health and how accessible they are; how often conversations about mental illness feature in daily life; and the extent to which individuals are socialized into evaluating their health/mental health. Additionally, cultural and contextual stigma around mental illness may dissuade patients from reporting their mental health accurately. Our lack of data on variables like stigma precluded an examination of these factors.

Our findings should not deter the use of PROMs (or even SRH and SRMH), as they represent ways in which patients can have a voice in their care and research, which is inherently valuable. Reducing their validity to whether they are correlated with CROMs may be an epistemic injustice, whereby clinician ratings are prioritized as superior or the standard.

3.5.1. Limitations

We assumed that being single-item measures signified ease of use. However, we did not collect qualitative or cognitive interviewing data on how accessible these measures were or how they were interpreted. Furthermore, our test-retest reliability sample (especially when stratified by language) was considerably smaller than our criterion validity samples.

3.5.2. Strengths

Most previous early psychosis and cross-cultural psychosis research has focused on CROMs rather than PROMs. Our study addressed this gap by testing PROMs in two distinct geo-cultural contexts and in three languages. Moreover, our study advances the field by highlighting the need to test PROMs in different languages and contexts, and by documenting the concord (or lack thereof) between PROMs and CROMs which may indicate legitimate differences in patient and clinician perceptions. Our study focused on two widely used PROMs that, being single item, can be feasibly integrated into clinical settings. The SRH merits further attention, given its association with physical health (an important domain in psychosis) at least in some contexts and its use in population surveys across countries (allowing comparisons between psychosis and general population samples).

3.5.3. Implications

PROMs can allow patients to play a more active role in their treatment. This potential, along with the inclusion of LMIC and HIC contexts, makes research like ours promising. More work on PROMs across contexts and languages, and critical thinking on how best to conceptualize and test the validity of PROMs are needed.

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3.7. Tables and Figures

Table 1. Baseline socio-demographic and clinical characteristics of patients who completed the SRH and SRMH at least at one timepoint during their follow-ups

Variable	Montréal Mean (SD) /Median/N(%)	Chennai Mean (SD) /Median/N(%)	Statistical Test	p-value
Age at entry (years)	24.16 (5.12) (N=133)	26.55 (5.26) (N=164)	t(295) = 3.94	<0.001
Gender			$\chi^2(2) = 7.40$	0.025
Men	85 (63.9)	82 (50.0)		
Women	47 (35.3)	82 (50.0)		
Transgender	1 (0.8)	0		
Total	**133**	**164**		
Preferred Language			$\chi^2(1) = 42.52$	<0.001
English$^{\#}$	73 (55.3)	31 (18.9)		
French/Tamil$^{\#}$	59 (44.7)	133 (81.1)		
Total	**132**	**164**		
Education			$\chi^2(1) = 0.00$	0.98
Less than High School	35 (26.7)	44 (26.8)		
High school or more	96 (73.3)	120 (73.2)		
Total	**131**	**164**		
Occupation Status			$\chi^2(3) = 35.25$	<0.001
Student	18 (14.1)	25 (15.4)		
Paid employment	30 (23.4)	25 (15.4)		
Homemaker$^{\#}$	0	37 (22.8)		
Unemployed	80 (62.5)	75 (46.3)		
Total	**128**	**162**		
Marital Status			$\chi^2(2) = 38.15$	<0.001
Single$^{\#}$	119 (90.2)	95 (57.9)		
Married/ Common Law relationship$^{\#}$	12 (9.1)	59 (36.0)		
Separated/ divorced / widowed	1 (0.8)	10 (6.1)		
Total	**132**	**164**		
Living Situation			$\chi^2(3) = 17.68$	<0.001
Alone$^{\#}$	12 (9.4)	2 (1.4)		
With family	103 (80.5)	136 (96.5)		
With friend / roommate	11 (8.6)	2 (1.4)		
In residence, group home or homeless	2 (1.6)	1 (0.7)		
Total	**128**	**141**		
SCID[1] Diagnosis Type			$\chi^2(1) = 21.21$	<0.001
Schizophrenia-spectrum Disorders	90 (68.7)	146 (90.1)		
Affective psychosis$^{\#}$	41 (31.3)	16 (9.9)		
Total	**131**	**162**		

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[1] SCID: Structured Clinical Interview for the DSM IV-TR criteria

Substance Abuse or Dependence (SCID)				
Yes#	41 (35.3)	17 (10.5)	$\chi^2(1) = 25.29$	<0.001
No	75 (64.7)	145 (89.5)		
Total	**116**	**162**		
DUP[2] (weeks) to presenting episode (Analysis on square root of mean)	44.11 (94.87) Median = 10.29 (0 – 684.29)	29.87 (47.59) Median = 11.29 (0.29 – 223.00)	t(179.82) = 1.55	0.12

P<0.05 are significant;
#: significant post hoc site differences;
Note: the sample sizes vary because of missing data.

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[2] DUP: Duration of Untreated Psychosis

Table 2. Test-retest reliability for Self-Rated Health and Self-Rated Mental Health

	Self-Rated Health			
	Sample	**N**	**ICC$_{2,1}$**[3]	**95% CI**
Site	Total	59	0.90	0.83, 0.94
	Montréal	30	0.72	0.49, 0.86
	Chennai	29	0.98	0.96, 0.99
Language	French	14	0.61	0.16, 0.85
	English	25	0.87	0.72, 0.94
	Tamil	20	0.98	0.94, 0.99
	Self-Rated Mental Health			
	Sample	**N**	**ICC$_{2,1}$**	**95% CI**
Site	Total	59	0.80	0.69, 0.88
	Montréal	30	0.64	0.36, 0.81
	Chennai	29	0.91	0.81, 0.96
Language	French	14	0.22	-0.35, 0.67
	English	25	0.86	0.71, 0.94
	Tamil	20	0.88	0.72, 0.95

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[3] ICC$_{2,1}$: Intra-class correlation coefficient, interpreted as (<0.40), fair (0.40-0.59), good (0.60-0.74), and excellent (0.75-1.00)

Table 3. Criterion Validity for SRH and SRMH across Sites

	Montréal	**Chennai**
SRH[4] & SAPS[5]	$\chi^2(1)=5.49$, n=102, V= 0.23	$\chi^2(1)=3.72$, n=123, V=0.17
SRMH[6] & SAPS	$\chi^2(1)=1.41$, n=102, V=0.12	$\chi^2(1)=6.74$, n=123, V=0.23
SRH & SANS[7]	$\chi^2(1)=2.57$, n=102, V=0.16	$\chi^2(1)=3.41$, n=158, V=0.15
SRMH & SANS	$\chi^2(1)=1.29$, n=102, V=0.11	$\chi^2(1)=3.00$, n=158, V=0.13
SRH & CDSS[8]	$\chi^2(1)=0.20$, n=101, V=0.04	$\chi^2(1)=1.55$, n=158, V=0.10
SRMH & CDSS	$\chi^2(1)=0.16$, n=101, V=0.04	$\chi^2(1)=0.42$, n=158, V=0.05
SRH & HAM-A[9]	$\chi^2(3)=7.54$, n=96, V=0.28	$\chi^2(1)=11.15$, n=157, V=0.27
SRMH & HAM-A	$\chi^2(3)=3.67$, n=96, V=0.20	$\chi^2(1)=7.31$, n=157, V=0.22
SRH & SOFAS[10]	$\chi^2(1)=4.50$, n=98, V=0.21	$\chi^2(1)=6.24$, n=159, V=0.20
SRMH & SOFAS	$\chi^2(1)=3.64$, n=98, V=0.19	$\chi^2(1)=5.01$, n=159, V=0.18
SRH & WQLI[11]	$\chi^2(1)=5.23$, n=102, V=0.23	$\chi^2(1)=4.28$, n=159, V=0.16
SRMH & WQLI	$\chi^2(1)=0.94$, n=102, V=0.10	$\chi^2(1)=2.79$, n=159, V=0.13
SRH & Physical Health (WQLI)	$\chi^2(1)=9.95$, n=99, V=0.317	$\chi^2(1)=2.29$, n=159, V=0.120

Note: the sample sizes vary because of missing data.

small-medium effect size (0.10-0.30)
medium-large effect size (>0.30)

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[4] SRH: Self-Rated Health
[5] SAPS: Scale for the Assessment of Positive Symptoms
[6] SRMH: Self-Rated Mental Health
[7] SANS: Scale for the Assessment of Negative Symptoms
[8] CDSS: Calgary Depression Scale for Schizophrenia
[9] HAM-A: Hamilton Rating Scale for Anxiety
[10] SOFAS: Social and Occupational Functioning Assessment Scale
[11] WQLI: Wisconsin Quality of Life Index

Table 4. Criterion Validity for SRH and SRMH across Languages

	French	**Tamil**	**English**
SRH[12] & SAPS[13]	$\chi^2(1)=2.16$, n=46, V=0.22	$\chi^2(1)=3.13$, n=98, V=0.18	$\chi^2(1)=6.97$, n=80, V=0.30
SRMH[14] & SAPS	$\chi^2(1)=1.82$, n=46, V=0.20	$\chi^2(1)=7.41$, n=98, V=0.28	$\chi^2(1)=0.36$, n=80, V=0.07
SRH & SANS[15]	$\chi^2(1)=0.85$, n=46, V=0.14	$\chi^2(1)=3.23$, n=127, V=0.16	$\chi^2(1)=5.97$, n=86, V=0.26
SRMH & SANS	$\chi^2(1)=5.89$, n=46, V=0.36	$\chi^2(1)=4.44$, n=127, V=0.19	$\chi^2(1)=0.05$, n=86, V=0.03
SRH & CDSS[16]	$\chi^2(1)=0.82$, n=46, V=0.13	$\chi^2(1)=1.41$, n=127, V=0.11	$\chi^2(1)=0.24$, n=85, V=0.05
SRMH & CDSS	$\chi^2(1)=0.16$, n=46, V=0.06	$\chi^2(1)=0.70$, n=127, V=0.07	$\chi^2(1)=0.24$, n=85, V=0.05
SRH & HAM-A[17]	$\chi^2(1)=0.19$, n=44, V=0.07	$\chi^2(1)=9.58$, n=126, V=0.28	$\chi^2(2)=9.96$, n=82, V=0.35
SRMH & HAM-A	$\chi^2(1)=0.34$, n=44, V=0.09	$\chi^2(1)=7.46$, n=126, V=0.24	$\chi^2(2)=4.40$, n=82, V=0.23
SRH & SOFAS[18]	$\chi^2(1)=4.21$, n=46, V=0.30	$\chi^2(1)=8.53$, n=128, V=0.26	$\chi^2(1)=2.62$, n=82, V=0.18
SRMH & SOFAS	$\chi^2(1)=4.42$, n=46, V=0.31	$\chi^2(1)=6.21$, n=128, V=0.22	$\chi^2(1)=1.05$, n=82, V=0.11
SRH & WQLI[19]	$\chi^2(1)=1.14$, n=46, V=0.16	$\chi^2(1)=8.92$, n=128, V=0.26	$\chi^2(1)=8.12$, n=86, V=0.31
SRMH & WQLI	$\chi^2(1)=0.10$, n=46, V=0.05	$\chi^2(1)=7.59$, n=128, V=0.24	$\chi^2(1)=1.44$, n=86, V=0.13
SRH & Physical Health (WQLI)	$\chi^2(1)=0.01$, n=45, V=0.012	$\chi^2(1)=3.54$, n=128, V=0.166	$\chi^2(1)=15.67$, n=84, V=0.432

Note: the sample sizes vary because of missing data.
small-medium effect size (0.10-0.30)
medium-large effect size (>0.30)

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[12] SRH: Self-Rated Health
[13] SAPS: Scale for the Assessment of Positive Symptoms
[14] SRMH: Self-Rated Mental Health
[15] SANS: Scale for the Assessment of Negative Symptoms
[16] CDSS: Calgary Depression Scale for Schizophrenia
[17] HAM-A: Hamilton Rating Scale for Anxiety
[18] SOFAS: Social and Occupational Functioning Assessment Scale
[19] WQLI: Wisconsin Quality of Life Index

Table 5. Self-Rated Health (SRH) Comparison with Community Samples

SRH Response Categories	Our Sample (Baseline - Montréal)	Our Sample (Baseline - Chennai)	Community Canada Health Survey (2017-2018) *Age Range: 15-34	World Health Survey: India (2003) *Age Range: 16-35	
	N (%)	**N (%)**	**N (%)**		**N (%)**
Poor	6 (6.9)	14 (8.6)	317 (1.2)	**Very Bad**	51 (1.0)
Fair	22 (25.2)	74 (45.4)	1462 (5.6)	**Bad**	394 (7.9)
Good	30 (34.5)	44 (27.0)	6483 (24.7)	**Moderate**	1096 (21.9)
Very Good	24 (27.6)	26 (16.0)	10642 (40.5)	**Good**	2060 (41.2)
Excellent	5 (5.7)	5 (3.1)	7382 (28.1)	**Very Good**	1401 (28.0)
Total (N)	87	163	26286	5002	
Mean	3.00	2.60	3.89	3.87	
SD	1.02	0.96	0.92	0.94	

Table 6. Self-Rated Mental Health (SRMH) Comparison with Community Samples

SRMH Response Categories	Our Sample (Baseline - Montréal)	Our Sample (Baseline - Chennai)	Community Canada Health Survey (2017-2018) *Age Range: 15-34
	N (%)	**N (%)**	**N (%)**
Poor	15 (7.4)	41 (25.2)	439 (1.7)
Fair	31 (36.0)	60 (36.8)	2011 (7.8)
Good	23 (26.7)	39 (23.9)	6286 (24.4)
Very Good	7 (8.1)	21 (12.9)	9318 (36.2)
Excellent	10 (11.6)	2 (1.2)	7680 (29.8)
Total (N)	86	163	25,734
Mean	2.60	2.28	3.85
SD	1.21	1.02	0.99

Figure 1: Self-Rated Health Response Frequencies of Similarly Aged Early Psychosis Samples and General Population Samples

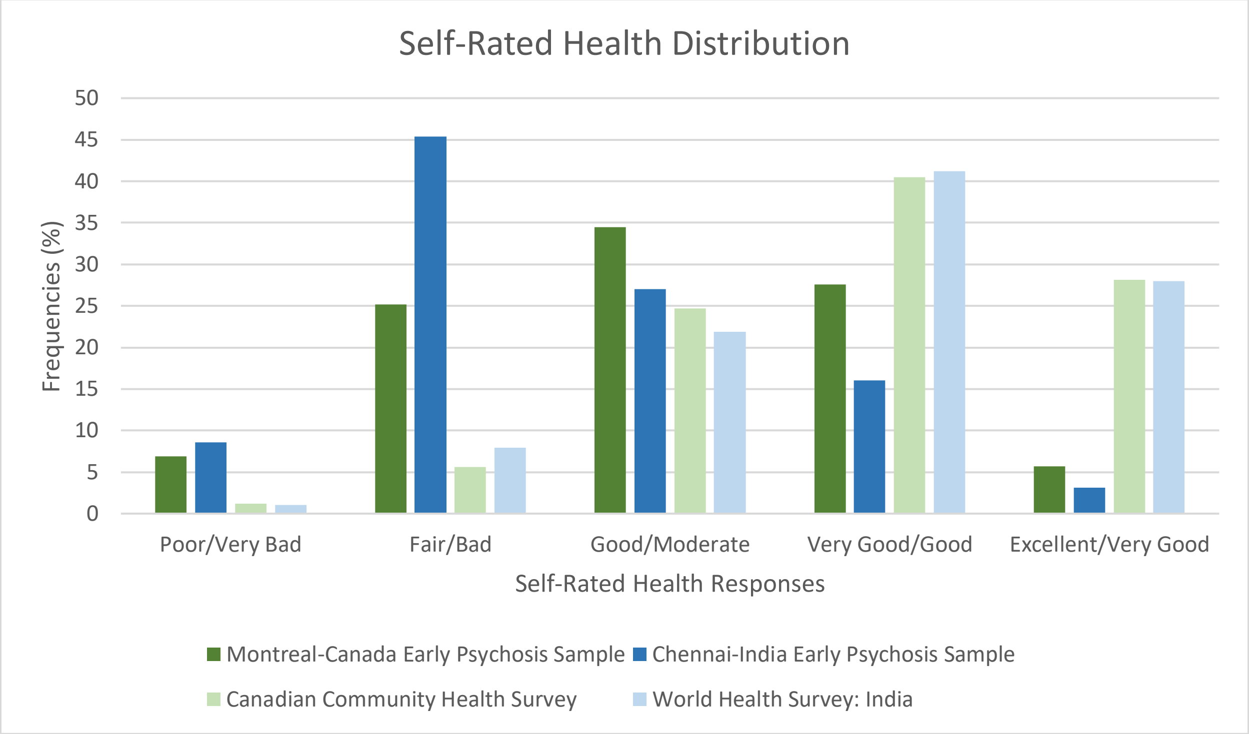
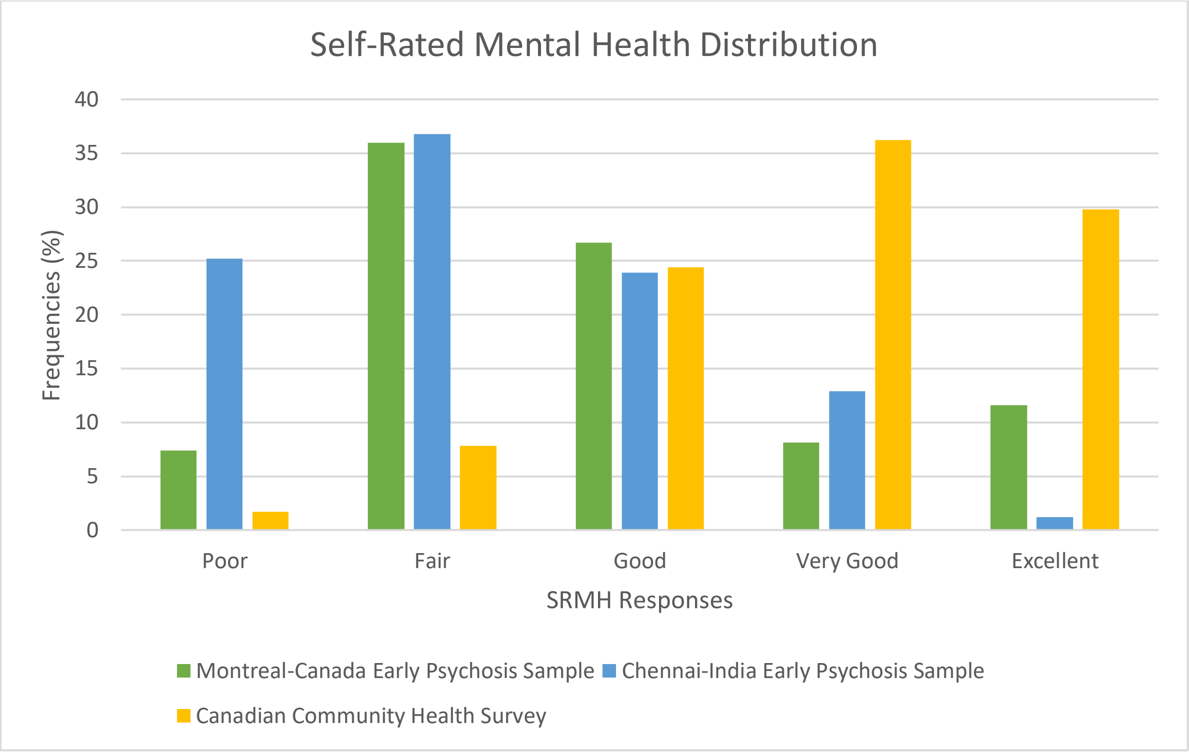


Figure 2: Self-Rated Mental Health Response Frequencies of Similarly Aged Early Psychosis Samples and General Population Samples



3.8. Supplementary Tables

Supplementary Table 1: Demographic characteristics of the test-retest reliability sample

	Montréal (N=30) N(%); Mean(SD)	**Chennai (N=29) N(%); Mean(SD)**	**Statistical Test**	**p-value**
Age at entry (years)	24.15 (5.31)	26.31 (5.12)	t(57)=1.59	0.12
Gender: Men	18 (60.0)	15 (51.7)	$\chi^2(1) = 0.41$	0.53
Women	12 (40.0)	14 (48.3)		
Education (years)	12.27 (2.26)	12.62 (3.91)	t(44.48)=0.42	0.67
Language: English	16 (53.3)	8[a] (28.6)	$\chi^2(1) = 3.66$	0.056
French/Tamil	14 (46.7)	20[a] (71.4)		

$P<0.05$ are significant;
Note: the sample sizes vary because of missing data.

Supplementary Table 2: Distributions of SRH and SRMH scores at Timepoint 1 (Test-Retest Sample)

PROM	Site	N	Possible range	Obtained range	Mean	Standard Deviation	Median	Interquartile Range
SRH	**Montréal**	30	1-5	1-4	2.93	0.74	3.00	0
	Chennai	29	1-5	2-5	3.48	0.95	4.00	1
	French	14	1-5	2-4	2.93	0.48	3.00	0
	English	25	1-5	1-4	3.12	0.93	3.00	2
	Tamil	20	1-5	2-5	3.50	1.00	4.00	1
SRMH	**Montréal**	30	1-5	1-4	2.97	0.77	3.00	1
	Chennai	29	1-5	2-5	3.38	0.98	4.00	2
	French	14	1-5	2-4	2.93	0.48	3.00	0
	English	25	1-5	1-4	3.12	0.93	3.00	2
	Tamil	20	1-5	2-5	3.40	1.05	3.50	2

Supplementary Table 3. Distributions of SRH and SRMH scores at entry into early psychosis services (Baseline)

PROM	Site	N	Possible range	Obtained range	Mean	Standard Deviation	Median	Interquartile Range
SRH	**Montréal**	86	1-5	1-5	3.00	1.03	3.00	2
	Chennai	163	1-5	1-5	2.60	0.96	2.00	1
	French	35	1-5	1-5	3.14	1.00	3.00	2
	English	80	1-5	1-5	2.85	1.07	3.00	2
	Tamil	132	1-5	1-5	2.55	0.93	2.00	1
SRMH	**Montréal**	86	1-5	1-5	2.60	1.21	2.00	1
	Chennai	163	1-5	1-5	2.28	1.02	2.00	2
	French	35	1-5	1-5	2.71	1.23	3.00	1
	English	80	1-5	1-5	2.51	1.11	2.00	1
	Tamil	132	1-5	1-5	2.23	1.03	2.00	2

Note: the sample sizes vary because of missing data.

Supplementary Table 4. Associations between SRH and SRMH across Sites and Languages

	Montréal	**Chennai**	
SRH & SRMH	$\chi^2(1)=8.68$, n=102, V=0.292	$\chi^2(1)=95.51$, n=159, V=0.775	
	French	**English**	**Tamil**
SRH & SRMH	$\chi^2(1)=5.01$, n=46, V=0.330	$\chi^2(1)=7.13$, n=86, V=0.288	$\chi^2(1)=90.84$, n=128, V=0.842

Note: the sample sizes vary because of missing data.

small-medium effect size (0.10-0.30)
medium-large effect size (>0.30)

Chapter 4: Third Manuscript

Title: Patient-reported outcome measures in early psychosis: A cross-cultural, longitudinal examination of the Self-Reported Health and Self-Reported Mental Health measures in early intervention programs in Chennai, India and Montréal, Canada

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Journals being considered are Psychiatry Research and Journal of Patient-Reported Outcomes

4.1. Abstract

Background: Despite being acknowledged as valuable, patient-reported outcome measures (PROMs) have been used infrequently in early psychosis, particularly in LMICs. Addressing this gap, we compared ratings on two well-established single-item PROMs, the Self-Rated Health (SRH) and Self-Rated Mental Health (SRMH), of persons receiving early intervention for psychosis in Chennai, India and Montréal, Canada. It was hypothesized that Chennai patients would report greater improvements in SRH and SRMH, even after controlling for relevant influences like symptoms.

Methods: Participants (Chennai N=168; Montréal N=165) completed the SRH and SRMH measures at entry to the service, months 12 and 24. Repeated measure proportional odds logistic regressions examined the effects of time (baseline to month 24), site (Chennai vs. Montréal), and relevant baseline (e.g., age, gender) and time-varying covariates (i.e., clinician-rated symptom severity) on SRH and SRMH scores.

Results: SRH (but not SRMH) scores were significantly different between the sites at baseline, with Chennai patients reporting poorer health (OR: 0.33; CI: 0.18,0.63). 'Months x Site' interactions were significant, with Chennai patients reporting higher increases in their health (OR: 7.03; CI: 3.13; 15.78) and mental health (OR: 2.29, CI: 1.03, 5.11) compared to their Montréal counterparts. Women in Chennai (but not Montréal) reported lower mental health than men. Higher anxiety and longer durations of untreated psychosis were associated with poorer SRH and SRMH, with negative symptoms being associated with SRH.

Conclusions: As hypothesized, Chennai patients reported greater improvement in their general health and mental health over two years. Cross-context (e.g., anxiety) and context-specific (e.g., gender) factors influence patient perceptions of their health. That the patten of results is not identical for health and mental health seems indicative of cultural variations in mind-body dichotomy. Our results also highlight the promise of integrating simple, brief patient-reported measures in early intervention for psychosis.

4.2. Introduction

Patient-reported measures are increasingly implemented in mental healthcare over the last several years (Fortney et al., 2017; Jones et al., 2021), especially as an important component of measurement based-care practices (Aboraya et al., 2018; Scott & Lewis, 2015; Waldrop & McGuinness, 2017). Within the context of early intervention services for psychosis, patient-reported measures have been used to gather patient information (without clinician interference or bias) regarding symptomatology, affect, quality of life, experiences with care etc. and have been seen as important tools in attenuating power imbalances and improving communication between patients and clinicians (Mejdahl et al., 2020; Weldring & Smith, 2013).

The Self-Rated Health (SRH) and Self-Rated Mental Health (SRMH) are two single-item self-report measures that have been shown to be reliable and valid in population surveys, both within and across nations (Levinson & Kaplan, 2014; Lundberg & Manderbacka, 1996; Mawani & Gilmour, 2010; Zajacova & Dowd, 2011). The SRH measure has been previously shown to predict both mortality and morbidity, while the SRMH measure was found to be correlated with the severity of mental illness, and the need for and/or responsiveness to care (Ahmad et al., 2014; Cullati et al., 2018).

While patient-reported measures provide space for patients to speak to their experience and symptoms, measures that are long or those that assess outcomes of little value for patients may be inaccessible and burdensome, inciting patient frustration with their own care (Fung & Hays, 2008; Nelson et al., 2015). Due to their simultaneous brevity and breadth, measures like the SRH and SRMH may fit in well within early intervention protocols without drastically increasing the time patients spend on completing assessments, while still providing valuable, less diagnosis-specific information to clinicians and other caregivers. The use of SRH and SRMH in general population surveys in many countries also allows for comparisons between those with psychosis and the general population within the same context, and for easier integration into early intervention services in diverse contexts and cross-national studies.

Ferrari et al.'s review highlighted the predominance of clinician-reported outcome measures over patient-reported outcome measures in early intervention in psychosis research (Ferrari et al., 2022), with most of this work having been predominately done in high-income, Western contexts (Hunter et al., 2009; Lysaker et al., 2022). Although measures like SRH and SRMH have been used in schizophrenia/psychosis samples (Cohen et al., 2021; Maguire et al., 2016), there have been few to no studies in first-episode psychosis and hardly any longitudinal investigations. Furthermore, while there have been some studies documenting the translatability and psychometric properties of patient-reported measures, few studies have conducted cross-cultural comparisons using PROMs (Cavelti et al., 2012; Millier et al., 2012; Reininghaus & Priebe, 2012).

Previous cross-cultural studies in psychosis have primarily focused on clinician-reported measures and have reported better outcomes in low and middle-income countries compared to high-income countries (Harrison et al., 2001; Jablensky et al., 1992). Likewise, the larger comparative first-episode psychosis study in Chennai, India and Montréal, Canada (of which the present report is a part) reported better clinician-reported outcomes in India (Malla et al., 2020). This "better outcomes" hypothesis has been critiqued on several counts (Cohen et al., 2008), including the lack of examination of whether subjective, patient-reported outcomes also show the same pattern. In other words, what if clinician-reported outcomes are better in LMICs but not outcomes reported by patients themselves?

Addressing these knowledge gaps, the current study sought to examine differences in the SRH and the SRMH between persons receiving a similarly structured two-year course of early intervention for psychosis in Chennai, India and Montréal, Canada. Our *apriori* hypothesis was that Chennai patients would report greater improvements in self-rated health and self-rated mental health over time than their Montréal counterparts, even after controlling for relevant demographic (e.g., gender) and clinical variables (e.g., symptoms).

4.3. Methods

4.3.1. Research Setting

A two-year prospective study with patients experiencing a first episode of psychosis was carried out at two early intervention services in Chennai and Montréal (Iyer et al., 2020; Malla et al., 2020). The Schizophrenia Research Foundation (SCARF), a non-governmental mental health organization ran the Chennai site, while two McGill University-affiliated programs under the name Prevention and Early Intervention Program for Psychosis (PEPP) comprised the Montréal site.

Both PEPP and SCARF provide similarly structured treatment created aligned with international guidelines for early intervention (IRIS, 2012; Ministry of Health and Long-Term Care, 2011). Treatment at both sites is offered for two years and comprises assertive case management, family interventions, lowest effective dosage of antipsychotic medication, and individualized psychosocial care (Iyer et al., 2015).

Relevant ethics boards in Chennai and Montréal approved this study. All participants >18 provided informed consent, while those below 18 years of age provided assent along with their parents'/guardians' providing consent.

4.3.2. Participant Sample

Patients were eligible for the two-year study if they were between 16 and 35 years old, had either affective or non-affective psychosis as diagnosed by the Structured Clinical Interview for the DSM IV-TR criteria (First et al., 2002), had been previously treated with antipsychotic medications for less than 30 days, and were able to communicate in either Tamil/English in Chennai or French/English in Montréal. Excluded were patients with substance-induced psychosis, organic brain disorders, an IQ of less than 70, or a pervasive developmental disorder. Those with concurrent substance use were still included.

4.3.3. Measures

Patient-reported outcome measures (PROMs) were completed, and clinician-rated outcome measures (CROMs) were administered in Tamil and English in Chennai and in French and English in Montréal. *All PROMs and CROMs were completed upon patients' entry to the program, as well as at Months 12 and 24 after entry into treatment*. Staff in Chennai and Montréal underwent training following similar protocols and were found to have good inter-rater reliability both within and across sites (Iyer et al., 2010).

4.3.3.1. Baseline Socio-Demographic Data and Diagnosis

The Structured Clinical Interview for the DSM IV-TR (First et al., 2002) was used to determine specific diagnoses, and the semi-structured Circumstances of Onset of Symptoms and Relapse Schedule (Malla et al., 2006) was used to estimate duration of untreated psychosis (measured in weeks). Detailed socio-demographic information (i.e., age of entry, relationship status, years of education, living situation, etc.) was also collected for all patients upon entry to the program.

4.3.3.2. PROMs: Self-Rated Health (SRH) and Self-Rated Mental Health (SRMH)

The SRH and SRMH are single-item PROMs designed to measure individuals' evaluations of their overall health and mental health, respectively. Both measures utilize a 5-point Likert-type response, in which a response of (1) corresponds to 'poor', (2) to 'fair', (3) to 'good', (4) to 'very good' and (5) to 'excellent' (Idler & Benyamini, 1997; Mawani & Gilmour, 2010).

The SRH and SRMH were chosen both for their brevity and because of their use in population surveys in both Canada (Statistics Canada, 2017/2018) and India (World Health Organization, 2003). Furthermore, we previously examined the psychometric properties of these two measures in the same study samples and an additional test-retest sample (Nair et al., under review). Test-retest reliability was found to be good at both sites. Results for criterion validity pointed to more correlations between SRH and clinician-rated outcomes in Montréal, and greater concord of the SRMH with clinician-rated outcomes in Chennai.

4.3.3.3. CROMs: Positive and Negative Symptoms

Positive and negative symptoms were evaluated using the Scale for the Assessment of Positive Symptoms (SAPS) and the Scale for the Assessment of Negative Symptoms (SANS), respectively (Andreasen, 1984; Andreasen, 1989). Global scores for SAPS and SANS were calculated at entry to the program, Month 12 and Month 24.

4.3.3.4. CROMs: Anxiety and Depression

Anxiety was reported using the 14-item Hamilton Anxiety Scale (HAS) (Hamilton, 1959) and depression was evaluated using the 9-item Calgary Depression Scale for Schizophrenia (CDSS) (Addington et al., 1990).

4.3.4. Data Analysis

All data was analysed using SPSS v.28 and R v.12.0+353 for Mac. Only those who had completed the SRH and SRMH at a minimum of two (out of the three) timepoints were included in the final analysis – a total of 74/73 patients in Montréal (for the SRH and SRMH, respectively) and 159 patients in Chennai. A significant proportion of individuals who were excluded had only completed the SRH and SRMH at baseline. A greater proportion of participants not included in the analysis were from Montréal. Baseline sociodemographic and clinical characteristics of those included in the analysis were examined using means, medians, and standard deviations for continuous variables, and using frequency distributions and percentages for categorical variables. The Kolmogorov-Smirnov test was used to examine the data sets for normality. To compare socio-demographic and clinical characteristics between the Montréal and Chennai cohorts, independent *t*-tests and Pearson chi-square tests were used for continuous and categorical variables, respectively. In addition, respondents and non-respondents were compared on key demographic and clinical variables.

Averages, medians and interquartile ranges were calculated for the SRH and SRMH at each timepoint for each site. Mann-Whitney tests were then used to compare responses across sites at each of the three time points. Distributions of the SRH and SRMH responses at each timepoint were also recorded.

A repeated measure proportional odds logistic regression was then performed using the ordLORgee function from the multgee package in R (Touloumis et al., 2013) for both SRH and SRMH. 'Months' (as a factor) and 'Site', as well as their interaction ('Months x Site'), were all used to create the basic model. Based on literature on factors associated with SRH and SRMH (e.g., anxiety) and known site differences (e.g., positive symptoms) (Malla et al., 2020, Iyer et al., 2020), potential confounding variables for the regression included age of entry, gender (male-identifying or female-identifying; all individuals in this study self-identified as one or the other), language (French, Tamil or English), years of education, relationship status (partner or no partner), SCID diagnosis type (schizophrenia-spectrum disorders or affective psychosis), substance abuse or dependence diagnosis (present or absent), duration of untreated psychosis (as measured in weeks) and four time-varying covariates (total scores on SAPS, SANS, CDSS and HAS). Interaction effects for sociodemographic factors whose distribution differed significantly between sites were also tested.

Each additional covariate was individually added to the basic model. Those covariates that had p-values below 0.10 when added to the basic model were included in the initial multivariable model. Correlation analyses (between co-variates) were then used to identify and remove covariates that were highly correlated. The Wald test statistic and corresponding p-value was used, along with meaningfulness based on theory/literature, to determine which one of the final nested models best fit the data.

Covariates in the final model were considered significant if *p*-values were <0.05 and were considered to show a trend if <0.10. Odds ratios were calculated for all the predictors in the final model.

4.4. Results

The larger study included 165 Montréal patients and 168 Chennai patients. Of these, 74 Montréal patients and 159 Chennai patients completed the SRH/SRMH measures at a minimum of two out of the three timepoints, and comprise the samples included in the present report.

4.4.1. Descriptive Statistics

4.4.1.1. Sociodemographic and Clinical Characteristics (Table 1)

The Chennai and Montréal samples were comparable in terms of duration of untreated psychosis, years of education completed, and depression severity at entry to the program. In relation to the Montréal sample, the Chennai sample was older, and had a more equal ratio of men to women, more non-English speakers than English speakers, more individuals who were in a relationship, fewer with substance abuse or dependence diagnoses, and a greater proportion of individuals diagnosed with schizophrenia-spectrum disorders (as opposed to those with affective psychosis). The Chennai sample also reported lower positive and negative symptom severity and anxiety at baseline, in comparison to the Montréal sample. These results are generally similar to what was previously reported for the larger study samples (Malla et al., 2020).

4.4.1.2. Respondents vs. Non-Respondents

Non-respondents were those who did not complete the SRH and SRMH measures at least twice over the course of their treatment. In Montréal, respondents and non-respondents were comparable on all considered sociodemographic and clinical characteristics except for positive and negative symptoms at baseline, for which respondents averaged higher symptom severity than non-respondents (SAPS: t(126.84)=2.53, p=0.013; SANS: t(137.67)=2.80, p=0.006). As only nine Chennai participants were non-respondents, they were not compared with respondents.

4.4.2. Basic Logistic Regression Models for SRH and SRMH (Tables 3 & 4)

As preliminary analyses, we compared the score distributions of SRH and SRMH across sites. With respect to SRH, patients in Montréal and Chennai showed significant differences at baseline, and Months 12 and 24. Patients in Montréal scored higher than those in Chennai at baseline, while the opposite was true at Months 12 and 24. The SRMH scores were comparable for both sites across time. (See Table 2 and Supplementary Tables 1 and 2 for detailed distributions, and Figures 1 and 2 for SRH and SRMH scores at baseline, Months 12 and 24 at the two sites).

Basic models for Self-Rated Health and Self-Rated Mental Health were run with ‘Months’ (as a factor), ‘Site’ and the ‘Months x Site’ interaction.

There was a significant main effect of site for SRH within the basic model regression. At baseline, Chennai demonstrated worse self-reported health in comparison to Montréal (Chennai: OR=0.43, 95%CI=[0.25,0.74]). The ‘Months x Site’ interaction effect was also significant, indicating that SRH scores improved significantly more in Chennai than in Montréal (M12: OR=3.72, 95%CI=[1.86-7.45]; M24: OR=6.00, C95%I=[2.96,12.16]).

For SRMH, there was a significant main effect of ‘Months’ at Months 12 and 24 (M12: OR=4.08, CI=[2.25-7.41]; M24: OR=4.87, CI=[2.53-9.37]), revealing that that SRMH scores in both Montréal and Chennai improved over time – although scores seem to have reached a plateau after the initial increase. The non-significant interaction 'Months x Site' effect indicates that scores increased similarly over time in Chennai and Montréal.

4.4.3. Self-Rated Health: Final Logistic Regression Model

Potential sociodemographic and clinical confounders showing a p-value below 0.10 when individually added to the Self-Rated Health basic model were relationship status, years of education, duration of untreated psychosis, and three time-varying covariates: negative symptoms, anxiety, and depression (see Table 5). Wald tests demonstrated that the best fitting model included only two out of the three time-varying covariates – negative symptoms (SANS) and anxiety (HAS) – which were incorporated into the final model.

Site (Chennai: OR=0.33, 95%CI=[0.18-0.63]) and the 'Months x Site' interaction (M12: OR=4.16, 95%CI=[1.96-8.85]; M24: OR=7.03, 95%CI=[3.13-15.78]) were shown to have more pronounced effects in the final model, after controlling for potential confounders. 'Months' as a main effect was still not significant which, along with the significant 'Months x Site' interaction, indicates that while SRH scores increased in Chennai, the improvement over time was not significant in Montréal. Relationship status (with respect to either having or not having a partner) and years of education were not significant in the final model. Those with greater scores on both the SANS and the HAS (indicating more severe negative symptoms or anxiety respectively), were more likely to report a lower score on the SRH measure (SANS: OR=0.98, 95%CI=[0.97-1.00]; HAS: OR=0.95, 95%CI=[0.91-0.98]). Those with longer duration of untreated psychosis also had slightly greater odds of reporting poorer health (OR=0.985, 95%CI=[0.994-0.999]). See Table 7 for reference.

4.4.4. Self-Rated Mental Health: Final Logistic Regression Model

For the final model for Self-Rated Mental Health, the potential confounders that were significant at a p-value <0.10 when added to the basic model included gender, relationship status, years of education, duration of untreated psychosis and all four time-varying covariates measuring positive symptoms, negative symptoms, anxiety, and depression (Table 6). Wald tests indicated that using only the anxiety-based time-varying covariate created the best fitting model, in the sense that neither the positive nor negative symptom covariates were improving the fit of the final model. Correlation analyses showed that gender and relationship status were too highly correlated to both be included in the final model, with Wald tests demonstrating that gender was a better fit for the final model.

The variable ‘Months’ showed even greater effects in the final model (M12: OR=3.20, 95% CI=[1.69-6.08]; M24: OR=3.56, 95% CI=[1.74-7.26]), demonstrating that, even when controlling for potential confounders, SRMH scores in both Montréal and Chennai improved between baseline and Month 12 and then plateaued between Month 12 and Month 24. SRMH scores at baseline between sites were still not significantly different. Differently from what was reported from the basic model, the Months x Site interaction in the final model was significant, indicating that Chennai, as compared to Montréal, showed a higher rate of increase in SRMH scores over time, despite scores at both sites plateauing between Months 12 and 24 (M12: OR=2.31, 95% CI=[1.07-4.97]; M24: OR=2.29, 95% CI=[1.03-5.11]). Gender and years of education were not significant in the final model. However, the significant gender x site interaction (Chennai: OR=0.38, 95% CI=[0.16-0.92]) indicated that women in Chennai (but not Montréal) were at greater risk of reporting lower SRMH scores compared to Chennai men. Those with more severe anxiety (OR=0.94, 95% CI=[0.91-0.98]) and longer durations of untreated psychosis (OR=0.987, 95% CI=0.997-0.999]) also had greater chances of self-reporting worse mental health. See Table 8 for reference.

4.5. Discussion

SRMH scores increased over time at both sites, although more pronouncedly in Chennai than in Montréal, even after accounting for several sociodemographic and symptom severity confounders. Conversely, *only* Chennai participants showed improved ratings to SRH over time. These results are in the hypothesized direction and are consistent with our previously reported findings of better clinician-rated symptom outcomes in Chennai (compared to Montréal) over the course of early intervention for psychosis at these two sites (Malla et al., 2020). Together, our findings suggest that at least when comparing Chennai and Montréal, the often-cited better outcomes of psychosis hypothesis in LMICs holds true for both clinical and subjective outcomes, and that the better subjective outcomes in Chennai may not entirely be attributable to better clinical outcomes as they persisted after symptom severity levels were accounted for.

With regards to the SRMH measure, the more pronounced effect of time (the largest odds ratio) suggests a positive intervention effect across sites. Previous studies have indicated that EIS for psychosis result in improved outcomes (clinical, functional, social, quality of life, etc.) for persons with psychosis (Addington et al., 2013; Amminger et al., 2011; Correll et al., 2018). Our study extends this finding for the first time to patient-reported perceptions of their mental health (using the SRMH) in first-episode psychosis.

4.5.1. Site variations in the extent of overlap between SRH and SRMH ratings

A set of findings taken together point to Montréal patients seeing their health and mental health as more distinct, and Chennai patients seeing these as more overlapping. Upon entry, there were site differences in only SRH, with Chennai patients perceiving their health (but not SRMH) as significantly lower than their Montréal counterparts, that persisted even after adjusting for potential confounders. Aligned with this, both the SRH and SRMH improved over time in Chennai, but only the SRMH improved significantly in Montréal. In other words, at entry, when they are most ill or experiencing higher levels of symptoms, Chennai patients seem to see both their health and mental health as impacted. Accordingly, over the course of treatment, they also experience improvements in both their health and mental health perceptions. Montréal patients, conversely, only report improvements in their mental health. Correlational analyses done in our earlier psychometric evaluation paper (Nair et al., under review) also revealed stronger correlations between SRH and SRMH ratings in Chennai, in comparison to Montréal. Taken together, these findings suggest that the ways in which patients perceive their physical and mental health (and ill-health) and the links between them, are notably influenced by culture (Kleinman et al., 1978).

The more marked differences between health and mental health in Montréal, in contrast to the overlap between the two outcomes in Chennai, aligns with previous research suggesting that Western societies maintain a more dualistic perspective with regards to the mind-body interaction (Gendle, 2016; Rintala, 1991). In seeing the body as it relates to physical health, and the mind as it pertains to mental health, the polarity of such a perspective might lend itself to less space for psychosomatic interpretations for one’s ill-health (Hoge et al., 2006; Kirmayer &

Young, 1998). Moreover, language may also influence how certain cultures situate physical health and mental health in relation to one another, namely when considering the relatedness between language and stigma (Simon et al., 1999; Volkow et al., 2021).

4.5.2. Cross-site influences on health and mental health perceptions

The duration of untreated psychosis and symptoms (anxiety and negative symptoms for SRH and only anxiety for SRMH) were all shown to have significant (albeit smaller than the Month x Site interaction effect) effects in predicting patient-reported health and mental health *across sites* in final models. Our first publication from the larger study reported that Chennai patients had significantly better negative (but not positive) symptom outcomes (Malla et al., 2020). Even after accounting for negative symptoms, site differences in SRH persisted, although negative symptoms also exerted an independent influence on SRH perceptions. In the case of SRMH, negative symptoms were not included in the final model as it did not improve fit. Aligned with the findings of our psychometric examination paper (Nair et al., under review), positive symptoms were not a significant predictor of SRH and only made a small contribution towards SRMH in the basic model (and was ultimately not retained in the final model). This suggests that patient's subjective perceptions of their health and mental health may not correspond with their experiences of positive symptoms and may even be tapping into a different construct. This lack of correspondence notwithstanding, the SRH and SRMH may represent something of importance pertaining to the nuanced and subjective experience of illness.

That anxiety negatively impacts health and mental health perceptions is congruent with prior literature in the general population (Ahmad et al., 2014) and in schizophrenia samples (Maguire et al., 2016). We entered anxiety as a time-varying covariate, further adding to the case for access to evidence-informed psychological intervention for comorbid conditions like anxiety through the course of treatment (Coplan et al., 2015).

Apart from quality of life, the negative influence of DUP has mostly been examined with respect to clinical and functional outcomes in first-episode psychosis (Howes et al., 2021). Our study points to longer DUPs negatively impacting patient-reported subjective outcomes, across two distinct contexts.

4.5.3. Site-specific perceptions on mental health

Another noteworthy finding from the SRMH final model was the indication that women experiencing a first episode of psychosis were more likely to report worse mental health than men, particularly in Chennai. Congruent with our own findings, the literature regarding the intersection of gender and mental health suggests that, in general, women self-report poorer mental health than men in the general population, across various psychopathologies and geographic contexts (Bramness et al., 2010; Shi et al., 2021; Tedstone Doherty & Kartalova-O'Doherty, 2010). Earlier, we reported that three patients (all women) in the Chennai sample (none in Montréal) died by suicide (Malla et al., 2020). Gender may shape experiences and perceptions of psychosis in particular ways in India, shaped by local norms around marriageability and roles of married women (Thara et al., 2003; Thara & Srinivasan, 1997) and needs further examination in the future.

4.5.4. Strengths & Limitations

A limitation of this study lies in the finding that Montréal non-respondents were more likely to report higher severity of clinician-rated positive and negative symptoms than respondents. This suggests that we may have left out those experiencing more severe first episodes of psychosis, possibly skewing our results to favor more positive outcomes. Another limitation is the lack of qualitative data from patients themselves about their perspectives on and conceptualizations of the measures being examined. Lastly, the Montréal site is responsible for addressing the needs of those within specific geographic catchment areas, while the Chennai sample comes from a larger and more diverse geographic area, which may have also impacted our results. However, in adjusting for key socio-demographic and clinical characteristics, we were able to mitigate this concern to some extent.

This is the first longitudinal exploration of both the SRH and SRMH measures within the context of first-episode psychosis. Sensitivity to change is an important but understudied property of instruments used in measurement-based care. In highlighting that the SRMH is sensitive to change in both contexts, while the SRH is only sensitive in Chennai, our work advances knowledge about how these two simple tools perform in two distinct contexts. Overall, our findings from these two measures at different time points over the course of early intervention in two contrasting cultural and geographical contexts and with respect to each other, is valuable and novel information that can help to implement a more multifaceted approach to measurement-based care. Other methodological strengths of this paper include our use of well-characterized samples and our breadth of carefully chosen confounding variables. Our integration of time-varying covariates allowed us to integrate into our models the dynamic nature of clinical symptoms throughout the course of treatment.

4.5.5. Implications

Broadly speaking, patient-reported measures offer the possibility of a more intersubjective approach to early psychosis care. Our findings indicate a need to continually re-assess both patient and clinician perceptions (as well as convergences and discrepancies between them) and validate the role of interpretation within the clinical context. This being said, the SRH and SRMH stand as important outcome measures in themselves. Measurement-based care should aim beyond just the reduction of psychotic symptoms, and rather, collect a diverse scope of outcome information that values the breadth and depth of the patient experience. Overall, the use of simple, accessible, brief PROMs like the SRH and SRMH in clinical settings should be welcomed, along with further investigations as to how exactly these patient-reported measures promote an understanding of psychosis that extends beyond just a diagnosis.

Our findings extend the field’s thinking around measurement-based systems of care, especially with regards to deconstructing the assumptions that patient-reported measures tap into identical, pre-ascribed constructs within all cultural contexts and at all stages of one’s treatment. Our study also provides clear evidence for patient-reported outcomes in first-episode psychosis varying by context, and that such outcomes are influenced by both cross-context (e.g., anxiety, DUP) and context-specific (e.g., gender) factors. Further studies might consider, by virtue of a qualitative approach, the nuanced ways in which patients experiencing psychosis across diverse contexts perceive their condition to affect their health and mental health – with the aim of discerning how these measures serve to illuminate the particularities of their illness experience.

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4.7. Tables and Figures

Table 1. Baseline socio-demographic and clinical characteristics of patients who completed the SRH and SRMH at a minimum of two timepoints

Variable	Montréal Mean (SD) /Median/N(%)	Chennai Mean (SD) /Median/N(%)	Statistical Test	p-value
Age at entry (years)	24.50 (4.77) (N=74)	26.46 (5.26) (N=159)	t(231) = 2.72	**0.007**
Gender Men Women Transgender **Total**	 47 (63.5) 26 (35.1) 1 (1.4) **74**	 80 (50.3) 79 (49.7) 0 **159**	$\chi^2(2) = 6.14$	**0.047**
Preferred Language English French/Tamil **Total**	 41 (55.4) 33 (44.6) **74**	 31 (19.5) 128 (80.5) **159**	$\chi^2(2) = 151.55$	<**0.001**
Years of Education	12.52 (2.78) (N=74)	11.85 (3.89) (N=159)	t(193.07) = 1.49	0.138
Relationship Has a partner No partner **Total**	 6 (8.2) 67 (91.8) **73**	 57 (35.8) 102 (64.2) **159**	$\chi^2(1) = 19.31$	<**0.001**
SCID[20] Diagnosis Type Schizophrenia-spectrum Disorders Affective psychosis **Total**	 48 (64.9) 26 (35.1) **74**	 143 (89.9) 16 (10.1) **159**	$\chi^2(1) = 21.48$	<**0.001**
Substance Abuse or Dependence (SCID) Yes No **Total**	24 (37.5) 40 (62.5) **64**	17 (10.7) 142 (89.3) **159**	$\chi^2(1) = 21.86$	<**0.001**
DUP[21] (weeks) to presenting episode (Analysis on square root of mean)	53.82 (112.95)	30.10 (47.84) Median =11.29	t(82.99) = 1.71	0.091

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[20] SCID: Structured Clinical Interview for the DSM IV-TR criteria

[21] DUP: Duration of Untreated Psychosis

	Median = 10.42 (0 – 684.29)	(0.29 – 223.00)		
SAPS[22] **Baseline** (global score)	37.96 (16.37) (N=68)	19.76 (9.69) (N=156)	t(88.14) = 8.54	<**0.001**
SANS[23] **Baseline** (global score)	25.51 (13.56) (N=73)	21.25 (15.71) (N=148)	t(219) = 1.98	**0.049**
CDSS[24] **Baseline** (total score)	4.10 (3.39) (N=67)	3.42 (4.68) (N=159)	t(168.81) = 1.23	0.221
HAS[25] **Baseline** (total score)	9.95 (7.44) (N=65)	3.99 (6.48) (N=158)	t(221) = 5.98	<**0.001**

P<0.05 are significant;
Note: the sample sizes vary because of missing data.

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[22] SAPS: Scale for the Assessment of Positive Symptoms

[23] SANS: Scale for the Assessment of Negative Symptoms

[24] CDSS: Calgary Depression Scale for Schizophrenia

[25] HAS: Hamilton Anxiety Scale

Table 2. Comparison of Self-Rated Health (SRH) & Self-Rated Mental Health (SRMH) between Montréal and Chennai at Baseline, Month 12 & Month 24

		Montréal: Average (n)	**Montréal: Median (IQR)**	**Chennai: Average (n)**	**Chennai: Median (IQR)**	**Test-Statistic***	**Effect size**	**p-value****
Baseline	**SRH**	3.00 (n=87)	3.00 (2-4)	2.60 (n=163)	2.00 (2-3)	5434.5	0.202	**0.001**
	SRMH	2.60 (n=86)	2.00 (2-3)	2.28 (n=163)	2.00 (1-3)	6064.5	0.115	0.069
Month 12	**SRH**	3.25 (n=87)	3.00 (2-4)	3.58 (n=137)	4.00 (3-4)	5005.5	0.141	**0.035**
	SRMH	3.36 (n=87)	3.00 (2-4)	3.51 (n=137)	4.00 (3-4)	5593.5	0.054	0.423
Month 24	**SRH**	3.34 (n=58)	3.00 (3-4)	3.76 (n=157)	4.00 (4-4)	3300.0	0.233	**<0.001**
	SRMH	3.52 (n=58)	3.00 (3-5)	3.62 (n=157)	4.00 (3-4)	4279.0	0.049	0.472

*Mann-Whitney U-Test

**p-values were considered significant at the 0.05 level

Table 3. Self-Rated Health (SRH) Basic Model

		Odds Ratio	**95% Confidence Interval**	***p*-value**
Site	Montréal	R		
	Chennai	0.43	0.25-0.74	**0.002**
Months	Baseline	R		
	Month 12	1.71	0.99-2.94	0.053
	Month 24	1.52	0.86-2.68	0.148
Months x Site	Baseline	R		
	Chennai x Month 12	3.72	1.86-7.45	**<0.001**
	Chennai x Month 24	6.00	2.96-12.16	**<0.001**

Table 4. Self-Rated Mental Health (SRMH) Basic Model

		Odds Ratio	**95% Confidence Interval**	***p*-value**
Site	Montréal	R		
	Chennai	0.65	0.37-1.13	0.124
Months	Baseline	R		
	Month 12	4.08	2.25-7.41	**<0.001**
	Month 24	4.87	2.53-9.37	**<0.001**
Months x Site	Montréal	R		
	Chennai x Month 12	1.87	0.91-3.84	0.087
	Chennai x Month 24	1.79	0.85-3.76	0.123

Table 5: SRH Individual Covariate Analyses with Basic Model

		Odds Ratio	**95% Confidence Interval**	***p*-value**
Age		0.99	0.96-1.03	0.739
Gender	Men	R		
	Women	0.79	0.55-1.11	0.175
SCID Diagnosis Type	Schizophrenia Spectrum Disorders	R		
	Affective Psychosis	0.89	0.55-1.45	0.639
Substance Abuse or Dependence	No	R		
	Yes	0.88	0.52-1.49	0.632
Relationship Status	Partner	R		
	No Partner	**1.50**	**1.03-2.21**	**0.037**
Duration of Untreated Psychosis		1.00	0.99-1.00	**0.012**
Years of Education		**1.10**	**1.05-1.15**	**<0.001**
SAPS[26] (time-varying)		1.00	0.98-1.01	0.576
SANS[27] (time-varying)		**0.98**	**0.97-0.99**	**0.006**
CDSS[28] (time-varying)		**0.92**	**0.88-0.97**	**0.002**
HAS[29] (time-varying)		**0.94**	**0.91-0.98**	**0.003**

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[26] SAPS: Scale for the Assessment of Positive Symptoms

[27] SANS: Scale for the Assessment of Negative Symptoms

[28] CDSS: Calgary Depression Scale for Schizophrenia

[29] HAS: Hamilton Anxiety Scale

Table 6: SRMH Individual Covariate Analyses with Basic Model

		Odds Ratio	**95% Confidence Interval**	***p*-value**
Age		0.97	0.94-1.01	0.141
Gender	Men	R		
	Women	**0.69**	**0.49-0.98**	**0.037**
SCID Diagnosis Type	Schizophrenia Spectrum Disorders	R		
	Affective Psychosis	0.96	0.61-1.51	0.854
Substance Abuse or Dependence	No	R		
	Yes	1.13	0.66-1.93	0.654
Relationship Status	Partner	R		
	No Partner	1.58	1.06-2.36	**0.025**
Duration of Untreated Psychosis		1.00	0.99-1.00	**<0.001**
Years of Education		1.06	1.01-1.12	**0.014**
SAPS[30] (time-varying)		0.99	0.97-1.00	0.057
SANS[31] (time-varying)		0.99	0.97-1.00	**0.028**
CDSS[32] (time-varying)		0.94	0.89-0.98	**0.005**
HAS[33] (time-varying)		0.94	0.91-0.97	**<0.001**

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[30] SAPS: Scale for the Assessment of Positive Symptoms

[31] SANS: Scale for the Assessment of Negative Symptoms

[32] CDSS: Calgary Depression Scale for Schizophrenia

[33] HAS: Hamilton Anxiety Scale

Table 7. Self-Rated Health (SRH) Final Model

		Odds Ratio	**95% Confidence Interval**	***p*-value**
Months	Baseline	R		
	Month 12	1.15	0.63-2.11	0.647
	Month 24	1.00	0.49-2.04	0.990
Site	Montréal	R		
	Chennai	0.33	0.18-0.63	**0.001**
Months x Site	Montréal	R		
	Chennai x Month 12	4.16	1.96-8.85	**<0.001**
	Chennai x Month 24	7.03	3.13-15.78	**<0.001**
Relationship Status	Partner	R		
	No Partner	1.45	0.93-2.26	0.097
Duration of Untreated Psychosis		0.985	0.994-0.999	**0.012**
SANS[34] (time-varying)		0.98	0.97-1.00	**0.020**
HAS[35] (time-varying)		0.95	0.91-0.98	**0.003**
Years of Education		1.05	1.00-1.11	0.074

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[34] SANS: Scale for the Assessment of Negative Symptoms

[35] HAS: Hamilton Anxiety Scale

Table 8. Self-Rated Mental Health (SRMH) Final Model

		Odds Ratio	**95% Confidence Interval**	***p*-value**
Months	Baseline	R		
	Month 12	3.20	1.69-6.08	**<0.001**
	Month 24	3.56	1.74-7.26	**<0.001**
Site	Montréal	R		
	Chennai	0.69	0.34-1.41	0.305
Months x Site	Montréal	R		
	Chennai x Month 12	2.31	1.07-4.97	**0.033**
	Chennai x Month 24	2.29	1.03-5.11	**0.042**
Gender	Men	R		
	Women	1.37	0.62-3.00	0.433
Gender x Site	Montréal	R		
	Chennai	0.38	0.16-0.92	**0.033**
Duration of Untreated Psychosis		0.987	0.997-0.999	**0.004**
HAS[36] (time-varying)		0.94	0.91-0.98	**0.001**
Years of Education		1.05	0.99-1.10	0.087

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[36] HAS: Hamilton Anxiety Scale

Figure 1. Means and Standard Deviations of Self-Rated Health (SRH) Scores in Montréal and Chennai over the course of two years

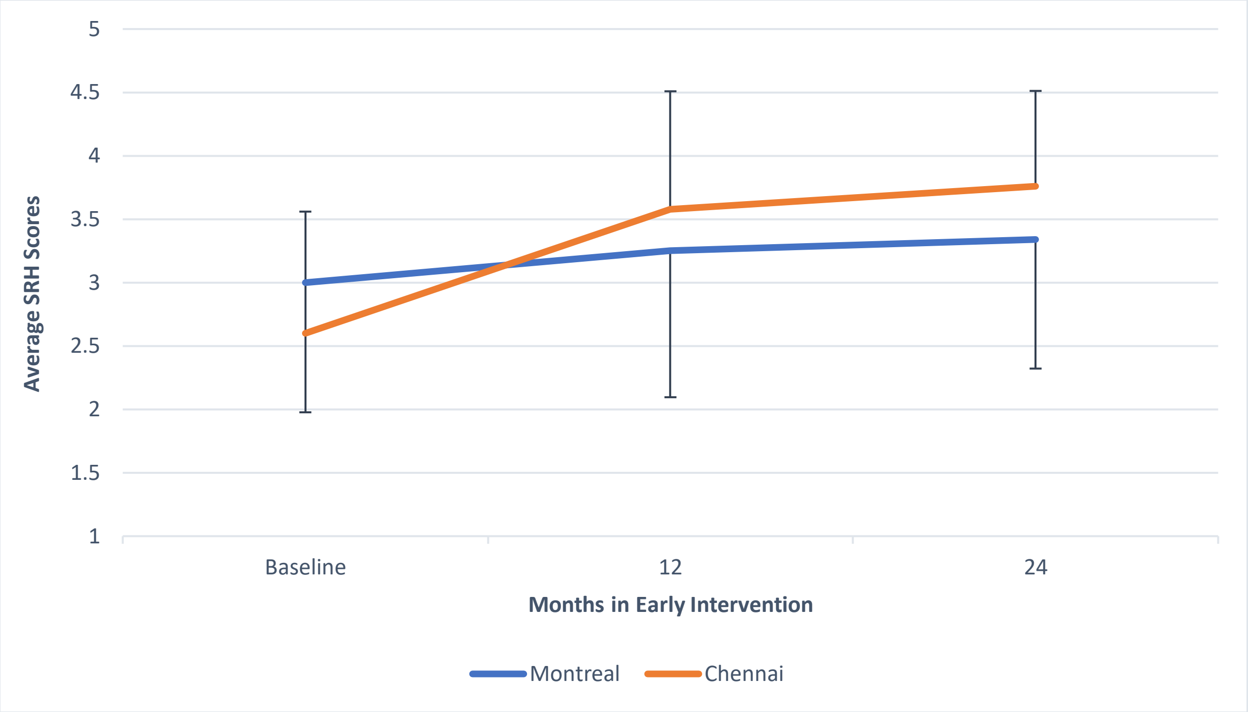
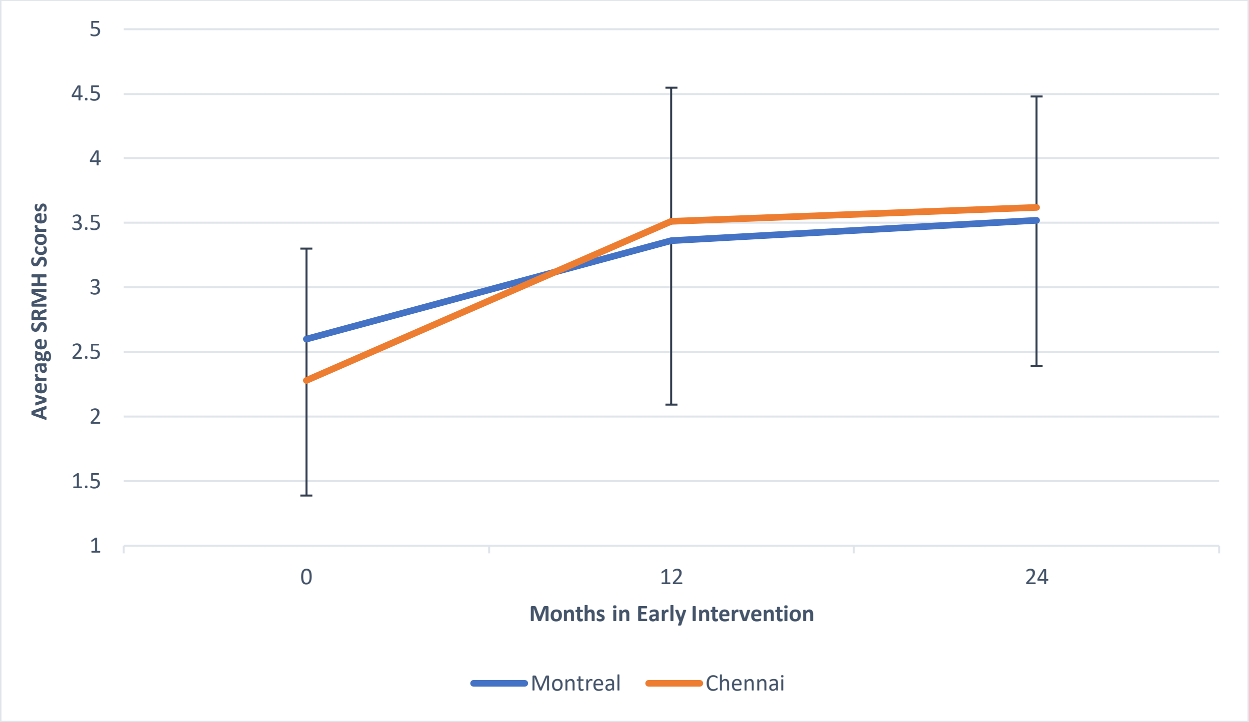


Figure 2. Means and Standard Deviations of Self-Rated Mental Health (SRMH) Scores in Montréal and Chennai over the course of two years



4.8. Supplementary Tables

Supplementary Table 1: Frequency of Self-Rated Health (SRH) Scores

	Total Sample (N=333) n (%)	**Chennai (N=168) n (%)**	**Montréal (N = 165) n (%)**
Baseline			
Poor	20 (6.0)	14 (8.3)	6 (3.6)
Fair	96 (28.8)	74 (44.0)	22 (13.3)
Good	74 (22.2)	44 (26.2)	30 (18.2)
Very Good	50 (15.0)	26 (15.5)	24 (14.5)
Excellent	10 (3.0)	5 (3.0)	5 (3.0)
Missing	83 (24.9)	5 (3.0)	78 (47.3)
Month 12			
Poor	7 (2.1)	0	7 (4.2)
Fair	37 (11.1)	22 (13.1)	15 (9.1)
Good	60 (18.0)	33 (19.6)	27 (16.4)
Very Good	87 (26.1)	62 (36.9)	25 (15.2)
Excellent	33 (9.9)	20 (11.9)	13 (7.9)
Missing	109 (32.7)	31 (18.5)	78 (47.3)
Month 24			
Poor	3 (0.9)	1 (0.6)	2 (1.2)
Fair	20 (6.0)	12 (7.1)	8 (4.8)
Good	50 (15.0)	25 (14.9)	25 (15.2)
Very Good	118 (35.4)	104 (61.9)	14 (8.5)
Excellent	24 (7.2)	15 (8.9)	9 (5.5)
Missing	118 (35.4)	11 (6.5)	107 (64.8)

Supplementary Table 2: Frequency of Self-Rated Mental Health (SRMH) Scores

	Total Sample (N=333) n (%)	**Chennai (N=168) n (%)**	**Montréal (N=165) n (%)**
Baseline			
Poor	56 (16.8)	41 (24.4)	15 (9.1)
Fair	91 (27.3)	60 (35.7)	31 (18.8)
Good	62 (18.6)	39 (23.2)	23 (13.9)
Very Good	28 (8.4)	21 (12.5)	7 (4.2)
Excellent	12 (3.6)	2 (1.2)	10 (6.1)
Missing	84 (25.2)	5 (3.0)	79 (47.9)
Month 12			
Poor	11 (3.3)	3 (1.8)	8 (4.8)
Fair	39 (11.7)	25 (14.9)	14 (8.5)
Good	55 (16.5)	30 (17.9)	25 (15.2)
Very Good	76 (22.8)	57 (33.9)	19 (11.5)
Excellent	43 (12.9)	22 (13.1)	21 (12.7)
Missing	109 (32.7)	31 (18.5)	78 (47.3)
Month 24			
Poor	4 (1.2)	2 (1.2)	2 (1.2)
Fair	24 (7.2)	16 (9.5)	8 (4.8)
Good	60 (18.0)	39 (23.2)	21 (12.7)
Very Good	95 (28.5)	83 (49.4)	12 (7.3)
Excellent	32 (9.6)	17 (10.1)	15 (9.1)
Missing	118 (35.4)	11 (6.5)	107 (64.8)

Chapter 5: Discussion – Overall Findings & Conclusions

This thesis comprised a review of reviews and two quantitative studies with the aims of [1] bringing attention to considerations of equity, diversity and inclusion, or lack thereof, applied to the evaluation of patient-reported measures in psychosis, [2] evaluating the psychometric properties of two such patient-reported outcome measures, Self-Rated Health (SRH) and Self-Rated Mental Health (SRMH), in first-episode psychosis in Chennai, India and Montréal, Canada, and [3] examining how SRH and SRMH change over a two-year course of treatment in early intervention services for psychosis, and the extent to which this varies according to context (Chennai, India vis-à-vis Montréal, Canada).

In collectively discussing the findings from all our studies, it will be demonstrated how these studies point to and address existing gaps in patient-reported measure research and cross-cultural research in early psychosis. Within this discussion, the main findings of these three papers will be outlined in relation to each other and the broader context of work focused on patient-oriented care and the illness experience, as well as cultural psychiatry. The strengths and limitations of this thesis will be highlighted before finally providing recommendations for future directions in this realm of research.

5.1. Summary of Main Findings

Through our review of reviews, we found that many of the literature syntheses on patient-reported measures in psychosis failed to take an approach that prioritized equity, diversity, and inclusion, with respect to both their approaches to reviewing existing studies and membership of their research teams. Regarding the former, we observed that the included reviews primarily focused on quantitative psychometric properties, while rarely commenting on the variety of sociodemographic characteristics of the samples with whom the measures were tested (i.e., their age, gender, ethnicity, language spoken etc.). Most of the measures within the reviews were tested only in high-income countries and in English, and the noticeable lack of examination of their cross-cultural validity across reviews further illuminated a knowledge gap with respect to research on PROMs and PREMs in low-and-middle income countries (LMICs) and across both cultural and linguistic contexts. The other key finding of our equity-based reviews of reviews was that service users were not included as members of the research teams conducting reviews of patient-reported measures. Aligned with this, reviews rarely synthesized and commented on how the patient perspective was considered in the creation or evaluation of measures in their included papers. This was particularly disconcerting given that these were reviews of measures aimed at purportedly bringing a more patient-oriented approach to care and research.

Our second study was a psychometric evaluation of two single-item patient-reported outcome measures (PROMs), the SRH and SRMH, in early intervention services for psychosis in two distinct geo-sociocultural contexts, Chennai, India and Montréal, Canada. The two measures were completed in Tamil and English in Chennai, and French and English in Montréal and were therefore also evaluated for their performance across these languages. In doing so, this study helped address some of the gaps identified in the review of reviews, particularly around the limited focus of PROMs in LMICs and across various linguistic versions. We found that both measures, across samples in Montréal and Chennai and across the three languages, demonstrated sensitivity and mostly good to excellent test-retest reliability. Findings in relation to validity pointed to differences between sites. While some clinician-rated outcomes (i.e., positive symptoms and functioning) were associated with the SRH measure in Montréal, they were more closely associated with the SRMH measure in Chennai.

The third manuscript built on our psychometric study, to evaluate how the SRH and SRMH vary over time and across the contexts of Montréal and Chennai, even after accounting for certain sociodemographic and clinical variables. Our results indicated that while SRH scores increased significantly only in Chennai, SRMH scores increased over the course of early intervention at both the Chennai and Montréal sites, with a greater rate of improvement in Chennai. In comparison to those in Montréal, women in Chennai reported poorer mental health in relation to men. Finally, longer duration of untreated psychosis and higher levels of symptom severity were shown to negatively impact SRH and SRMH scores.

5.2. Synthesis and Significance of Studies

Significance for Cultural Psychiatry, particularly in Early Psychosis

Taken together, our studies make the case for greater and deeper attention to "context" (along with its attendant dimensions like culture, language and gender) in psychosis research, more generally, and in work on patient-reported measures, more specifically.

Our review of reviews adds to growing concerns about the limited attention to equity and diversity in psychosis research (Burkhard et al., 2021). In having to choose from an extensive range of patient-reported measures, researchers and measurement-based systems of care often rely on reviews to help narrow down their search (Al Sayah et al., 2021; Palmatier et al., 2018). Given the extent of research published on social and environmental determinants of psychosis (Anglin et al., 2021; Bourque et al., 2012; Morgan & Hutchinson, 2010; Tsuang, 2000), it remains crucial that reviews on patient-reported measures in psychosis cater to and comment on this diversity to be beneficial for measurement-based care. Beyond reviews, patient-reported measures can only be used across varied cultural and linguistic contexts and with diverse populations within multicultural contexts if they are developed with the socio-demographic and clinical diversity of the end-users themselves in mind.

Foregrounding this missing focus on context and culture, our second and third papers demonstrate that single-item patient-reported measures can be feasibly integrated into early intervention contexts. However, these measures should first be more closely examined across various languages and cultures.

Our work illustrates the potential valuable contributions to cultural psychiatry of integrating common PROMs across early intervention services in diverse contexts. It provides clear evidence for cross-national variations in patient-reported measures (and not only clinician-reported outcomes, which have hitherto been the primary focus of cultural psychiatry) and for some mechanisms underpinning patient-reported outcomes playing similar roles across contexts and others' roles being varied across contexts.

Furthermore, our findings strengthen and extend prior research on cultural variations in mind-body dichotomy to early psychosis, with Western societies tending to hold a more dualistic perspective and societies like India tending to have more integrated perspectives of health and mental health. Understanding these underlying differences in perspectives of health and ill-health between contexts is invaluable when implementing holistic care, like that provided in early intervention services.

Significance for Patient-Reported Measures in Psychiatry, particularly in Early Psychosis

Patient-oriented care and research prides itself in being able to extract a less biased and therefore more authentic understanding of the patient's experience. Thus, it is crucial that patient-reported measures are not only patient-oriented, but also patient-centered and reflective of patients' values (Roe et al., 2022; Trujols et al., 2013). This can be achieved by involving patients themselves in co-designing, co-implementing, co-evaluating, and co-writing studies with the intention of inclusively incorporating their opinions and perspectives. While the recovery movement and patient-oriented approaches have facilitated greater awareness of patient-centred care, the corresponding research needs to actively match and reflect this shift in values and voices.

The social and environmental fabric into which an individual's life experiences are embedded can shape both the development and course of illness and recovery, especially in the context of a diagnosis like psychosis (Cantor-Graae, 2007; Myers, 2011). While individuals experiencing psychosis may have similar difficulties in grappling with their symptoms across contexts, social and cultural dimensions may influence the ways in which individuals pay attention or attribute meaning to these symptoms, or their overarching diagnostic categories (Luhrmann & Marrow, 2016). So, while the SRH and SRMH may be seen as sweeping, nonspecific patient-reported measures, their ability to encapsulate a wide breadth of meaning for each individual and for sets of individuals across contexts may serve to illuminate the breadth of the patient experience.

Rather than patients having to constantly present their case in the framework of psychiatric jargon – that is not always easily translatable across language and context – descriptors such as 'good' or 'poor', as used in the SRH and SRMH, allow for greater accessibility to a wider range of patients. Prioritizing diagnostic neutrality and minimizing the medicalization of symptoms within the context of the clinical encounter has been shown to improve care (Luhrmann & Marrow, 2016). Thus, using self-reported measures like the SRH and SRMH which are not diagnostically specific, may give patients an avenue to speak of their health and mental health in terms that leave more space to the expression of their subjective experience of psychosis, or rather to their ‘illness experience’ (Kleinman, 1988).

As a construct whose complexity and specificity fails to be captured by the mere use of clinician-reported and/or quantitative measures, the ’illness experience’ encompasses the ways in which individuals experiencing distress categorize, interpret, and speak of their own illness, and its full exploration has particular relevance within mental health care (Kleinman & Seeman, 2000; Pierret, 2003). Using a phenomenologically grounded lens to understand the textures and cultural variations of the experience of psychosis, through a combination of both extensive qualitative methodology and short, simply designed patient-reported measures, may play a very important role towards placing patients and their lived experiences at the centre of their treatment and care.

Because of their focus on the self-report of health or illness, patient-reported measures can reduce the power imbalances between patients and clinicians. Their use also helps in creating spaces in which patients can demonstrate insight into their own condition. Clinical constructions of insight are founded on three dimensions – 1. the patients’ construction of their own experience, 2. the clinician’s interpretation of the patient’s experience, and 3. the interactions between the patient and the clinician (Marková & Berrios, 1992). However, what clinicians consider as “adequate” insight depends on how much they value the perspectives of patients towards their experience of psychosis, versus their own understanding of it. Moreover, If patient-reported measures are truly patient-centred in both their creation and orientation (Trujols et al., 2013), they may then serve as a helpful interface between patients and clinicians, namely by helping clinicians gain more insight into the multidimensionality of the patient experience.

Historically, clinicians have held the upper hand in the patient-clinician alliance and, consequently, clinician-rated measures have been regarded as more valuable than their patient-rated counterparts. Due to their allegedly more ‘objective’ approach in assessing the patient’s experience, clinician-rated measures are often seen to judge the severity and need for care more accurately (Hamilton et al., 2017). On the contrary, patient-reported measures have been labelled as ‘subjective’ - a marker that allows for services to easily disregard their utility and importance. Such dichotomies of objectivity and subjectivity remain synonymous with positive and negative, continuing to damage how individuals perceive their identities, agency, and avenues for recovery. Discrepancies between patient-reported and clinician-reported measures have been seen as indicative of poor validity of patient-reported measures, rather than reflective of potential genuine differences between patient and clinician perceptions.

Contrary to the often-reduced validity attributed to them, patient-reported measures offer the possibility of a more intersubjective approach to early psychosis care. Intersubjectivity is "the ability to share in another's lived experience" (Stern, 2005), and within the context of mental health, it indicates the interactive co-construction of the patient narrative (Fuchs, 2010). Our results not only indicate that we need to spend more time addressing the often-observed discrepancies between patient and clinician-reports of the same phenomena, but also validate the role of interpretation in clinical contexts. To situate hermeneutics outside the realm of psychosis is to deny patients of their illness experience and clinicians the knowledge and expertise they bring to the clinical encounter. Rather, in approaching patient-reported measures as an avenue for intersubjectivity, we could allow patient and clinical perspectives to both supplement and complement one another and improve the therapeutic alliance in the process.

5.3. Strengths and Limitations of Studies

The main strength of our studies lies their ability to complement one another in both situating a knowledge gap and subsequently addressing some of those missing element. More specifically, the first manuscript identified an equity-focused gap in the literature pertaining to patient-reported measures in psychosis and the following two, consequently, addressed some of these equity-based concerns by virtue of their methodologies. Novel in both their approach and findings, Studies II and III, as seen together, make up one of the first cross-cultural, combined psychometric and longitudinal explorations of the SRH and SRMH measures in early psychosis.

Despite our advocacy for truly patient-oriented measures, our studies focus on the SRH and the SRMH, two measures which were not created by or co-developed with patients. However, their ease of use and simplicity still warrants a deeper understanding of their suitability within early psychosis. Moreover, as we wanted to evaluate a wider range of reviews, our first study includes both systematic and non-systematic reviews. Although this did not allow for our review to be as standardized in its methodology, it gave us the unique opportunity to examine the breadth of the field. Lastly, our second and third studies were purely quantitative in nature, eliminating the possibility of a more nuanced understanding of how patients interpret the single-item SRH and SRMH measures and their responses (‘good’, ‘poor’, etc.). A qualitative exploration as to what exactly patients are referencing when answering these questions could help to better elucidate how patients “measure” and conceptualize their own health and mental health.

5.4. Recommendations for Future Directions

Regarding future avenues for research, studies should consistently include patients in the design, creation, and implementation of future patient-reported measures, and reviews of PROMs and PREMs should also be sure to include patients in the selection, rating, and evaluation processes. Future reviews might take a more systematic approach to documenting the various elements of equity that are touched upon in each of their individual studies.

With respect to future psychometric studies, such examinations of measures should consistently disaggregate results by a variety of sociodemographic and clinical characteristics (i.e., age, gender, linguistic background, ethnicity, etc.). This way, services that are using these measures can appropriately assess whether using these measures would be helpful, especially considering the demographic of their own service-users.

Lastly, although our studies have provided hints as to what constructs the SRH and SRMH might by tapping into, further explorations of the links between overall health, physical health, and mental health in diverse contexts would benefit our understanding of how culture plays into individual interpretations of health. Explorations of both contextual and individual conceptualizations of these wider constructs would pave the way for future research on patient-reported measures to be even more coherent and invaluable.

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