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ShareDisk: A novel visual tool to assess perceptions about who should be responsible for supporting persons with mental health problems

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Abstract

Objectives: Views on who bears how much responsibility for supporting individuals with mental health problems may vary across stakeholders (patients, families, clinicians) and cultures. Perceptions about responsibility may influence the extent to which stakeholders get involved in treatment. Our objective was to report on the development, psychometric properties and usability of a first-ever tool of this construct.

Methods: We created a visual weighting disk called 'ShareDisk', measuring perceived extent of responsibility for supporting persons with mental health problems. It was administered (twice, 2 weeks apart) to patients, family members and clinicians in Chennai, India (*N* = 30, 30 and 15, respectively) and Montreal, Canada (*N* = 30, 32 and 15, respectively). Feedback regarding its usability was also collected.

Results: The English, French and Tamil versions of the ShareDisk demonstrated high test–retest reliability (*r*s = .69–.98) and were deemed easy to understand and use.

Conclusion: The ShareDisk is a promising measure of a hitherto unmeasured construct that is easily deployable in settings varying in language and literacy levels. Its clinical utility lies in clarifying stakeholder roles. It can help researchers investigate how stakeholders' roles are perceived and how these perceptions may be shaped by and shape the organization and experience of healthcare across settings.

Keywords

ShareDisk, responsibility, mental illness, psychosis, culture, stakeholders, assessment tool

Introduction

A large body of research indicates that the outcomes of treated schizophrenia are more favourable in low- and middle-income countries (LAMICs) than in higher-income countries, at least on select domains (Cohen, Patel, Thara, & Gureje, 2007; Craig, Siegel, Hopper, Lin, & Sartorius, 1997; Iyer, Mangala, Thara, & Malla, 2010; Jablensky et al., 1992). These findings are complex and resist simple explanations. However, they suggest that factors owing to the sociocultural context of treatment may contribute to differential outcomes.

We have been conducting a study of two-year prospective outcomes of first-episode psychosis (FEP) in India and Canada which hypothesized that outcomes would be superior in India and that this would be ascribable to the greater family involvement in the lives and treatment of individuals with psychosis in the Indian context. An important additional objective of this study was to examine the reasons for differing levels of family involvement across contexts.

Higher family involvement in certain contexts may be related to greater perceived responsibility of families to care for and support an ill family member, relative to other stakeholders such as service providers or ill persons themselves. This sense of responsibility emerged in focus groups, conducted with patients, families and clinicians in India and Canada during an earlier pilot phase of our study (Iyer, Loohuis, Pope, Rangaswamy, & Malla, 2014; Iyer et al., 2015).

A critical literature review (Pope, Malla, & Iyer, 2018) on perceptions of responsibility for supporting individuals with mental health problems revealed that divergent views between countries about who should bear responsibility for care may both reflect and drive differences in the organization of mental health care across contexts (e.g., availability of mental health services and of government-provided supports for persons with mental health problems) (WHO, 2018). At the individual level, discrepancies in the perceived roles and responsibilities of key stakeholders (i.e., patients, service providers, family caregivers) in the mental health care context can lead to confusion about the division of responsibilities and impair collaboration between them (Wittenberg, Kwekkeboom, Staaks, Verhoeff, & de Boer, 2018). Families may feel left out of their loved one's treatment despite being deeply involved in their care (Lavis et al., 2015; Lavoie, 2018; Stensrud, Høyer, Granerud, & Landheim, 2015); patients may not feel they have a voice in their own treatment (Farrelly et al., 2016; Knaak, Mantler, & Szeto, 2017); and service providers may take on responsibilities that they feel families should assume (Pope, Jordan, Venkataraman, Malla, & Iyer, 2019). Moreover, different stakeholders' views of their own and each other's responsibilities iteratively shape, and are shaped by, the roles and responsibilities assumed by each. Responsibilities are thus likely seen in relative rather than absolute terms.

Given the potential for varying perspectives across and within sociocultural settings on who bears how much responsibility for supporting individuals with mental health problems, there is a need to measure key stakeholders' relative views in this regard. In this report, we describe the development and psychometric properties of a visual weighting disk measuring perceived extent of relative responsibility in two distinct contexts: Chennai, India and Montreal, Canada. Ours is the first-ever tool that measures this construct and does so in a manner that is impervious to confounding influences of language and culture. We developed such a tool because there was no available measure of this construct.

Methods

Setting and Participants

This study was conducted in Montreal, Canada and Chennai, India. In Montreal, participants were recruited from two specialized early intervention services within the McGill University first-episode psychosis network in Montreal, Canada; namely, the Prevention and Early Intervention Program for Psychosis (PEPP-Montreal) and PEPP-MUHC (McGill University Health Centre). In Chennai, the setting was the first-episode psychosis program of the Schizophrenia Research Foundation (SCARF).

Both PEPP programs are publicly funded, open-referral outpatient assessment and treatment services for persons aged 14 to 35 experiencing a first episode of affective or non-affective psychosis (Iyer et al 2015). Treatment comprises two years of intensive, phase-specific medical and psychosocial treatment delivered by a team comprising a case manager and a psychiatrist. Case managers are mental health professionals from a variety of disciplinary backgrounds (e.g., social work, counselling, nursing). Exclusion criteria include prior antipsychotic treatment for longer than 30 days, organic or clear substance-induced psychosis, IQ less than 70, epilepsy, and pervasive developmental disorder (see Iyer, Jordan, MacDonald, Joober, & Malla, 2015 for a detailed program description).

SCARF is a non-profit, non-governmental mental health organization in Chennai, India that treats individuals with schizophrenia and associated disorders. In collaboration with PEPP, SCARF established a first-episode psychosis program in 2003 that shares all the key features of the PEPP program (e.g., inclusion and exclusion criteria, assertive case management, flexible use of low-dose antipsychotic medication, family intervention, open referral system, etc.) (Iyer et al 2010).

Measures

Weighting disk.

We required an instrument measuring stakeholders' *relative* judgments of responsibility that could be used with ease in two distinct sociocultural settings (Chennai and Montreal), in a variety of languages (Tamil, English, and French). As we were unable to find any existing instruments meeting these criteria, author Iyer designed a measure that reduced reliance on language or literacy and was simple, intuitive, and quick to use and score. A visual weighting disk (Figure 1) was thus created with three centrally mounted, interlocking coloured disks representing the individual with mental health problems, their family, and their treatment team, respectively, set against a larger backing disk displaying a scale from 0 to 100. We call this tool the “ShareDisk” whose segments were labelled "patient", "family", and "treatment team", or the equivalent terms in French and Tamil for French- and Tamil-speaking participants, respectively. The words were translated and back-translated with careful discussion involving team members from both sites. Participants were asked to rotate the coloured disks until the size of each segment corresponded to their view of the relative responsibility of each stakeholder, with a larger segment indicating greater responsibility. They were asked to consider the attribution of responsibilities for supporting patients with mental illnesses, generally, and not with respect to their own specific case (see instructions under Figure 1). The instructions were translated into French and Tamil following WHO-recommended procedures for forward and backward translation(WHO, 2019).

To score the ShareDisk, the percentage responsibility allocated to each stakeholder (ranging from 0% to 100%) was calculated. The disk was inspired by similar instruments used to measure quality of life among individuals with HIV/AIDS (Hickey et al., 1996) and bladder cancer (Somani, Gimlin, Fayers, & N'Dow, 2009). It overcomes some of the challenges associated with questionnaires and more language-dependent measures, allowing it to be used cross-culturally with minimal adaptation. Moreover, because the ShareDisk requires respondents to consider the size of each of the three segments in relation to each other, it is a useful measure of respondents' estimations of the *relative* responsibilities of individuals with mental health problems, families, and service providers/treatment teams.

In addition to the physical paper tool, we developed an online version of the ShareDisk to increase participation from patients and family members who may have been unable to complete the disk in person. The online ShareDisk was designed to be used in the same way as the paper version, that is, by manipulating the size of the three segments to correspond to one's view of the relative responsibilities of each stakeholder. In the online version, participants were asked to click and drag each segment until they were satisfied with the size of each.

Feedback questionnaire.

To assess the ShareDisk s ease of use, we created a brief, easy-to-understand feedback questionnaire asking participants to rate how easy the tool was to complete, understand, and answer. The first two questions were rated on a 10-point Likert-type scale. In the first, participants rated the ease of completing the scale from 1 to 10 and in the second, they rated the ease of understanding it (1 being “very difficult” to 10 being “very easy”). The third question was rated categorically (Was the disk measure difficult to answer? Yes/Somewhat/No).

Procedure

To establish its psychometric properties, the ShareDisk was administered by trained research assistants to patients, their family members (first-degree relatives, spouses, or partners), and service providers (case managers and psychiatrists) from PEPP and SCARF. Research assistants provided ShareDisk instructions in English or Tamil in Chennai, or French or English in Montréal, depending on the participant's preferred language. The same participants completed the disk at two time points, approximately two weeks apart, to allow the examination of test-retest reliability. In addition, feedback questionnaires were administered to a subset of patients at both sites to elicit their views on the tool's ease of use.

Data Analysis

Test-retest reliability was calculated with intra-class correlation analysis, using a two-way random model with absolute agreement. Responses on the feedback questionnaire were analyzed using descriptive statistics. Analyses were performed for each linguistic group separately to determine whether there were differences in test-retest reliability between groups. Test-retest analyses were also re-run comparing the PEPP participants who completed the disk in person (n = 59) with those who completed the disk online (n = 18) to determine whether the mode of administration affected the ShareDisk's reliability.

Results

A total of 77 participants (30 patients, 32 family members, and 15 service providers) were recruited to establish the test-retest reliability of the ShareDisk at PEPP. Of these, 44 participants completed the tool in English and 33 completed it in French. Only 18 participants completed the ShareDisk online; the remainder completed the tool in person; 11 patients completed feedback questionnaires. At SCARF, 75 participants (30 patients, 30 family members, and 15 service providers) were recruited to establish test-retest reliability. Of these, 46 participants completed the ShareDisk in Tamil and 29 completed it in English. All participants completed the ShareDisk in person; 10 patients completed feedback questionnaires. Demographic characteristics of PEPP and SCARF participants are reported in Table 1.

Reliability

At PEPP, both the English and French versions of the ShareDisk demonstrated high test-retest reliability. Specifically, the tool completed in English demonstrated high test-retest reliability with respect to participants' judgments of patients' (r = .88), families' (r = .69) and service providers' (r = .81) responsibilities for supporting persons with mental health problems. The ShareDisk completed in French similarly demonstrated high test-retest reliability with respect to participants' judgments of patients' (r = .71), families' (r = .84) and service providers' (r = .88) responsibilities for supporting persons with mental health problems.

The English and Tamil versions of the ShareDisk at SCARF also demonstrated high test-retest reliability. The tool completed in English exhibited high test-retest reliability with respect to participants' judgments of patients' (r = .98), families' (r = .94) and service providers' (r = .98) responsibilities for supporting persons with mental health problems. The ShareDisk completed in Tamil also demonstrated high test-retest reliability with respect to participants' judgments of patients' (r = .93), families' (r = .86) and service providers' (r = .89) responsibilities for supporting persons with mental health problems.

No significant differences were found in test-retest reliability when comparing the in-person and online administrations.

Participant feedback

Feedback obtained on the ShareDisk at PEPP revealed that participants felt the tool was easy to complete (M = 7.63; SD = 1.84), easy to understand (M = 8.27; SD = 2.14), and easy to answer (n = 7/11; 70%). Participants at SCARF likewise felt the ShareDisk was easy to complete (M = 8, SD = 0), understand (M = 7.90, SD = .31), and answer (n = 10/10; 100%).

We also adapted the framework provided by Bowen et al. (2009) for designing feasibility intervention studies to reflect on eight aspects of feasibility with respect to this tool (see Table 2). This allowed us to identify areas in which the tool already meets these feasibility considerations and pertinent future directions.

Discussion

The objective of this report is to describe the development and psychometric properties of a visual weighting disk (ShareDisk) that measures perceived level of responsibility for supporting people with mental health problems. Our results reveal that the ShareDisk has very good test-retest reliability in two distinct sociocultural settings (Chennai, India and Montreal, Canada) and three languages, with no differences between modes of administration (in person or online). Furthermore, the tool was deemed easy to use by participants.

This construct of perceptions of responsibility has generally been ignored in mental healthcare research. Exceptionally, Hadas & Midlarsksy (2000) used a measure of personal/locus of control orientation to assess whether older adults with emotional distress saw themselves or people/forces other than themselves as responsible for causing or solving an individual’s problem. They found that such perceptions were linked to older adults accepting or rejecting psychotherapy. This work suggests that an individual’s locus of control may influence their health service utilization. Our ShareDisk extends the measurement of locus of responsibility in a substantive way by explicitly ascertaining how individuals distribute responsibilities in the context of treatment between patients, the treatment team, and their families/carers. Its novelty also lies in its use of a visual device and in its assessment of the weighing of relative (rather than absolute) judgments of responsibility.

The ShareDisk has promising clinical and research utility. Clinically, it can be used to ascertain key stakeholders' views of the distribution of responsibilities in the context of treatment and to stimulate a dialogue about roles and responsibilities. This should be welcome in treatment settings given that expectations about responsibilities for care are not always explicitly discussed, to the detriment of therapeutic relationships (Wittenberg et al., 2018). This tool can also be used in global health research to quantify attitudes about healthcare responsibilities and to elucidate how differences in views across stakeholders and settings influence the organization and experience of care.

Strengths

The weighting disk is a novel measure of a hitherto unmeasured construct: perceptions of relative responsibility for supporting individuals with mental health problems. It is easy to use, score, and interpret. Minimal training is required to administer the measure, and because it is largely language-free, it can be effectively deployed in different linguistic settings and with participants of varying literacy levels.

That the construct of perceptions of relative responsibility emerged from focus groups conducted with all pertinent stakeholder groups across two different settings in India and Canada is indicative of its content and construct validity (Iyer et al., 2014; Iyer et al., 2015). Informed by these focus groups, we have pursued additional research on this topic, including a critical literature review to build a conceptual framework of factors influencing views regarding of responsibility for supporting persons with mental illnesses (Pope et al., 2018) and a descriptive qualitative descriptive inquiry with multiple stakeholders regarding their perceptions of responsibility (Pope et al., 2019). The review and the qualitative study further supported the relevance of this construct and the need to understand individuals' perceptions of their own responsibilitiesy vis-à-vis their perceptions of other stakeholders' roles and responsibilities. The ShareDisk provides an engaging and time-efficient method to assess such a nuanced concept of relative perceptions of responsibility. As indicated in Table 2, we have collected data using the ShareDisk from patients, families and service providers in Chennai, India and Montreal, Canada to test our idea that stakeholders across the two sites will differ in their perceptions of how responsibility for recovery should be divided, which we intend to publish within a mixed methods paper in the future.

Limitations

We were unable to assess the ShareDisk for convergent and discriminant validity because there are no other existing measures of the same or opposing constructs, to our knowledge. As such, our psychometric testing was limited to test-retest reliability and feasibility (ease of use). Feedback questionnaires were also administered only to patients and not other stakeholders, and also not to those who completed the measure online. This limits our ability to comment on the ease of use of the online version that was completed without the presence of a staff member.

Implications

Differing views about the loci of responsibility for supporting individuals with mental health problems within and across countries may both influence, and be influenced by, the organization and experience of mental health care. By measuring different stakeholder groups' views of the relative responsibilities of individuals with mental health problems, their families, and service providers, we can better understand these relationships with a view to improving outcomes. Varying perceptions of who should be responsible for supporting individuals with mental health problems may contribute to unmet support needs among persons with mental illnesses. Understanding these views can help define relevant stakeholders’ roles more clearly, which can improve mental health services and strengthen stakeholder accountability.

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Declaration of Interest

SI has received a grant and salary award from the Canadian Institutes of Health Research; and a salary award from the Fonds de recherche du Que´bec–Sante´. **AM** in the past 3 years, has provided research consultation, given lectures at conferences supported by Lundbeck and Otsuka as well as been on an advisory board meeting for the same two companies. **Other authors have no declaration of interests.**

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Tables

Table 1

Demographic Characteristics of Participants

	PEPP *M(SD); n(%)*	**SCARF** *M(SD); n(%)*
Patients (*N* = 30 at each site)		
Age at entry	24.58 (4.98)	25.93 (5.06)
Gender (male)	16 (53.33%)	17 (56.70%)
Education (years)	12 (2.26)	12.2 (3.90)
Family members		
Age (51-60 age bracket)	18 (60.0%)	14 (46.66%)
Gender (female)	23 (79.33%)	16 (53.33%)
Education (at least a Bachelor's degree)	14 (48.22%)	6 (20.00%)
Relationship to patient (parent)	25 (83.33%)	16 (53.33%)
Service providers		
Age (21-30 yrs)	1 (6.66%)	11 (73.33%)
(31-40 yrs)	6 (40.00%)	2 (13.33%)
(41-50 yrs)	4 (26.66%)	2 (13.33%)
(51-60 yrs)	4 (26.66%)	---
Gender (female)	7 (46.66%)	13 (86.66%)
Role: Case manager	8 (53.33%)	15 (100%)
Screening clinician	2 (13.33%)	---
Psychiatrist	5 (33.33%)	---
Discipline: Social Work	4 (26.66%)	8 (53.33%)
Psychology	---	7 (46.66%)
Nursing	4 (26.66%)	---
Medicine	5 (33.33%)	---
Occupational Therapy	1 (6.66%)	---
Counselling	1 (6.66%)	---

PEPP: Prevention and Early Intervention Program for Psychosis; SCARF: Schizophrenia Research Foundation.

Table 2

Adaptation of Bowen et al.'s (2009) framework for examining feasibility of the ShareDisk

Principle	**Question**	**What we know**	**Next steps**
Acceptability	To what extent is the ShareDisk judged as suitable, satisfying, or attractive to relevant stakeholder groups?	Feedback from patient participants with FEP that tool is easy to complete, understand and answer	Feedback from family and clinician participants, working in FEP initially, and then other contexts
Demand	To what extent is the ShareDisk likely to be used or seen as useful (i.e., how much demand or perceived demand will be there?)	Tool was created in response to stakeholder consultations that revealed differences between contexts in how responsibility for supporting recovery is distributed between patients, families and treatment providers. Since no tool was available to quickly assess these perceptions in a larger sample, this tool was created.	Future interest in using or use of this tool following its dissemination will be tracked.
Implementation	To what extent can the ShareDisk be successfully delivered to targeted participants in a specified context?	111/165 (67%) and 117/168 (70%) patients; and 63/124 (51%) and 116/168 (69%) family members at PEPP and SCARF, respectively consenting to our larger study filled out this tool at least once during follow-up. In addition, 30 clinicians (psychiatrists and case managers) in Montreal; and 29 case managers in Chennai completed tool.	In future applications of the tool, uptake and factors facilitating or hindering implementation can be tracked.
Practicality	To what extent can the ShareDisk be used with intended participants using existing resources, without outside intervention?	The measure has been designed to be an intuitive, straightforward, non-verbal tool which can be completed in a few minutes by respondents with minimal instruction.	
Adaptation	To what extent does the ShareDisk perform with a new format or a different population?	We have used the tool with instructions in English, Tamil, and French; in person and online; in Montreal and Chennai; with patients, case managers, psychiatrists and families. These point to its potential for wide generalizability.	In the future, this tool could be deployed with diverse health populations and in diverse settings (geography, linguistic, etc.).
Integration	To what extent can the ShareDisk be integrated within an	This is a low-cost tool; and the same dsk can be used repeatedly. The paper version does not	

	existing system?	require any infrastructure.	
Expansion	To what extent can the ShareDisk be expanded to provide a new program or service?	-	Thus, far the tool has been used for research. But, it could be deployed as a clinical tool to facilitate conversations about sharing of responsibility and roles for recovery between patients, families and treatment providers.
Limited efficacy testing	Does the ShareDisk show promise of being successful with a targeted population, even in a highly controlled setting?	NA	Data analyses currently underway from our large-scale study where we employed the tool in two similarly structed treatment settings in Chennai, India and Montreal, Canada. If the tool picks up differences in stakeholders' perceptions across sites (e.g., all Chennai stakeholders assign more responsibility to families), this would be indication of its "efficacy" or its validity. Similar investigations with specified hypotheses can be conducted (e.g., More responsibility will be assigned to young adults with psychoses compared to adolescents).

Figure

Image 1. ShareDisk.

Instructions (given verbally): We would like to know your general opinion about the relative role and responsibility of people with mental health problems, families of people with mental health problems, and psychiatrists/case managers (i.e., the "treatment team") in helping people with mental health problems get better and move towards valued goals (e.g., getting a satisfying job). People often see the roles of these three parties as being more or less important in relation to each other. This disk allows you to show me how much of a role you think each of these three parties should have by giving the person with the bigger role a larger area of the disk, and the person with the smaller role a smaller area of the disk. Please adjust/move around the colored disks labeled "Patient", "Family", and "Treatment Team" until their relative size accurately represents your view of the role of each in relation to each other.

Note: Tool can be used or modified for clinical and research purposes at no cost, with permission from its creator and this paper's first author at srividya.iyer@mcgill.ca