

Measuring social integration in a pilot randomized controlled trial of critical time: intervention-task shifting in Latin America

Medindo a integração social em um estudo clínico randomizado piloto de intervenção no tempo crítico: transferência de cuidados na América Latina

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Abstract

Global mental health movements increasingly highlight the importance of social integration for individuals living with severe mental illnesses. However, this important individual-level outcome is rarely measured in programs. As part of RedeAmericas, a pilot regional randomized controlled trial of critical time intervention — task shifting — will be conducted, which includes social integration as an outcome measure. It is a time-limited care coordination model to enhance continuity of support for people with severe mental illness during critical periods of transition. Given the challenges of measuring social integration, particularly for a multi-country study with unique cultural contexts, this paper has described the measurement approach used to create a composite measure that uses items from disability and quality of life instruments in addition to other key items.

Keywords: social isolation; mental health; interpersonal relations.

Resumo

Ações globais de saúde mental destacam cada vez mais a importância da integração social de indivíduos portadores de transtornos mentais graves. No entanto, este resultado raramente é mensurado individualmente nos programas existentes na atualidade. Como parte do RedeAmericas, um estudo clínico piloto randomizado controlado regional de intervenção no tempo crítico — transferência de cuidados — será conduzido, o qual inclui a integração social como um resultado de mensuração. A intervenção no tempo crítico — transferência de cuidados é um modelo de tratamento comunitário com tempo limitado que tem como objetivo melhorar a continuidade do apoio às pessoas com doença mental grave, durante períodos críticos de transição. Sob os desafios de mensurar a integração social, especialmente em um estudo multicêntrico que inclui países com contextos culturais únicos, este trabalho descreveu a abordagem de mensuração utilizada na criação de uma medida composta, que utiliza itens de instrumentos de avaliação de incapacidade e qualidade vida, além de outros elementos-chave.

Palavras-chave: isolamento social; saúde mental; relações interpessoais.

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■ INTRODUCTION

Global mental health movements increasingly highlight the importance of social integration for individuals with severe mental illnesses¹⁻⁴. In Latin America, there are regional and country-specific mental health policies that support social inclusion of people with severe mental disorders^{5,6}. While some countries have tried to incorporate social integration in their community-based mental health services, this individual-level program goal is rarely measured. For example, in Brazil, the Ministry of Health promotes actions that facilitate deinstitutionalization, replacing the hospital for treatment services in the community. The main provisions of the Brazilian deinstitutionalization are the Psychosocial Care Centers (CAPS), which are designed for people with severe mental disorders, those having difficulty integrating into their families and the community, and those with repeated hospitalizations. As a strategic initiative of the Brazilian Psychiatric Reform, the function of CAPS is to provide day care, promote social inclusion by means of inter-agency initiatives, regulate entrance into the network of mental health care, and support mental health in primary health care^{7,8}. Although the number of CAPS is increasing, they are still insufficient to meet the population's needs. With few specialized practitioners for CAPS clients, it has not been feasible thus far to monitor the program goal of social integration. Also, without monitoring, the mental health system cannot assess whether the current mode of operation of these services is effective in the social integration of this population⁹.

■ SOCIAL INTEGRATION CONCEPTS AND MEASURES REVIEW

Social integration may refer to various overlapping concepts (i.e. social inclusion, participation in society) and have multiple meanings. There are a few promising efforts to provide a conceptual framework for individual-level social integration. The International Classification of Functioning, Disability, and Health (ICF) is a World Health Organization (WHO) framework that includes participation in society and a complementary measure, the WHODAS 2.0^{10,11}. From the USA literature, Wong and Solomon¹² have proposed a more theoretical and specific framework for 'community integration' of individuals with mental illnesses, which includes a combination of physical, social, and psychological integrations. Another framework, the Capabilities Approach, comes from Amartya Sen and the development literature. It considers not only a person's functioning (activities, achievements), but also their freedoms, whether they have the opportunities and the environment necessary to function as they

wish¹³⁻¹⁵. A final example is an alternative framework in which social integration includes participation in sub-communities as part of an inclusion continuum, which consumers may choose for themselves¹⁶. While there are some promising conceptual frameworks, measurement of social integration is in the early stages, and there is currently no widely accepted single measure of it. Most studies that attempt to evaluate social integration rely on disability and/or quality of life measures; however, those instruments are often insufficient to capture local aspects of integration and they need adaptation and augmentation¹⁷.

■ MEASURING SOCIAL INTEGRATION IN THE CRITICAL TIME INTERVENTION – TASK SHIFTING PILOT RANDOMIZED CONTROLLED TRIAL IN LATIN AMERICA

RedeAmericas aims at generating progress towards community health care for individuals with severe mental disorders (CHC-SMD) in Latin America. As CHC-SMD has evolved in the region, with notable exceptions such as Chile, mental health and primary care clinics have developed in parallel and the connections between services are often weak¹⁸⁻²⁰. Mental health clinics are the main locale for provision of outpatient services to individuals with severe mental disorders; but, they generally lack general health services, do not provide *in vivo* community-based services, have not built strong connections to the communities that use their services, and do not involve users and their families in shaping the offered services^{21,22}.

The vision of CHC-SMD includes an integrated system of community-based primary care and secondary mental health services that are accessible to all people with severe mental disorders and their families, and that promotes full community integration. Assessing community integration is an integral component of the pilot regional randomized controlled trial (RCT) of critical time intervention — task shifting (CTI-TS), which will be conducted in Brazil, Chile, and Argentina. CTI is a time-limited care coordination model to enhance continuity of support for patients with severe mental illnesses during critical periods of transition (e.g. hospital discharge, initiation of community-based services)²³⁻²⁵. CTI-TS will include peer support workers in addition to previously tested versions of CTI that use community mental health workers²⁶.

The primary outcomes of the CTI-TS pilot RCT are to improve quality of life and reduce unmet needs. Among the secondary outcomes is to improve the social integration of the study participants. One of the goals of CTI-TS is to strengthen participation in community activities. The CTI team will help clients develop plans to increase their

community participation and help to address any contextual issues, such as accessibility or stigma so clients can meet their individual goals.

There is no globally recognized single measure of social integration. Given the challenges of defining the concept of social integration and considering that the RedeAmericas research project needs to be applicable in two languages and three cultural contexts, a composite measure of social integration that utilizes established instruments and selected additional items was the most feasible approach for a multi-country RCT of an adapted intervention.

Our composite measure draws upon domains in the WHO Disability Assessment Schedule (WHODAS 2.0) and the WHO Quality of Life instrument (WHOQOL-BREF)^{11,27}. We have extended these instruments in order that they capture broader aspects of integration. For the WHOQOL-BREF, two recreation-related items from the WHOQOL long version were added. For the WHODAS 2.0, two items related to integration were added: how much difficulty do you have establishing a new or maintaining an ongoing romantic/intimate relationship and how much difficulty do you have interacting with three or more people (non-kin) in your community that you would consider friends? While the WHODAS 2.0 asks about difficulties in sexual activities, it does not assess romantic opportunities, an important missing element highlighted in other cross-cultural work²⁸. Regarding non-kin relationships, most concepts of social integration aim at capturing social relationships beyond the family, and

this question fills a gap in the disability and quality of life assessments.

As a composite measure, social integration will likely be analyzed by summing a core set of selected items for a summary score²⁹. In addition to the extended WHODAS 2.0 and WHOQOL-BREF, we will have information about individuals' participation in key-group activities (peers, spiritual/religious, and law/civic). Participation in these things was identified by RedeAmericas working group as activities that CTI-TS may influence and/or that may be particularly salient for the Latin American context. Nevertheless, we have an extensive pretesting protocol that allows for feedback from affected individuals on items/issues that may be missing from certain domains, which will provide us an opportunity to incorporate changes before the pilot RCT begins.

CONCLUSIONS

Social integration is an important goal of both the CTI-TS intervention as well as the CAPS in Brazil, in particular. Mental health programs often assume that such programs increase social integration without directly measuring if this is true. Our results will provide valuable feedback to individual clinics on their program efforts. As CTI-TS is more widely disseminated, it would be informative to know how the intervention affects social integration. Furthermore, creation of the composite measure may yield useful information regarding one strategy for how to assess social integration.

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