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Adaptation of the Barriers to Access to Care Evaluation (BACE) scale to the Brazilian social and cultural context

Adaptação da Escala de Avaliação das Barreiras ao Acesso ao Cuidado (BACE) para o contexto social e cultural brasileiro

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Abstract

Introduction: A significant gap between the number of individuals who need mental health care and the ones who actually have access to it has been consistently demonstrated in studies conducted in different countries. Recognizing the barriers to care and their contributions to delaying or preventing access to mental health services is a key step to improve the management of mental health care. The Barriers to Access to Care Evaluation (BACE) scale is a 30-item self-report instrument conceived to evaluate obstacles to proper mental health care. The main constraint in the investigation of these barriers in Brazil is the lack of a reliable instrument to be used in the Brazilian social and cultural context.

Objective: To describe the translation and adaptation process of the BACE scale to the Brazilian social and cultural context.

Method: The translation and adaptation process comprised the following steps: 1) translation from English to Brazilian Portuguese by two authors who are Brazilian Portuguese native speakers, one of whom is a psychiatrist; 2) evaluation, comparison and matching of the two preliminary versions by an expert committee; 3) back-translation to English by a sworn translator who is an English native speaker; 4) correction of the back-translated version by the authors of the original scale; 5) modifications and final adjustment of the Brazilian Portuguese version.

Results and conclusion: The processes of translation and adaptation described in this study were performed by the authors and resulted in the Brazilian version of a scale to evaluate barriers to access to mental health care.

Keywords: Mental disorders, barriers of care, services, prevention.

Resumo

Introdução: Uma lacuna significativa entre o número de indivíduos que necessitam de cuidado na área de saúde mental e aqueles que efetivamente têm acesso a ela tem sido consistentemente demonstrada em estudos realizados em diferentes países. Reconhecer as barreiras ao cuidado e suas contribuições no sentido de retardar e até impedir o acesso a serviços de saúde mental é um passo essencial para melhorar o manejo em saúde mental. A escala Barriers to Access to Care Evaluation (BACE) é um instrumento de autorrelato, composto de 30 itens, concebido para avaliar os obstáculos ao cuidado adequado em saúde mental. O principal empecilho na investigação dessas barreiras no Brasil é a inexistência de um instrumento confiável para ser utilizado no contexto social e cultural brasileiro.

Objetivo: Descrever o processo de tradução e adaptação da escala BACE para o contexto social e cultural brasileiro.

Método: O processo de tradução e adaptação incluiu os seguintes passos: 1) tradução do inglês para o português brasileiro por dois autores, falantes nativos de português brasileiro, sendo que um deles é psiquiatra; 2) avaliação, comparação e correspondência das duas versões preliminares por um comitê especialista; 3) retrotradução para inglês por um tradutor juramentado, falante nativo de inglês; 4) correção da versão retrotraduzida pelos autores da escala original; 5) alterações e ajustes finais da versão em português brasileiro.

Resultados e conclusão: Os processos de tradução e adaptação aqui descritos foram realizados pelos autores e resultaram na versão brasileira de uma escala para avaliar as barreiras ao acesso ao cuidado em saúde mental.

Descritores: Transtornos mentais, barreiras do cuidado, serviços, prevenção.

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Introduction

Mental disorders are highly prevalent and have been associated with considerable suffering and impacts on emotional and physical health, functioning, and costs. Worldwide, epidemiological surveys have estimated rates of lifetime prevalence of mental disorders among adults ranging from 12.2 to 48.6%, and 12-month prevalence rates ranging from 8.4 to 29.1%.¹ One of the most critical factors involved in the burden of mental disorders is the fact that only a minority of individuals with these disorders receive proper treatment in specialized primary care settings,^{1,2} especially at early disease stages. In Brazil and in other developing countries, where psychiatric assistance has severe deficiencies, this difference is even bigger.^{3,4}

There are several reasons suggested for the difficulty obtaining access to mental health care. They include failure to acknowledge that a significant problem is happening, not knowing where to search for help, a perception that the treatments available are not efficient or are deleterious, a belief that the disorder will resolve spontaneously, a desire to deal with the problem by oneself, and/or not being able to afford expenses related to care.^{1,5} Recently, stigma-related barriers have been the subject of great attention among researchers, with prospective studies and systematic reviews showing that stigma has a negative impact on the use of mental health services as well as on the outcomes of mental disorders.^{2,6-8} In addition, in developing countries, difficulties arising from the offer of care and the physical access to it play an important role in hindering the interaction between individuals and services.

Recognizing these barriers and their individual contributions to delaying or preventing access to mental health services is a key step to overcome obstacles. It is widely known that, the longer the search for treatment, the worse the prognosis, particularly in patients with severe mental disorders. Specifically, a longer duration of untreated psychosis is associated with more severe symptomatology, increased number of relapses, and functioning impairment, affecting the quality of life of patients and carers.^{9,10} Finally, data on several other mental disorders, including major depression, bipolar disorder and drug and alcohol dependence,¹¹ also indicate that early recognition and treatment is crucial to improve illness course and prognosis and to reduce treatment complexity and costs.

Instrument

In this context, the Barriers to Access to Care Evaluation (BACE) scale was developed in the Health Services and

Population Research Department of the Institute of Psychiatry, King's College, in London, England.¹²

The BACE scale is a 30-item self-report instrument conceived to evaluate barriers to access to mental health care. Respondents should indicate whether each item/issue has ever stopped or delayed or discouraged him/her from getting or continuing to get professional care for a mental problem, by checking one of four possible answers: not at all (0), a little (1), quite a lot (2), or a lot (3).

The final version of the original BACE scale resulted from a four-stage process that included: 1) compilation of barrier items as described by barrier studies identified in a systematic review conducted by the authors (BACE v1); 2) editing of items by a panel of experts (BACE v2); 3) testing of BACE v2 items by participants; and 4) modifications to BACE v2 on the basis of psychometric findings (BACE v3). This final version provides flexibility to assess the extent of a barrier and the frequency with which it is experienced by respondents.

Preliminary evidence points to adequate reliability, validity and acceptability of the BACE scale, as well as test-retest reliability, internal consistency, content and construct validity, and adequacy for use in populations with mental disorders, based on readability levels and respondent opinion ratings.¹² So far, the BACE scale has been translated to two different languages (not yet published), and is being used in clinical protocols in several countries. Thus, according to available data, BACE stands out as an accurate, easy-to-apply, user-friendly instrument with good psychometric properties that has the potential to advance research in the field.¹²

The aim of this study was to describe the translation and adaptation process of the BACE scale to the Brazilian social and cultural context.

Methods

The first step was to obtain the consent of the authors of the original scale (Dr. Sarah Clement and Dr. Graham Thornicroft), which was asked for and granted. After that, the translation and adaptation of the instrument from English to Brazilian Portuguese was performed according to specific guidelines¹³ and considering at all times the importance of accommodating the instrument to the current language, setting, and time.¹⁴

The translation process of both the scale and its instructions consisted of the following steps: 1) translation from English to Brazilian Portuguese by two authors who are Brazilian Portuguese native speakers, one of whom is a psychiatrist; 2) evaluation, comparison and matching of the two preliminary versions by an expert committee; 3) back-translation to English by a sworn translator who is an English native speaker; 4) correction of the back-

translated version by the authors of the original scale; 5) modifications and final adjustment of the Brazilian version. These steps are illustrated in Figure 1.

Results

All steps of the translation process were followed as planned, and a final Brazilian version of the scale was produced. The most significant adaptations were required for terms whose literal translation was not currently used in Brazil. Only slight changes had to be made. Examples of these terms as present in the original version, in the translation to Brazilian Portuguese, in the back-translated version, and in the final version are presented in Table 1. Table 2 shows the complete Brazilian version of the BACE scale.

Discussion

The processes of translation and adaptation described in this study were performed by the authors and resulted in a Brazilian Portuguese version of a scale to evaluate barriers to access to mental health care. To date, the BACE scale is the only available instrument to evaluate barriers of care in Brazil. Brazil has several challenges to confront when it comes to the development of research in psychiatry, but recently, prevention and early intervention have become a main focus.^{15,16} In this context, the lack of translated and culturally adapted instruments to evaluate factors involved in the offer of care and services has been a limitation for the advance of early interventions in this country.

The Brazilian version of the BACE scale can be used to generate critical data regarding both avoidance of mental health care and the lack of an adequate mental health system in the country.¹⁷ It is noteworthy that data regarding barriers to access to mental care in Brazil are scarce and limited.¹⁸ In addition, BACE

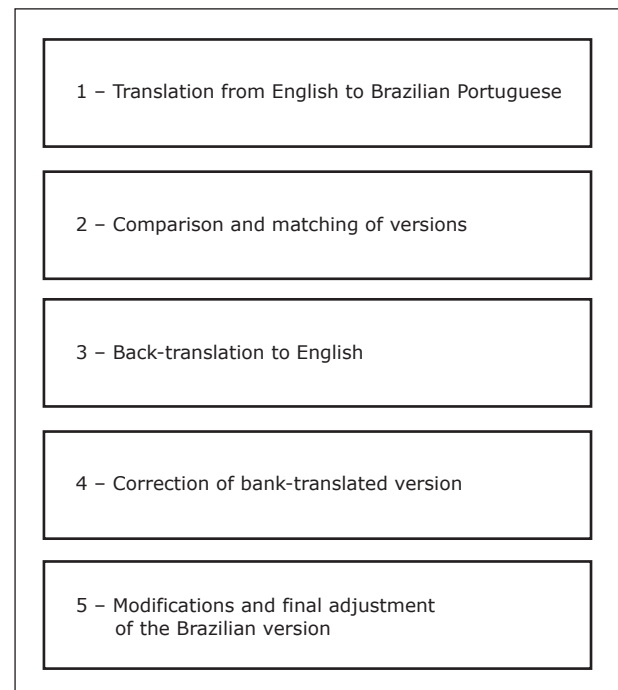


Figure 1 - Translation and adaptation process to Brazilian Portuguese of the Barriers to Access to Care Evaluation (BACE) scale

overcomes limitations of previous instruments. One of the main advantages of the BACE over prior measures is that it provides a comprehensive list of barriers, considering a given construct (e.g., stigma) as a group, as well as exploring the elements that compose it. Previous instruments typically consider barriers through dichotomous outcomes (e.g., yes or no), when in fact users of health care systems frequently refer to barriers in a dimensional way (e.g., not at all, a little, quite a lot, or a lot).¹² In the study of Sheffield et al., for example, high school students were asked to indicate what would stop them from seeking help from a source (school counselor, doctor, psychologist/psychiatrist), if they were

Table 1 - Examples of terms and expressions changed during the translation and adaptation process

Version	Terms and expressions		
	Item 6	Item 24	Item 27
Original English version	Problems with transport or travelling to appointments.	... (my children) might be taken into care...	... taking time off work.
Translation to Brazilian Portuguese	Dificuldades com o uso do transporte ou a ida para as consultas.	... (meus filhos) possam ser levados para cuidados...	... dispensa do trabalho.
Back-translation	Difficulty finding transportation to attend consultations.	... (my children) might be taken away by social workers...	... taking a leave from work.
Final Brazilian Portuguese version	Dificuldades com o uso do transporte ou no trajeto para as consultas.	... (meus filhos) possam ser levados pelo serviço social ou para abrigos...	... ausência ou dispensa do trabalho.

Table 2 - Final Brazilian version of the Brazilian Portuguese of the Barriers to Access to Care Evaluation (BACE) scale

Questão	Isso já me impediu, retardou ou desencorajou DE MANEIRA NENHUMA	Isso já me impediu, retardou ou desencorajou UM POUCO	Isso já me impediu, retardou ou desencorajou BASTANTE	Isso já me impediu, retardou ou desencorajou MUITO
1. Não ter certeza de onde ir para receber cuidado profissional	0	1	2	3
2. Querer resolver o problema sozinho(a)	0	1	2	3
3. Preocupação de que eu poderia ser visto(a) como fraco(a) por ter um problema de saúde mental	0	1	2	3
4. Medo de ser colocado(a) num hospital contra a minha vontade	0	1	2	3
5. Preocupação de que poderia prejudicar as minhas chances quando procurar emprego Não se aplica ()	0	1	2	3
6. Dificuldades com o uso do transporte ou a ida para as consultas	0	1	2	3
7. Pensar que o problema melhoraria sozinho	0	1	2	3
8. Preocupação sobre o que a minha família poderia pensar, dizer, fazer ou sentir	0	1	2	3
9. Sentir-se constrangido(a) ou envergonhado(a)	0	1	2	3
10. Preferir receber formas alternativas de cuidado (p. ex.: medicina tradicional/cura religiosa ou medicina alternativa/terapias complementares)	0	1	2	3
11. Não ser capaz de pagar os custos financeiros envolvidos	0	1	2	3
12. Preocupação de que eu poderia ser visto(a) como 'louco(a)'	0	1	2	3
13. Pensar que o cuidado profissional provavelmente não ajudaria	0	1	2	3
14. Preocupação de que eu poderia ser visto como um pai/mãe ruim Não se aplica ()	0	1	2	3
15. Profissionais do meu grupo étnico ou cultural não estarem disponíveis	0	1	2	3
16. Estar muito mal para pedir ajuda	0	1	2	3
17. Preocupação de que pessoas que eu conheço poderiam descobrir	0	1	2	3
18. Não gostar de falar sobre os meus sentimentos, emoções ou pensamentos	0	1	2	3
19. Preocupação de que as pessoas poderiam não me levar a sério se elas descobrissem que eu estava recebendo cuidado profissional	0	1	2	3
20. Preocupações sobre os tratamentos disponíveis (p. ex.: efeitos colaterais das medicações)	0	1	2	3
21. Não querer um problema de saúde mental nos meus registros médicos	0	1	2	3
22. Ter tido experiências prévias ruins com cuidado profissional para saúde mental	0	1	2	3
23. Preferir receber ajuda de familiares ou amigos	0	1	2	3
24. Preocupação de que meus filhos possam ser levados pelo serviço social ou para abrigos ou de que eu possa perder o acesso ou a guarda sem o meu consentimento Não se aplica ()	0	1	2	3
25. Pensar que eu não tinha um problema	0	1	2	3
26. Preocupação sobre o que meus amigos poderiam pensar, dizer ou fazer	0	1	2	3

(cont.)

(cont.)

27.	Dificuldade para conseguir dispensa do trabalho Não se aplica ()	0	1	2	3
28.	Preocupação sobre o que as pessoas no trabalho poderiam pensar, dizer ou fazer Não se aplica ()	0	1	2	3
29.	Ter dificuldades para cuidar dos meus filhos enquanto eu recebo cuidados profissionais Não se aplica ()	0	1	2	3
30.	Não ter ninguém que pudesse me ajudar a receber cuidado profissional	0	1	2	3

to experience a mental illness, by selecting items from a list of possible barriers.¹³ Similar methods have been adopted in other studies.^{14,15}

Even though the availability of the BACE scale in Portuguese is a significant advance for the field, its validation for a mentally ill population is a necessary next step before the instrument can be adopted across a number of settings – a challenge that will be pursued by the authors. Nevertheless, availability of the Brazilian Portuguese version of the BACE scale offers a new and robust way to measure barriers to treatment, including treatment stigma, with an instrument that can be completed by individuals with any type of mental health problem, receiving any type of professional care, and covering all types of treatment stigma.¹²

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