



Translation and adaptation of the “Diabetes Distress Scale – DDS” in Brazilian culture*

Tradução e adaptação do “Diabetes Distress Scale – DDS” na cultura brasileira

Traducción y adaptación de la “Diabetes Distress Scale – DDS” en la cultura brasilera

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ABSTRACT

Objective: To translate and adapt the Diabetes Distress Scale for the Brazilian culture. **Methods:** The process followed international standards for adaptation of an instrument: translation, back translation and evaluation by a panel of judges, and pretest. **Results:** The stages of translation and back translation were performed successfully, and the evaluation of the synthesis version by the expert panel resulted in modification of items, ensuring the equivalence between the original and translated versions. During the pretest, there were reformulations of some items, making them clearer and easier to understand. **Conclusion:** The Brazilian version of the Diabetes Distress Scale received satisfactory results with respect to the process of translation and cultural adaptation.

Keywords: Diabetes mellitus; Quality of life; Validation studies; Translating

RESUMO

Objetivo: Traduzir e adaptar o Diabetes Distress Scale para a cultura brasileira. **Métodos:** o processo seguiu as normas internacionais para adaptação de um instrumento: tradução, retrotradução e avaliação por um grupo de juízes e pré-teste. **Resultados:** as etapas de tradução e retrotradução foram realizadas com sucesso, e a avaliação da versão síntese pelo comitê de juízes resultou em alteração de itens, assegurando as equivalências entre a versão original e a traduzida. Durante o pré-teste, foram realizadas reformulações de alguns itens, tornando-os mais claros e de fácil compreensão. **Conclusão:** a versão brasileira do Diabetes Distress Scale encontrou resultados satisfatórios em relação ao processo de tradução e adaptação cultural.

Descritores: Diabetes mellitus; Qualidade de vida; Estudos de validação; Tradução

RESUMEN

Objetivo: Traducir y adaptar la Diabetes Distress Scale para la cultura brasilera. **Métodos:** el proceso siguió las normas internacionales para la adaptación de un instrumento: traducción, retrotraducción y evaluación por un grupo de jueces y pre test. **Resultados:** Las etapas de traducción y retrotraducción fueron realizadas con éxito, y la evaluación de la versión síntesis por el comité de jueces dio como resultado la alteración de ítems, asegurando las equivalencias entre la versión original y la traducida. Durante el pre test, fueron realizadas reformulaciones de algunos ítems, volviéndose más claros y de fácil comprensión. **Conclusión:** la versión brasilera de la Diabetes Distress Scale encontró resultados satisfactorios en relación al proceso de traducción y adaptación cultural.

Descriptorios: Diabetes mellitus; Calidad de la vida; Estudios de validación; Traducción

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INTRODUCTION

Diabetes mellitus (DM) is a disease which impacts the patient's and their family's lives, caused by the routine to control it on a daily basis. For the treatment of DM, additionally to the use of medicines, various self-care activities are needed, such as following a food plan, monitoring blood glucose and the practice of physical activities. Furthermore, these patients must deal with the fact of having to live all their lives with a disease responsible for medical complications that impair health and therefore the health-related quality of life⁽¹⁾.

The disease is difficult to control and it can affect mood and self-esteem, leading to frustration and symptoms related to depression and anxiety, which are often associated with several difficulties when facing the daily routine, treatment and fear of developing future complications⁽²⁾. The psychological suffering is not only difficult to tolerate, but also may prevent the patient to assume self-care behaviors, compromising the glycemic control⁽³⁾.

The literature⁽⁴⁾ indicates that, when planning diabetes education programs, the attention to the psychosocial aspects by the health professional team in the assessment of patients and family members is crucial, as well as the diagnosis, during regular appointments or hospitalizations, in the emergence of complications of the disease or when they identify problems in dealing with the treatment⁽⁴⁾. Constant measurements of attitudes facing the disease, expectations regarding the treatment and outcome measures of affection/mood, quality of life, emotional, social and financial resources are identified as critical during all phases of treatment⁽⁵⁾.

Therefore, to assess the attitudes facing the disease, it is necessary to consider the values and opinions of individuals and their expectations regarding the probability of achieving psychological and social changes⁽⁵⁾. In this regard, assessment questionnaires have been used as a tool for measuring the patient's perception of the disease, as well as the evaluation of new therapies⁽⁵⁾. Through these instruments, it has been shown that it is possible to identify problems faced by patients, this is possibly associated with non-adherence or acceptance of the disease, it is also effective to assess the emotional suffering associated with the routine of living with diabetes⁽⁶⁾. Scales and Questionnaires facilitate the joint efforts to improve the quality of care⁽⁵⁾. The purpose is to ensure that the collected information is standardized in order to be compared reliably⁽⁶⁾.

Among the tools available to assess distress related to DM in the international literature, the Diabetes Distress Scale (DDS)⁽⁷⁾ is used in different cultures and in different environments of clinical practice⁽⁸⁻¹¹⁾. This is an instrument which provides reliable psychometric

characteristics and due to the lack of translation into Brazilian Portuguese, we have decided to develop its cultural adaptation.

DDS is an instrument developed in the United States of America (USA), its initial release consisted of 28 items organized in four domains⁽¹²⁾. The authors adapted this version and presented another one consisting of 17 items divided into four subscales⁽⁷⁾ specifically for the evaluation of diabetes-related emotional distress. In the international literature^(10,11), it is evident the use of DDS in clinical protocols for mapping the diabetic distress level. The advantage of DDS, compared to other tools available in the literature,⁽¹³⁾ is that this specifically allows us to identify the subscales separately: emotional burden; physician-related distress; regimen-related distress; and diabetes-related interpersonal distress, enabling direct interventions. This tool also helps identifying people at high risk of developing distress and help preventing the negative effects on disease self-care demand^(4,7). Guidelines from International Diabetes Federation (IDF)⁽¹⁴⁾ recommend the inclusion of emotional distress assessment related to the disease, in order to assist in metabolic control.

Considering the importance of the distress influence on the role of self-care and the lack of specific instruments in Brazil to assess the distress of people with diabetes, this study aims to present the process of translation and cultural adaptation of the Diabetes Distress Scale – DDS tool⁽⁷⁾ to Brazilian culture.

METHODS

This study was based on the theoretical framework of cultural adaptation of the instrument in question, following the guidelines outlined in the literature^(15,16), which comprises five stages: 1 – Authorization from the DDS first author; 2 – Initial translation 3 – Translation synthesis; 4 – Back-translation or translation to the original language (back-translation), 5 – Committee of judges; 6 – Pretest final version.

Cultural Adaptation Procedure and Validation

The first step of this research was the translation of the instrument to the target language in order to communicate accurately the context of the original scale for the Brazilian reality. This stage was performed by two translators, they should be fluent in the original instrument language and should be native in the target language. One of the translators was informed about the purpose of the study, which allowed a cultural and idiomatic equivalence, but the other translator was not informed, this strategy provided the extraction of unexpected meanings of the original instrument. The result consisted of two Portuguese versions, called "I",

respectively, T1 and T2. The translated versions into Portuguese were compared by the researchers involved in the project and a third bilingual translator whose native language is English and who was not involved in the first step of translation. Thus, we created a consensus version in Portuguese, called T1, 2.

Later, with the consensus version (T1,2), the next step was the back translation, which consisted of translating the instrument content in the second language into the original language. Other two independent translators, who are native speakers of English, participated of this stage. They had no information about the objectives, subject and original instrument. Each translator produced an English version (RT1 and RT2). This procedure allowed us to evaluate if the Portuguese version corresponded adequately to the English version, ensuring the quality of the instrument cultural adaptation.

For the continuity of the work, a committee of nine judges was organized, and they were: a professional translator; a medical specialist in Diabetes; a nutritionist; three nurses with experience in Diabetes also in adaptation and validation of tools; a person with Diabetes invited as a patient; besides that, two researchers. Then each committee member received an invitation letter and an agreement term for participation of this study, it was accompanied by an original version of the instrument, the translations into Portuguese, synthesis and back translations and also an assessment tool specifically developed for this step. An independent initial assessment was conducted by the committee members, which conducted the verification on the title, on the items, on the instructions, in the procedure of answer scores and on the registration form. Thus, each item was evaluated, considering the semantic, idiomatic, conceptual and experimental equivalence.

Semantic equivalence is related to the meaning of words (vocabulary, grammar); idiomatic equivalence refers to idiomatic expression and colloquialisms (eg, feeling at home); experimental equivalent approaches situations consistent with the cultural context (eg, to use a car/to use a public transportation; difficulty to use a fork); and finally, the conceptual equivalence refers to the concept explored (eg, exploring the different ways that people understand health) ⁽¹⁷⁾.

After this step, a meeting was held with all members, in order to suggest changes. The committee task was, therefore, to consolidate all versions of the questionnaire and indicate which characteristics should be considered in the pretest version. The items which showed 100% agreement were kept unchanged to its relevance and clarity. While the items which showed disagreement were discussed with the other judges to reach a consensus to reorganize the question.

The next step was the instrument application in a sample of 30 to 40 subjects of the target population, in order to ensure that the adapted version maintained the equivalence to the original version ⁽¹⁶⁾. Thus, the pretest is designed to assess not only the translation quality, but also to verify the practical aspects of its application, how to identify words or questions difficult to understand, in addition to evaluate its acceptability and record the time spent on its application ⁽¹⁷⁾.

The pretest was conducted involving a sample of 40 subjects with type 2 diabetes. The participants were informed about the purpose of the scale and received information for its evaluation, considering the understanding of items and words and possible doubts that the participants had to fill the instrument.

The study was conducted in the Diabetes Mellitus, Hypertension and Obesity Ambulatory (DMHO) of a Teaching Hospital in a city of Sao Paulo State.

The study included patients of both genders, during the follow-up service with type 2 Diabetes mellitus (DM2) people, who were also diagnosed over a year ago, receiving treatment with oral hypoglycemic agents and/or insulin, literate and capable of understanding verbal communication. We excluded people with chronic complications in advanced stage: hemodialysis treatment, amaurosis, presence and sequelae of stroke or heart failure, and amputations at any level of the lower limb.

Data collection was performed according to routine procedures, between October 2010 and January 2011, at a time that preceded the nursing and/or medical visits in a private room. The participants received, previously, the necessary information and the Consent Form was presented. After the signature, we applied the DDS instrument – Brazilian version. For data collection, we used the Diabetes Distress Scale – DDS instrument, specific to evaluate the diabetes-related emotional distress. This instrument consists of 17 items in the short version ⁽⁷⁾. Thus, the total items were divided into four subscales, covering the life of the person with diabetes: emotional burden (5 items); physician-related distress (4 items); regimen-related distress (5 items); diabetes-related interpersonal distress (3 items). The scale used is the Likert-type ranging between 1 (no distress) to 6 (severe distress) points. The participant marks a “circle” to indicate the degree of agreement with the statement of each sentence. On a scale of values, the number 1 represents the situation indicated that the statement is not a problem experienced by the participant, and the number 6 indicates a serious problem. The sum of the answers of four subclasses divided by the number of items generates a total score ranging from 1 to 6. In the subscales evaluation, the partial score, also calculated by the mean, ranges between 1 and 6 for each. The authors consider that a score equal or greater than 3 means a

landmark to differentiate between high and low distress level of each item ⁽⁷⁾.

Regarding ethical issues, the project was approved by the Ethical Committee of the Faculty of Medical Sciences, UNICAMP, process No. 50/2010. The participants with diabetes who agreed to participate in the study signed a Consent Form, in two copies, the interviews were individual and occurred in a single moment.

RESULTS

The process of translation and cultural adaptation of the instrument followed the methodology proposed in the literature. The changes in the items were made based on suggestions from patients, specialists and researchers, with the objective of improving the clarity and interpretation for the population.

The semantic, idiomatic, conceptual and cultural instrument equivalence was evaluated by a committee of judges, who contributed to DDS items assessment regarding the relevance and understanding of what was written. During this stage, questions 1, 3, 4, 5, 6, 10, 11, 12, 13, 15 and 17 achieved a concordance rate of 100% on the scale among committee members, not going through any modifications. The other questions had to go through simple grammatical changes, such as inversion of words in the sentence or any term replacement for corresponding synonymous. The terms "a longo prazo" (item 7), "constantemente" (item 8), "autoajuda" (item 9), "oprimido" (item 14) and "autogerenciamento" (item 16) were replaced by "com o passar do tempo", "frequentemente", "autocuidado", "arrasado", "controlando", respectively, considering that the changes would facilitate the understanding

Table 1 – Evaluation of semantic equivalence between the original instrument in English and the final version in Portuguese, 2011

	Original	Final
1	Feeling that my doctor doesn't know enough about diabetes and diabetes care.	Sentir que meu médico não sabe o suficiente sobre o diabetes e seus cuidados.
2	Feeling that diabetes is taking up too much of my mental and physical energy every day.	Sentir que, a cada dia, o Diabetes está acabando com a minha energia física e mental.
3	Not feeling confident in my day-to-day ability to manage diabetes.	Não sentir confiança em minha capacidade para lidar com o dia a dia do Diabetes.
4	Feeling angry, scared and/or depressed when I think about living with diabetes.	Sentir-me com raiva, assustado e/ou deprimido, quando penso em viver com Diabetes.
5	Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes.	Sentir que meu médico não me dá orientações claras sobre como lidar com meu Diabetes.
6	Feeling that I am not testing my blood sugars frequently enough.	Sentir que eu não estou testando os meus níveis de açúcar no sangue com a devida frequência.
7	Feeling that I will end up with serious long-term complications, no matter what I do.	Sentir que eu acabarei tendo sérias complicações com o passar do tempo, não importa o que eu faça.
8	Feeling that I am often failing with my diabetes routine.	Sentir que eu estou falhando frequentemente com minha rotina do Diabetes.
9	Feeling that friends or family are not supportive enough of self-care efforts (e.g. planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods).	Sentir que os amigos ou a família não apoiam de maneira satisfatória meus esforços de autocuidado (ex: planejam atividades que entram em conflito com meus horários, encorajam-me a comer comidas "erradas").
10	Feeling that diabetes controls my life.	Sentir que o Diabetes controla minha vida.
11	Feeling that my doctor doesn't take my concerns seriously enough.	Sentir que meu médico não leva suficientemente a sério minhas preocupações.
12	Feeling that I am not sticking closely enough to a good meal plan.	Sentir que não estou seguindo, com a devida disciplina, um bom plano de refeições.
13	Feeling that friends or family don't appreciate how difficult living with diabetes can be.	Sentir que os amigos e a família não percebem o quanto pode ser difícil viver com Diabetes.
14	Feeling overwhelmed by the demands of living with diabetes.	Sentir-me arrasado pelas exigências de se viver com Diabetes.
15	Feeling that I don't have a doctor who I can see regularly enough about my diabetes.	Sentir que não tenho um médico que eu possa consultar com regularidade suficiente sobre meu Diabetes.
16	Not feeling motivated to keep up my diabetes self management.	Não me sentir motivado a continuar controlando o meu Diabetes.
17	Feeling that friends or family don't give me the emotional support that I would like.	Sentir que os amigos ou a família não me dão o apoio emocional que eu gostaria.

of the population. For item 2, the terms included were “física e mental”, as presented in the original instrument specifications.

After modifications to the items terminology, the final pretest version was obtained, which was applied to a sample of 40 subjects. The participants reported difficulty in three questions, regarding the terms used, which required the researcher explanation to the participants about question meaning; consequently, only after explaining the questions, the participants understood what was being asked. Thus, the terms have been replaced by others of better understanding, or removed from the sentence such as “sugando minhas energias” for “acabando com minhas energias”, “não me dá orientações suficientemente claras” for “não me dá orientações claras” and “motivado a continuar autogerenciando meu Diabetes” by “motivado a continuar controlando meu Diabetes”. The final version obtained during the process of adaptation is presented in Table 1.

DISCUSSION

The process by which the Brazilian version of the Diabetes Distress Scale was submitted meets the criteria of equivalence between the original and the translated instrument. The methodological rigor employed in the stages of this study enabled a version that preserved the meaning and content of the original instrument. The DDS is used to assess the emotional distress related to DM, being an instrument for helping in research with diabetic patients in the international sphere^(4,10,11), validated in other languages^(8,9).

According to the literature^(15,16), the pretest ensures the original version preservation, improving the understanding and finding errors and problems on application. Based on the achievement of pretest, we found words and expressions that might cause confusion and it could interfere with the results. The low level of education and functional illiteracy are factors that may make this process difficult. In our study, these aspects were taken into consideration, so the changes made have improved the clarity and ease of understanding, bringing it nearer to the population of interest reality.

It is necessary to adapt the language from the cultural and conceptual point of view of the population of interest, but without losing the original purpose of the instrument. There was a percentage of 100% agreement on most items of the instrument, in the individual analysis performed by the committee of judges⁽¹⁸⁾. For other items, the members meeting collaborated to achieve agreement among the judges and accept

suggestions in order to facilitate understanding of the instrument. It is noteworthy that the composition of this committee followed the literature guideline^(15,16), it was composed by different health professionals with experience in cultural adaptation and on the topic, in addition a professional with expertise in English and Portuguese language.

The evaluation of the patient psychological and social aspects, caused by the disease imposition, enables the planning of interventions involving the use of educational theories, which involves behavioral approaches and addresses the cognitive, social and cultural aspects on the construction of knowledge and ability to reduce the impact of disease on these individuals daily lives.

In recent decades, researchers developed evaluation measures in order to enhance understanding of the factors that may operate in the successful treatment of DM. With regard to specific instruments to assess aspects of life and routine of patients with Diabetes, scales were developed, which each differing in objective and specific content⁽¹⁹⁾. In Brazil, some of the existing adapted and validated tools are: Diabetes mellitus Knowledge (DKN-A) Diabetes mellitus Attitude (ATT-19); Diabetes Quality of Life Measure (DQOL-Brasil); Diabetes Quality of Life for Youths (DQOLY- Brasil), Diabetes 39 (D-39); Insulin Management Diabetes Self-efficacy (IMDSES); Problem Areas in Diabetes (PAID); and Summary of Diabetes Self-Care Activities Questionnaire (QAD)⁽¹³⁾. It is essential to have tools which can help to identify individual needs, and thus promote interventions that can collaborate confronting the disease, as well as support the design of effective educational interventions, which consequently result in optimization quality of nursing care⁽²⁰⁾. It is necessary to recognize the influences of each specific disease, so the nurse can guide preventive actions, identify and intervene early in health problems that can compromise the biopsychosocial aspects of the person.

In conclusion, it is important to note that translation and cultural adaptation of an instrument is a process that requires more effort than just semantics and idiomatic issues, it is necessary to adapt the language from the cultural and conceptual reality point of view of the study population.

CONCLUSION

In this study, we may argue that the DDS Brazilian version found satisfactory results regarding to the translation and cultural adaptation process. However, it is necessary that the DDS continues to be tested with respect to psychometric properties evaluation, such as

reliability and validity in different sociocultural contexts of the Brazilian reality.

This is an easy instrument of application, making it feasible for clinical practice. The psychological needs must be assisted and evaluated constantly, since the routine care of diabetes is exhausting and requires the patient to take an active role in treatment. Therefore, identifying the difficulties faced by the patient will help achieve the goals of improved glycemic control, promoting the active role of self-care and intensifying the psychological care of patients.

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It is considered that this study achieved its objectives, as well as contributed to provide a tool for research and clinical practice, which can assess the impact of the disease in diabetic patients and it can help the intervention to promote a better confrontation with the disease.

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