



Adaptation and psychometric assessment of the instrument “Partners of Adults with Type 1 Diabetes Distress Scale” in a Brazilian population

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ARTICLE INFO

Keywords:

Type 1 diabetes
Psychological stress
Partners
Psychometric
Translation scale

ABSTRACT

Objectives: To adapt the instrument “Partners of Adults with Type 1 Diabetes Distress Scale” (Partner-DDS) into Brazilian culture, and to evaluate the psychometric characteristics of the adapted version.

Methods: All the cultural adaptation steps of the measure's instruments were followed. The psychometric properties such as reliability (stability by test-retest; internal consistency), and convergent construct validity were performed.

Results: Of all 72 partners, 69.4% were male, mean age: 42.69 ± 14.09 years, mean of marriage duration: 14.74 ± 12.41 years, and mean schooling: 11.81 ± 3.91 years.

The internal consistency of the instrument (Cronbach Alpha) was 0.90. The intra-class coefficient (stability) was 0.80 (0.72–0.84). The Spearman coefficient (convergent construct validity) between the Partner-DDS scale and the Anxiety subscale of the Hospital Anxiety and Depression Scale (HADS-A) was 0.4273 ($p < 0.0002$).

Conclusions: The steps of the instruments' cultural adaptation were appropriately performed. The Brazilian version of the Partner-DDS scale demonstrates reliable psychometric properties for being used in POPWT1D distress evaluation in Brazil.

Innovation: The cultural adaptation of Partner-DDS scale into Brazilian Portuguese is a helpful innovation to assess the emotional burden in POPWT1D. This tool could be used to provide education and psychological support for this population.

1. Background

The literature has been shown that partners of persons with type 1 diabetes (POPWT1D) have considerable distress, which could affect not only their quality of life, but their relationships, and also the glucose management of their spouses [1].

Studies have been demonstrating a high level of distress among persons with type 1 diabetes (PWT1D) [2-4]. Likewise, the psychosocial issues and the emotional burden impact diabetes management and the glycemic results have been reported [5-6]. However, few studies investigated the mental health and the psychological experiences of POPWT1D [7].

Fisher, et al. (2002) demonstrated that partners of persons with type 2 diabetes (POPWT2D) have high levels of distress even higher than their spouses, mostly when the partner is female gender. Polonsky et al. pointed out that levels of partners' diabetes distress are high, especially due to concerns related to the risks of hypoglycemia [7]. Although the emotional

involvement of POPWT1D is variable, high levels of anxiety, concerns related to hypoglycemia, and future diabetes complications can cause exhaustion for partners and their relationships [1].

A Brazilian study found a high frequency of clinical meaningful anxiety and depressive symptoms among POPWT1D, associated with severe hypoglycemia episodes as well as chronic diabetes complications of their spouses [8].

Family and POPWT1Ds exert great influence in acceptance and adaptation to the daily demands of diabetes management [9-12]. Studies related to chronic diseases and social support demonstrated that partner emotional support is the most important support source with relevant effects when compared to other sources of support as another family member or friends [1,9,13-17].

The acknowledgment that a chronic disease can be a shared stressor between PWT1Ds, and their partners justifies the investigation of distress sources and the adoption of strategies focused on ways to deal with these

Abbreviations: T1D, type 1 diabetes; PWT1D, persons with T1D; POPWT1D, partners of persons with T1D; Partner-DDS, Partner Diabetes Distress Scale; HAD-D, depression subscale of the Hospital Anxiety and Depression Scale; HAD-A, anxiety subscale of the Hospital Anxiety and Depression Scale.

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<http://dx.doi.org/10.1016/j.pecinn.2023.100155>

Received 21 June 2022; Received in revised form 10 April 2023; Accepted 16 April 2023

Available online xxx

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stressors [18]. Specific evaluation of distress sources of POPWT1D can help to tailor meaningful clinical strategies aimed to improve the proper involvement in the spouses' treatment. The quality of the marital relationship is related to diabetes personal adaptation. Moreover, better diabetes adaptation is associated with lower suffering, higher quality of life, and marital satisfaction [1].

Polonsky et al. [7] developed an important tool to evaluate and measure the levels of distress in POPWT1D denominated “*Partner Diabetes Distress Scale*” (*Partner-DDS*) [7]. The *Partner-DDS* scale is a meaningful and useful tool to address the most important sources of distress related of having a close relationship with someone with a chronic disease such as T1D, especially regarding to the concerns related to hypoglycemia, the disease management, and its complications. The *Partner-DDS* scale is easily understandable and psychometric properties of the original instrument are appropriate [7]. But this instrument needs to be adapted to Brazilian culture to be used in the Brazilian population. Considering it, the current study aims to perform the adaptation of the instrument “*Partners of Adults with Type 1 Diabetes Distress Scale*” (*Partner-DDS*) into Brazilian culture and to evaluate the psychometric characteristics of the adapted version.

2. Methods

2.1. Subjects

Seventy-two POPWT1D whose spouses were followed in three diabetes clinics in Campinas, Sao Paulo, Brazil took part in this study. Two of these clinics were public (State University of Campinas) and one was a private diabetes clinic. The study was developed between March 2018 and March 2019.

The inclusion criteria were: POPWT1D aged 18 years old or older whose spouses received T1D diagnoses for at least 6 months and the exclusion criteria were: history of severe psychopathology (such as schizophrenia, bipolar disorders, addictions, dementia syndromes), a cognitive impairment that prevent the participants to answer the study questionnaires, and chronic diseases that caused severe stress (cancer, stroke, transplant, and patients on dialysis).

The POPWT1D were invited to participate in this study during the routine appointments of their spouses. When PWT1D was not followed by your partner during their appointments, the invitation was made through PWT1D, and if their partner agreed to participate, they received a phone call to schedule an interview with the research team.

2.2. Cultural adaptation procedure

The *Partner-DDS* cultural adaptation followed the steps recommended by Beaton et al. [19].

After the author's authorization, the instrument was translated to the target language, Brazilian Portuguese. This stage was performed by two translators proficient in English who were native Portuguese speakers. One of the translators had experience in the cultural adaptation of questionnaires and the other one did not.

The translated versions named T1 and T2 were compared by the researchers involved in this study and a conciliated Portuguese version (T1,2) was obtained.

The next stage was the back translation of the T1,2 Brazilian version to English, performed by two translators, whose mother tongue was English. Both translators performed separately two independent versions, named RT1 and RT2. Posteriorly, a research committee evaluated all versions regarding the semantic, idiomatic, conceptual, and experimental equivalences. Two endocrinologists, one psychiatrist, one psychologist, two dieticians, one linguist, and one POPWT1D made up the research committee. All the differences among the committee were discussed until the consensus was reached.

The flowchart below illustrates all the stages performed (Fig. 1).

2.3. Psychometric properties assessment

The psychometric properties evaluated were: reliability (internal consistency and stability) [20-22], and construct validity [20].

2.3.1. Reliability

2.3.1.1. Internal consistency. The internal consistency was evaluated by Cronbach Alpha [24]. The Alpha equal to or higher than 0.7 indicated adequate reliability of the instrument adapted version [28]. Additionally, the current study analyzed the internal consistency for each subscale of the *Partner-DDS* subscale.

2.3.1.2. Stability. Stability was evaluated by test-retest [22-24]. The *Partner-DDS*, the Brazilian version was applied two times in the same participants, in 2 weeks- 3 months intervals. The re-tests were made in 50 participants, based on literature guidelines [25]. To evaluate temporal stability, the Intra-class coefficient (ICC) was used [26]. The correlation was classified as weak if ICC was >0.5 , moderate if ICC was 0.5–0.7, and strong if ICC was ≤ 0.8 . [27].

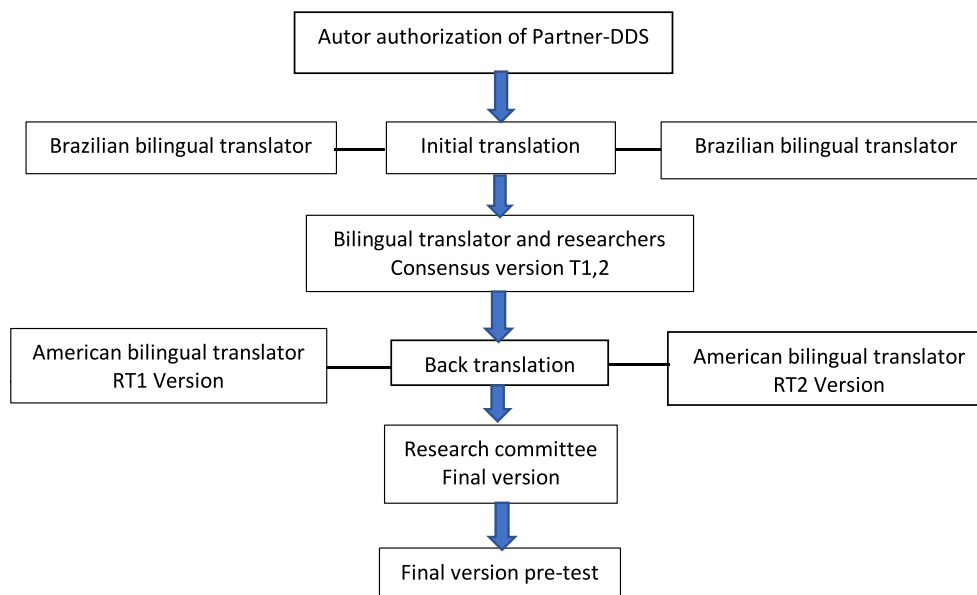


Fig. 1. Flowchart of the stages of the Process of Cultural Adaptation of the *Partner-DDS* instrument described by Beaton et al.

2.3.2. Convergent construct validity

The convergent construct validity [20] was evaluated by the correlation between the Partner- DDS scale and the Anxiety subscale of the Hospital Anxiety and Depression Scale (HADS-A) [29], and we considered the possibility of a significant positive correlation between the distress levels and anxiety levels. We opted to use this scale because the distress construct and the anxiety construct are interchangeable. Also, the correlation of the anxiety subscale of the hospital anxiety and depression scale and the distress scale is moderate based on our previous studies [30]. Moreover, we do not have gold standard instruments to measure T1D partners anxiety that were translated to Portuguese and that were culturally adapted for the Brazilian population.

The Spearman correlation was used to analyze this correlation [31], and the following indexes were adopted: Spearman correlation 0.1–0.29- weak correlation; 0.30–0.49- moderate correlation; ≥ 0.5 strong correlation [27].

2.4. Measures

2.4.1. Sociodemographic data

The sociodemographic data of POPWT1D and PWT1D included: Age, sex, schooling (years), income, according to IBGE [32], and duration of marital relationship. Clinical data of PWT1D were: age at T1D diagnoses and time of T1D.

2.4.2. Instruments

The Partner-DDS scale has 21 items and uses a Likert scale, in which the respondent answers the number that indicates the degree of concordance with each question. The instrument has 4 subscales including the main aspects of the partners' suffering: My partner's diabetes management (7 items); How best to help (5 items); Diabetes and me (5 items); e Hypoglycemia (4 items) [7]. Level 0 represents that the situation described in the answer is not felt at all for the partner, and level 4 represents that it was felt in the highest level. The sum of the 4 subscales answers divided by the total items results in a score that varies between 0 and 4.

For the subscales, the partial score also varies between 0 and 4. The score ≥ 2 indicates clinical meaningful distress (moderate and high distress) [7].

The Cronbach alpha of the original scale was 0.95 for the total score and 0.85–0.93 for the subscales [7].

The “Hospital Anxiety and Depression Scale” (HADS) is used to evaluate anxiety and depressive symptoms in persons with chronic diseases and it was adapted to Brazilian culture by Botega, et al. [29]. The scale has 14 items, being 7 to evaluate anxiety (HADS-A), and 7 to evaluate depressive symptoms (HADS-D). The levels between 0 and 3 indicate the level of the answer for each question and scores ≥ 8 in each subscale indicate clinical meaningful symptoms, according to literature [33].

2.5. Statistical methods

Descriptive analyses were performed with measures of mean values for numerical variables and frequency (percentage) for categorical variables.

The relation between two numerical variables was measured by Spearman's correlation coefficient [30]. To evaluate test- re-test, confidence interval inter-class was used (ICC) [26]. Internal consistency was performed by Cronbach alpha [34].

All analyses were made with SAS version 9.4 for Windows [35]. Statistical significance was 0.05.

3. Results

3.1. Sociodemographic data

Of all the POPWT1D, 69.4% were male, aged 42.6 (± 14.09) years. The mean schooling was 11,81 ($\pm 3,91$) years, and mean income was until 3 minimum wage [31].

The sociodemographic characteristics of POPWT1D and PWT1D and clinical data of PWT1D were described in Table 1.

3.2. Cultural adaptation

The specialists' committee suggested adding the meaning of the term hypoglycemia between parenthesis (low levels of glucose) to make sure that all participants could understand this medical term. In addition, there were other suggestions recommended by the committee.

In the title, the term “diabetic” was changed by “person with diabetes” (PWT1D); in question 2, the term “confuse” was changed by “unclear”; in question 3, the phrase “exclude me of your diabetes” was changed by “don't allow me to take part in your diabetes care”; in question 5 the word “demands” was changed by “requirements”; in question 7, the expression “I speak less” was changed by “I shut up” about it; in question 9, the word “notice” was changed by “perceive”; in question 13, the phrase “to help my spouse to better control their diabetes” was changed by “ to help my spouse be more successful in their diabetes control”.

3.3. Psychometric properties evaluation of Partner-DDS, Brazilian version

3.3.1. Reability

3.3.1.1. Internal consistency. The Cronbach Alpha of *Partner- DDS*, Brazilian version was 0.90 (optimal consistency), and the subscales Alpha ranged from 0.66 to 0.90. The subscales A, B, and C presented optimal consistency, and the subscale D showed regular consistency. These results are summarized in Table 2.

Table 1

Personal, sociodemographic characteristics of POPWT1Ds and PWT1Ds reported by the partners.

Variables	N (%)	Mean	S.D.	Median	Min	Max
POPWT1Ds						
Age (years)	–	42.69	14.09	40.00	20.00	84.00
Male gender	50 (69.4%)	–	–	–	–	–
Education level (years of study)	–	11.81	3.91	11.00	3.00	27.00
Length of relationship (years)	–	14.74	12.41	12.00	0.50	47.00
Income reaching until 3 Brazilian minimal wages	33 (45.8%)	–	–	–	–	–
PWT1Ds						
*Age (years)	–	41.18	12.74	39.00	17.00	73.00
*Female gender	52 (72.22%)	–	–	–	–	–
*Education level (years of study)	–	11.68	4.05	11.00	2.00	25.00
*Years of T1D	–	23.53	11.69	23.00	1.00	58.00
*Age at diagnosis	–	16.78	12.49	14.00	0.00	62.00

Total N = 72.

* Variables associated with PWT1Ds self-reported by POPWT1Ds; D.P.: standard deviation.

Table 2
Partner-DDS - Cronbach alpha of total scale and subscales - internal consistency.

Subscales	Number of items	alpha
A. My partner's diabetes management	7	0.90
B. How best to help	5	0.85
C. Diabetes and me	5	0.83
D. Hypoglycemia	4	0.66
Total Scale	21	0.90

Subscales of the *Brazilian version Partner-DDS*, number of items of each subscale and Cronbach alpha of the total scale and each subscale.

Table 3
Intraclass correlation coefficient (ICC) - correlation between test and retest (CI-95%) of the *Partner-DDS* Brazilian version instrument.

Subscales	ICC
A. My partner's diabetes management	0.84 (0.74–0.91)
B. How best to help	0.75 (0.60–0.85)
C. Diabetes and me	0.72 (0.55–0.83)
D. Hypoglycemia	0.76 (0.61–0.86)
<i>Distress Total</i>	0.80 (0.68–0.88)

ICC: intraclass correlation coefficient; Subscales and total scale: strong correlation; subscales B, C and D: moderate correlation; IC: Confidence interval.

Table 4
Scores subscale *HADS-A* and Brazilian version of *Partner-DDS*.

Instrumentos	Mean	S.D.	Median	Min.	Max.
B-HADS-A	7.14	4.63	6.00	0.00	20.00
B-Partner-DDS	1.21	0.77	1.00	0.29	3.33

B-HADS-A: Anxiety subscale of the Brazilian Version Hospital Anxiety and Depression Scale; B-Partner-DDS: Instrument *Partner-DDS* Brazilian version; D.P.: standard deviation.

3.3.1.2. Stability. The Partner-DDS stability, obtained by test-retest resulted in an ICC de 0.80 (0.72–0.84) (CI: 95%), indicating a strong magnitude correlation (See [Table 3](#)).

3.3.2. Convergent construct validity

The comparison between the Brazilian version of the Partner-DDS scale and the Anxiety subscale of the Hospital Anxiety and Depression Scale resulted in a Spearman Coefficient: 0.4273 ($p < 0.0002$), indicating a moderate correlation.

The mean scores and the standard deviation of these instruments are reported in [Table 4](#).

4. Discussion and conclusions

4.1. Discussion

This study performed the cultural adaptation of the original English version of the Partner-DDS scale for the Brazilian Portuguese and into Brazilian culture, and also evaluated the psychometric properties of the adapted version. Until the present moment, the Partner-DDS is available only in English and French languages [36].

The literature pointed out that the distress associated with living with a PWT1D was not assessed by instruments such Beck Depression Inventory, The Spielberger Trait Anxiety Inventory, and the conflict subscale of Spanier's Dyadic Adjustment Scale (DAS) [37]. These instruments measure specifically anxiety and depressive symptoms. Thus, the Partner-DDS cultural adaptation will allow the assessment and measurement of the PWT1D distress from the Brazilian population.

All the recommended steps for the questionnaire's adaptation were followed to guarantee the instrument reliability. Based on the results

found in this current study, the Brazilian version of the Partner-DDS is understandable, stable, and displays adequate psychometric characteristics.

Regarding internal consistency, only the subscale D (distress with hypoglycemia) presented regular consistency due to the question 18. This question refers to the partners' concerns about their spouses having hypoglycemia while driving. Considering that the majority of the POPWT1D who took part in the current study referred that their spouses did not drive, they answered no to the hypoglycemia distress while driving question. We need to highlight that reliability of the instruments is not a static property, thus it should be reevaluated in different populations [21].

Therefore, the Partner-DDS scale should be replicated in a larger and diverse population and a confirmatory factor analysis (CFA) should be performed to confirm the instrument dimensionality.

Is crucial to remark that familial support is the main support source of persons with chronic diseases [38], and POPWT1D may present a considerable emotional burden resulting from a close daily relationship with the diabetes of their spouses [9,11,39,40]. The mental health of POPWT1D and the impact of living close to the requirements of T1D management are topics few studied. Thus, the Brazilian Partner-DDS scale could be a relevant instrument to assess distress in Brazil in research. We expect that the knowledge obtained by this assessment can guide health professionals to implement educational and clinical support to help POPWT1D populations.

Moreover, the adapted version could be used in clinical studies, allowing data collection in a trusted and standardized way. It can help the development of new psychosocial approaches for POPWT1D. It might help PWT1D to achieve better glycemic results, as well contribute to improving POPWT1D quality of life, that are affected negatively by their spouses' disease.

This study has some limitations. The principal one was the retest interval. Most of the studies recommend two or three weeks between test and retest. However, in our study, the interval was around 2 months due to the scheduled appointments of PWT1D. Another limitation is due to the study population. Most of PWT1D from our university do not drive. This particularity had some impact in the question 18 and in the subscale D. And finally, this study sample was obtained by convenience.

4.2. Innovation

The familial support is crucial for PWT1D on their T1D management and literature reports that POPWT1D also have high distress levels themselves. Instruments that assess distress in POPWT1D are needed and we do not have an appropriated scale for use in Brazil. Therefore, the cultural adaptation of Partner-DDS scale into Brazilian Portuguese is a helpful innovation to assess the emotional burden in POPWT1D. This tool also could be used to provide education and psychological support for this population.

In addition, the Brazilian version of Partner-DDS scale could be used in research allowing data to be collected in large scale in a reliable and standardized way. The knowledge obtained in research would guide the multi-disciplinary teams to implement measures that contribute with PWT1D support and also to improve the quality of live of POPWT1D who are psychologically affected by their partner's disease.

4.3. Conclusions

The Partner-DDS scale was adapted into Brazilian culture and can be used to evaluate the distress of POPWT1D in Brazil. The adapted version demonstrated adequate psychometric properties, and it can be used in clinical practice and research.

Ethics approval and consent to participate

This study followed the principles of the Declaration of Helsinki and was approved by the University Ethics in Research Committee in May 2017 (Ethics Committee on Research-Unicamp): CAAE number: 68202017.0.0000.5404. All the partners who agreed to participate in this study signed the Consent Form.

Funding

Coordenação de Aperfeiçoamento de Pessoal de Nível Superior - Brasil (CAPES) - Código de Financiamento 001.

Credit authorship contribution statement

EB developed and conducted the study, made initial data interpretation and text writing. MSVMS contributed to the study design, text writing, English version, and critical suggestions. EJP contributed with text review, critical suggestions, and analytic review. All authors read and approved the final manuscript.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Edimariz Buin reports financial support was provided by Coordenação de Aperfeiçoamento de Pessoal de Nível Superior - Brasil (CAPES).

Acknowledgments

Lawrence Fisher, PhD, co-author of the original scale, who authorized us to adapt the instrument to Brazilian culture.

Andreia Pastore, MSc; Bruno Maroneze, MSc PhD; Lindemberg Silveira, MD PhD; Ticiane Bovi, MSc PhD; Thais Brasil, MSc; Carl Albert Mathieu; Terrence E, Hill; Walkyria Volpini, MD PhD (specialists committee).

Paulo Oliveira Fanti, who performed statistical analyses for support on statistical analyses.

We thank all participants in this study.

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