

Validation and Cultural Adaptation of the Problem Areas in Diabetes-5 (PAID-5) Scale to European Portuguese

Validação e Adaptação Cultural da Escala “Problem Areas In Diabetes-5” (PAID-5) para Português Europeu

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ABSTRACT

Introduction: Diabetes distress syndrome (DDS) can lead to poor outcomes and should be assessed with adapted and validated tools. One of these tools is the Problem Areas in Diabetes (PAID) scale, which assesses diabetes distress in people suffering from diabetes (PsD). A short five-item form, PAID-5, is an easier and quicker alternative to be used in clinical and research practices, than the previous one with 20-items and has been validated by the original authors. This study intended to perform the cultural adaptation and validation of the PAID-5 scale in European Portuguese.

Methods: To create the Portuguese version of PAID-5, translation-back translation, a clinical review, and a cognitive debriefing panel were performed. A convenience sample of 90 PsD was studied in three primary healthcare units for reliability and validity tests. Reliability was studied by the internal consistency (Cronbach's alpha) and the interval coefficient correlation (ICC) under a test-retest design. Structural validity was studied by principal component analysis. The construct validity was tested by the sensitivity of the PAID-5 total score with age, most recent HbA1c test, and socioeconomic class by the Socio-Economic Deprivation Index (SEDI). Criterion validity was tested by correlating the PAID-5 total score with the psychological distress questions of the Diabetes Health Profile 18 Questions (DHP-PDQ).

Results: A Cronbach's alpha coefficient value of 0.905 and an ICC of 0.905 were computed. In a sample of n = 90 PsD, 55.6% were males, 63.3% aged 65 years or more, SEDI was 5.2 ± 0.8 [3 to 6], 44.4% studied for less than 4 years, and 18.9% were living alone. The Spearman correlation between PAID-5 and DHP-PDQ total scores was $\rho = 0.382$, $p < 0.001$, between PAID-5 total score and age was $\rho = -0.207$, $p = 0.050$ and between PAID-5 total score and most recent HbA1c knowledge was $\rho = 0.275$, $p = 0.040$. There was no significant relationship between PAID-5 total score and SEDI $\rho = 0.080$, $p = 0.452$.

Conclusion: DDS can now be assessed in the Portuguese context, accounting for better intervention by primary care teams. PAID-5 has good psychometric properties and is a reliable scale to identify diabetes-specific distress in the Portuguese diabetic population.

Keywords: Diabetes Mellitus/psychology; Emotions; Portugal; Psychometrics; Surveys and Questionnaires

RESUMO

Introdução: A síndrome ‘Sofrimento pela Diabetes’ (SpD) deve ser detetada por instrumentos adaptados e validados um deles sendo a escala *Problem Areas in Diabetes* (PAID), uma formulação com cinco frases em vez das 20 da versão original de PAID, que é mais fácil e rápida de aplicar para fins clínicos e de investigação, tendo já sido validada pelos autores originais. Este estudo teve como objetivo realizar a adaptação cultural e validação da escala PAID-5 para o Português Europeu.

Métodos: Para criar a versão portuguesa de PAID-5 realizou-se tradução, retrotradução, revisão clínica e painel de *debriefing*. Numa amostra de conveniência de n = 90 pessoas com diabetes provenientes de três Unidades de Cuidados de Saúde Primários estudou-se a consistência interna e a fiabilidade. Realizou-se uma validação de constructo pelo alfa de Cronbach e pelo coeficiente de correlação intraclasse (ICC) em teste e reteste. Para validação estrutural utilizou-se a análise dos componentes principais e para validade de constructo usou-se a sensibilidade do somatório de PAID-5 com o mais recente valor de Hemoglobina A1c (HbA1c) e classe socioeconómica (SEDI). A validade de critério foi estudada correlacionando o somatório de PAID-5 com as questões de perfil psicológico de *Diabetes Health Profile – 18* (DHP-PDQ).

Resultados: A consistência interna, alfa de Cronbach, foi de 0,905 e o ICC de 0,905, numa amostra de 90 pessoas, sendo 55,6% homens e 63,3% tendo idade \geq a 65 anos. O valor de SEDI foi de $5,2 \pm 0,8$ [3 a 6], 44,4% tinha formação académica inferior ao quarto ano e 18,9% viviam sós. A correlação de Spearman entre as pontuações totais de PAID-5 e de DHP-PDQ foi de $\rho = 0,382$, $p < 0,001$, com o valor mais recente da HbA1c de $\rho = 0,275$, $p = 0,040$ e entre as pontuações totais de PAID-5 e SEDI de $\rho = 0,080$, $p = 0,452$.

Conclusão: A síndrome SpD pode agora ser detetada no contexto português para melhor intervenção das equipas em Cuidados de Saúde Primários. A escala PAID-5 tem boas propriedades psicométricas e é fiável para a identificação da síndrome SpD na população diabética portuguesa.

Palavras-chave: Diabetes Mellitus/psicologia; Emoções; Inquéritos e Questionários; Portugal; Psicometria

INTRODUCTION

Diabetes is a highly prevalent chronic disease. In 2021, 10.5% of adults aged between 20 and 79 lived with diabetes, with an expected rise to 12.2% by 2045. The International Diabetes Federation (IDF) confirms that diabetes is one of the 21st century's fastest-growing global health emergencies. Approximately 6.7 million adult deaths oc-

curred because of diabetes or its complications in 2021, corresponding to 12.2% of global deaths from all causes. According to the IDF, 13% of adults in Portugal were living with diabetes in 2021, making Portugal the fourth European country with the highest prevalence rate of diabetes.¹

People suffering from diabetes (PsD) have a significant

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and active role in controlling the disease, as they need specific diet, exercise, and adequate dosing of cutting-edge medication.² Self-management and worry about long-term complications such as ischemic heart disease or myocardial infarction, stroke, retinopathy, nephropathy, and neuropathy can be sources of stress. This can lead to a negative emotional impact called 'diabetes distress syndrome' (DDS), linked to non-adherence to lifestyle modifications, worse glycemic control, and poor health status.^{3,4} DDS is part of this patient's daily life and has a prevalence rate of 36.0% in patients with type 2 diabetes.⁵ Such a situation must be addressed in clinical practice at periodic intervals, like when a change in disease treatment or specific life circumstances occurs or when distress is suspected.⁶ Therefore, to evaluate DDS, specific, validated tools are needed.

As a specific instrument to assess DDS, the Problem Areas in Diabetes (PAID) scale meets this need.^{7,8} It has shown good psychometric properties and has already been translated and validated into several languages.⁹⁻¹⁷ The PAID scale has 20 questions scored from 0 (not a problem) to 4 (serious problem) and allows the assessment of the negative emotional impact on PsD, with higher scores meaning more suffering. Lower levels of DDS can help improve the metabolic profile.³ A short version of PAID, PAID-5,¹⁸ includes five questions: (i) feeling scared when you think about living with diabetes; (ii) feeling depressed when you think about living with diabetes; (iii) worrying about the future and the possibility of serious complications; (iv) feeling that diabetes is taking up too much of your mental and physical energy every day; and (v) coping with complications of diabetes, to be answered on a Likert scale from not having a problem (0) to having a serious problem (4) with intermediates of minor problems, moderate problems and somewhat serious problems. This short version has been developed and validated, making it easier to apply in clinical and research practices for type 1 and type 2 diabetes. The PAID-5 has satisfactory sensitivity (94%) and specificity (89%) for recognition of diabetes-related emotional distress, correlated with the PAID-20 total score ($p = 0.92$, $p < 0.001$) and also with the WHO-5 score ($p = -0.47$, $p < 0.001$).¹⁸

This study intended to adapt PAID-5 to the European Portuguese language and validate it for the Portuguese culture.

METHODS

For linguistic equivalence, after obtaining permission from the author, Brian McGuire, to translate and use PAID-5, our aim was to create a Portuguese version of PAID-5, equivalent to the original version. Therefore, following scientific recommendations,¹⁹ we asked two Portuguese translators to perform a first translation from the original PAID-5.

Then, these two translated versions were merged into a consensual version by a panel of experts, and the outcome was sent to an English professional translator to perform a back translation. These researchers analyzed this back translation and compared it to the original one to verify if there were semantic differences. This last version was compared to the original, and the first version of the Portuguese PAID-5 was created.

Still in this cross-cultural adaptation phase, we applied this version to a sample of 25 PsD in order to evaluate the comprehension and the burden of questions to be answered.

Between August and October 2022, data were gathered from PsD in three primary healthcare units in central Portugal. One of the investigators, on randomly selected days, invited PsD to participate in this study before or after their clinical appointment on site.

As inclusion criteria, this study accepted PsD patients with type 1 or type 2 diabetes who attended their family physician appointments with European Portuguese as their native language and agreed to participate.

Besides the Portuguese version of PAID-5, the diabetes distress questions of the Diabetes Health Profile (DHP-18) were included in the (DHP-PDQ).²⁰ The DHP-PDQ is a measurement instrument of psychological and behavioral outcomes resulting from living with diabetes that has already been culturally adapted and validated for the Portuguese population.²¹

Context characterization questions for age, sex, number of co-inhabitants, average monthly financial income, level of formal education, and diabetes-related questions such as diabetes monitoring, knowledge of, and level of the most recent hemoglobin A1c (HbA1c), were also included.

This study aimed to test whether a higher score on the PAID-5 scale was associated with aging, knowledge about the most recent HbA1c test, and a lower socioeconomic index class.

An adapted formula for readability was performed (<https://readable.com/features/readability-formulas/>) to test for perceptibility, and we used descriptive statistical methods to characterize the sample and the Kolmogorov-Smirnov test for the distribution of the variables.

Reliability was first tested by the internal consistency of Cronbach's alpha for the first 25 patients, for credibility in the development of the process, and by the total sample. We also checked Cronbach's alpha to see if each item on the scale was excluded. The reproducibility test-retest was analyzed through the intraclass correlation coefficient (ICC).

To test the construct validity of the Portuguese version of PAID-5, we tested the structural validity and the known-group validity. The former test was accomplished by an exploratory factor analysis, previously confirmed by the

Kaiser-Meyer-Olkin (KMO) measure of sample adequacy and by the Bartlett sphericity test. The known-group validity was tested by correlating the total scores obtained by PAID-5 in different subsamples according to the patient's age, Socioeconomic Deprivation Index (SEDI) class,²² and most recent knowledge of the HbA1c test.

SEDI, as defined by Lamnisos *et al*,^{22,23} is a multidimensional concept measuring the relative disadvantage experienced by an individual or social group. It is a composite index formed by income, education, employment, housing, household, transportation, and demographics. For income, a definition of €500 was made due to the expected age, retirement, and relative level of income.

For criterion validity, we computed the Spearman correlation coefficient to assess the linear relationship between PAID-5 and the total score of the domain "psychological distress" from DHP-18. Participation was voluntary and confidential, and all participants gave previous written informed consent.

This study was approved by the Central Regional Health Authority's Ethics Committee and the coordinators of all primary care units. A *p* value of < 0.05 was defined for significant difference.

RESULTS

To confirm the content validity, there was no evidence of any difficulty in how the Portuguese version of PAID-5 was understood, and participants reported no doubts. Therefore,

we made no changes between the first and second phases of the study.

The adapted ease-readability formula result was 61.02, meaning that it had a standard perceptibility. A response rate of 100% was obtained. The mean time to complete PAID-5 questions was 1.26 minutes, with values ranging from 0.37 seconds to 2.46 minutes.

According to Table 1, in a sample of 90 participants, 55.6% were males, 63.3% were aged 65 years or more, 52.2% had more than four years of formal education, 57.8% were receiving more than €500 per month, and 81.1% lived with at least one person (81.1%). Regarding the average monthly income question, 26 out of 90 patients did not answer that question, and so a calculated SEDI of 5.2 ± 0.8 in a maximum of 6 was obtained. For diabetes-related questions, 50.0% did not do any capillary glycemic control, 62.2% knew their most recent HbA1c, and 38.9% had the most recent HbA1c value over 6.5%.

As shown in Table 2, our study population generally experienced low levels of DDS.

The PAID-5 scores obtained in this study are presented in Table 2.

As for data normality, the one-sample Kolmogorov-Smirnov test indicated PAID-5 and DHP-PDQ scores, SEDI, and HbA1c had a non-normal distribution with a Lilliefors significance correction of < 0.001. The Spearman correlation between PAID-5 and DHP-PDQ total scores was significant and showed a weak positive correlation between the two scales

Table 1 – Total sample characterization (n = 90)

Variable	Value	n	%
Sex	Male	50	55.6%
	Female	40	44.4%
Age (years)	≥ 65	57	
	< 65	33	63.3%
	Min. – Max.	21 – 92	36.7%
	Mean ± standard deviation	64.5 ± 12.4	
Education (years)	≤ 4	40	44.4%
	> 4	47	52.2%
	Missing	3	3.3%
Monthly income (€)	≤ 500	12	13.3%
	> 500	52	57.8%
	Missing	26	28.9%
Living alone	Yes	17	18.9%
	No	73	81.1%
SEDI	Mean ± standard deviation	5.2 ± 0.8	
Performing diabetes control	Yes	45	50.0%
	No	45	50.0%
Knowledge of the most recent HbA1c	Yes	56	62.2%
	No	34	37.8%
Most recent HbA1c score	≤ 6.5%	21	23.3%
	> 6.5%	35	38.9%
	Do not know	34	37.8%

HbA1c: hemoglobin A1c

Table 2 – Descriptive of PAID-5 scores about diabetes stress (n = 90)

PAID-5 question	Mean	Median	Standard deviation
Being afraid of living with diabetes	1.5	1.5	1.2
Feeling depressed of living with diabetes	1.2	1.0	1.3
Feeling worried about the future and complications	2.3	2.0	1.2
Feeling that diabetes requires physical and mental energy	1.5	2.0	1.3
Dealing with complication associated with diabetes	1.8	2.0	1.3

($r = 0.382$, $p < 0.001$).

For reliability, a total Cronbach's alpha coefficient value of 0.915 and, if an item was deleted, an alpha ranging from 0.884 to 0.911 was obtained. Regarding reproducibility, the test-retest ICC was 0.915 with a 95% confidence interval of 0.837 to 0.950.

To test the structural validity, factor analysis confirmed a one-factor solution accounting for 72.79% of the explained variance. KMO was 0.788, showing this was an adequate sample size for carrying out the factor analysis. In addition, the Bartlett sphericity test was significant ($\chi^2 = 88.411$, $p < 0.001$), indicating that the correlations between items were sufficiently substantial for carrying out the factor analysis.

Table 3 reveals that age and SEDI class showed a non-significant correlation with the PAID-5 total score, while knowledge of the most recent HbA1c test was significantly correlated with the PAID-5 total score, with PAID increasing while HbA1c decreased.

Still, regarding the PAID total score, Mann-Whitney U non-significant differences were found for sex, $p = 0.987$, diabetes control, $p = 0.052$, knowledge of the most recent HbA1c test, $p = 0.419$, SEDI level under or above the median, $p = 0.334$, monthly income (under or above €500), $p = 0.318$ and living alone or not, $p = 0.668$. For education (under or above four years) PAID-5 total score was significantly higher in those with more than four years (8.7 ± 5.2 vs 4.7 ± 4.7 , $p = 0.034$).

DISCUSSION

The goal of this study was to adapt and validate the European Portuguese version of a simple and complete scale on diabetes distress, whose long and short version were already validated in other languages with good psychometric properties.⁷⁻¹⁸

The Portuguese PAID-5 scale showed good comprehensibility with a short time to answer.

Cronbach's alpha coefficient value showed excellent

internal consistency of the PAID-5 scale,¹⁹ confirming the scale's validity for the Portuguese culture. McGuire *et al*¹⁸ obtained a Cronbach's alpha coefficient value of 0.83. This value is also in line with a Norwegian study.^{14,24} In addition, the average measure ICC was excellent (0.915). This value is also in line with the Norwegian version of the PAID-5 ICC measure.²⁴

The unidimensional structure of the Portuguese version of PAID-5 was verified. A statistically significant correlation with DHP-PDQ reinforced the validity of the PAID-5 scale. This correlation was weak, meaning that these two scales do not measure the same causes of diabetes distress. These scales are not the same but are complementary, and physicians can now use both to have a complete assessment. A significant strength of PAID-5 is that it takes less than a minute to complete, making it easier to use during patient appointments.

The PAID-5 total score correlated negatively with age, with younger patients scoring higher, and suffering more from diabetes distress. Other studies also showed a weak negative association between these two variables.^{7,8,12,15} This result can be related to younger patients projecting diabetes as an obstacle in their future lives and needing to develop coping mechanisms.

Knowledge of the most recent HbA1c test had a weak positive correlation with the total score of the PAID-5 scale, showing that PsD who knew their most recent HbA1c value obtained higher scores on the scale. There is doubt regarding this analysis since it is impossible to know if patients are regularly aware of the most recent HbA1c value or if they knew this value because of recently acquired information during a medical appointment. Patients can suffer by knowing a result whose interpretation can be doubtful for them. This is an important research question since this study was on validation of a questionnaire on PsD and not just on diabetes as a disease.

Table 3 – Correlations between PAID-5 total score and age, most recent HbA1c knowledge, and SEDI class

Variable	n	Spearman correlation	p-value
Age	90	-0.032	0.763
Most recent HbA1c knowledge	56	-0,275	0.040
SEDI class	90	0.080	0.452

SEDI: socio-economic deprivation index; HbA1c: hemoglobin A1c

Regarding the SEDI class, the lack of a statistically significant correlation with PAID-5 means that diabetes distress is a social cross-sectional problem.

As reported in previous studies with PAID-20,^{7-11,13,15,17} our study also revealed the most severe emotional problem was 'worrying about the future and the possibility of serious complications'. This means that PsD patients seem afraid of developing complications which can be long-time stressors. The study's sample generally experienced low levels of diabetes distress, as all the questions had a mean score between 1.2 and 2.3. Future research on this low level of distress, namely on how doctor's empathy can lead to patient empowerment and Patient-Centered Medicine practice, is justified.^{25,26}

This study has some limitations. We obtained a convenience sample, predominantly composed of patients with type 2 diabetes, even though it was obtained on randomly selected days. Another limitation consists of missing data due to some patients' incomplete answers. Although the sample was relatively heterogeneous, with patients aged between 21 and 92 years old from both urban and rural contexts, another limitation of the study is just covering the central region of Portugal. To continue the validation process, we suggest using the European Portuguese version of the PAID-5 scale on larger and more heterogeneous samples from different parts of Portugal.

Despite these limitations, the results suggest that the European Portuguese version of the PAID-5 scale is an understandable and easy-to-apply instrument, presenting good psychometric values of reliability and validity; therefore, it can be considered adequate to measure diabetes distress in persons suffering from diabetes in Portugal. It allows the assessment of this problem in order to improve medical care, resulting in better health status and quality of life for patients with diabetes.

In the presence of diabetes distress, verifying the PAID-5 scale's responsiveness to change is now pertinent. Further studies can also ascertain if this scale is a valuable tool to evaluate caregivers' perceptions of the person's diabetes distress once their knowledge of perceptions can contribute to the early identification of this problem.

CONCLUSION

The results of this study suggest the adequacy of the validation process of PAID-5 to measure diabetes distress in Portugal. The PAID-5 European Portuguese version is

a simple, easy-to-apply, and reliable measure of diabetes distress. This scale is as an easy tool to identify diabetes distress that can be used in further research and in clinical practice.

AUTHOR CONTRIBUTIONS

CP: Conception of the study, methods, software, data collection and management, resources for the study, manuscript writing and critical review, supervision.

LMS: Conception of the study, methods, software, data management, analysis and validation, resources for the study, manuscript writing and critical review.

IR: Conception of the study, methods, resources for the study, critical review of the manuscript and supervision.

PF: Software, data analysis and validation, critical review of the manuscript.

PROTECTION OF HUMANS AND ANIMALS

The authors declare that the procedures were followed according to the regulations established by the Clinical Research and Ethics Committee and to the Helsinki Declaration of the World Medical Association updated in 2013.

DATA CONFIDENTIALITY

The authors declare having followed the protocols in use at their working center regarding patients' data publication.

COMPETING INTERESTS

LMS has received payments from Departamento de Formação Médica do Serviço de Saúde da Região Autónoma da Madeira and from Administração Regional de Saúde do Alentejo.

IR has received consulting fees from Novo Nordisk; payment or honoraria from Boehringer Ingelheim, Astra Zeneca and MSD for lectures, presentations, speakers' bureaus, manuscript writing or educational events; support for attending meetings and/or travel from MSD, Ferrer Portugal and Novo Nordisk.

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