FACULDADE DE MEDICINA
UNIVERSIDADE Ð
COIMBRA

MESTRADO INTEGRADO EM MEDICINA – TRABALHO FINAL

CLÁUDIA SOFIA FONSECA PEREIRA

Cultural adaptation and validation of the PAID-5 scale to European Portuguese

ARTIGO CIENTÍFICO ORIGINAL

ÁREA CIENTÍFICA DE MEDICINA GERAL E FAMILIAR

Trabalho realizado sob a orientação de:
INÊS ROSENDO CARVALHO E SILVA, PROFESSORA DOUTORA
LUIZ MIGUEL DE MENDONÇA SOARES SANTIAGO, PROFESSOR DOUTOR

NOVEMBRO/2022

Faculdade de Medicina da Universidade de Coimbra

Adaptação cultural e validação da escala PAID-5 para Português Europeu

Cultural adaptation and validation of the PAID-5 scale to European Portuguese

Cláudia Sofia Fonseca Pereira [1]

Luiz Miguel de Mendonça Soares Santiago [1,2]

Inês Rosendo Carvalho e Silva [1,3]

[1]FMUC – Faculdade de Medicina, Universidade de Coimbra, Portugal

[2]CEISUC – Centro de Estudos e Investigação em Saúde da Universidade de Coimbra

[3]USF Coimbra Centro – ACES Baixo Mondego, Coimbra, Portugal

Contact: claudia.sharapova@gmail.com

RESUMO

Introdução: A diabetes é uma doença crónica de alta prevalência a nível mundial. As pessoas com diabetes têm um papel ativo no controlo desta doença relativamente ao cumprimento da medicação, de uma alimentação específica e da prática de exercício físico. Outra preocupação está relacionada com as complicações a longo prazo associadas à diabetes. A contínua necessidade de autogestão da doença e o receio de complicações podem resultar no desenvolvimento de *diabetes distress* (sofrimento associado à diabetes). Este tipo de stress especificamente associado à diabetes pode levar a um pior controlo metabólico, pelo que deve ser avaliado com instrumentos adaptados e validados. A escala *Problem Areas in Diabetes* (PAID) permite a deteção do *diabetes distress* em pessoas com diabetes. Existe uma versão curta, PAID-5, mais rápida e fácil de utilizar no contexto clínico e de investigação que não está validada em Portugal.

Objetivo: Realizar a adaptação cultural e validação da escala PAID-5 para o Português Europeu.

Métodos: Conduzimos um trabalho metodológico de tradução, retro tradução e adaptação cultural para o contexto português da escala PAID-5. Realizámos este estudo em três Unidades de Saúde Familiar portuguesas com uma amostra de conveniência de n=90 pessoas com diabetes. Efetuámos análise descritiva para caracterização da amostra. Realizámos a validação de constructo e validação concorrente com as questões de sofrimento psicológico da escala Diabetes Health Profile – 18 (DHP-PDQ). Procurámos associação da pontuação total da escala PAID-5 com as variáveis: idade, valor mais recente da $HbA1_c$ e classe SEDI, através da Correlação de Pearson. Considerámos um valor de p<0,05 como estatisticamente significativo.

Resultados: Participaram neste estudo 90 pessoas com diabetes, 55,6% do sexo masculino e 63,3% com idade superior ou igual a 65 anos. A idade variou entre 21 e 92 anos. O tempo médio para completar o questionário PAID-5 foi de 1,26 minutos. A consistência interna pelo coeficiente alfa de Cronbach da escala PAID-5 foi 0,915 e o Coeficiente de Correlação Intraclasse foi de 0,905. A correlação de Pearson mostrou ser estatisticamente significativa a relação entre as pontuações totais do PAID-5 e a escala concorrente DHP-PDQ (ρ=0,382, p<0,001) e também entre a pontuação total do PAID-5 e as variáveis idade (ρ=-0,207, p=0,050) e o valor mais recente da $HbA1_c$ (ρ=0,275, p=0,040).

Discussão: A versão portuguesa do PAID-5 é um instrumento fiável para utilizar no contexto português assim permitindo perceber o *distress* associado à diabetes, que será um dos fatores

para a pior qualidade de vida**.** A correlação de Pearson demonstrou que as pontuações totais do PAID-5 e DHP-PDQ estão correlacionadas de uma forma positiva e fraca (ρ=0,382), revelando que as duas escalas se relacionam, mas medem diferentes domínios de *diabetes distress.* Os doentes jovens e aqueles que têm um valor recente da HbA1$_c$ mais elevado apresentaram significativamente maior distress pela diabetes. A escala PAID-5, com boas propriedades psicométricas e fácil de utilizar, permite assim a deteção de *diabetes distress* obviando a problemas futuros, sendo esta medida diferente da mensurável por outros instrumentos como a escala DHP.

Conclusão: Foi possível realizar a adaptação cultural e iniciar a validação da escala PAID-5, obtendo-se um instrumento de consistência interna apreciável e fiável para aplicar em Portugal.

Palavras-chave: Diabetes, Distress, PAID-5, Escala.

ABSTRACT

Introduction: Diabetes is a chronic, high-prevalence disease worldwide. People suffering from diabetes have an active role in controlling their condition by taking medication, having a specific diet, and exercising. They also worry about diabetes-related long-term complications. The continuous need to self-management the disease and the fear of developing complications can result in diabetes distress. This diabetes-specific distress can lead to poor outcomes and should be assessed with adapted and validated tools. The Problem Areas in Diabetes (PAID) scale detects diabetes distress in people with diabetes. There is a short form, PAID-5, which is easier and quicker to use in clinical and research practices and is not validated in Portugal.

Purpose: To accomplish the cultural adaptation and validation of the PAID-5 scale to European Portuguese.

Methods: We applied a methodological work of translation, back-translation, and cultural adaptation of the PAID-5 scale to the Portuguese context. We held this study in three Portuguese Primary Care Units with a n=90 convenience sample. We used descriptive analysis to characterize the sample. We conducted construct validation and concurrent validation with Diabetes Health Profile – 18 psychological distress questions (DHP-PDQ). We searched for the association of the PAID-5 total score with the variables: age, most recent HbA1$_c$ value, and SEDI class, using Pearson Correlation. We considered a significant statistical p-value of <0.05.

Results: In a total of 90 people suffering from diabetes participating in this study, 55.6% were male, and 63.3% were aged 65 years or more. Age ranged from 21 to 92 years old. The mean time to complete PAID-5 was 1.26 minutes. The internal consistency by Cronbach's alpha coefficient was 0.915, and the Intraclass Correlation Coefficient was 0.905. Pearson correlation showed a statistically significant relationship between the total scores of the PAID-5 and the concurrent scale DHP-PDQ (ρ=0.382, p<0.001), and between the PAID-5 total score and the variables age (ρ=-0.207, p=0.050) and most recent HbA1$_c$ value (ρ=0.275, p=0.040).

Discussion: The Portuguese version of the PAID-5 scale is a reliable instrument to use in the Portuguese context to detect diabetes distress, which can lead to lower quality of life. Pearson correlation showed that the PAID-5 and DHP-PDQ total scores had a weak positive relationship (ρ=0.382), meaning the two scales are related but measure different domains of diabetes distress. Younger patients and those who had higher HbA1$_c$ values showed significantly higher distress. The PAID-5 scale, with good psychometric properties and easy to

use, allows the detection of diabetes distress to avoid future problems and is different from the domain measurable by other instruments such as the DHP scale.

Conclusion: It was possible to perform the cultural adaptation and start validating the PAID-5 scale, thus obtaining an instrument with an appreciable and reliable internal consistency to apply in Portugal.

Keywords: Diabetes, Distress, PAID-5, Scale.

Acronyms

ACES – Agrupamento de Centros de Saúde

ARS – Administração Regional de Saúde

DHP – Diabetes Health Profile

DHP-PDQ – Diabetes Health Profile - psychological distress questions

HbA1$_c$ – Glycated Hemoglobin

ICC – Intraclass Correlation Coefficient

IDF – International Diabetes Federation

PAID – Problem Areas in Diabetes

SEDI – SocioEconomic Deprivation Index

USF – Unidade de Saúde Familiar

Table of Contents

- I: Authorization to use and translate PAID-5
- II: Translations 1 and 2 to European Portuguese
- III: Back-translation
- IV: European Portuguese PAID-5 final version
- V: DHP-psychological distress questions (DHP-PDQ)
- VI: USF coordinator's authorizations
- VII: ARS Centro Ethics Committee authorization

Introduction

Diabetes is a high-prevalence chronic disease worldwide. In 2021, 10.5% of adults between the age of 20-79 lived with diabetes, with an expected rise to 12.2% by 2045. International Diabetes Federation (IDF) findings confirm that diabetes is one of the 21st century fastest growing global health emergencies. It is estimated that 6.7 million adult deaths occurred because of diabetes or its complications in 2021, corresponding to 12.2% of global deaths from all causes in this age group. According to IDF, 13% of adults in Portugal had diabetes in 2021, with Portugal being the fourth country in Europe with higher diabetes prevalence. (1)

People suffering from diabetes have a significant and active role in controlling their disease. They need to have a specific diet, exercise, and have proper doses of medication. (2) This self-management and their worry about long-term complications such as heart attack, stroke, retinopathy, nephropathy, and neuropathy can be a source of stress. This can lead to a negative emotional impact called diabetes distress, linked to non-adherence to lifestyle modifications, worse glycemic control, and poor health status. (3, 4) Diabetes distress is part of this patient's daily life and has a prevalence of 36% in people who have type 2 diabetes. (5) We should address this in clinical practice at periodic intervals, when a change in disease treatment occurs, life circumstances changes, or distress is suspected. (6) To measure diabetes distress, we need validated tools.

The Problem Areas in Diabetes (PAID) scale (7, 8) meets this need, being a specific instrument to assess diabetes distress. This scale has been shown to have good psychometric properties and has already been translated and validated into several languages. (9-17) The PAID scale has 20 questions scored from 0 to 4, being "0- Not a problem", "1- Minor problem", "2- Moderate problem", "3- Somewhat serious problem", and "4- Serious problem". It allows us to assess the negative emotional impact on people suffering from diabetes regarding the disease and its consequences on their lives, with higher scores meaning suffering more from diabetes distress. The PAID scale is an essential tool for diabetes management as lower diabetes distress can help to control the metabolic profile. (3) There is a short form named PAID-5 (18) with only five questions regarding items 3 (Feeling scared when you think about living with diabetes), 6 (Feeling depressed when you think about living with diabetes), 12 (Worrying about the future and the possibility of serious complications), 16 (Feeling that diabetes is taking up too much of your mental and physical energy every day), and 19 (Coping with complications of diabetes) from the original PAID scale. In previous studies (18, 19), the PAID-5 scale showed good psychometric properties and is easier to apply in clinical and research practices.

One diabetes-specific scale named Diabetes Health Profile (DHP) to assess the psychological and behavioral outcomes resulting from living with diabetes has already been translated and validated into Portuguese. DHP-18 is a short form of DHP with three domains: psychological distress (dysphoric mood, hopelessness feelings, irritability), with six items; barriers to activity (perceived limitation to activity, operant anxiety), with seven items; and disinhibited eating (lack of control when eating, response to food suggestions, and emotional arousal from eating) with five items. Each item is scored from 0 to 3, taking 5 to 6 minutes to complete. (20, 21)

Our study emerged from the need to have a specific and more straightforward tool to assess diabetes distress so we can help patients deal with it, leading to better outcomes in controlling their disease.

Our goal was to adapt PAID-5 to the Portuguese context and validate it. We aimed to do a construct and concurrent validation by the correlation between the PAID-5 total score and the DHP-18 psychological distress questions (DHP-PDQ) total score. We also proposed evaluating the relationship between the distress as measured by the PAID-5 total score and sociodemographic and clinical variables.

Materials and Methods

Study Design

We aimed to do a cultural adaptation and validation of the PAID-5 scale to European Portuguese. The study's first phase was a methodological work of translation, back translation, and cultural adaptation. The second phase consisted of a construct and concurrent validation at the same time as we analyzed the relationship between the PAID-5 total score and sociodemographic and clinical variables.

In the first phase, we made the translation, back translation, and cultural adaptation as Beaton *et al.* (22) proposed after the original author, Prof. Brian McGuire, gave us permission to use and translate PAID-5. (Attachment I) Two randomly European Portuguese native speakers proficient in English translated the original version to Portuguese independently (Attachment II). Then, a group of counselors concluded as to the best version that was afterward back-translated to English by a professional translator while blinded to the original version (Attachment III). The researchers analyzed this translation and compared it to the original one to verify if there were many semantic differences. We made an European Portuguese prefinal version. (Attachment IV)

Besides PAID-5, we added demographic questions to the questionnaire like gender, age, number of cohabitants, average monthly financial income, education, and diabetes-related questions such as diabetes monitoring, knowledge and value of the most recent glycated hemoglobin ($HbA1_c$). We calculated the corresponding SocioEconomic Deprivation Index (SEDI) class considering: four years or less of education = 1, more than four = 0; average monthly financial income lower than 500€ = 1, higher than 500€ = 0; living alone = 1, not living alone = 0. We aimed to study how the PAID-5 total score correlates with age, the most recent $HbA1_c$ value, and SEDI class. We also added six questions on the DHP-PDQ for concurrent validation. (Attachment V) DHP-18 has already been translated and validated into Portuguese (21), and we had permission to use it.

In the cross-cultural adaptation phase, we applied the questionnaire to a n=25 convenience people suffering from diabetes sample to evaluate comprehension and effort requested to answer. Most participants completed the questionnaire by themselves as we timed PAID-5 answers. In the next phase, we applied the questionnaire to 65 more patients. For some patients, orally applied questions and help to fill in the answer was necessary due to vision or literacy difficulties.

Data collection

We held this study in the last semester of 2022 with people suffering from diabetes from three primary care units with authorization from the respective coordinators. (Attachment VI) A representative sample of at least 51 responses was defined to have more than ten answers per question. (23) We included patients who met the following criteria: followed in General Practice appointments, with type 1 or 2 diabetes diagnosis, European Portuguese as the mother language, and agreeing to participate.

The questionnaires were applied at USF Coimbra Centro, USF Mondego, and USF Montemuro, in a convenience sample, before or after the patient's appointment in a medical office, by one of the researchers. We invited 90 patients to participate in this study, and all accepted after a brief explanation. Participation was voluntary and confidential; all of them gave written informed consent. ARS Centro Ethical Committee approved this study. (Attachment VII)

Data analysis

After entering the collected data into Excel® software, we used SPSS® (Statistical Package for the Social Sciences) version 25 for Windows® to conduct statistical analysis.

We used descriptive statistical methods to characterize the sample. We used Kolmogorov-Smirnov to test the variable's distribution.

To analyze PAID-5 internal consistency, we calculated Cronbach's alpha coefficient for the first 25 patients and the total sample. We also checked Cronbach's alpha if each item on the scale was excluded. Intraclass Correlation Coefficient (ICC) and one-way ANOVA were used to test for reliability. In the cross-cultural adaptation phase, we performed the Total Variance Explained, the Kaiser-Meyer-Olkin measure of sample adequacy, and the Bartlett sphericity test. We also used Flescher adapted formula to test for readability.

In the validation phase, we calculated Cronbach's alpha coefficient value for DHP-PDQ. We computed Pearson Correlation to assess the linear relationship between PAID-5 and DHP-PDQ for concurrent validation. We analyzed the PAID-5 total scores according to the patient's age, SEDI class, and most recent $HbA1_c$ value using Pearson correlation. We considered values ranging from 0.00 to 0.19 to be a very weak correlation, 0.20 to 0.39 weak, 0.40 to 0.69 moderate, 0.70 to 0.89 strong, and 0.90 to 1.00 a very strong correlation.

We calculated each p-value to investigate if there were statistically significant differences. In all statistical tests, we considered a statistically significant value of less than 0.05.

Results

Throughout the questionnaire application, we unnoticed difficulties regarding question comprehension. We made no changes between the first and second phases of the study. The final European Portuguese version of PAID-5 score was "0- Não é um problema", "1- Problema minor", "2- Problema moderado", "3- Problema algo grave" and "4- Problema grave". The final European Portuguese version of the five questions was:

1. Ter medo quando pensa sobre viver com diabetes.
2. Sentir-se deprimido(a) quando pensa sobre viver com diabetes.
3. Preocupar-se sobre o futuro e a possibilidade de vir a ter complicações graves.
4. Sentir que diabetes requer demasiada energia mental e física todos os dias.
5. Lidar com as complicações associadas à diabetes.

The Adapted Flesch formula result was 61.02, meaning it has a standard readability, corresponding to an eighth or ninth-grade level. We obtained a response rate of 100%. The mean time to complete PAID-5 questions was 1.26 minutes, with values ranging from 0.37 seconds to 2.46 minutes. Participants reported no doubts.

Cross-cultural adaptation phase

We obtained a total Cronbach's alpha coefficient value of 0.905. We verified that "Cronbach's alpha if item deleted" values varied from 0.869 to 0.896. The average Intraclass Correlation Coefficient measure was 0.905 with a 95% confidence interval from 0.837 to 0.950, F (28,112) = 10.519, p<0.001. The one-way ANOVA result was F = 13.603, p<0.001. The Total Variance Explained reported 72.79% of the variance is accounted for by one component. Kaiser-Meyer-Olkin's measure of sampling adequacy was 0.788, showing sample size adequation for carrying out the factor analysis. The Bartlett sphericity test was significant (x^2 (10) = 88.411, p<0.001), indicating that the correlations between items were sufficiently substantial for carrying out the factor analysis.

Sample characterization in the validation phase

According to table 1, a sample of 90 participants was studied, 55.6% male, 63.3% aged 65 years or more, 52.2% with more than four years of education, 57.8% with a monthly income above 500€ (28.9% did not answer), and 81.1% living with at least one person. Concerning diabetes-related questions, 50.0% were not on home blood monitoring, 62.2% knew their most recent HbA1$_c$, and 38.9% had the most recent HbA1$_c$ value over 6.5%. Age ranged from 21 to 92 years old.

Table 1. Total sample characterization – frequency and percentage in the validation phase.

	Frequency	Percentage
Gender		
Male	50	55.6%
Female	40	44.4%
Age		
< 65 years old	33	36.7%
≥ 65 years old	57	63.3%
Education		
≤ 4 years	40	44.4%
> 4 years	47	52.2%
Did not answer	3	3.3%
Average monthly financial income		
≤ 500 €	12	13.3%
> 500 €	52	57.8%
Did not answer	26	28.9%
Number of cohabitants		
0	17	18.9%
> 0	73	81.1%
Diabetes Monitoring		
Yes	45	50.0%
No	45	50.0%
Most recent HbA1$_c$ knowledge		
Yes	56	62.2%
No	34	37.8%
Most recent HbA1$_c$ value		
≤ 6.5%	21	23.3%
> 6.5%	35	38.9%
Did not know	34	37.8%
Primary Care Unit		
Montemuro	45	50.0%
Mondego	34	37.8%
Coimbra Centro	11	12.2%

The PAID-5 scale obtained a total Cronbach's alpha coefficient value of 0.915. We verified that "Cronbach's alpha if item deleted" values ranged from 0.884 to 0.911. The one-way ANOVA result was F = 22.067, p<0.001. The average ICC measure was 0.915 with a 95% confidence

interval from 0.884 to 0.939 [F(89,445) = 11.721, p<0.001]. DHP-PDQ obtained a Cronbach's alpha coefficient value of 0.806.

Table 2 shows the mean, median, and standard deviation of numeric values of PAID-5 (from 0 to 4) and DHP-PQD answers.

Table 2. The PAID-5 and DHP-PDQ scores results – mean, median, and standard deviation in each question.

	N		Mean	Median	Std. Deviation
	Valid	**Missing**			
$PAID_1$	90	0	1.5	1.5	1.2
$PAID_2$	90	0	1.2	1.0	1.3
$PAID_3$	90	0	2.3	2.0	1.2
$PAID_4$	90	0	1.5	2.0	1.3
$PAID_5$	90	0	1.8	2.0	1.3
DHP_1	90	0	0.5	0.0	0.7
DHP_2	90	0	0.5	0.0	0.7
DHP_3	90	0	0.8	1.0	0.9
DHP_4	90	0	0.3	0.0	0.7
DHP_5	90	0	0.5	0.0	0.8
DHP_6	90	0	0.7	1.0	0.9

The one-sample Kolmogorov-Smirnov test indicated PAID-5 and DHP-PDQ total scores had a normal distribution with a Lilliefors Significance Correction <0.001. Pearson correlation between PAID-5 and DHP-PDQ total scores was statistically significant and showed a weak positive correlation between the two scales ($\rho=0.382$, $p<0.001$).

Total Score Analysis

According to Table 3, we found a significant statistical difference related to age and most recent $HbA1_c$ values with the PAID-5 total score. Age had a weak negative correlation, and the most recent $HbA1_c$ value had a weak positive correlation. SEDI class results showed a non-significant statistical difference.

Table 3. Pearson Correlation between PAID-5 total score and age, most recent HbA1$_c$ value, and SEDI class.

		Age	Most recent HbA1$_c$ value	SEDI class
PAID-5 total score	**Pearson Correlation (ρ)**	-0.207	0.275	0.080
	Sig. (2-tailed)	0.050	0.040	0.452
	N	90	56	90

Discussion

The main goal of this work was to adapt and start the validation to the Portuguese version of a simple and complete scale on diabetes distress, in which both full form and short version were already validated in other languages with good psychometric properties. (7-19)

The PAID-5 scale showed good comprehensibility with a short time to answer. Cronbach's alpha coefficient value of 0.905 in the cultural adaptation phase and 0.915 in the validation one showed an excellent internal consistency (24), confirming the scale's validity for the Portuguese culture. In addition, the "Cronbach's alpha coefficient if each item was deleted" was not higher than the overall Cronbach's alpha, confirming their relevance. McGuire *et al.* (18) obtained a Cronbach's alpha coefficient value of 0.86 in the first and 0.83 in the second subsample. Our value is also in line with a Norwegian PAID-5 study. (19)

In the cross-cultural adaptation phase, the Total Variance Explained showed that 72.8% of the variance is accounted for by one only component, meaning a reasonable degree of correlation between the questions. The Kaiser-Meyer-Olkin measure of sampling adequacy indicated that the strength of the relationships among variables was average (KMO = 0.788), so it was acceptable to proceed with the analysis. Bartlett's test of sphericity, which tests the overall significance of all the correlations within the correlation matrix, was significant, indicating that it was appropriate to use the factor analytic model on our data.

The average ICC measure was excellent, being 0.905 in the cross-cultural adaptation phase and 0.915 in the validation phase, meaning that the value of each question answer does not depend on the others. This value is in line with the Norwegian version of the PAID-5 ICC measure. (19) One-way ANOVA result was significant, showing that we could interpret the results.

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 field of diabetes distress. These scales are not the same but complementary, and health professionals can now use both to have a complete assessment. A significant strength of PAID-5 is taking less time to complete making it easier to use during patient appointments.

The PAID-5 total score correlated negatively with age, meaning that younger patients scored higher on the PAID-5 scale, suffering more from diabetes distress. PAID-20 studies (7, 8, 12, 15) also showed a weak negative association. This result can be related to younger patients projecting diabetes as an obstacle in their life, as they can have worse coping mechanisms. Other studies found no statistically significant differences. (10, 14, 17, 18)

The most recent HbA1$_c$ value had a weak positive correlation with the total score of the PAID-5 scale, showing that people with higher HbA1$_c$ values obtained higher scores on the scale. This association is in line with previous PAID studies. (7-9, 11-14, 16, 17) This can mean that patients with the worst metabolic control have more negative emotions regarding diabetes or that the negative emotions can lead to poor outcomes. The original PAID-5 study found no statistically significant differences. (18)

Regarding the SEDI class, there was no statistically significant difference, meaning that the socioeconomic class does not appear to correlate with the PAID-5 total score, with diabetes distress being an all-around problem.

As reported in previous studies with PAID-20 (7-11, 13, 15, 17), our study also reported the most severe emotional problem as "Worrying about the future and the possibility of serious complications". People suffering from diabetes are afraid of developing complications which can be a long-time stressor. The study population generally experienced low levels of diabetes distress, as all the questions had a mean score between 1.2 and 2.3.

This study has some limitations. Our sample was a convenience one and consisted predominantly of patients with type 2 diabetes. Another limitation relies on some patients' incomplete answers. Although our sample was relatively heterogeneous, with patients aged between 21 and 92 years old from both urban and rural contexts, another limitation is that this study was held only in the central region of Portugal. To continue the validation process, we suggest using the European Portuguese version of the PAID-5 scale on further investigations with a larger and more heterogeneous sample from different Portugal regions.

Despite these limitations, the results indicate 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, so considered good to measure diabetes distress in Portugal. It allows assessing this problem to improve medical care, resulting in better health status and quality of life for people suffering from diabetes.

In the presence of diabetes distress, verifying the PAID-5 scale responsiveness to changes in diabetes treatment will be pertinent. Further studies can also ascertain if this scale is a valuable tool to evaluate caregivers' perception of the person's diabetes distress once knowledge of caregivers' perceptions could 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 within the Portuguese settlement.

We found statistically significant differences between the distress measured by the PAID-5 scale and the variables age and most recent $HbA1_c$ value. Younger patients and those with higher $HbA1_c$ values had higher distress scores.

The PAID-5 European Portuguese version is a simple, easy-to-apply, and reliable measure of diabetes distress. Therefore, we recommend this scale as a tool for further investigations and clinical practice.

Agradecimentos

Agradeço à Professora Doutora Inês Rosendo e ao Professor Doutor Luiz Miguel Santiago pelo desafio de elaborar este artigo científico original, pelo voto de confiança e pela mentoria.

Agradeço ao Dr. Miguel Pereira e à Drª. Cátia Solis pela ajuda neste trabalho.

Agradeço a toda a minha família, mas em especial aos meus pais, à minha irmã e ao João Pedro pelo apoio, pela paciência e pela motivação não só neste projeto, mas em todo o meu percurso académico.

Agradeço ao João pelo apoio incondicional durante todos estes anos e aos meus amigos pelo companheirismo.

References

1.   International Diabetes Federation. IDF Diabetes Atlas, 10th edn. Brussels, Belgium: 2021. Available from: https://www.diabetesatlas.org.

2.   Chamberlain JJ, Rhinehart AS, Shaefer CF, Jr., Neuman A. Diagnosis and Management of Diabetes: Synopsis of the 2016 American Diabetes Association Standards of Medical Care in Diabetes. Ann Intern Med. 2016;164(8):542-52.

3.   Fisher L, Glasgow RE, Strycker LA. The relationship between diabetes distress and clinical depression with glycemic control among patients with type 2 diabetes. Diabetes Care. 2010;33(5):1034-6.

4.   Snoek FJ, Bremmer MA, Hermanns N. Constructs of depression and distress in diabetes: time for an appraisal. Lancet Diabetes Endocrinol. 2015;3(6):450-60.

5.   Perrin NE, Davies MJ, Robertson N, Snoek FJ, Khunti K. The prevalence of diabetes-specific emotional distress in people with Type 2 diabetes: a systematic review and meta-analysis. Diabet Med. 2017;34(11):1508-20.

6.   5. Facilitating Behavior Change and Well-being to Improve Health Outcomes: Standards of Medical Care in Diabetes-2021. Diabetes Care. 2021;44(Suppl 1):S53-s72.

7.   Snoek FJ, Pouwer F, Welch GW, Polonsky WH. Diabetes-related emotional distress in Dutch and U.S. diabetic patients: cross-cultural validity of the problem areas in diabetes scale. Diabetes Care. 2000;23(9):1305-9.

8.   Polonsky WH, Anderson BJ, Lohrer PA, Welch G, Jacobson AM, Aponte JE, et al. Assessment of diabetes-related distress. Diabetes Care. 1995;18(6):754-60.

9.   Amsberg S, Wredling R, Lins PE, Adamson U, Johansson UB. The psychometric properties of the Swedish version of the Problem Areas in Diabetes Scale (Swe-PAID-20): scale development. Int J Nurs Stud. 2008;45(9):1319-28.

10.   Lygidakis C, Uwizihiwe JP, Bia M, Kallestrup P, Dukundane D, Asiimwe-Kateera B, et al. Cultural adaptation and psychometric evaluation of the Kinyarwanda version of the problem areas in diabetes (PAID) questionnaire. Health Qual Life Outcomes. 2021;19(1):183.

11.   Beléndez M, Hernández-Mijares A, Marco J, Domínguez JR, Pomares FJ. Validation of the Spanish version of the Problem Areas in Diabetes (PAID-SP) Scale. Diabetes Res Clin Pract. 2014;106(3):e93-5.

12.   Cichoń E, Kiejna A, Gondek TM, Obrębski M, Sutkowska E, Lloyd CE, et al. PAID-PL-The Polish Version of the Problem Areas in Diabetes Scale: Perfect Reliability and a One-Factor Structure. Diabetes Metab Syndr Obes. 2021;14:4433-41.

13.   Huang MF, Courtney M, Edwards H, McDowell J. Validation of the Chinese version of the Problem Areas in Diabetes (PAID-C) scale. Diabetes Care. 2010;33(1):38-40.

14.   Graue M, Haugstvedt A, Wentzel-Larsen T, Iversen MM, Karlsen B, Rokne B. Diabetes-related emotional distress in adults: reliability and validity of the Norwegian versions of the Problem Areas in Diabetes Scale (PAID) and the Diabetes Distress Scale (DDS). Int J Nurs Stud. 2012;49(2):174-82.

15.   Huis In 't Veld EM, Makine C, Nouwen A, Karşıdağ C, Kadıoğlu P, Karşıdağ K, et al. Validation of the Turkish version of the problem areas in diabetes scale. Cardiovasc Psychiatry Neurol. 2011;2011:315068.

16.   Sayed Ahmed HA, Mohamed SF, Elotla SF, Mostafa M, Shah J, Fouad AM. Psychrometric Properties of the Arabic Version of the Problem Areas in Diabetes Scale in Primary Care. Front Public Health. 2022;10:843164.

17.   Sigurdardottir AK, Benediktsson R. Reliability and validity of the Icelandic version of the Problem Area in Diabetes (PAID) Scale. Int J Nurs Stud. 2008;45(4):526-33.

18.   McGuire BE, Morrison TG, Hermanns N, Skovlund S, Eldrup E, Gagliardino J, et al. Short-form measures of diabetes-related emotional distress: the Problem Areas in Diabetes Scale (PAID)-5 and PAID-1. Diabetologia. 2010;53(1):66-9.

19.   Vislapuu M, Broström A, Igland J, Vorderstrasse A, Iversen MM. Psychometric properties of the Norwegian version of the short form of The Problem Areas in Diabetes scale (PAID-5): a validation study. BMJ Open. 2019;9(2):e022903.

20.   Meadows KA, Abrams C, Sandbaek A. Adaptation of the Diabetes Health Profile (DHP-1) for use with patients with Type 2 diabetes mellitus: psychometric evaluation and cross-cultural comparison. Diabet Med. 2000;17(8):572-80.

21.   Santos Cruz R, Leitão CE, Lopes Ferreira P. Determinantes do estado de saúde dos diabéticos. Revista Portuguesa de Endocrinologia, Diabetes e Metabolismo. 2016;11(2):188-96.

22.   Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the process of cross-cultural adaptation of self-report measures. Spine (Phila Pa 1976). 2000;25(24):3186-91.

23.   Delgado A, Lima M. Contributo para a avalição concorrente de uma medida de adesão aos tratamentos. Psicologia, Saúde e Doenças. 2001;II:81-100.

24.   Terwee CB, Bot SD, de Boer MR, van der Windt DA, Knol DL, Dekker J, et al. Quality criteria were proposed for measurement properties of health status questionnaires. J Clin Epidemiol. 2007;60(1):34-42.

Attachments

Attachment I – Authorization to use and translate PAID-5

De: McGuire, Brian
Enviado: 2 de fevereiro de 2022 16:31
Para: LuizMiguel Santiago
Assunto: Re: Request for "Short-form measures of diabetes-related emotional distress: the Problem Areas in Diabetes Scale (PAID)-5 and PAID-1" cross-adaptation for european spoken portuguese

Dear Luiz, many thanks for your email. Yes please feel free to go ahead and translate the PAID-5/PAID-1.

Best wishes

Brian

Prof. Brian McGuire

Professor of Clinical Psychology,

Co-Director Centre for Pain Research,

National University of Ireland, Galway, Ireland.

Attachment II – Translations 1 and 2 to European Portuguese

	0 - Não é um problema	1 -É um problema minor	2 - É um problema moderado	3- É um problema mais ou menos sério	4- É um problema sério
Sentires medo quando pensas sobre viver com diabetes					
Sentires deprimido quando pensas sobre viver com diabetes					
Sentires preocupado acerca do futuro e da possibilidade de ocorrer complicações sérias					
Sentires que a diabetes está a utilizar demasiada energia física e mental todos os dias					
Lidar com complicações da diabetes					

	0 - Não é um problema	1- Problema minor	2 -Problema moderado	3 -Problema algo grave	4-Problema grave
Ter medo quando pensa sobre viver com diabetes					
Sentir-se deprimido(a) quando pensa sobre viver com diabetes					
Preocupar-se sobre o futuro e a possibilidade de vir a ter complicações graves					
Sentir que diabetes requer demasiada energia mental e física todos os dias					
Lidar com as complicações associadas à diabetes					

Attachment III – Back-translation

	It's not a problem	Minor problem	Moderate problem	Somewhat serious problem	Serious problem
Being afraid when you think about living with diabetes					
Feeling depressed when you think about living with diabetes					
Feeling worried about the future and the possibility of having serious complications					
Feeling that diabetes requires too much mental and physical energy on a daily basis.					
Dealing with complications associated with diabetes.					

Attachment IV – European Portuguese PAID-5 final version

	0 Não é um problema	1 Problema minor	2 Problema moderado	3 Problema algo grave	4 Problema grave
1. Ter medo quando pensa sobre viver com diabetes.	☐	☐	☐	☐	☐
2. Sentir-se deprimido(a) quando pensa sobre viver com diabetes.	☐	☐	☐	☐	☐
3. Preocupar-se sobre o futuro e a possibilidade de vir a ter complicações graves.	☐	☐	☐	☐	☐
4. Sentir que diabetes requer demasiada energia mental e física todos os dias.	☐	☐	☐	☐	☐
5. Lidar com as complicações associadas à diabetes.	☐	☐	☐	☐	☐

Attachment V – DHP-psychological distress questions (DHP-PDQ)

DHP

	3 **Sempre**	**2** **Geralmente**	**1** **Às vezes**	**0** **Nunca**
1. Perde a cabeça quando as pessoas insistem que faça os testes de controlo do açúcar e siga a dieta?	☐	☐	☐	☐

	3 **Muitíssimo mais**	**2** **Muito mais**	**1** **Um pouco mais**	**0** **Nada**
2. Há mais discussões ou aborrecimentos em casa do que haveria se não tivesse diabetes?	☐	☐	☐	☐

	3 **Muito frequentemente**	**2** **Frequentemente**	**1** **Às vezes**	**0** **Nunca**
3. Fica deprimido(a) ou "em baixo" por causa da sua diabetes?	☐	☐	☐	☐
4. A sua diabetes fá-lo(a) perder a cabeça ou gritar?	☐	☐	☐	☐
5. Fica suscetível, irritado(a) ou de mau humor por causa da diabetes?	☐	☐	☐	☐
6. Perde a calma por coisas sem importância?	☐	☐	☐	☐

Attachment VI – USF coordinator's authorizations

Consentimento

Eu, _João Carlos Monteiro Arcanjo_____, coordenador(a) da USF_ MONDEGO ___, declaro que autorizo a recolha de dados pessoais dos utentes desta instituição para o estudo "Adaptação cultural e validação da escala PAID (Problem Areas in Diabetes) para Português Europeu".

V. Luarbinho Bispo 24 6/ 2022

Assinatura   USF MONDEGO
_____   Dr. João Arcanjo
                    Coordenador

DECLARAÇÃO DE AUTORIZAÇÃO

ESTUDOS DE INVESTIGAÇÃO NA USF COIMBRA CENTRO

Pedro José da Costa Félix de Morais Sousa, responsável do Conselho Técnico da USF Coimbra Centro (USF CC), declara para os devidos efeitos, que autoriza a realização do Estudo de Investigação "Adaptação cultural e validação da escala PAID (Problem Areas in Diabetes) para Português Europeu", proposto por Cláudia Sofia Fonseca Pereira e a recolha de dados dos utentes desta unidade de saúde.

A recolha dos dados deverá ser efetuada pelo investigador principal, ou por voluntários identificados e comunicados previamente à USF CC pelo mesmo.
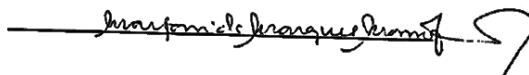
Coimbra, 15 de julho de 2022

_____

Pedro Morais Sousa

Conselho Técnico da USF Coimbra Centro

Consentimento

Eu, _Margarida Helena da Silva Marques Nunes Guimarães_, coordenador(a) da USF _Condemudo_, declaro que autorizo a recolha de dados pessoais dos utentes desta Instituição para o estudo "Adaptação cultural e validação da escala PAID (Problem Areas in Diabetes) para Português Europeu".

Castro Daire , 17/06/2022

Assinatura

_____

GOVERNO DE PORTUGAL
MINISTÉRIO DA SAÚDE

ARSC ADMINISTRAÇÃO REGIONAL DE SAÚDE DO CENTRO, I.P.

COMISSÃO DE ÉTICA PARA A SAÚDE

PARECER FINAL: FAVORÁVEL	DESPACHO: *Tomado conhecimento e deliberado homologar o Parecer final da Comissão de Ética para a Saúde.* *28.10.2022* Conselho Diretivo da A.R.S. do Centro, I.P.

ASSUNTO:	Parecer sobre o Projeto 80/2022 – *"Adaptação cultural e validação da escala Problem Areas in Diabetes (PAID-5) para Português Europeu".*	Drª Rosa Reis Marques Presidente,

Dr. Mário Ruivo
Vogal,

O parecer anterior continha as seguintes recomendações:

- Necessidade de incluir a autorização para a criação da versão portuguesa do PAID-5;
  Dr. Fernanda Cravo
- Falta de referência do tamanho da amostra e dos procedimentos para a validação.

A investigadora principal enviou, entretanto, a esta Comissão a autorização do autor do PAID-5 e redefiniu os procedimentos metodológicos.

Assim sendo, esta Comissão de Ética emite um parecer favorável.

O Relator: Prof. Doutor Pedro Lopes Ferreira

O Presidente da CES: Prof. Doutor Fontes Ribeiro

Ressalva: A CE-ARSC enfatiza que a aprovação de um estudo não significa que venha a ter qualquer responsabilidade por danos ou outros atos ilícitos que possam vir a ser praticados no âmbito do mesmo. As opiniões apresentadas nas publicações, relatórios ao governo ou outros resultados desta investigação são da responsabilidade exclusiva dos investigadores.