

Journal Pre-proof

Dimensionality and psychometric properties of the Parent Diabetes Distress Scale - Greek (PDDS-Gr)

Emmanouil S. Benioudakis, Argyroula Kalaitzaki, Eleni Karlafti, Maria A. Makri, Theodosia Arvanitaki, Maria-Alexandra Kalpou, Christos Savopoulos, Triantafyllos Didangelos

DOI: <https://doi.org/10.22365/jpsych.2023.020>

To appear in: Psychiatriki Journal

Received date: 21 June 2023

Accepted date: 7 September 2023

Please cite this article as: Emmanouil S. Benioudakis, Argyroula Kalaitzaki, Eleni Karlafti, Maria A. Makri, Theodosia Arvanitaki, Maria-Alexandra Kalpou, Christos Savopoulos, Triantafyllos Didangelos, Dimensionality and psychometric properties of the Parent Diabetes Distress Scale -Greek (PDDS-Gr), Psychiatriki (2023), doi: <https://doi.org/10.22365/jpsych.2023.020>

This is a PDF file of an article that has undergone enhancements after acceptance, such as the addition of a cover page and metadata, and formatting for readability, but it is not yet the definitive version of record. This version will undergo additional copyediting, typesetting and review before it is published during the production process, errors, may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

RESEARCH ARTICLE

Dimensionality and psychometric properties of the Parent Diabetes Distress Scale - Greek (PDDS-Gr)

Emmanouil S. Benioudakis,^{1,2} Argyroula Kalaitzaki,³ Eleni Karlafti,² Maria A. Makri,⁴ Theodosia Arvanitaki,⁵ Maria- Alexandra Kalpou,⁶ Christos Savopoulos,² Triantafyllos Didangelos²

¹Psychiatric Clinic, General Hospital of Chania, Chania, Crete

²Diabetes Center, 1st Propaedeutic Department of Internal Medicine, Medical School, 'AHEPA' University General Hospital, Aristotle University of Thessaloniki, Thessaloniki, Macedonia

³Department of Social Work, Laboratory of Interdisciplinary Approaches to the Enhancement of Quality of Life, Health Sciences Faculty, Hellenic Mediterranean University, Heraklion, Crete

⁴Department of Biomedical Sciences, University of West Attica, Athens

⁵Pediatric Diabetes outpatient clinic, Pediatric Department, General Hospital of Chania, Chania, Crete

⁶Department of Psychology, National and Kapodistrian University of Athens, Athens

ARTICLE HISTORY: Received 21 June 2023 / Revised 22 August 2023 / Published Online 29 September 2023

ABSTRACT

Type 1 diabetes (T1D) is a chronic disease characterised by insulin deficiency due to autoimmune destruction of beta-pancreatic cells. T1D, formerly known as juvenile diabetes, is the most common form of diabetes in children and adolescents. On diagnosis, parents of children with T1D experience considerable stress, because they need to care for a child in a challenging and life-threatening situation that requires adherence to an intensive medical regimen, constant monitoring of, and coping with their child's condition. T1D is a complex condition that affects both children and their parents in many aspects of their daily lives. This study presents the psychometric properties of the Greek translation of the Parent Diabetes Distress Scale (PDDS), which assesses diabetes distress in parents of children with T1D. A sample of 95 parents, mainly mothers (88.4%), with a mean age of their children 12.2 years (± 3.6) and a diabetes duration of 4.7 years (± 3.4), completed the Greek translation of the PDDS. Exploratory factor analysis (EFA) revealed a five-factor model: 'Parent/child relationship distress', 'Personal distress', 'Child diabetes management distress', 'Future distress', and 'Healthcare team distress'. Confirmation Factor Analysis (CFA) confirmed the construct validity of the scale. The internal consistency indices (Cronbach alpha) for the subscales ranged from 0.69 to 0.89, while the unidimensional structure had an alpha of 0.90. Furthermore, convergent validity was shown with moderate positive correlations between the PDDS-Gr and the subscales of the DASS-21 (depression, anxiety, and stress), the child's age (in years), and the HbA_{1c} value. Finally, parents of children with inadequate glycemic control (HbA_{1c} $\geq 7\%$) presented higher scores on both the unidimensional structure and the subscales 'Parent/child relationship distress' and 'Healthcare team distress' of the PDDS-Gr. The PDDS-Gr is a valid and reliable tool for assessing diabetes distress in parents of children with T1D and can be used in both clinical and research settings.

KEYWORDS: Type 1 diabetes mellitus, diabetes distress, parental stress, children, factor analysis.

Corresponding Author: Emmanouil Benioudakis, Stilponos Kyriakidi 1, 55636, Thessaloniki, Greece, e-mail: empeniou@auth.gr

Introduction

Type 1 diabetes (T1D), previously known as juvenile diabetes, is a chronic disease characterised by insulin deficiency due to autoimmune destruction of pancreatic beta cells.^{1,2} T1D is the most common form of diabetes, affecting 1.2 million children and adolescents (for brevity, the term children will be used henceforth to describe both youngsters and adolescents) throughout the world, with varying prevalence among countries.³ The prevalence of T1D in Greece is 0.24%, with more than half of the cases occurring in children over the age of 14 years.⁴ T1D is complex to manage, as it requires multiple daily injections or the use of an insulin pump. In addition, successful diabetes management requires frequent blood glucose testing through self-monitoring or continuous glucose monitoring (CGM).^{3,5}

For parents, the diagnosis of T1D is a traumatic and devastating event,⁶ with feelings of fear, anger, frustration, guilt, helplessness, hopelessness, sorrow, despair, and profound grief.⁷ They also experience considerable stress,⁸ and high levels of depression and anxiety.^{8,9} Parents have to maintain their typical parenting roles and at the same time care for a child with a challenging and life-threatening situation that requires adherence to an intensive medical regimen, including constant monitoring of, and coping with, their child's condition.^{10,11} One recent review indicated that parental distress ranges from 10% to 74%, with approximately 34% of parents reporting distress on diagnosis and approximately 20% reporting distress after 1 to 4 years.⁷ Parental anxiety, depression, and stress are associated with low parental self-efficacy with regards to diabetes management, while parental stress is also associated with poorer glycemic control.¹⁰ In addition, diabetes-related parental distress is associated with children's depressive symptoms,¹⁰ more problematic child behavior, and lower child self-reported quality of life.^{7,10}

Although parental distress has been extensively studied, presently little is known about parental distress specifically related to their child's diabetes,^{7,12} and neither is there such an instrument in Greek. Therefore, the aim of this study is to translate the PDDS into Greek (hereafter referred to as PDDS-Gr), a scale that was developed specifically for use with parents of children with T1D,¹² and examine its dimensionality and psychometric properties. However, in order to ensure the applicability of the 20-item PDDS in the Greek cultural context and to reveal the underlying structure, an Exploratory Factor Analysis (EFA) was first conducted.

Material and methods

Procedure

Initially, two independent native speakers translated the PDDS into Greek. A reconciled version of the PDDS was developed and then a bilingual person performed a backward translation. A cultural adaptation was performed by all authors. Finally, two experts in the field, a psychologist and a pediatric diabetologist, performed the face validity process; based on their expertise, they were asked to examine the extent to which the PDDS-Gr reflected the construct of diabetes distress (DD) in parents related to their child's condition. Permission to access and use the PDDS was granted by the *Behavioral Diabetes Institute-San Diego*. The study has been approved by the Ethics Committee of the Aristotle University of Thessaloniki with reference number 114/2023 and has been carried out in accordance with the Declaration

of Helsinki. The questionnaire is freely available from <https://behavioraldiabetes.org/scales-and-measures/>

Participants

Parents of children with T1D were invited to participate in the study both by the Diabetes Center of the 'AHEPA' General University Hospital of Thessaloniki and by associations of parents of children with type 1 diabetes throughout Greece. The announcement described the project and included a Google form link with further study information. Participants provided online informed consent of their rights (e.g., anonymity and voluntary participation). Ninety-five parents of children aged between 7 and 21 completed the survey. The majority of parents were mothers (88.4%), married (86%), employed (76%), with a university-level education (67.4%), and their average age was 45.2 years (± 5.8). Exclusion criteria were non-Greek-speaking parents, parents of T1D children outside the predefined age range, other types of diabetes mellitus, and a diabetes duration of 5 months or less. Finally, a random subsample of 17 parents voluntarily participated in the cognitive debriefing process and were retested four weeks later in order to assess the test-retest reliability of the scale. The detailed sociodemographic characteristics of the sample and the subsample are presented in **Table 1**.

Measures

The *Parent Diabetes Distress Scale (PDDS)* is a 20-item self-report measure of parental distress related to their child's diabetes. Items are scored using a 5-point Likert scale ranging from 0 (*not at all*) to 4 (*a great deal*). The original version has four subscales: 'Personal distress' (*six items*); 'Teen diabetes management distress' (*four items*); 'Parent/teen relationship distress' (*eight items*); and 'Healthcare team distress' (*two items*). The total score ranges from 0 to 80, with higher scores indicating more parental distress.¹² In this study, the reliability indices (Cronbach alpha coefficients) for the unidimensional structure of the PDDS-Gr and its subscales were $\alpha_{\text{total}} = 0.9$, $\alpha_{\text{personal distress}} = 0.8$, $\alpha_{\text{teen diabetes management distress}} = 0.65$, $\alpha_{\text{parent/teen relationship distress}} = 0.86$, and $\alpha_{\text{healthcare team distress}} = 0.79$.

The *Depression Anxiety and Stress Scale (DASS-21)* is a 21-item self-report measure of depression, anxiety and stress. Items are scored on a 4-point Likert scale ranging from 0 (*did not apply to me at all*) to 3 (*applied to me very much or most of the time*). Each scale contains seven items, and higher scores indicate higher frequency of symptoms. The Greek version of the DASS-21 is both reliable and valid.^{13,14} In this study, the Cronbach alpha coefficients were $\alpha_{\text{depression}} = 0.91$, $\alpha_{\text{anxiety}} = 0.88$, and $\alpha_{\text{stress}} = 0.91$.

Statistical Analysis

The translated version of the PDDS-Gr was sent to a panel of three independent experts in diabetes mellitus (i.e., a pediatrician and two psychologists) to assess the content validity index (CVI). They were asked to evaluate the PDDS-Gr items for content equivalence on a 3-point Likert scale: 1 = necessary, 2 = useful but not necessary, and 3 = unnecessary. The total CVI was calculated by dividing all items ranked as 1 (necessary) by the total number of PDDS-Gr items (i.e., 20). An unforced exploratory factor analysis (EFA) with principal axis factoring and varimax rotation was conducted to investigate the construct validity of the PDDS-Gr. Sampling adequacy was assessed by the Kaiser-Meyer-Olkin (KMO) and Bartlett's test of sphericity. Subsequently, a confirmatory factor analysis (CFA) with maximum likelihood was carried out to determine whether the five-factor or the unidimensional model proposed by EFA provided a better fit. Model fit was assessed with the chi-square (χ^2), the root mean square error of approximation (RMSEA), the standardized root mean square residual (SRMSR), the Tucker-Lewis Index (TLI), and the comparative fit index (CFI).¹⁶ Test-retest reliability was assessed with the intraclass correlation coefficient (ICC) 2-way mixed-effects model for measurements, and internal consistency of the unidimensional PDDS-Gr and its subscales was

assessed with Cronbach's alpha coefficients, composite reliabilities, and average variance extracted (AVE) reliability of the final CFA model.¹⁷ Construct validity was investigated by calculating the two-tailed Spearman's correlation coefficients among the PDDS-Gr and its five subscales with the DASS-21 and its subscales (depression, anxiety, and stress), the parents' report of their child's most recent glycated hemoglobin (HbA_{1c}), the child's age (in years), and diabetes duration (in years). Medium-to-high correlations ($r > \pm 0.4$) were taken as evidence for convergent validity.¹⁸ Differential validity (known groups method) was assessed by independent samples t-test between children with and without adequate metabolic control of the last reported HbA_{1c} value. The last HbA_{1c} value was regrouped according to the International Society for Pediatric and Adolescent Diabetes (ISPAD) guidelines (2022).^{19,20} The significance level was set at $p < 0.05$. All analyses, besides the confirmatory factor analysis (CFA), were conducted using SPSS version 26 (SPSS Inc., Chicago, IL, USA). CFA was conducted with AMOS version 20.

Results

Translation, cultural adaptation, face validity, and cognitive debriefing

During the translation process, the word 'teen' in the source language (English) was replaced by the word 'child' in the target language (Greek) and is thus reported in this survey. Any discrepancies that arose were discussed and resolved, and a consensus version in Greek was created. As a result, the panel of experts who conducted the face validity found that the PDDS-Gr scale reflected parental distress related to their child's diabetes. Finally, parents participating in the cognitive debriefing stage reported that the PDDS-Gr was readily understandable.

Content validity

An excellent content validity index of 95% was found among the panel of experts.²¹ Item 20 was unanimously assessed as 'useful but not necessary'.

Structural validity

Exploratory factor analysis (EFA)

An unforced EFA using the principal component analysis method for factor extraction and varimax rotation was used. Additionally, a cut-off of ≥ 0.50 was applied to identify meaningful factor loadings using the latent root criterion of retaining factors with eigenvalues greater than 1.0. A five-factor structure was identified, with the extracted factors explaining 67.8% of the total variance. KMO coefficient was equal to 0.827 and Barlett χ^2 value was 1006.8 ($p < 0.001$). The final communalities estimates after rotation were high (> 0.49) for all items. All factor loadings exceeded 0.50, ranging from 0.50 to 0.85. A forced one-factor, unidimensional solution was also conducted and all factor loadings were between 0.38 and 0.79. Both the five-factor model and the unidimensional structure are presented in **Table 2**. The 20 items of the PDDS-Gr were allocated into five factors: 'Parent/child relationship distress' (1,2,3,5,10,14,17,20); 'Personal distress' (9,12,15,19); 'Child's diabetes management distress' (4,6,7,8); 'New factor (Future distress)' (13,18); and 'Healthcare team distress' (11,16). Some items were allocated into different factors than in the original version. More specifically, item 2 loaded on the 'Parent/child relationship distress' factor rather than the 'Personal distress' factor, while items 6 and 7 loaded on the 'Child's diabetes management distress' factor rather than the 'Personal distress' and 'Parent/child relationship distress' factors, respectively.

Confirmatory Factor Analysis (CFA)

CFA was applied to test how well the five-factor model and the unidimensional structure of the PDDS-Gr fit the data. After the improvements suggested by modification indices, both the five-factor model ($\chi^2 = 170.5(143)$, $p = 0.058$, CMIN/DF = 1.193, RMSEA = 0.045, SRMR = 0.0739, TLI = 0.959, and CFI = 0.969), and the unidimensional structure of the PDDS-Gr ($\chi^2 = 171.6(134)$, $p = 0.016$, CMIN/DF = 1.281, RMSEA = 0.055, SRMR = 0.0759, TLI = 0.941, and CFI = 0.958), presented a good fit of the data.

Descriptive statistics of the PDDS-Gr, metabolic control and parental distress

Each PDDS-Gr subscale score was calculated as the mean of the contributing items (with scores ranging from 0 to 4). The mean total scale score was 1.58 (± 0.74) and the mean subscale scores were 'Parent/child relationship distress' 1.35 (± 0.91); 'Personal distress' 1.45 (± 1.05); 'Child's diabetes management distress' 2.5 (± 0.95); 'Future distress' 1.55 (± 1.1); and 'Healthcare team distress' 0.8 (± 1.0). In addition, 41 parents reported $HbA_{1c} \geq 7\%$ and 53 reported $HbA_{1c} < 7.0\%$. Statistically significant differences were found in the parental distress (total PDDS-Gr and two subscales) between those whose children did and those whose children did not report adequate metabolic control: total PDDS-Gr ($M = 28.7$, $SD = 13.7$ vs. $M = 35.5$, $SD = 15.9$), $t(92) = 2.2$, $p = 0.029$, $d = 0.45$; 'Parent/child relationship distress' ($M = 9.3$, $SD = 6.4$ vs. $M = 10.8$, $SD = 8.0$), $t(92) = 2.3$, $p = 0.021$, $d = 0.48$; and 'Healthcare team distress' ($M = 1.2$, $SD = 1.7$ vs. $M = 2.2$, $SD = 2.5$), $t(92) = 2.3$, $p = 0.012$, $d = 0.50$.

Test-retest reliability

The ICC of the 17 parents who were retested four weeks later was 0.96 ($p < 0.001$), which indicates excellent reliability. When six parents who had visited their doctor in the previous four weeks were excluded, the ICC increased slightly to 0.97.

Internal consistency, split-half, and composite reliability

Cronbach's alpha coefficient of the 20-item PDDS-Gr was 0.90 and for its subscales 'Parent/child relationship distress' 0.89, 'Personal distress' 0.78, 'Child's diabetes management distress' 0.77, 'Future distress' 0.69, and 'Healthcare team distress' 0.79. In addition, the Guttman Split-half coefficient was 0.83. Finally, the Composite reliabilities of the final CFA model were adequate, while AVEs of the final CFA model were relatively low for the subscales 'Personal distress' (0.47), 'Child's diabetes management distress' (0.48), and for the unidimensional structure (0.3). Internal consistency reliabilities are presented in **Table 2**.

Construct validity

The unidimensional PDDS-Gr and its subscales showed moderate positive correlations with the three subscales of the DASS-21 (i.e., depression, anxiety, and stress), indicative of good convergent validity. The new factor 'Future distress' also showed a moderately positive correlation with the child's age. The correlations are presented in **Table 3**.

Discussion

This study reports the translation, cultural adaptation, and psychometric properties of the PDDS¹² in the Greek language (i.e., PDDS-Gr). The PDDS-Gr was rigorously validated, and the 20-item scale proved to be an acceptable, reliable, and valid tool for assessing parental distress in parents of children with T1D in Greece. A notable advancement of this study was that we included parents of children ≥ 7 years old, as opposed to the initial version,¹² which included children ≥ 11 years old. This is consistent with the latest ISPAD guidelines (2022) according to which age-appropriate educational interventions are effective from school age, start at diagnosis and need to be a continuous process.²²

EFA identified five different areas of parental DD, with four of them being similar to the original PDDS and thus the original naming was retained: the 'Parent/child relationship distress' subscale (eight items) describes parents' distress over their relationship with their children, such as diabetes-related conflicts and disagreements; the 'Personal distress' subscale (four items) focuses on parents' own personal distress and worries (e.g., lack of understanding and support); the 'Child's diabetes management distress' subscale (four items) describes parents' distress over their child's T1D management, such as worrying about inadequate diabetes management; and the 'Healthcare team distress' subscale (two items), which focuses on parents' distress over the adequacy of their child's healthcare.¹² The 'new factor' in the Greek version of the PDDS showed an adequate reliability of 0.69 and consisted of two items (13: 'Worrying that my teen will soon leave home and I cannot protect them' and 18: 'Concerned that my teen is not prepared to deal with the world of insurance and doctors once he/she is an adult'), referring to future worries, and thus, it was named 'Future distress'. This new factor is consistent with the Greek traditional values, roles, and duties of the Greek family,^{23,24} within which parents are caring, protective and supportive.^{25,26} The role of 'in-group', defined as «people concerned with me, people with whom I can establish interdependencies»,²⁷ is fundamental both in traditional and modern Greek culture/family. The 'in-group' behavior is characterized by cooperation, protection, and help^{27,28} and members of Greek families develop strong bonds and are characterized by extreme interdependence at all levels of existence.^{24,28,29}

The unidimensional PDDS-Gr had high internal consistency, slightly lower than the original PDDS (0.90 vs. 0.94), and excellent stability over time (ICC = 0.961). Cronbach's alpha coefficients of the subscales 'Parent/child relationship distress' and 'Personal distress' were slightly lower than the original version (0.89 vs. 0.96 and 0.78 vs. 0.88, respectively), but the subscales 'Child's diabetes management distress' and 'Healthcare team distress' showed slightly higher alpha coefficients (0.77 vs. 0.75 and 0.79 vs. 0.75, respectively). Thus, both the Greek and the original PDDS validation reported 'Child's diabetes management' as the highest-scoring parenting distress subscale and 'Healthcare team distress' as the lowest one.¹²

Convergent validity was confirmed with low to moderate positive correlations between both the unidimensional structure and the five factors of the PDDS-Gr and the DASS-21 subscales (depression, anxiety, and stress) and the child's age (in years). It was reasonable to find correlations between parental distress as measured with the PDDS-Gr and stress as measured with the DASS-21, since distress occurs when stress is severe and/or prolonged and resources are lacking to deal with it.^{30,31} Besides, the terms 'stress' and 'distress' are frequently used interchangeably in the literature due to their conceptual similarity.^{30,32} These results are consistent with both the initial PDDS validation¹² and the literature.^{11,33-35} Not surprisingly, the new factor 'Future distress' positively correlated with the child's age, as the older the child gets, the greater the parental future worries are.

Differential validity was confirmed by the significant differences in parental distress between those with children with HbA_{1c} ≥ 7% (inadequate metabolic control) and those with children with HbA_{1c} < 7% (adequate metabolic control). Parents who reported the most recent HbA_{1c} greater than 7% scored significantly higher on the unidimensional PDDS-Gr and its subscales 'Parent/child relationship distress' and 'Healthcare team distress'. Our results are consistent with the findings of previous studies that found an association between a higher level of parental emotional distress and poorer metabolic control in children.^{36,37}

The 20-item PDDS-Gr is a psychometrically reliable tool for assessing multiple domains of parental T1D distress among Greek parents and can be used both in clinical settings and for research purposes. The PDDS-Gr can be used to improve parental well-being, enhance pediatric diabetes management, and help healthcare providers identify elevated scores and allow for individualized interventions. Key strengths of the present study are the design that allowed test-retest reliability assessment and the use of validated psychometric instruments

that allowed the examination of convergent and differential validity. The present study has certain limitations that should be acknowledged. Firstly, the sample size of parents involved was relatively small. Secondly, it is important to note that the CFA was conducted on the same sample as the EFA, potentially raising concerns about the robustness of the results. Lastly, mothers were overrepresented, which could introduce gender-related biases to the findings.

Conclusion

This study presented the translation and psychometric properties of the PDDS-Gr. The findings showed that the unidimensional structure of the PDDS-Gr and of its five-dimensions ('Parent/child relationship distress', 'Personal distress', 'Child's diabetes management distress', 'Future distress', and 'Healthcare team distress') had high internal consistency, convergent and differential validity. The PDDS-Gr successfully reflected the same constructs as those described in the initial PDDS version with the addition of one culturally related subscale.

Acknowledgments

The authors would like to thank all the study participants.

References

1. ElSayed NA, Aleppo G, Aroda VR, Bannuru RR, Brown FM, Bruemmer D, et al. American Diabetes Association. 2. Classification and diagnosis of diabetes: Standards of Care in Diabetes-2023. *Diabetes Care* 2023, 46:S19-S40, doi: 10.2337/dc23-S002
2. Ferber C, Mao CS, Yee JK. Type 1 Diabetes in Youth and Technology-Based Advances in Management. *Adv Pediatr* 2020, 67:73-91, doi: 10.1016/j.yapd.2020.04.002
3. Ogle GD, James S, Dabelea D, Pihoker C, Svensson J, Maniam J et al. Global estimates of incidence of type 1 diabetes in children and adolescents: Results from the International Diabetes Federation Atlas, 10th Edition. *Diabetes Res Clin Pract* 2021, 109083, doi: 10.1016/j.diabres.2021.109083
4. Liatis S, Dafoulas GE, Kani C, Politi A, Litsa P Sfikakis PP, Makrilakis K. The prevalence and treatment patterns of diabetes in the Greek population based on real-world data from the nation-wide prescription database. *Diabetes Res Clin Pract* 2016, 118:162-7, doi: 10.1016/j.diabres.2016.06.018
5. Rodbard D. Continuous Glucose Monitoring: A Review of Recent Studies Demonstrating Improved Glycemic Outcomes. *Diabetes Technol Ther* 2017, 19:S25-S37, doi: 10.1089/dia.2017.0035
6. Landolt MA, Vollrath M, Laimbacher J, Gnehm HE, Sennhauser FH. Prospective study of posttraumatic stress disorder in parents of children with newly diagnosed type 1 diabetes. *J Am Acad Child Adolesc Psychiatry* 2005, 44:682-9, doi: 10.1097/01.chi.0000161645.98022.35
7. Whittemore R, Jaser S, Chao A, Jang M, Grey M. Psychological experience of parents of children with type 1 diabetes: a systematic mixed-studies review. *Diabetes Educ* 2012, 38:562-79, doi: 10.1177/0145721712445216
8. Moreira H, Frontini R, Bullinger M, Canavarro MC. Caring for a child with type 1 diabetes: links between family cohesion, perceived impact, and parental adjustment. *J Fam Psychol* 2013, 27:731-42, doi: 10.1037/a0034198
9. Streisand R, Mackey ER, Elliot BM, Mednick L, Slaughter IM, Turek J, et al. Parental anxiety and depression associated with caring for a child newly diagnosed with type 1 diabetes: opportunities for education and counseling. *Patient Educ Couns* 2008, 73:333-8, doi: 10.1016/j.pec.2008.06.014

10. Bassi G, Mancinelli E, Di Riso D, Salcuni S. Parental Stress, Anxiety and Depression Symptoms Associated with Self-Efficacy in Paediatric Type 1 Diabetes: A Literature Review. *Int J Environ Res Public Health* 2020, 18:152, doi: 10.3390/ijerph18010152
11. Lowes L, Lyne P. A normal lifestyle: parental stress and coping in childhood diabetes. *Br J Nurs* 1999, 8:133-9, doi: 10.12968/bjon.1999.8.3.6698
12. Hessler D, Fisher L, Polonsky W, Johnson N. Understanding the Areas and Correlates of Diabetes-Related Distress in Parents of Teens With Type 1 Diabetes. *J Pediatr Psychol* 2016, 41:750-8, doi: 10.1093/jpepsy/jsw002
13. Osman A, Wong JL, Bagge CL, Freedenthal S, Gutierrez PM, Lozano G. The Depression Anxiety Stress Scales-21 (DASS-21): further examination of dimensions, scale reliability, and correlates. *J Clin Psychol* 2012, 68:1322-1338, doi: 10.1002/jclp.21908
14. Lyrakos GN, Arvaniti C, Smyrnioti M, Kostopanagiotou G. Translation and validation study of the depression anxiety stress scale in the Greek general population and in a psychiatric patient's sample. *Eur Psychiatry* 2011, 26:1731, doi:10.1016/S0924-9338(11)73435-6
15. Hair JF, Anderson RE, Black WC. *Multivariate Data Analysis*. 7th ed. Pearson, New York, 2014
16. Hu L, Bentler PM. Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling: A Multidisciplinary Journal* 1999, 6:1-55, doi:10.1080/10705519909540118
17. Bagozzi RP, Yi Y. On the evaluation of structural equation models. *JAMS* 1988, 16:74-94, doi: 10.1007/BF02723327
18. Cohen J. A power primer. *Psychol Bull* 1992, 112:155-159, doi: 10.1037//0033-2909.112.1.155
19. Katzell RA, Dyer FJ. Differential validity revived. *Journal of Applied Psychology* 1977,62:137145, doi: 10.1037/0021-9010.62.2.137
20. de Bock M, Codner E, Craig ME, Huynh T, Maahs DM, Mahmud FH, et al. ISPAD Clinical Practice Consensus Guidelines 2022: Glycemic targets and glucose monitoring for children, adolescents, and young people with diabetes. *Pediatr Diabetes* 2022, 23:1270-1276, doi: 10.1111/pedi.13455
21. Davis LL. Instrument review: Getting the most from a panel of experts. *In Applied Nursing Research* 1992, 5:194-197, doi:10.1016/s0897-1897(05)80008-4
22. Lindholm Olinder A, DeAbreu M, Greene S, Haugstvedt A, Lange K, Majaliwa ES, et al. ISPAD Clinical Practice Consensus Guidelines 2022: Diabetes education in children and adolescents. *Pediatr Diabetes* 2022, 23:1229-1242, doi: 10.1111/pedi.13418
23. Georgas J. Intrafamily Acculturation of Values in Greece. *Journal of Cross-Cultural Psychology* 1991, 22:445-457, <https://doi.org/10.1177/0022022191224001>
24. Polemi-Todoulou M, Vassiliou V, Vassiliou G. The Grouping Process Across Cultural Change. *Group* 1998, 22:105-119, doi: 10.1023/A:1022179613725
25. Potamianou A, Safilios-Rotbschild C. Trends of Discipline in the Greek Family. *Human Relations* 1971, 24:387-395, doi: 10.1177/001872677102400504
26. Mylonas K, Gari A, Giotsa A, Pavlopoulos V, Panagiotopoulou P. Greece. In: Georgas J, Berry JW, van de Vijver F, Kagitçibasi C, Poortinga YH. (Ed), *Families across cultures: A 30 nation psychological study*. Cambridge University Press, New York, NY, 2006
27. Vasiliou VG, Vassiliou G. Variations of the group process across cultures. *Int J Group Psychother* 1974, 24:55-65, doi: 10.1080/00207284.1974.11492269
28. Triandis H, Vassilou VA. A Comparative Analysis of Subjective Culture, Technical report, Dept. of Psychology, University of Illinois, Urbana, 1967. Available at: <https://apps.dtic.mil/sti/pdfs/AD0663889.pdf>
29. Tsididaki A. Family functioning and strengths in families raising a child with cerebral palsy. *Res Dev Disabil* 2020, 106:103767, doi: 10.1016/j.ridd.2020.103767

30. Matthews G. Distress. In: G. Fink (Ed.), *Stress: Concepts, cognition, emotion, and behavior*. Academic Press, San Diego, 2016
31. Ridner, SH. Psychological distress: concept analysis. *Journal of Advanced Nursing* 2004, 45:536-545, doi:10.1046/j.1365-2648.2003.02938.x
32. McKenzie SH, Harris MF. Understanding the relationship between stress, distress and healthy lifestyle behaviour: a qualitative study of patients and general practitioners. *BMC Fam Pract* 2013,14:166, doi: 10.1186/1471-2296-14-166
33. Robinson EM, Weaver P, Chen R, Streisand R, Holmes CS. A model of parental distress and factors that mediate its link with parental monitoring of youth diabetes care, adherence, and glycemic control. *Health Psychol* 2016, 35:1373-1382, doi: 10.1037/hea0000406
34. Cunningham NR, Vesco AT, Dolan LM, Hood KK. From caregiver psychological distress to adolescent glycemic control: the mediating role of perceived burden around diabetes management. *J Pediatr Psychol* 2011, 36:196-205, doi: 10.1093/jpepsy/jsq071
35. Tsamparli A, Kounenou K. The Greek family system when a child has diabetes mellitus type 1. *Acta Paediatrica* 2007, 93:1646-1653, doi:10.1111/j.1651-2227.2004.tb00857.x
36. Viaene AS, Van Daele T, Bleys D, Faust K, Massa GG. Fear of Hypoglycemia, Parenting Stress, and Metabolic Control for Children with Type 1 Diabetes and Their Parents. *J Clin Psychol Med Settings* 2017, 24:74-81, doi: 10.1007/s10880-017-9489-8.
37. Eilander MMA, Snoek FJ, Rotteveel J, Aanstoot HJ, Bakker-van Waarde WM, Houdijk ECAM, et al. Parental Diabetes Behaviors and Distress Are Related to Glycemic Control in Youth with Type 1 Diabetes: Longitudinal Data from the DINO Study. *J Diabetes Res* 2017, 2017:1462064, doi: 10.1155/2017/1462064

Table 1. Parents and youngsters' sociodemographic characteristics

Characteristics	Total sample (n=95) Mean \pm SD / N (%)	Re-test sample (n=17) Mean \pm SD / N (%)
<i>Parents</i>		
Age (in years)	45.2 \pm 5.8	45.1 \pm 7.3
Gender (female)	84 (88.4)	13 (76.5)
Educational Level		
Primary and secondary	31 (32.6)	5 (29.4)
University	64 (67.4)	12 (70.6)
Family status		
Married	82 (86.3)	15 (88.2)
Divorced	10 (10.3)	1 (5.9)
Other	3 (3.1)	1 (5.9)
Employment		
Paid work (employed)	74 (77.8)	12 (70.5)

Unemployed	19 (20)	4 (23.5)
Other	2 (2.1)	1 (5.9)
Income status		
Low	13 (13.7)	4 (23.5)
Average	61 (64.2)	12 (70.6)
High	21 (22.1)	1 (5.9)
<i>Psychosocial characteristics</i>		
DASS-21		
Depression	5.6 ± 4.9	N/A
Anxiety	4.2 ± 4.4	N/A
Stress	7.4 ± 4.9	N/A
<i>Children</i>		
Age (in years)	12.2 ± 3.6	12.8 ± 3.7
Gender (female)	52 (54.7)	11 (64.7)
Diabetes duration (in years)	4.7 ± 3.4	4.7 ± 3.2
HbA _{1c} (last recorded)	6.9 ± 0.7	7.1 ± 0.7
CSII use	58 (61.1)	11 (64.7)
CGM use	79 (83.2)	15 (88.2)
CSII Closed-Loop use	26 (27.3)	7 (41.2)

Note: DASS-21(0-21): Depression Anxiety and Stress Scale; N/A: Not Applicable; HbA_{1c}: hemoglobin A1c; CGM: Continuous Glucose Monitoring; CSII: Continuous subcutaneous insulin infusion

Table 2. Factor analysis and internal consistency reliability of the 20-item PDDS-Gr

Item wording PDDS (item No.)	Five-factor solution ^a											
	Parent/ Child relations hip distress		Personal distress		Child's diabetes manage ment distress		Future distress		Healthca re team distress		PDDS (unidimen sional) ^b	
	EF A	CF A	EF A	CF A	EF A	CFA	EF A	CF A	EF A	CF A	EF A	CFA

Feeling that my teen doesn't do enough to manage his/her diabetes. (10)	0.8 0	0.8 6	0.7 6	0.8 0.8
Feeling that I can't trust my teen to take good care of his/her diabetes. (3)	0.7 3	0.7 0.7	0.6 4	0.62 0.62
Feeling uncertain about how to motivate my teen to take better care of his/her diabetes. (17)	0.7 2	0.8 4	0.7 8	0.82 0.82
Frustrated because my teen ignores my suggestions about diabetes. (14)	0.7 2	0.8 0.8	0.7 4	0.74 0.74
Feeling unappreciated for all the ways I try to help my teen manage diabetes. (2)	0.7 0	0.6 6	0.6 4	0.63 0.63
Feeling that my teen and I just don't work well together when it comes to diabetes. (1)	0.6 8	0.4 6	0.3 8	0.35 0.35
Worrying that my teen will ignore or forget diabetes if I don't keep reminding him/her. (5)	0.6 2	0.6 6	0.6 3	0.69 0.69
Worrying that my nagging about diabetes is hurting my relationship with my teen. (20)	0.5 0	0.7 0.7	0.7 9	0.80 0.80
Frustrated by the lack of understanding and support for diabetes I get from friends and family members. (15)	0.7 2	0.6 8	0.5 4	0.45 0.45
Feeling that no one notices that diabetes is hard on me, not just on my teen. (9)	0.7 0	0.7 0.7	0.6 3	0.53 0.53
Frustrated that I am the only one who takes responsibility for helping my teen manage diabetes. (19)	0.6 4	0.7 1	0.6 4	0.56 0.56
Worrying that others will blame me if my teen's diabetes is not well-controlled. (12)	0.5 6	0.6 8	0.6 5	0.57 0.57
Feeling that trying to help my teen with his/her diabetes is always a battle. (7)	0.7 8	0.8 6	0.5 2	0.42 0.42
Feeling that diabetes is taking up too much of my mental and physical energy every day. (6)	0.7 7	0.9 0.9	0.5 4	0.44 0.44
Worrying about my teen's low blood sugars when he/she is sleeping. (8)	0.6 9	0.5 1	0.4 6	0.35 0.35

Worrying about my teen's low blood sugars when he/she is away from home. (4)	0.63	0.38				0.40	0.32
Concerned that my teen is not prepared to deal with the world of insurance and doctors once he/she is an adult. (18)			0.78	0.8		0.54	0.48
Worrying that my teen will soon leave home and I cannot protect him. (13)			0.74	0.6		0.48	0.36
Worrying that my teen doesn't have the right doctor for him/her. (11)					0.85	0.69	0.46 0.41
Worrying that my teen doesn't get all of the expert medical help he/she needs. (16)					0.78	0.96	0.66 0.53

<i>Score range</i>	0-32	0-16	0-16	0-8	0-8	0-80
<i>Mean ± sd</i>	10.8 ± 7.3	5.8 ± 4.2	10.1 ± 3.8	3.1 ± 2.2	1.6 ± 2	31.6 ± 14.9
<i>Eigenvalue</i>	7.35	2.25	1.53	1.32	1.08	N/A
<i>% variance explained</i>	36.79	11.25	7.68	6.63	5.44	
<i>Composite reliability (CFA)</i>	0.89	0.78	0.77	0.66	0.81	0.89
<i>AVE (CFA)</i>	0.51	0.47	0.48	0.5	0.69	0.32
<i>Cronbach's alpha</i>	0.89	0.78	0.77	0.69	0.79	0.90

Note: ^a Unforced five-factor solution with principal components analysis and varimax rotation; factor loadings ≥ 0.50 are presented

N/A: Not Applicable

AVE: Average Variance Extracted

Table 3. Correlations of the PDDS-Gr and its subscales with validity measures

Variables	Parent/child relationship distress	Personal distress	Child's diabetes management distress	Future distress	Healthcare team distress	PDDS-Gr unidimensional
DASS-21						
Depression	0.48**	0.53**	0.52**	0.50**	0.36**	0.63**
Anxiety	0.34**	0.38**	0.43**	0.46**	0.22**	0.46**
Stress	0.50**	0.50**	0.48**	0.43**	0.43**	0.60**
Children						
HbA1c (last recorded)	0.27**	0.15	0.10	0.07	0.30**	0.25*
Age (in years)	0.23*	0.03	0.0	0.47**	0.17	0.21*
Diabetes duration (in years)	0.11	0.11	-0.24*	0.09	0.08	0.01

Note: DASS: Depression Anxiety and Stress Scale; HbA_{1c}: hemoglobin A1c.

*p<0.05, **p<0.01

ΕΡΕΥΝΗΤΙΚΗ ΕΡΓΑΣΙΑ

Διαστάσεις και ψυχομετρικές ιδιότητες της ελληνικής έκδοσης της Γονεϊκής Κλίμακας Δυσφορίας για τον Διαβήτη (PDDS-Gr)

Εμμανουήλ Σ. Μπενιουδάκης,^{1,2} Αργυρούλα Καλαϊτζάκη,³ Ελένη Καρλάφτη,² Μαρία Α. Μακρή,⁴ Θεοδοσία Αρβανιτάκη,⁵ Μαρία-Αλεξάνδρα Κάλπου,⁶ Χρήστος Σαββόπουλος,² Τριαντάφυλλος Διδάγγελος²

¹Ψυχιατρική Κλινική, Γενικό Νοσοκομείο Χανίων, Χανιά, Κρήτη

²Διαβητολογικό Κέντρο, Α' Προπαιδευτική Παθολογική Κλινική, Πανεπιστημιακό Γενικό Νοσοκομείο 'ΑΧΕΠΑ', Αριστοτέλειο Πανεπιστήμιο Θεσσαλονίκης, Θεσσαλονίκη, Μακεδονία

³Εργαστήριο Διεπιστημονικής Προσέγγισης για τη Βελτίωση της Ποιότητας Ζωής, Τμήμα Κοινωνικής Εργασίας, Ελληνικό Μεσογειακό Πανεπιστήμιο, Ηράκλειο, Κρήτη

⁴Τμήμα Βιοϊατρικών Επιστημών, Πανεπιστήμιο Δυτικής Αττικής, Αθήνα

⁵Εξωτερικό παιδοδιαβητολογικό Ιατρείο, Παιδιατρική Κλινική, Γενικό Νοσοκομείο Χανίων, Χανιά, Κρήτη

⁶Τμήμα Ψυχολογίας, Εθνικό και Καποδιστριακό Πανεπιστήμιο Αθηνών, Αθήνα

ΙΣΤΟΡΙΚΟ ΑΡΘΡΟΥ: Παραλήφθηκε 21 Ιουνίου 2023/ Αναθεωρήθηκε 22 Αυγούστου 2023/
Δημοσιεύθηκε Διαδικτυακά 29 Σεπτεμβρίου 2023

ΠΕΡΙΛΗΨΗ

Ο Σακχαρώδης Διαβήτης τύπου 1 (ΣΔ1) είναι μια χρόνια νόσος που χαρακτηρίζεται από ανεπάρκεια ινσουλίνης λόγω αυτοάνοσης καταστροφής των βήτα-κυττάρων του παγκρέατος. Ο ΣΔ1, παλαιότερα γνωστός ως νεανικός διαβήτης, είναι η πιο κοινή μορφή διαβήτη σε παιδιά και εφήβους. Κατά τη διάγνωση, οι γονείς παιδιών με ΣΔ1 βιώνουν σημαντικά επίπεδα στρες, καθώς πρέπει να φροντίζουν ένα παιδί με μια δύσκολη και απειλητική για τη ζωή κατάσταση που απαιτεί την τήρηση ενός εντατικού ιατρικού σχήματος, καθώς και τη συνεχή παρακολούθηση και αντιμετώπιση της εκάστοτε κατάστασης των παιδιών τους. Ο ΣΔ1 είναι μια σύνθετη κατάσταση που επηρεάζει τόσο τα παιδιά όσο και τους φροντιστές τους σε πολλές πτυχές της καθημερινής τους ζωής. Σε αυτή την εργασία παρουσιάζονται οι βασικές ψυχομετρικές ιδιότητες της ελληνικής μετάφρασης του ερωτηματολογίου Parent Diabetes Distress Scale (PDDS) το οποίο αξιολογεί τη δυσφορία αναφορικά με τον διαβήτη σε γονείς παιδιών με ΣΔ1. Ένα δείγμα 95 γονέων, κυρίως μητέρων (88.4%), με μέση ηλικία παιδιών 12.2 έτη (± 3.6) και διάρκεια διαβήτη 4.7 έτη (± 3.4), συμπλήρωσαν το μεταφρασμένο στα ελληνικά PDDS (PDDS-Gr). Η διερευνητική παραγοντική ανάλυση (EFA) ανέδειξε ένα μοντέλο πέντε παραγόντων 'Δυσφορία σχέσης γονέα/παιδιού', 'Προσωπική δυσφορία', 'Δυσφορία διαχείρισης του διαβήτη του παιδιού', 'Δυσφορία για το μέλλον' και 'Δυσφορία αναφορικά με την ομάδα υγειονομικής περίθαλψης'. Η επιβεβαιωτική παραγοντική ανάλυση (CFA) επιβεβαίωσε την κατασκευαστική εγκυρότητα της κλίμακας. Οι δείκτες εσωτερικής συνοχής (Cronbach alpha) για τις υποκλίμακες κυμαίνονταν από 0.69 έως 0.89, ενώ η μονοδιάστατη δομή είχε δείκτη εσωτερικής συνοχής $\alpha = 0.90$. Επιπλέον, η συγκλίνουσα εγκυρότητα επιβεβαιώθηκε με τις μέτρια θετικές συσχετίσεις που βρέθηκαν μεταξύ του PDDS-Gr και των υποκλιμάκων του, με το DASS-21 (κατάθλιψη, άγχος και στρες), την παιδική ηλικία (έτη) και την τιμή HbA_{1c} . Τέλος, οι γονείς παιδιών με ανεπαρκή γλυκαιμικό έλεγχο ($HbA_{1c} \geq 7\%$) παρουσίασαν υψηλότερες

βαθμολογίες, τόσο στη μονοδιάστατη δομή, όσο και στις υποκλίμακες 'Δυσφορία σχέσης γονέα/παιδιού' και 'Δυσφορία αναφορικά με την ομάδα υγειονομικής περίθαλψης' του PDDS-Gr. Το PDDS-Gr είναι ένα έγκυρο και αξιόπιστο εργαλείο για την αξιολόγηση της δυσφορίας του διαβήτη σε γονείς παιδιών με ΣΔ1 και μπορεί να χρησιμοποιηθεί, τόσο για κλινικές, όσο και για ερευνητικές μελέτες.

ΛΕΞΕΙΣ ΚΥΡΙΑΡΧΙΟΥ: Σακχαρώδης διαβήτης τύπου 1, δυσφορία διαβήτη, γονεϊκό άγχος, παιδί, παραγοντική ανάλυση.

Επιμελητής συγγραφέας: Εμμανουήλ Μπενιουδάκης, Στίλπωνος Κυριακίδη 1, 55636, Θεσσαλονίκη, Ελλάδα, e-mail: empeniou@auth.gr

Journal Pre-proof