Internal structure and psychometric properties of Diabetes Distress Scale for Type 1 Diabetes

F. Griva,[1] P. Thomakos,[2] O. Kepaptsoglou,[2] M. Ginieri-Coccossis,[1]
A. Mitrakou,[3] Ch. Zoupas,[2] G. Vaslamatzis[1]

[1]First Department of Psychiatry, Eginition Hospital, University of Athens,
[2]Diabetes Center and Clinic, Hygeia Hospital, Athens,
[3]Department of Clinical Therapeutics, Alexandra Hospital, University of Athens, Greece

Diabetes-related distress (DD) refers to the worries and concerns about the nature and complications of Type 1 diabetes (T1D) and the frustration with the burdens of its management. Research suggests that sources of DD among people with T1D differ from those among Type 2. Many adults with T1D experience difficulties that are often unrecognised, unaddressed and mismanaged. The Diabetes Distress Scale for Type 1 diabetes (T1-DDS), is a newly developed instrument that is used to identify the specific sources of DD, exclusively for adults with T1D. The aim of the study was to examine the factorial structure of T1-DDS in Greek population and to evaluate its psychometric properties for use in research and clinical practice. A sample of 102 adults with type 1 diabetes, aged 38.85 (±10.08) years, females 63%, BMI 21.45 (±5.84) kg/m^2, diabetes duration 21.35 (±13.73) years, HbA1c 7.5% (±1.2;58 mmol/mol) completed the translated T1-DDS. Exploratory factor analysis (EFA) and confirmatory (CFA) factor analysis were used to investigate the factor structure of the scale. Reliability was explored by internal consistency. Convergent validity was assessed through correlations with measures of psychological distress and diabetes status variables. Differential validity was assessed on the basis of known-group comparisons, with expected differences in distress for gender and age. Confirmatory factor analysis provided a low fit for the 7-factor model. Exploratory factor analysis supported a conceptually justifiable 5-factor model in the Greek sample. Internal consistencies of all five factors ranged from α=0.76 to 0.89. As expected, all factors were correlated with psychological distress [(r=0.510, p<0.01) for the total scale]. Management distress was positively correlated with HbA1c (r=0.397, p<0.01) and BMI (r=0.296, p<0.01), and Family/Friends distress was negatively correlated with duration of diabetes (r=−0.298, p<0.01). Further analyses showed that men exhibited higher score in relations to the social context of diabetes management (t=2.164, p<0.05 for Negative Social Perceptions), (t=2.572, p<0.05 for Family/Friends distress), and younger participants reported significantly higher distress in relation to reactions from friends and family (t=2.106, p<0.05). The Greek version of T1-DDS is a valid and reliable measure of diabetes-related distress that can be used in clinical practice to address personal needs and direct targeted interventions.

Key words: Type 1 diabetes, diabetes related distress, validity, reliability, factor analysis.

Introduction

A demanding lifelong condition like type 1 diabetes (T1D) generates emotional and psychosocial challenges. Diabetes-related distress (DD) refers to the worries and concerns about the nature and complications of T1D and the frustration with the burdens of its management. DD is highly prevalent among adults with T1D, has a chronic rather than episodic manifestation and has been found to be distinct from clinical depression.[1] Research suggests that sources of DD among people with T1D differ from those among type 2. While Polonsky et al.[2] identified four main sources of distress for people with type 2 diabetes, including Regimen Distress, Emotional Burden, Interpersonal Distress and Physician Distress, it has been suggested that people with T1D experience a different set of worries and concerns than those with type 2. A recent study identified the following seven major sources of DD among type 1 adults.[3] Powerlessness reflects a sense of helplessness over controlling the symptoms, and involves worries about long-term consequences and difficulties in dealing with erratic blood glucose numbers. Management Distress includes frustrations associated with specific demands of T1D such as blood glucose monitoring and insulin dose adjustment, while Eating Distress highlights concerns with eating habits and constrains. Hypoglycemia Distress reflects worries about detecting and addressing hypoglycemic symptoms and Physician Distress includes disappointment with health care professionals in terms of support and understanding. Social distress is identified in Negative Social Perceptions of other people, including potential employers, and in Family/Friends Distress related to the involvement of significant others in diabetes management. The identification of these factors lead to developing a reliable and valid assessment device, the Diabetes Distress Scale for Type 1 diabetes (T1-DDS), that is used to identify the specific sources of DD for adults with T1D and to provide an index of overall diabetes-related emotional distress for use in clinical and research settings.[3] DD has been associated with poor glycemic control and problematic self-care behaviour and is considered a significant problem in diabetes.[1,4] Research suggests that DD can be effectively addressed with targeted interventions to improve both psychological well-being as well as diabetes-related health outcomes.[5,6] The difficulties of people with type 1 diabetes are often unrecognised and mismanaged[3] and T1-DDS can provide information for those at risk for developing DD. No such instrument is available in Greek for clinical practice and to our knowledge, this is the first study to validate T1-DDS in a different context from the one that was originally developed. Thus, the purpose of the present study was to examine the factorial structure of T1-DDS in Greek population and to evaluate its psychometric properties for use in research and clinical practice.

Material and method

Procedure

The T1-DDS was translated by independent Greek and English native speakers, following a forward-backward-forward procedure. In addition, the instrument was split translated using a committee-based approach.[7] Any discrepancies that emerged from the comparison of the two approaches were discussed and a few minor adjustments were applied. The administration of the scale took place at the diabetes clinics of a general and a private hospital in Athens, under protocols approved by the ethics committee of the School of Medicine of the University of Athens. Participants were informed in written of the purpose of the study, their ensured anonymity and data protection, the possibility of non-participation without any health implications for the care they will receive, and the ability to communicate with the researchers.

Participants

Participants were 102 adults with type 1 diabetes aged 38.85 (±10.08) years, females 63%, BMI 21.45 (±5.84) kg/m^2, diabetes duration 21.35 (±13.73) years, HbA1c 7.5% (±1.2;58 mmol/mol).

Measures

Diabetes Distress

The T1-DDS[3] is a 28-item measure consisting of seven subscales, each including 3–5 items. Items are scored on a 6-point Likert scale ranging from 1 ("not a problem") to 6 ("a very serious problem") covering a broad range of worries and concerns associated with diabetes, including powerlessness (e.g., feeling worried that I will develop serious long-term complications, no matter how hard I try), hypoglycemia

distress (e.g., feeling frightened that I could have a serious hypoglycemic event while driving), management distress (e.g., I don't give my diabetes as much attention as I probably should), eating distress (e.g., feeling that my eating is out of control) physician distress (e.g., feeling that I don't get help I really need from my diabetes doctor), friend or friend-related distress (e.g., feeling that my friends or family act like "diabetes police"), and negative social perceptions (e.g., I have to hide my diabetes from other people"). Internal consistency estimates for subscale scores have been reported ranging from 0.76 to 0.87, with test-retest reliabilities ranging from 0.60 to 0.783.

Psychological Distress

The Symptom Checklist Short (SCL-10R)[8] is widely used measure for psychological distress. It assesses a number of symptoms that involve depression, anxiety, obsessive-compulsive, interpersonal sensitivity, hostility, phobic anxiety, psychoticism, paranoid ideation and somatisation (e.g., "How often did you feel like you were worrying too much?") on a 5-point Likert scale ("not at all" to "very often"). Internal reliability in the present sample was 0.89.

Demographics and diabetes status

Demographic measures included age, gender, educational level, married/living with a partner and diabetes duration. Diabetes status included BMI, and the latest HbA1c measurement.

Statistical analysis

A confirmatory factor analysis (CFA) with maximum likelihood procedure was carried out using AMOS version 21. The fit of the model was assessed through the chi square (x^2), the root mean square error of approximation (RMSEA), and baseline comparison indexes (comparative fit index, CFI and Tucker-Lewis Index, TLI). Because of a low model fit, an exploratory factor analysis (EFA) using principal components analysis with promax rotation was conducted to investigate the construct validity of the scale. For the EFA, the adequacy of the sample was valued with the Kaiser-Meyer-Olkin test (KMO) and a Bartlett's test of sphericity. The internal consistency of the subscales was analysed with Cronbach's alpha. Convergent validity was assessed through correlations of the subscales with psychological distress and

HbA1c. Differential validity was assessed on the basis of known-group comparisons, such as expected differences in distress between men and women, and younger and older participants, based on past research.[3] Statistically significant level was set at 0.05 and analyses were conducted using SPSS version 21.

Results

Factorial structure

The CFA indicated a low fit between the data and the original 7-factor model [(χ^2=340,6 (179), p<0.05, RMSEA=0.092, TLI=0.807 and CFI=0.836) and consequently an EFA was conducted to assess the structure of the translated T1-DDS. The EFA yielded a 5-factor solution (eigenvalues≥1.00) with a KMO coefficient equal to 0.79 and a Barlett x^2 value equal to 1223.6 (p<0.001). The five factors were identified as Powerlessness, Management Distress, Physician Distress, Negative Social Perceptions and Family/Friend Distress. The Eating Distress items (three items) and the Hypoglycemia Distress items (four items) loaded on the conceptually justifiable factors of Management Distress and of Powerlessness, respectively. On the total, twenty-three items were single-loading items, highly loaded on their designated factor (table 1). Five items (#1, 3, 5, 8, 13) were cross-loading items and were omitted from the scale. The results of the EFA without these items, showed a KMO coefficient equal to 0.79 and a Barlett χ^2 value equal to 1609.4 (p<0.001). The proportion of total variance explained was 42.3%. Factor loadings are presented in table 2. CFA revealed an adequate fit for the five-factor model [(RMSEA=0.07, TLI=0.95 and CFI=0.96)]. The chi-square test of the model was not significant (p>0.05), as expected.

Internal consistency reliability and scale descriptives

Internal consistency of the T1-DDS scale was excellent (α=0.92) and Cronbach's alpha for all factors ranged from (α=0.76 to 0.89) (table 2). Regarding intercorrelations between the scales of the T1-DDS, all of them were found to be significant at the 1% level. Mean levels of reported distress varied across the five subscales, suggesting that the sample experienced higher levels of DD in some areas and lower levels in others (table 2).

Table 1. Factor loadings from the results of exploratory factor analysis.

Item no.	Item	1	2	3	4	5
27	Feeling I can never be safe from the possibility of a serious hypoglycemic event	0.854	0.185	−0.056	−0.099	0.017
15	Feeling frightened that I could have a serious hypoglycemic event when I'm asleep	0.776	−0.057	0.241	−0.088	−0.358
21	Feeling that I've got to be perfect with my diabetes management	0.739	−0.253	−0.252	0.172	0.260
25	Feeling that no matter hard I try with my diabetes, it will never be good enough	0.700	0.053	−0.229	0.181	0.243
22	Feeling frightened that I could have a serious hypoglycemic event while driving	0.692	0.101	0.143	0.022	−0.358
9	Feeling that there is too much equipment and stuff I must always have with me	0.616	−0.058	0.043	−0.041	0.159
16	Feeling that thoughts about food and eating control my life	0.561	−0.149	0.153	0.000	0.181
18	Feeling that my diabetes doctor doesn't really understand what it's like to have diabetes	−0.030	0.950	0.006	−0.158	0.143
26	Feeling that my diabetes doctor doesn't know enough about diabetes and diabetes care	−0.132	0.896	0.031	0.023	−0.058
14	Feeling that I don't get help I really need from my diabetes doctor about managing diabetes	0.075	0.873	−0.072	0.061	−0.013
7	Feeling that I can't tell my diabetes doctor what is really on my mind	−0.015	0.702	0.022	0.213	0.092
17	Feeling that my friends or family treat me as if I were more fragile or sicker than I really am	0.030	−0.036	0.869	0.127	0.036
20	Feeling that my friends or family act like "diabetes police"	−0.007	0.057	0.779	0.037	0.097
6	Feeling that my family and friends make a bigger deal out of diabetes than they should	−0.058	−0.113	0.774	0.116	0.182
11	Feeling that my friends and family worry more about hypoglycemia than I want them to	0.134	0.113	0.592	−0.121	0.141
2	Feeling that I don't eat as carefully as I probably should	−0.119	−0.176	0.092	0.859	0.078
23	Feeling that my eating is out of control	−0.062	0.171	−0.071	0.749	0.120
28	Feeling that I don't give my diabetes as much attention as I probably should	0.172	0.130	0.000	0.740	−0.178
12	Feeling that I don't check my blood glucose level as often as I probably should	0.055	0.023	0.198	0.659	−0.128
4	Feeling that people treat me differently when they find out I have diabetes	−0.164	−0.027	0.302	0.019	0.716
19	Feeling concerned that diabetes may make me less attractive to employers	0.130	0.145	0.000	0.001	0.674
24	Feeling that people will think less of me if they knew I had diabetes	0.294	−0.195	0.248	−0.153	0.437
10	Feeling like I have to hide my diabetes from other people	0.243	0.212	0.227	−0.072	0.432

Table 2. Descriptive statistics for and internal consistencies of the T1-DDS scales.

Distress subscales	Number of items	Mean (SD)	Median	Skewness (SE)	Kurtosis (SE)	Mean Inter-item correlation	Reliability Cronbach's alpha
Powerlessness/ Hypoglycemia	7	2.87 (1.22)	2.57	0.566 (0.245)	−0.439 (0.485)	0.438	0.84
Management/ Eating	4	2.86 (1.32)	2.75	0.357 (0.245)	−0.945 (0.485)	0.490	0.79
Physician Distress	4	1.58 (0.80)	1.25	0.851 (0.245)	−0.709 (0.485)	0.469	0.76
Negative Social Perceptions	4	2.32 (1.17)	2.25	0.697 (0.245)	−0.376 (0.485)	0.402	0.72
Friends/Family Distress	4	2.68 (1.32)	2.50	0.646 (0.245)	−0.543 (0.485)	0.496	0.84
Total Distress	23	2.51 (0.86)	2.34	0.479 (0.245	−0.399 (0.485)	0.272	0.89

Relationships between T1-DDS scales and validity measures

Validity coefficients yielded significant relationships with psychological distress for all factors (table 3). HbA1c was positively correlated with Management distress (r=0.397, p<0.01). BMI was positively correlated with Management distress (r=0.296, p<0.01), and duration of diabetes was negatively correlated with Family/friends distress (r=−0.298, p<0.01). These correlations provided support for the convergent validity of the T1-DDS. Regarding differential validity, comparisons based on gender and age (median split <39 years) revealed that men exhibited significantly higher scores compared to women on Negative Social Perceptions (t=2.164, p<0.05) and Family/friends distress (t=2.572, p<0.05), and that younger participants reported significantly higher distress in relation to reactions from Friends and family (t=2.106, p<0.05) than older participants.

Discussion

The main purpose of the present study was to investigate the reliability and construct validity of the translated version of the T1-Diabetes Distress Scale in a Greek population. With respect to the dimensionality of the measure, our initial results did not replicate the seven-factor structure of the original scale. However, in the more parsimonious five-factor solution, the items of the Eating Distress subscale in the original T1-DDS loaded on the Management Distress subscale and the items of the original Hypoglycemia Distress subscale loaded on the Powerlessness subscale. Both of these factor combinations were considered conceptually justifiable. Hypoglycemia dis-

Table 3. Relationships with validity measures.

Distress subscales	Psychological distress	HbA1c	BMI	Duration of diabetes
Powerlessness	0.481**	0.098	0.007	−0.109
Management distress	0.267**	0.397**	0.296**	−0.024
Physician distress	0.227*	0.082	0.105	0.044
Negative social perceptions	0.454**	−0.020	0.046	−0.021
Family/Friend distress	0.330**	0.117	0.046	−0.298**
Total distress	0.510**	0.188	0.126	−0.132

*p<0.05, **p<0.01,

tress reflects a lack of confidence that the person will identify and address hypoglycemic symptoms quickly enough to avoid progression to a severe hypoglycemic episode, and in that sense, it is encapsulated in the broader sense of helplessness over the uncontrollable, highlighted in the Powerlessness factor. In a similar way, concerns that one's eating is out of control, is associated with disappointment with one's own self-care efforts, as reflected in the Management distress factor. The confirmatory factor analysis provided support for a five-factor model that proved to be an adequate fit for the data. The internal consistency reliabilities were quite satisfactory ranging from 0.79 to 0.89, comparable to those reported for the original scale.[3] In addition, the means scores of the subscales suggested, as in the original study, that the mean level of distress is not uniform across the five areas of DD. Powerlessness and Management distress received the highest mean item rating reflecting the frustrations of dealing with the unpredictable nature T1D and the constant demands of day-to-day self-care. The social dimensions of distress, including social perceptions, and reactions from significant others displayed the next highest mean rating, followed by distress associated with health care providers. Information in relation to subscale scores and highly scored individual items can be proven valuable on identifying sources of distress and addressing them in clinical practice.

Significant associations were observed between the diabetes distress subscales and psychological distress as expected. The highest associations were observed for powerlessness and negative social perceptions suggesting that worry related to unpredictability of T1D and uneasiness about it in social contexts are two areas closely related to psychological well-being.[2] The strong and positive correlations of HbA1c and BMI with management distress is a finding in line with the original study and reflects the frustrations and worries associated with the demands and constrains of diabetes regimen.[3] In the original study, BMI was solely associated with the distress on eating habits and constrains, however in the present study, items of the Eating Distress subscale are included in the Management subscale, and hence the respective association between BMI and Management distress in our study. An interesting

finding was also the negative significant association of diabetes duration with the friends and family distress factor, suggesting that distress about the reactions and involvement of significant others in managing diabetes tends to diminish as time goes by. Interventions concerning the family or significant others may be important in dealing with this kind of distress upon the time of the diagnosis and during the first years after the diagnosis.

Regarding participant demographics men reported significantly higher distress than women in relation to the social context of diabetes management. This finding was not in line with the original study that reported higher distress for women on all distress dimensions in comparison to men. Cultural factors may explain this conflicting finding if we take into consideration that the original scale was administered to a US sample, one with a quite different cultural background to the one in this study. Interdependent social relations, similar to those found in other Mediterranean-region countries[9] may place an additional emotional burden to men with diabetes in their social environment. The predominant role of family and friends may be especially onerous for men traditionally expected to exhibit higher levels of autonomy and independence. In addition, higher distress in relation to how one is viewed and evaluated by others, can be partly explained by the social role traditionally assigned to men as those not exhibiting vulnerability, especially in their social environment. Significant higher distress was also observed in younger participants, corroborating the results of the original study, and adding to the growing literature documenting that younger adults with diabetes have significantly more problems with diabetes management and glycemic control, and report higher general and diabetes-related distress than older adults.[10]

Findings of the present study suggest that the Greek adaptation of T1-DDS is a valid and reliable measure that can be used in clinical practice to address the personal and social needs of people with T1D. There are, however, limitations to be identified for the present study, starting with sample size and the need for the results to be replicated in larger samples. In addition, because of the cross-sectional design of the study, it was not possible to examine the T1-DDS sensitivity over time or its test-retest reliability.

Implications for practice

Although emotional burden is common among people with diabetes, diabetes distress remains largely undetected. DD has been shown to affect not only psychological well-being but is also associated with poor glycemic control. The present study presents the first validated measure in Greek for people with T1D, that can be used in clinical practice to identify potential barriers to self-care behaviours and glycemic control. Because different individuals experience distress from different sources, as it was evident in the present study, a practitioner can directly identify these sources by reviewing the subscale scores, or those highly scored individual items. Although replication of the study findings in larger samples is needed, it was possible to identify populations that may be more vulnerable to develop diabetes distress, such as men, younger people and those who have been recently diagnosed with T1D. This information may also direct clinical conversations in detecting distress and ultimately addressing it.

Conclusion

The sources of distress may vary within patients, and T1-DDS when used in clinical settings, provides the opportunity to identify emotional distress allowing valuable information to direct clinical conversations and targeted interventions. The T1-DDS has been used so far in interventions to measure changes in distress reduction and subsequent glycemic control improvement. The Greek version of the T1-DDS may serve as a valuable measure of diabetes-related emotional distress for use in research and clinical practice.

Παραγοντική δομή και ψυχομετρικές ιδιότητες της κλίμακας για τη Δυσφορία στον Διαβήτη Τύπου 1

Φ. Γρίβα,[1] Π. Θωμάκος,[2] Ό. Κεπαπτσόγλου,[2] Μ. Τζινιέρη-Κοκκώση,[1]
Α. Μητράκου,[3] Χρ. Ζούπας,[2] Γρ. Βασλαματζής[1]

[1]Α' Ψυχιατρική Κλινική, Αιγινήτειο Νοσοκομείο, Εθνικό και Καποδιστριακό Πανεπιστήμιο Αθηνών,
[2]Διαβητολογικό Κέντρο και Κλινική, Νοσοκομείο Υγεία,
[3]Θεραπευτική Κλινική, Νοσοκομείο Αλεξάνδρα, Εθνικό και Καποδιστριακό Πανεπιστήμιο Αθηνών, Αθήνα

Η δυσφορία που σχετίζεται με τον διαβήτη, αναφέρεται στις ανησυχίες και τους προβληματισμούς σχετικά με τη φύση και τις επιπλοκές του διαβήτη τύπου 1 και την επιβάρυνση της διαχείρισης του. Η έρευνα δείχνει ότι τα άτομα με διαβήτη τύπου 1 αντιμετωπίζουν διαφορετικές πηγές άγχους και δυσφορίας που διαφέρουν από εκείνες των ατόμων με διαβήτη τύπου 2, με αποτέλεσμα οι δυσκολίες τους να μην αναγνωρίζονται και να μην αντιμετωπίζονται άμεσα και αποτελεσματικά. Η κλίμακα για τη Δυσφορία στο Διαβήτη Τύπου 1 (Diabetes Distress Scale T1-DDS) είναι μια πρόσφατα ανεπτυγμένη κλίμακα που έχει στόχο να εντοπίσει τις δυσκολίες που αντιμετωπίζουν τα άτομα με διαβήτη Τύπου 1. Σκοπός της μελέτης ήταν να εξεταστεί η παραγοντική δομή και οι ψυχομετρικές ιδιότητες της Κλίμακας για τη Δυσφορία στο Διαβήτη Τύπου 1. Ένα δείγμα 102 ενηλίκων με διαβήτη τύπου 1,

ηλικίας 38,85 (±10,08) έτη, γυναίκες 63%, ΔΜΣ 21,45 (±5,84) kg/m^2, διάρκεια διαβήτη 21,35 (±13,73) έτη, HbA1c 7,5%±1,2 • 58 mmol/mol) συμπλήρωσαν το μεταφρασμένο T1-DDS. Η επιβεβαιωτική παραγοντική ανάλυση έδειξε χαμηλή προσαρμογή για το μοντέλο των 7-παραγόντων. Η διερευνητική παραγοντική ανάλυση υποστήριξε ένα εννοιολογικά δικαιολογημένο μοντέλο 5-παραγόντων για το ελληνικό δείγμα. Οι δείκτες εσωτερικής συνοχής και για τους πέντε παράγοντες (διαχείριση, αβοηθητότητα, αρνητικές κοινωνικές αντιλήψεις, δυσφορία με το προσωπικό υγείας, και τη στάση των φίλων και της οικογένειας) κυμαίνονταν μεταξύ α=0,79 και 0,89. Και οι πέντε παράγοντες της κλίμακας σχετίζονταν θετικά με την ψυχολογική δυσφορία [(r=0,510, p<0,01) για ολόκληρη την κλίμακα]. Ο παράγοντας της διαχείρισης σχετιζόταν θετικά με τη γλυκοζυλιωμένη αιμοσφαιρίνη (r=0.397, p<0,01) και με τον δείκτη μάζας σώματος (r=0,296, p<0,01), ενώ ο παράγοντας της δυσφορίας για τις αντιδράσεις στο κοντινό περιβάλλον σχετιζόταν αρνητικά με τη διάρκεια του διαβήτη (r=−0,298, p<0.01). Αναλύσεις με βάση τη μέθοδο των γνωστών ομάδων έδειξαν ότι οι άνδρες παρουσίαζαν υψηλότερη βαθμολογία σε σχέση με το κοινωνικό πλαίσιο της διαχείρισης του διαβήτη (t=2,164, p<0.05 για τις αρνητικές κοινωνικές αντιλήψεις), (t=2,572, p<0,05 για τις αντιδράσεις από φίλους και οικογένεια), και ότι οι νεότεροι συμμετέχοντες ανέφεραν σημαντικά υψηλότερη δυσφορία σε σχέση με τις αντιδράσεις από τους φίλους και την οικογένεια (t=2,106, p<0,05). Η ελληνική έκδοση του T1-DDS είναι ένα έγκυρο και αξιόπιστο μέτρο της ανησυχίας που σχετίζεται με τον διαβήτη, που μπορεί να χρησιμοποιηθεί στην κλινική πρακτική για την αντιμετώπιση προσωπικών αναγκών και να κατευθύνει πιο στοχευμένες παρεμβάσεις.

Λέξεις ευρετηρίου: Σακχαρώδης διαβήτης τύπου 1, σχετιζόμενη με τον διαβήτη δυσφορία, εγκυρότητα, αξιοπιστία, παραγοντική ανάλυση.

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Corresponding author: Fay Griva, First Department of Psychiatry, Eginitio Hospital, School of Medicine, University of Athens, 72–74 Vas. Sofias Ave., GR-115 28 Athens, Greece, Tel: (+30) 210-74 87 776
e-mail: faygriva@gmail.com