Diabetes-Related Emotional Distress in Dutch and U.S. Diabetic Patients

Cross-cultural validity of the Problem Areas in Diabetes Scale

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OBJECTIVE — To examine the cross-cultural validity of the Problem Areas in Diabetes Scale (PAID) in Dutch and U.S. diabetic patients.

RESEARCH DESIGN AND METHODS — A total of 1,472 Dutch people with diabetes completed the PAID along with other self-report measures of affect. Statistics covered Cronbach's α, exploratory factor analysis (EFA), and confirmatory factor analysis (CFA), Pearson's product-moment correlation, and *t* tests. Psychometric properties of PAID were compared for Dutch and U.S. diabetic patients.

RESULTS — Internal consistency of the Dutch PAID was high and stable across sex and type of diabetes. Test–retest reliability was high. Principal component analyses confirmed 1 general 20-item factor, whereas EFA identified 4 new subdimensions: negative emotions, treatment problems, food-related problems, and lack of social support. These dimensions were confirmed with CFA and were replicated in the U.S. sample. The PAID and its subscales demonstrated moderate to high associations in the expected direction with other measures of affect. Dutch and U.S. subjects reported having the same problem areas, with U.S. patients reporting higher emotional distress levels both in type 1 and type 2 diabetes.

CONCLUSIONS — The Dutch and U.S. 20-item PAID appeared to be psychometrically equivalent, which allowed for cross-cultural comparisons.

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Diabetes is a demanding disease with a major effect on the quality of life of patients and their families (1,2). Research has suggested that psychological distress frequently occurs in people with diabetes and is often related to difficulties in coping with the daily regimen and worries about developing late complications (3,4). Psychological distress is not only burdensome itself, but also it can impede the self-care behaviors of the patients, thereby compromising glycemic control (5–7). To quantify levels of emotional distress in people with diabetes, various measures have been developed in the U.K., Germany, Canada, and U.S. (8–11). As Glasgow et al. (12) recently showed, research must establish the relative strengths and weaknesses of the various diabetes-specific instruments, particularly their sensitivity to detect changes and intervention effects (12). We further emphasize the importance of cross-cultural validation of such questionnaires. Psychosocial research in diabetes could benefit significantly from standardization of instruments to allow for international comparison of results (13).

The Problem Areas in Diabetes Scale (PAID) is a brief self-report measure of diabetes-related distress that has been found to be valid and clinically useful in U.S. type 1 and type 2 diabetic patients (14–16). PAID scores have been found to show positive associations with HbA_{1c} and are a major predictor of poor adherence to treatment not involving general emotional distress. The PAID seems to be a good candidate for the measurement of diabetes-related distress across countries, but its cross-cultural validity has yet to be established. Ishii et al. (17) found evidence to support the clinical utility of a Japanese version of the PAID in a sample of predominantly type 2 diabetic patients. In this article, we report on the validation of the Dutch version of the PAID by comparing PAID scores across samples of Dutch and U.S. diabetic patients.

RESEARCH DESIGN AND METHODS

Subjects

As part of a large survey (18), 3,000 randomly selected patients of the 40,000 members of the Dutch Diabetes Association were mailed a booklet of self-report questionnaires, including the PAID. To determine test–retest reliability, a random sample of 250 patients from the total group was invited for a second assessment ~2 months later. PAID data from a U.S. sample of 256 type 1 and type 2 diabetic patients at the Joslin Diabetes Center (Boston, MA) (15) were reanalyzed and compared with the Dutch sample.

Measures

Self-reported demographic and clinical characteristics of the subjects included age, sex, marital status, monthly income, years of education, age at onset of diabetes, treatment regimen, number of complications, most recent HbA_{1c} level, comorbidity, fre-

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Abbreviations: CFA, confirmatory factor analysis; CFI*, robust comparative fit index; DKA, diabetic ketoacidosis; EFA, exploratory factor analysis; ENE, Energy subscale; HFS, Hypoglycemia Fear Survey; NWB, Negative Well-Being subscale; PAID, Problem Areas in Diabetes Scale; PWB, Positive Well-Being subscale; SMBG, self-monitoring of blood glucose; STAI, State Trait Anxiety Inventory; WBQ-12, 12-item Well-Being Questionnaire.

A table elsewhere in this issue shows conventional and Système International (SI) units and conversion factors for many substances.

quency of self-monitoring of blood glucose (SMBG), history of severe hypoglycemia, hospital admission because of diabetic ketoacidosis (DKA), and a history of psychological/psychiatric treatment (yes/no). In addition, patients were asked how burdensome they perceived their diabetes to be on a 4-point Likert scale (from "very burdensome" to "not burdensome"), their satisfaction with life in general on a 5-point Likert scale (from "very satisfied" to "very unsatisfied"), and how they perceived their health status on a 5-point Likert scale (from "very good" to "very bad"). Subjects were classified as having type 1 diabetes if they were <40 years of age when their diabetes was diagnosed and required insulin therapy at the time of diagnosis. Those who did not meet these criteria were classified as having type 2 diabetes (19).

The PAID is a self-report questionnaire that consists of 20 statements that Polonsky et al. (14) identified as common negative emotions related to living with diabetes (e.g., "feeling alone with diabetes" and "worrying about the future and the possibility of serious complications"). Each item can be rated on a 6-point Likert scale ranging from 1 ("not a problem") to 6 ("a serious problem"). Completing the PAID generally takes 3–5 min. To facilitate interpretation, PAID scores are transformed to a 0–100 scale, with higher scores indicating greater emotional distress. Welch et al. (15) found support for the convergent and discriminative validity of the PAID in U.S. patients. Factor analysis yielded 1 (20-item) emotional adjustment factor that proved to have high internal consistency (Cronbach's $\alpha = 0.95$). Two authors (F.J.S. and F.P.) translated the PAID into Dutch. A back translation into English was made by a professional native-speaking translator and revealed no substantial differences.

The Worry subscale of the Dutch version of the Hypoglycemia Fear Survey (HFS) was used to measure fear of hypoglycemia (20,21). This scale contains 13 items with a 5-point Likert scale ranging from 0 ("never") to 4 ("always"). The Dutch Worry scale was found to have good internal consistency (Cronbach's $\alpha = 0.92$)

The Dutch version of the 12-item (Bradley) Well-Being Questionnaire (WBQ-12) was used to measure general emotional well-being (18,22). The WBQ-12 consists of three 4-item subscales: Negative Well-Being (NWB), Energy (ENE), and Positive Well-Being (PWB). Items are rated on a 4-point Likert-scale ranging from 3 ("all the time") to 0 ("not at all"). Subscale scores can be calculated for the NWB, PWB, and ENE. The WBQ-12 was found to have good internal consistency ($\alpha = 0.73$–0.87) and good test–retest reliability (0.66–0.80). Factorial and convergent validity proved satisfactory.

Anxiety as a personality trait was assessed with the Dutch version of the Trait Anxiety subscale of the State Trait Anxiety Inventory (STAI) (23,24). The STAI scale consists of 20 items that refer to how patients feel in general scored on a 4-point Likert scale from 1 ("hardly ever") to 4 ("almost always"). The Dutch STAI has good internal consistency ($\alpha = 0.90$) and test–retest reliability (0.85).

Statistical analysis

SPSS 7.5 (SPSS, Chicago) (25) and EQS 5.1 for Windows (26) were used to carry out statistical analyses.

A cross-validation design was used in which the total sample was randomly divided into groups 1 and 2. Then both groups were split into subgroups 1a and 2a (men with type 1 diabetes), 1b and 2b (men with type 2 diabetes treated with insulin), 1c and 2c (men and women with type 2 diabetes treated with diet and/or oral hypoglycemic agents), 1d and 2d (women with type 1 diabetes), and 1e and 2e (women with type 2 diabetes treated with insulin). Based on the findings of Welch et al. (15), subdimensions of the PAID were expected to be highly correlated, in which case factor analysis with oblimin rotation is considered the most appropriate technique (27). Therefore, exploratory factor analysis (EFA) with oblimin rotation was performed in group 1 as a whole. In group 2, we conducted confirmatory factor analysis (CFA) to test the models that were found in group 1 using the maximal likelihood estimation method. The robust comparative fit index (CFI*) was used to evaluate the fit of the models to the data. A CFI* >0.90 is generally considered to be an indication of adequate fit (28).

In the EFAs, pairwise deletion was used to handle missing data, whereas listwise deletion was used in group 2 (CFA) as demanded by the EQS program. A maximum of 2 missing values was estimated for 32 cases (4.4%) using the mean of their remaining items; 21 cases (2.9%) with more than 2 missing values on the PAID were deleted from group 2. Cronbach's α coefficients were calculated in groups 1 and 2. Factorial validity of the PAID was reexamined in the U.S. sample (15) using CFAs.

Mean PAID scores found in the Dutch sample were compared with those found in the U.S. sample using *t* tests. Similar to Welch et al. (15), we expected type 1 diabetic patients to report higher levels of emotional distress than type 2 diabetic patients. No significant differences were expected in mean PAID scores between Dutch and U.S. patients.

To investigate convergent validity and stability of the Dutch PAID in the total group, Pearson's product moment correlation was used. A low positive association ($r = 0.10$–0.20) was expected between the PAID and self-reported HbA_{1c} level. Moderately high correlations ($r = 0.30$–0.50) were expected between the PAID and the other measures of effect (e.g., STAI, WBQ-12, HFS). Women were expected to have significantly higher PAID scores than men. Discriminative validity was investigated with *t* tests in the whole sample, and we expected patients with psychological comorbidity and/or a history of severe hypoglycemia to score higher on the PAID than the others.

To adjust for the high number of statistical tests (40–50), only *P* values ≤ 0.001 were considered to be significant.

RESULTS — The questionnaire was returned by 1,472 people with diabetes (49%). No data were available for the nonrespondents. Sex was almost equally distributed, with there being 722 women (49%). Mean age was 51 ± 16 years. Most subjects (75%) were married or cohabitating with a partner; 96% were Caucasian and of Dutch origin. Mean duration of diabetes was 16 ± 12 years. A total of 739 subjects were classified by us as having type 1 diabetes (51%), 502 had type 2 diabetes treated with insulin (35%), and 199 had type 2 diabetes treated with diet and/or oral hypoglycemic agents (14%). Because of missing data, the type of diabetes for 32 patients could not be determined. HbA_{1c} level was self-reported by 854 patients (57%), of whom 63% had type 1 diabetes. Most recent mean HbA_{1c} level in the total sample was 7.7 ± 1.5% with no significant difference in type of diabetes. HbA_{1c} level was reported to have been determined on average 2.5 ± 2.4 months before the questionnaire assessment. A total of 582 subjects (41%) indicated that they suffered from 1 or more diabetes-related complications, of whom 64% had retinopathy (type not specified). The Dutch sample appeared to be comparable with the U.S. sample

Table 1—*PAID mean scores on items and subdimensions for the Dutch and U.S. samples with type 1 and type 2 diabetes*

Subdimension	Type 1 diabetes		Type 2 diabetes	
	The Netherlands	U.S.	The Netherlands	U.S.
n	739	135	701	121
Diabetes-related emotional problems	16.9 ± 12.8	22.4 ± 15.2*	15.1 ± 13.5	17.9 ± 15.6
Feeling scared when you think about living with diabetes	1.0 ± 1.2	1.9 ± 1.8*	0.9 ± 1.4	1.8 ± 1.9*
Feeling depressed when you think about living with diabetes	1.2 ± 1.4	1.8 ± 1.7*	1.1 ± 1.4	1.4 ± 1.7
Not knowing if the mood or feelings you are experiencing are related to your blood glucose	1.7 ± 1.5	1.9 ± 1.7	1.6 ± 1.6	1.8 ± 1.7
Feeling overwhelmed by your diabetes regimen	1.5 ± 1.5	1.6 ± 1.7	1.4 ± 1.5	1.3 ± 1.6
Worrying about low blood sugar reactions	1.6 ± 1.5	2.1 ± 1.7*	1.3 ± 1.5	1.2 ± 1.5
Feeling angry when you think about living with diabetes	1.1 ± 1.4	1.6 ± 1.7	1.0 ± 1.4	1.2 ± 1.6
Worrying about the future and the possibility of serious complications	2.3 ± 1.5	2.8 ± 1.7*	2.0 ± 1.6	2.5 ± 1.9
Feeling guilty or anxious when you get off track with your diabetes management	1.8 ± 1.5	2.5 ± 1.6*	1.6 ± 1.6	2.0 ± 1.7
Not accepting diabetes	0.9 ± 1.4	1.0 ± 1.4	0.8 ± 1.4	1.0 ± 1.4
Feeling that diabetes is taking up too much mental and physical energy	1.2 ± 1.4	1.7 ± 1.7*	1.1 ± 1.5	1.1 ± 1.4
Coping with complications of diabetes	1.5 ± 1.5	1.7 ± 1.6	1.5 ± 1.6	1.4 ± 1.6
Feeling constantly burned out by the constant effort to manage diabetes	1.2 ± 1.4	1.8 ± 1.7*	1.0 ± 1.4	1.3 ± 1.6
Treatment-related problems	2.8 ± 3.0	3.9 ± 3.6*	2.3 ± 3.0	3.2 ± 3.3
Not having clear and concrete treatment goals for your diabetes care	1.1 ± 1.3	1.3 ± 1.5	0.9 ± 1.2	1.2 ± 1.4
Feeling discouraged with your diabetes regimen	1.0 ± 1.2	1.8 ± 1.7*	0.8 ± 1.1	1.4 ± 1.7*
Feeling unsatisfied with your diabetes physician	0.8 ± 1.2	0.8 ± 1.3	0.7 ± 1.3	0.6 ± 1.2
Food-related problems	3.6 ± 3.3	4.6 ± 3.6*	3.7 ± 3.7	4.8 ± 3.9
Uncomfortable interactions around diabetes with family/friends (e.g., other people telling you what to eat)	1.3 ± 1.5	1.2 ± 1.4	1.1 ± 1.6	1.3 ± 1.4
Feelings of deprivation regarding food and meals	1.2 ± 1.4	1.6 ± 1.5*	1.3 ± 1.5	1.7 ± 1.6
Feeling constantly concerned about food	1.1 ± 1.3	1.9 ± 1.6*	1.3 ± 1.5	1.8 ± 1.6*
Social support–related problems	1.4 ± 2.1	2.6 ± 2.7*	1.6 ± 2.4	1.8 ± 2.4
Feeling alone with diabetes	0.9 ± 1.3	1.6 ± 1.7*	1.0 ± 1.5	1.1 ± 1.5
Feeling that friends/family are not supportive of diabetes management efforts	0.5 ± 1.0	0.9 ± 1.3*	0.6 ± 1.2	0.7 ± 1.2
PAID 20-item scale	24.6 ± 18.7	33.4 ± 22.2*	22.5 ± 19.8	27.8 ± 23.2

*$P \leq 0.001$. Items can range from 0 to 5.

(15) in terms of age, sex, age at onset of diabetes, diabetes duration, distribution of type 1 and type 2 diabetes, and percentage of type 2 patients treated with insulin (~70%). However, mean HbA_{1c} level appeared to be higher in the U.S. sample (9.9 ± 1.8%).

The percentage of missing values was low for all Dutch PAID items and ranged from 1.9 ("feeling overwhelmed by your diabetes regimen") to 3.9% ("coping with complications of the diabetes").

Principal components analyses were performed in group 1 (n = 736) with 2–4 components. In the 3 analyses, all 20 items had high loadings on the first principal component (ranging from 0.49 to 0.81). None of the items had a loading on the second, third, or fourth principal component that exceeded their loading on the first principal component with >0.10. Eigen values of the 4 components were 9.9, 1.2, 1.0, and 0.9, which accounted for 49.5, 5.9, 5.1, and 4.4% of the variance, respectively. These findings show a large general (20-item) factor to be present, as found earlier in the U.S. sample. Next, forced EFAs with 2–4 factors were conducted using oblimin rotation. In the 2- and 3-factor solutions, a clear 13-item "diabetes-related emotional problems" factor was found, but the second and third factor were less homogeneous and not easy to interpret. The 4-factor solution could more clearly be interpreted as negative emotions (12 items), treatment problems (3 items), food-related problems (3 items), and lack of social support (2 items). Two items showed double loadings: "feeling alone with your diabetes" (0.55 for social support and 0.48 for negative emotions) and "feeling unsatisfied with your diabetes physician" (0.68 for treatment problems and 0.35 for lack of social support). By using CFAs in groups 2a–e (n = 736), the 1-factor model was just rejected with a robust CFI* of 0.89, whereas the 4-factor model was accepted with a CFI* of 0.94. In accordance with U.S. findings, Cronbach's α as a measure of internal consistency proved to be high for the PAID as a whole in groups 1a–e and 2a–e (0.93–0.95) and thus appeared to be stable across sex, type of diabetes, and treatment regimen. Cronbach's α for the 4 dimensions for type 1 and type 2 diabetes were in the range of 0.93 (emotions), 0.74–0.76 (treatment), 0.70–0.74 (food), and 0.69–0.72 (social support).

The factor structure of the PAID was reanalyzed in the U.S. sample using CFA. Similar to the findings of Welch et al. (15), the 1-factor model was accepted with a robust CFI* of 0.93. However, the 4-factor model proved to be statistically superior with a CFI* of 0.95, which confirms the Dutch model. Cronbach's α for the 4 PAID subdimensions in the U.S. sample were in the same range as the Dutch and ranged from 0.72 (social support) to 0.95 (emotions).

The Dutch PAID was completed for a second time by a sample of 202 subjects (response rate 81%) 66 ± 14 days after the

Table 2—*Correlations of PAID and PAID subdimensions with other measures of effect and self-reported HbA_{1c} and SMBG*

	WBQ-12			HFS	STAI	HbA_{1c}	SMBG
	NWB	ENE	PWB	(Worry subscale)	(Trait Anxiety subscale)	(Self-Report)	(Self-Report)
PAID total	0.51	−0.50	−0.53	0.53	0.61	0.11	0.13
Emotional problems	0.52	−0.50	−0.52	0.53	0.60	0.12	0.15
Treatment problems	0.33	−0.39	−0.40	0.33	0.42	0.12	0.12
Food problems	0.33	−0.34	−0.35	0.33	0.41	0.05 (NS)	0.02 (NS)
Lack of support	0.44	−0.37	−0.40	0.37	0.49	0.08 (NS)	0.06 (NS)

All correlations were statistically significant at $P < 0.001$ except those marked NS.

first assessment. Pearson's correlation between these 2 assessments was 0.83 for the total PAID and 0.80 (emotions), 0.64 (treatment), 0.74 (food), and 0.76 (social support) for the subdimensions, which suggests good stability.

Mean scores for the 20 PAID items, the total PAID, and subdimensions are shown in Table 1 by disease type for the Dutch and U.S. samples. U.S. type 1 diabetic patients reported significantly higher levels of emotional distress than the Dutch on all 4 subdimensions. In type 2 diabetic patients, the differences were less pronounced, but a trend was observed. Both in the Dutch and U.S. samples, "worrying about the future and the possibility of serious complications" had the highest mean score in type 1 and type 2 diabetic patients followed by "feelings of guilt or anxiety when you get off track with your diabetes management" and "not knowing if the mood or feelings you are experiencing are related to your blood glucose." All 3 items are included in the negative emotions subdimension of the PAID.

Convergent validity was examined by calculating product-moment correlations between the PAID and other measures of affect ($P < 0.001$). The associations found were all according to expectations and are summarized in Table 2. Perceived burden of diabetes correlated strongly (0.60) with total PAID, whereas a negative association ($r = -0.46$) was found when rating of overall satisfaction with life. Perceived health status correlated −0.35 with the PAID total. Age and income showed weak negative associations with the PAID total (−0.12 and −0.14, respectively), whereas duration of diabetes and years of education did not correlate significantly with the PAID. As expected, a weak positive correlation was found between PAID total and self-reported HbA_{1c} level and frequency of SMBG. Women showed higher total PAID scores than men (26.6 ± 19.9 vs. 20.9 ± 18.1, respectively; $P < 0.001$).

Discriminative validity was supported by the finding that subjects with a history of psychological/psychiatric treatment (n = 175) had significantly higher scores on the total PAID than subjects without such history (34.6 ± 22.0 vs. 22.0 ± 18.2, respectively). Patients reporting 1 or more severe hypoglycemic events during the past 6 months (defined as requiring assistance of another person, n = 236) had significantly higher total PAID scores compared with subjects without hypoglycemic episodes (28.6 ± 20.4 vs. 22.4 ± 18.7, respectively). Also, subjects reporting 1 or more DKA episodes during the past 12 months (n = 27) had higher scores than subjects without DKA episodes (31.8 ± 21.9 vs. 23.5 ± 19.2, respectively) ($P < 0.001$).

CONCLUSIONS — In this study, the reliability and validity of the PAID were examined across Dutch and U.S. patients with diabetes. The Dutch PAID had good internal consistency and factorial validity, and we found support for its convergent and discriminative validity. The Dutch PAID was relatively stable during a period of 2 months, but further research is needed to examine long-term stability and responsiveness to change. Similar to the findings of Welch et al. (15), we found that the factor structure can be represented by a 1-factor model, which supports the current use of the total score of the PAID. However, a 4-factor solution appeared to best fit the Dutch and U.S. data. Further research is needed to determine whether this 4-factor model can be replicated in other cultural adaptations of the PAID, including in Japanese subjects (17). The utility of this model in clinical practice has yet to be proved.

When comparing PAID scores across U.S. and Dutch type 1 and type 2 diabetic patients, similar problem areas were identified as the most stressful, but the U.S. patients reported higher levels of distress. This may reflect cross-cultural differences in experienced distress between Dutch and U.S. patients similar to those found in anxiety disorders and depression (29,30). Alternatively, differences in mean scores may be biased by patient selection, although no substantial differences in demographic and clinical characteristics between both samples were observed. The Dutch sample consisted of members of the Dutch Diabetes Association who were willing to fill out questionnaires, whereas Welch et al. (15) studied consecutive outpatients at an U.S. specialist diabetes clinic. Unfortunately, a more detailed comparison of clinical characteristics between both samples was not possible in this study because the data from the Dutch sample were based on self-report. The apparent difference in mean HbA_{1c} level between the Dutch and U.S. patients may reflect a true difference in glycemic control but may also have been caused by social desirability and/or differences in laboratory procedures. Future studies comparing PAID scores across cultures should include objective measures of glycemic control and health care received to control for differences in quality of diabetes care. Psychometric research on the PAID in different care settings and various ethnic and socioeconomic patient groups across cultures is warranted. In summary, the Dutch PAID is a promising brief assessment tool that may stimulate international comparison of the experience of living with diabetes and effects of interventions.

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