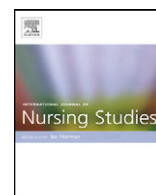




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Diabetes-related emotional distress in adults: Reliability and validity of the Norwegian versions of the Problem Areas in Diabetes Scale (PAID) and the Diabetes Distress Scale (DDS)

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ABSTRACT

Background: Regular assessment of diabetes-related emotional distress is recommended to identify high-risk people with diabetes and to further prevent negative effects on self-management. Nevertheless, psychological problems are greatly under diagnosed. Translating and testing instruments for psychosocial assessment across languages, countries and cultures allow for further research collaboration and enhance the prospect of improving treatment and care.

Objectives: To examine the psychometric properties of the Norwegian versions of the Problem Areas in Diabetes Scale and the Diabetes Distress Scale.

Design: Cross-sectional survey design.

Settings: A sample comprising adults with diabetes (response rate 71%) completed the Problem Areas in Diabetes Scale and the Diabetes Distress Scale, which were translated into Norwegian with standard forward–backwards translation.

Participants: The study included 292 participants with type 1 (80%) and type 2 diabetes (20%) aged 18–69 years, 58% males, mean diabetes duration 17.3 years (11.6), mean HbA_{1c} 8.2% (1.6).

Methods: We used exploratory factor analysis with principal axis factoring and varimax rotation to investigate the factor structure and performed confirmatory factor analysis to test the best fit of a priori-defined models. Convergent and discriminate validity were examined using the Short Form-36 Health Survey, Hospital Anxiety and Depression Scale and demographic and disease-related clinical variables. We explored reliability by internal consistency and test–retest analysis.

Results: Exploratory factor analysis supported a four-factor model for the Diabetes Distress Scale. Confirmatory factor analysis indicated that the data and the hypothesized

Abbreviations: CFI, comparative fit index; CFA, confirmatory factor analysis; DDS, Diabetes Distress Scale; EFA, exploratory factor analysis; HADS, Hospital Anxiety and Depression Scale; HbA_{1c}, glycosylated hemoglobin; PAID, Problem Areas in Diabetes Scale; RMSEA, root mean square error of approximation; SF-36, Short Form-36 Health Survey.

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model for the Diabetes Distress Scale fit acceptably but not for the Problem Areas in Diabetes Scale. Greater distress assessed with both instruments correlated moderately with lower health-related quality of life and greater anxiety and depression. The instruments discriminated between those having additional health conditions or disabilities, foot problems or neuropathy. Women and participants with higher HbA_{1c} levels reported significantly higher diabetes-related emotional distress.

Conclusions: The Norwegian versions of the Problem Areas in Diabetes Scale and the Diabetes Distress Scale have satisfactory psychometric properties and can be used to map diabetes-related emotional distress for diagnostic or clinical use. The Diabetes Distress Scale also contributes to identifying sub-domains of distress and seems promising for use in clinical trials.

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What is already known about the topic?

- Both mild and serious psychological problems are greatly under diagnosed among people with diabetes.
- Regular assessment of diabetes-related emotional distress is recommended to identify high-risk people with diabetes and to further prevent negative effects on self-management.
- International psychosocial research in diabetes could benefit from standardized instruments to promote further international comparison of results.

What this paper adds

- The Norwegian versions of the Problem Areas in Diabetes Scale and Diabetes Distress Scale have satisfactory psychometric properties to map individual levels of diabetes-related emotional distress among people with diabetes for diagnostic or clinical use and provide an opportunity for health care professionals to carry out more goal-oriented consultations.
- A four-factor model was supported for the Diabetes Distress Scale enabling identification of specific sub-domains of distress and seems promising for use in clinical trials. Both instruments discriminated between those having additional health conditions or disabilities, foot problems or neuropathy.
- Poor metabolic control was positively associated with higher Problem Areas in Diabetes Scale scores and Diabetes Distress Scale scores, pointing toward early identification of emotional challenges to benefit diabetes outcomes and prevent severe health problems in the future.

1. Introduction

The continued gap between clinical results and treatment goals (Eeg-Olofsson et al., 2007; Cooper et al., 2009) has led to increased awareness of the relationships between treatment outcomes and diabetes-related emotional distress and depressive symptoms. Many people living with diabetes do not reach recommended treatment goals despite new and better oral medication, better insulin and improved technologies for insulin delivery. Regular assessment of disease-specific emotional distress is recommended to identify high-risk people with diabetes and to further prevent negative effects on diabetes management (Fisher et al., 2009). Some people with

diabetes need help to present their individual concerns and to address essential emotional problems in order to be able to increase their self-care efforts. Nevertheless, both mild and serious psychological problems are greatly under diagnosed among people with diabetes (Pouwer et al., 2006).

The Problem Areas in Diabetes Scale (PAID) (Polonsky et al., 1995; Welch et al., 1997, 2003) and the Diabetes Distress Scale (DDS) (Polonsky et al., 2005) are commonly used for mapping diabetes-related problem areas and emotional distress. They were developed in the United States and are also translated and validated for use in some European populations (Snoek et al., 2000; Sigurdardóttir and Benediktsson, 2008). Both instruments display good psychometric properties and are used for clinical screening and in research. The PAID items were solicited from 10 health care providers at the Joslin Diabetes Clinic and from patients' comments into an item pool, resulting in a final measure after piloting of 20 items (Polonsky et al., 1995). The DDS is more conceptually driven and draws items from four pre-established domains of diabetes-related distress (Polonsky et al., 2005). Snoek et al. (2000) maintain that international psychosocial research in diabetes could benefit from standardized instruments to promote further international comparison of results.

Translating and testing instruments for psychosocial assessment across languages, countries and cultures allow for further research collaboration and enhance the prospect of improving treatment and care. Valid and reliable instruments to map disease-related emotional distress and to discriminate between levels of diabetes-related emotional problems and those who are clinically depressed are needed. Furthermore, the availability of sound instruments is important in order to compare results from different behavioral and psychosocial interventions in diabetes (Peyrot and Rubin, 2007). To our knowledge including both PAID and DDS in the same study allowing for consideration of the properties of both instruments in the same sample, have not previously been described internationally.

In the present study, we examine the psychometric properties of the Norwegian versions of the PAID and the DDS instruments and hypothesized that the PAID and DDS scores would be negatively associated with self-rated health-related quality of life (Short Form-36 Health Survey (SF-36)) and positively associated with general anxiety and

depression levels (Hospital Anxiety and Depression Scale (HADS)) as variants of the same construct, and would discriminate diabetes-related emotional distress at a group level.

2. Methods

2.1. Design and sample

We invited everyone with type 1 or 2 diabetes, visiting an endocrinology outpatient clinic at a larger University Hospital in Western Norway between October 2008 and February 2009 to participate in this cross-sectional survey study. Inclusion criteria were aged 18–69 years, diagnosed with diabetes for at least 1 year and able to complete a Norwegian questionnaire. The patients were informed about the purpose of the study and the possibility to withdraw at any time. They gave written consent and completed the questionnaires confidentially. Of 411 people fulfilling the inclusion criteria, 292 (71%) completed the questionnaire, while 41 (10%) declined participation, and 78 (19%) originally agreeing to participate did not return the questionnaire. We examined test–retest reliability among 103 patients visiting the outpatient clinic during the last 8 weeks of the data collection period. With 4-weeks between test and retest, they received the instruments for a second assessment by mail (response rate 41%).

We collected information about age, sex, type of diabetes, diabetes duration and treatment regimen from medical records. Further, the physician recorded diabetes complications (cardiovascular disease, stroke, nephropathy, retinopathy, neuropathy, gastric problems, erectile dysfunction and foot problems) and other health conditions or disabilities during consultation. Blood was taken to determine glycosylated hemoglobin (HbA_{1c}) and analyzed using a DCA-2000 (Bayer, Elkhart, IN, USA).

2.2. Measures

The Problem Areas in Diabetes Scale (Polonsky et al., 1995) comprises 20 items covering frequently reported emotional states. Previous research (Welch et al., 1997) supports using a total score (with one general 20-item factor), but both four-factor and two-factor solutions have been reported (Snoek et al., 2000; Sigurðardóttir and Benediktsson, 2008). The response choices were first rated on a 6-point Likert scale (from “not a problem” to “a serious problem”) (Polonsky et al., 1995) later modified to a 5-point scale (Welch et al., 2003). Scale scores are transformed to a 0–100 scale, with 100 indicating greater distress. The responsiveness of PAID has been tested, supporting its sensitivity to change over time (Welch et al., 2003).

The Diabetes Distress Scale (Polonsky et al., 2005) has 17-items and four subscales: emotional burden (5 items), physician-related distress (4 items), regimen distress (5 items) and diabetes-related interpersonal distress (3 items). The responses are on a Likert scale (1–5) and scale scores are transformed to a 0–100 scale, with 100 indicating greater distress.

An academic translation procedure was followed, with two bilingual professional forward-translators. A consensus meeting compared the two forward translations to ensure content and semantic equivalence, and another bilingual native English-speaking translator back-translated into English. We met with experts in the field and pilot tested relevant patients to confirm that the questionnaires were clear and understandable for clinical use (Guillemin et al., 1993).

We used the SF-36 mental health summary scale dimensions: vitality, social functioning, role-emotional and mental health (Ware et al., 2000) and the HADS anxiety and depression subscales (Zigmond and Snaith, 1983) to examine convergent validity. The SF-36 is available in Norwegian, has good psychometric properties (Loge et al., 1998) and is previously used in populations with and without diabetes (Goldney et al., 2004). HADS measures symptoms of anxiety and depression and self-rated feelings during the past week (Bjelland et al., 2002), and has also been used among people with diabetes (Collins et al., 2009).

2.3. Statistical analysis

We used SPSS version 17.0 and AMOS for Windows (SPSS Inc., Chicago, IL, USA). The factor structure was investigated by exploratory factor analysis (EFA) using principal axis factoring and varimax rotation. We determined the number of factors from the criterion eigenvalue ≥ 1 , supplied with judgment based on scree plots. We determined the allocation of items to factors by rotated factor loadings ≥ 0.5 in absolute value. Items with all loadings below 0.5 or more than one loading of least 0.5 in absolute value were not allocated to any factor. The resulting factor structure was compared with those reported in the literature. We considered forced four-, two- and one-factor solutions and confirmatory factor analysis (CFA) to test for fit of a priori-defined models were conducted. Model fit was based on root mean square error of approximation (RMSEA; preferably less than 0.08) and comparative fit index (CFI; preferably at least 0.95). In case of inferior model fit, explorative post hoc investigations were carried out including the few most indicated model modifications.

In the computation of scale scores, we performed missing substitution, replacing missing data by the mean of scores, if at least 50% of the items in a scale were answered (Fayers and Machin, 2007). We assessed convergent validity by Pearson correlations to examine the relationships of PAID and DDS scale scores with the SF-36 mental health summary scale dimensions and HADS subscales.

Relationships between PAID and DDS and sex, type of diabetes, diabetes-related complications and other health conditions or disabilities were examined by exact Mann–Whitney *U*-tests and relationships with treatment regimen by Kruskal–Wallis tests. Relationship between the scales and age, diabetes duration and metabolic control (HbA_{1c}) were explored by Pearson correlations. We defined statistical significance as $P < 0.05$.

We used Cronbach's alpha to determine internal consistency for PAID and DDS total scores and the DDS subscales. Values ≥ 0.70 are regarded as satisfactory

(Fayers and Machin, 2007). Test–retest reliability was examined by intraclass correlation coefficients.

2.4. Ethical considerations

The Western Norway Committee for Medical and Health Research Ethics approved the study, which was performed according to the Declaration of Helsinki.

3. Results

The study included 292 Norwegian adults with type 1 (80%) and type 2 diabetes (20%) aged 18–69 years (Table 1). The nonparticipants ($n = 119$) did not differ in mean age (42.3 years vs. 43.0 years, $P = 0.66$), sex (male 168 vs. 77 and female 124 vs. 42, $P = 0.18$) or HbA_{1c} (8.2% vs. 8.5%, $P = 0.09$).

3.1. Exploratory and confirmatory factor analysis

Exploratory factor analysis for PAID yielded a three-factor model. However, the scree plot did not distinguish clearly between factors ≥ 2 , and we used a forced four-factor structure consistent with the Snoek et al. model (2000). The four factors were not clearly related to the Snoek et al. model (Table 2.). Factor 1 was somewhat consistent with the Snoek et al. emotional problems subscale, factor 2 with the lack of social support subscale and factor 4 with the treatment problems subscale. Factor 3 was not clearly related to any Snoek et al. subscale. Seven of 20 items were not clearly related to a single factor. Likewise, a forced two-factor model did not give a clear picture and showed no support for the Sigurðardóttir and Benediktsson model (2008). Confirmatory factor analysis of the proposed models for PAID, showed mixed results. We found no clear support for a one-factor solution in CFA (RMSEA = 0.103 and CFI = 0.85), and this improved somewhat after including the three most indicated error

covariances, between items 1 and 2, 17 and 18, and 12 and 19 (CFI = 0.91, RMSEA = 0.080). For the two-factor model by Sigurðardóttir and Benediktsson (2008) (factor 1: items 3, 4, 6–8, 10, 14, 15, 17, 18 and 20, and factor 2: items 1, 2, 5, 9, 11–13, 16 and 19) RMSEA = 0.102 and CFI = 0.856. After modifications were included by introducing correlated errors of items 1 and 2, 12 and 19, and 17 and 18, the results improved (RMSEA = 0.080 and CFI = 0.914). For the four-factor solution reported by Snoek et al. (2000), the estimated error variance of item 17 was negative, setting it to 0 gave CFI = 0.90 and RMSEA = 0.088, which improved (CFI = 0.92, RMSEA = 0.080) after the most indicated modification by introducing correlated errors of items 12 and 19. The mean for PAID was 23.1 (SD 18.0). Some data were missing (85% of the respondents had no missing data), whereas 4% ($n = 11$) had more than 50% missing and were excluded. We performed missing substitution in 11%.

For DDS, the EFA supported a four-factor model (Table 3). All items could be allocated to a single factor, supporting the Polonsky et al. model for DDS (2005) except that one item (“feeling that I will end up with serious long-term complications no matter what I do”) was allocated to regimen distress instead of emotional burden. The mean DDS score was 18.9 (SD 15.5). The lowest score was in physician-related distress (mean 10.8, SD 15.7) and the highest in emotional burden (mean 25.0, SD 21.5). Few data were missing (94% had complete data); one participant (0.3%) had more than 50% missing and was excluded. Missing substitution was performed in 5%. The difference in the percentage of missing data for PAID in this study (PAID 85% vs. DDS 94%) could not be allocated to any specific items contributing to this difference.

We fitted the original four-factor model for DDS, giving CFI = 0.92 and RMSEA = 0.082. The single most indicated modification was to include an error correlation between items 1 and 8, giving CFI = 0.94 and RMSEA = 0.074 an acceptable fit after one data-driven modification. The CFI was just below acceptable, indicating moderate fit. According to the criteria for acceptable goodness-of-fit values, the factor solutions between the data and the theoretical model might be considered acceptable, confirming the four DDS subscales (Polonsky et al., 2005), although the modification may have inflated the model fit.

3.2. Convergent and discriminant validity

We found consistently moderate correlations between PAID and DDS and previously validated scale scores (Table 4). The DDS subscales had the lowest correlations: physician-related (0.17–0.26) and interpersonal distress (0.27–0.38). Lower health-related quality of life and greater HADS scores were associated with higher levels of diabetes-related emotional distress ($P < 0.001$).

Moreover, differences in PAID and DDS scores between people with additional health conditions or disabilities versus diabetes only were found. Mean scores were higher for PAID (32.0 (SD 22.8) vs. 21.1 (SD 16.9), $P = 0.002$) and DDS (24.6 (SD 19.8) vs. 17.2 (SD 14.3), $P = 0.03$). Scales discriminated well between diabetes-related emotional distress levels among people with and without foot problems ($P = 0.004$) and neuropathy ($P = 0.05$).

Table 1
Characteristics of 292 participants (aged 18–69 years) with type 1 and type 2 diabetes.

Sex, n (%)	
Men	168 (57.5%)
Women	124 (42.5%)
Age, mean (SD)	42.3 (14.2)
Diabetes duration, mean (SD)	17.3 (11.6)
Type of diabetes, n (%)	
Type 1	235 (80.5%)
Type 2	57 (19.5%)
Treatment, n (%) ($n = 276$)	
Diet and exercise only	4 (1.4%)
Tablets	15 (5.1%)
Tablets and insulin	16 (5.5%)
Insulin	257 (88.0%)
HbA _{1c} , mean % (SD) ^a	8.2 (1.6)
Late complications, n (%) ($n = 247$ –264)	
Cardiovascular disease, n (%)	22 (8.4%)
Stroke	4 (1.5%)
Nephropathy	35 (13.5%)
Eye problems	62 (23.5%)
Neuropathy	41 (16.2%)
Foot problems	27 (10.9%)
Other diseases or disabilities ($n = 216$)	49 (22.7%)

^a HbA_{1c}: glycosylated hemoglobin.

Table 2

Forced four- and two-factor solutions for the PAID as reported from previous research are not confirmed for 292 Norwegian participants (aged 18–69 years) with type 1 and type 2 diabetes.

PAID ^{a,b} items	Forced four-factor solution				Forced two-factor solution	
	1	2	3	4	1	2
3. Feeling scared when you think about living with diabetes.	0.67	0.25	0.41	0.20	0.81	0.31
6. Feeling depressed when you think about living with diabetes.	0.68	0.33	0.36	0.20	0.78	0.38
7. Not knowing if the mood or feelings you are experiencing are related to your blood glucose.	0.43	0.45	0.35	0.31	0.54	0.56
8. Feeling overwhelmed by your diabetes regimen.	0.54	0.45	0.30	0.40	0.61	0.60
9. Worrying about low blood sugar reactions.	0.19	0.32	0.33	0.23	0.32	0.43
10. Feeling angry when you think about having diabetes.	0.83	0.22	0.20	0.12	0.77	0.25
12. Worrying about the future and the possibility of serious complications.	0.26	0.16	0.78	0.12	0.57	0.29
13. Feeling guilty or anxious when you get off track with your diabetes management.	0.45	0.21	0.41	0.25	0.60	0.34
14. Not accepting diabetes.	0.65	0.22	0.11	0.36	0.60	0.39
16. Feeling that diabetes is taking up too much mental and physical energy.	0.39	0.54	0.36	0.31	0.51	0.64
19. Coping with complications of diabetes.	0.22	0.24	0.71	0.20	0.52	0.38
20. Feeling constantly burned out by the constant effort to manage diabetes treatment-related problems.	0.39	0.46	0.42	0.39	0.54	0.64
1. Not having clear and concrete treatment goals for your diabetes care.	0.17	0.23	0.17	0.62	0.25	0.55
2. Feeling discouraged with your diabetes regimen.	0.29	0.24	0.19	0.84	0.38	0.64
15. Feeling unsatisfied with your diabetes physician.	0.38	0.15	0.18	0.23	0.41	0.26
4. Uncomfortable interactions around diabetes with family/friends (e.g. other people telling you what to eat).	0.33	0.48	0.24	0.13	0.39	0.47
5. Feelings of deprivation regarding food and meals.	0.37	0.50	0.15	0.37	0.37	0.63
11. Feeling constantly concerned about food.	0.33	0.35	0.24	0.34	0.40	0.49
17. Feeling alone with diabetes.	0.38	0.72	0.22	0.19	0.43	0.66
18. Feeling that friends/family are not supportive of diabetes management efforts.	0.07	0.66	0.11	0.16	0.12	0.60

^a PAID: Problem Areas in Diabetes Scale.

^b The sub-dimensions for the samples in the Netherlands and the United States (Snoek et al., 2000) are used to present results for the 20 items of the scale; Bold: ≥ 0.5 .

The PAID and DDS scores were positively associated with HbA_{1c} (Table 4). Further, emotional burden and regimen distress were associated with metabolic control. Women had higher scores for both PAID and DDS ($P=0.001$ and $P=0.003$, respectively) and for the four DDS subscales ($P=0.001$ – 0.04). For DDS, younger patients had greater diabetes-related emotional distress, with a negative correlation with age for DDS and for emotional burden and regimen distress. No significant association was identified with diabetes duration, treatment regimen or type of diabetes. However, emotional burden nearly reached statistical significance (mean type 1 diabetes 26.3 vs. type 2 diabetes 19.3, $P=0.07$).

3.3. Internal consistency and test–retest reliability

Cronbach's alpha was 0.95 for PAID, 0.92 for DDS and 0.81–0.87 for the DDS subscales. Test–retest reliability was high. The intraclass correlation coefficients were 0.79 for PAID and 0.76 for DDS.

4. Discussion

The availability of standardized instruments across languages, countries and cultures enhances the prospect of comparing results from multinational and cross-cultural research. The results from the current study suggest that

the Norwegian versions of PAID and DDS have satisfactory psychometric properties to map individual levels of diabetes-related emotional distress among people with diabetes for diagnostic or clinical use. The instruments can discriminate distressed subjects and might be considered as alternatives to structured or semi-structured interviews. The correlations between the measures of diabetes-specific emotional distress and generalized distress were moderate, supporting that although related, they capture different aspects of distress.

The PAID questionnaire was originally not conceptualized as a multi-domain scale (Polonsky et al., 1995). The one-solution factor structure reported by the developers lends support to using all 20 items (Welch et al., 1997). Findings from our study did not support the two-factor solution for PAID identified by Sigurdardottir and Benediktsson (2008) nor the four-factor solution identified by Snoek et al. (2000). Previous research on the factor structure also shows lack of empirical support for the proposed factor structure (Huang et al., 2010). One explanation could be cultural differences in the experience of psychological problems. Findings from a study among adults with type 1 diabetes in a population from the United States and in a UK cohort suggest that there might be some differences (Lloyd et al., 2003). Nevertheless, from a clinical perspective, the total score of 20 items is a reliable instrument that provides an opportunity for health care

Table 3

Exploratory factor analysis for the 17-item DDS produced a four-factor solution for 292 Norwegian participants (aged 18–69 years) with type 1 and type 2 diabetes.

DDS ^a items	DDS-sub dimensions	Factors			
		1	2	3	4
1. Feeling that diabetes is taking up too much of my mental and physical energy every day.	Emotional burden	0.74	0.20	0.24	0.23
3. Feeling angry, scared and/or depressed when I think about living with diabetes.		0.67	0.32	0.20	0.13
8. Feeling that diabetes controls my life.		0.73	0.24	0.26	0.21
11. Feeling that I will end up with serious long-term complications, no matter what I do.		0.39	0.50	0.20	0.13
14. Feeling overwhelmed by the demands of living with diabetes.		0.65	0.36	0.20	0.34
2. Feeling that my doctor doesn't know enough about diabetes and diabetes care.	Physician-related distress	0.11	0.03	0.73	0.07
4. Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes.		0.15	0.20	0.80	0.19
9. Feeling that my doctor doesn't take my concerns seriously enough.		0.27	0.20	0.66	0.26
15. Feeling that I don't have a doctor who I can see regularly about my diabetes.		0.18	0.09	0.53	0.15
5. Feeling that I am not testing my blood sugars frequently enough.	Regimen distress	0.02	0.52	0.06	0.06
6. Feeling that I am often failing with my diabetes regimen.		0.30	0.79	0.12	0.17
10. Not feeling confident in my day-to-day ability to manage diabetes.		0.38	0.62	0.17	0.30
12. Feeling that I am not sticking closely enough to a good meal plan.		0.28	0.57	0.17	0.32
16. Not feeling motivated to keep up my diabetes self-management.		0.37	0.65	0.10	0.23
7. Feeling that friends or family are not supportive enough of my self-care efforts (e.g. planning activities that conflict with my schedule, encouraging me to eat the "wrong" food).	Interpersonal distress	0.12	0.24	0.20	0.69
13. Feeling that friends or family don't appreciate how difficult living with diabetes can be.		0.28	0.15	0.17	0.76
17. Feeling that friends or family don't give me the emotional support that I would like.		0.22	0.24	0.24	0.73

^a DDS: Diabetes Distress Scale. Bold: ≥ 0.5 .

Table 4

Pearson correlation coefficients for PAID, DDS and the DDS subdimensions with the SF-36 mental health summary scale subdimensions and HADS subscales for 292 Norwegian participants (aged 18–69 years) with type 1 and type 2 diabetes ($n = 266$ –287).

	Diabetes-related emotional distress ^a				Total scales	
	DDS subdimensions ^b					
	EB	PD	RD	ID	DDSc	PAID ^d
SF-36 mental health scales ^{a,e}						
Vitality	−0.42***	−0.20**	−0.43***	−0.30***	−0.45***	−0.45***
Social functioning	−0.48***	−0.22***	−0.44***	−0.33***	−0.48***	−0.50***
Emotional role limitation	−0.51***	−0.29***	−0.44***	−0.36***	−0.52***	−0.52***
Mental health	−0.51***	−0.24***	−0.46***	−0.38***	−0.52***	−0.50***
HADS scales ^{a,f}						
HADS-A	0.52***	0.26***	0.39***	0.36***	0.50***	0.54***
HADS-D	0.44***	0.17**	0.34***	0.27***	0.41***	0.45***
Age	−0.15*	−0.08	−0.21**	−0.04	−0.17**	−0.12
HbA _{1c} ^g	0.21***	0.04	0.47***	0.09	0.29***	0.21**
Duration	−0.08	−0.06	−0.08	−0.05	−0.09	−0.11

^a Higher scores indicate greater emotional distress, greater anxiety and depression and better health-related quality of life.

^b DDS subdimensions: emotional burden (EB), physician-related distress (PD), regimen distress (RD) and diabetes-related interpersonal distress (ID).

^c DDS: Diabetes Distress Scale.

^d PAID: Problem Areas in Diabetes Scale.

^e SF-36: SF-36 Health Survey.

^f HADS: Hospital Anxiety (HADS-A) and Depression (HADS-D) Scale.

^g HbA_{1c}: glycosylated hemoglobin.

* $P < 0.05$.

** $P < 0.01$.

*** $P < 0.001$.

professionals to carry out more goal-oriented consultations. The clinical sensitivity of PAID in detecting diabetes-related distress has been shown to be reasonable compared with other measures (Hermanns et al., 2006). Thus, the PAID questionnaire might be used as part of clinical assessment to consider individuals' own perspectives on areas of distress and enables clinicians to approach patients with emotional challenges more appropriately.

The DDS appears to have a more robust factor structure. The factor model identified in our study is almost in accordance with Polonsky et al. (2005). Thus, it seems as the instrument enables the assessment of sub-domains of diabetes-related emotional distress, although some data-driven modifications were needed that may have inflated the model fit. Further, EFA did not support the allocation of one item. Nevertheless, the instrument shows potential for use in clinical trials to capture domains of distress. Also, longitudinal relationships are shown in previous research (Fisher et al., 2010). However, more research in larger populations and different settings is needed to establish the relative strength and weaknesses of the instrument and psychometric properties in relation to sensitivity and responsiveness.

To our knowledge, the findings in the current study are unique as they shed light on the use of both instruments in a sample of mainly people with type 1 diabetes. The mean level of distress in the current sample is roughly similar to the levels in some European populations reported previously (Snoek et al., 2000; Sigurðardóttir and Benediktsson, 2008), but somewhat lower than US populations (Welch et al., 1997; Snoek et al., 2000), and higher than the fairly low scores of type 1 diabetes survivors in the follow-up cohort reported by Lloyd et al. (2010). The considerable differences in populations and settings in studies conducted across the world underline the importance of conceptually equivalent versions of the instruments in each target country and in different cultures, and well-established methods to test psychometric properties in different settings. Our internal consistency exceeded 0.90 for both scales. Thus, the number of items can potentially be reduced. An important issue is how to reduce the number of items while retaining measurement precision. International research collaboration might allow for further work on pooled data from different countries and cultures and the development of manuals and scoring procedures.

The moderately significant correlations between higher diabetes-related emotional distress and lower health-related quality of life and more depression and anxiety symptoms are concept-related and as expected providing evidence of convergent validity. This supports previous research focusing on better understanding the mechanisms of depressed mood. Diabetes-related distress is previously shown to be more strongly linked with behavioral and biological variables than major depressive disorder (Fisher et al., 2007, 2008). In the study by Snoek et al. (2000) patients were asked how burdensome they perceived their diabetes to be on a 4-point Likert scale (from very burdensome to not burdensome). The results showed that perceived burden of diabetes was significantly correlated with the total PAID scale scores. In order

to guide initiatives to improve treatment and follow-up in diabetes health care a better understanding of emotional problems among patients is needed. The inclusion of well-validated and feasible patient-reported outcomes as part of standards of care would enhance both the priority and delivery of quality, patient-centered care, and serve as a way to individualize evidence-based treatment based upon emotional aspects and patient preferences (Glasgow et al., 2008). The registration-rates of emotional problems among health professionals are previously found to be low (Pouwer et al., 2006). Also, in the DAWN study, it was shown that many providers were not able to identify and evaluate psychological problems and to provide the support their patients needed (Peyrot et al., 2005). Standardized patient-reported data may be useful to identify patient preferences and goals, and may provide an opportunity for health care professionals to better understand self care and behaviors and quality of life-related issues among persons with diabetes (O'Connor et al., 2011).

Routinely including measures of diabetes-related emotional distress in diabetes health care and follow-up is recommended in clinical guidelines (IDF, 2006) and might be particularly helpful for people with diabetes attempting to improve glycemic control (Fisher et al., 2010). Patient reported measurement tools add to the identification of specific psychological problems related to the disease and disease specific measures might be preferable to generic instruments. Sound patient reported outcome measures on diabetes-specific emotional distress and problem areas can lead to an increased awareness and hence these instruments might guide health care professionals to improved diagnosis and a greater attention for emotional aspects of diabetes. The development of the DDS was more conceptually driven, and the scale was constructed with four subscales to assess pre-established domains of diabetes-related distress (Polonsky et al., 2005). Thus, this measure might be of greater value to test interventions that target emotional problems and to evaluate effects of training health professionals to recognize psychological problems. Also, further investigation of indicators related to self-management and measures on motivation for self-management should be explored in future studies. In the present study, poor metabolic control was positively associated with higher PAID and DDS scores. Further, greater distress on DDS emotional burden and regimen distress was associated with higher HbA_{1c}. These findings indicate that disease-related distress is a critical variable monitoring change in metabolic control over time. The importance of considering psychological and social factors in enhancing treatment results is significant. According to Kartal and Inci (2011) well validated measures are essential to enhance nurses understanding of patients needs. Early identification of emotional challenges and clinical intervention targeting vulnerable people with diabetes might prevent severe health problems in the future. In a 6 month longitudinal pilot study among 61 patients completing the PAID instrument prior to a clinical encounter a therapeutic dialogue was facilitated (Chawla et al., 2010). In that study, providing health care professionals with results of a scale completed by their

patients at the same visit had the most effect at the initial encounter, and also on at-risk patients suffering from poor glycemic control.

In the present study, there was a significant tendency for women to report higher level of distress and more problems related to diabetes than men. Similar findings have also been reported elsewhere (Snoek et al., 2000). One explanation might be that women to a higher degree than men focus on emotional distress and mental health aspects. However, one might also speculate that the sex based differences are related to the increasing demands of the disease that might be put on women compared to men. Traditionally women have other roles in the family and in the society including greater extent of caring and coordination tasks to fulfill. In this case, the demands of the disease might be more challenging. Regardless, the presence of sex based differences observed in the present study contributes to the PAID and DDS's validity.

This study has limitations. The study population is relatively homogeneous ethnically, and the results might be representative in outpatient clinics with mainly Caucasian inhabitants. More multinational and cross-cultural research studies are needed to enhance the understanding of culture when interpreting the findings. Further, 80% had type 1 diabetes indicating low power in detecting differences between types of diabetes and treatment regimens. If the sample had included more people with type 2 diabetes the prevalence of diabetes-related distress might have been lower (Welch et al., 1997; Huang et al., 2010). In future studies description of socio-cultural factors, as well as burden of disease in relation to the health care system and setting might be appropriate. Interpretation of scale scores would need to take into account the different cultural background of the participants. The current study was conducted in a Nordic country. In Norway, the quality of diabetes care relies on a well organized public health care system and high degree of treatment equality as treatment and stays in hospital are mostly free of charge. One strength was the response rate of 71%.

5. Conclusion

The Norwegian versions of PAID and DDS seem to be valid and reliable and contribute uniquely in assessing diabetes-related emotional distress. Both instruments have satisfactory psychometric properties to map individual levels of distress among people with diabetes for diagnostic or clinical use. For the use of these instruments in clinical trials the DDS might have some advantages as it also contributes to identifying sub-domains of distress.

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