

Diabetes Distress and Associations With Demographic and Clinical Variables: A Nationwide Population-Based Registry Study of 10,186 Adults With Type 1 Diabetes in Norway

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Diabetes distress data from a nationwide register-based cohort of adults with type 1 diabetes (N = 10,186)



Prevalence of diabetes distress. Associations with demographic and clinical variables.

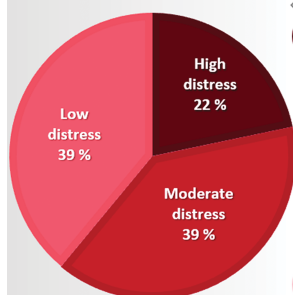


Data from the Norwegian Diabetes Register for Adults.



The 20-item Problem Areas in Diabetes (PAID-20) scale.

Distress levels:



The five most endorsed PAID-20 items:

- 1 Worry about the future and diabetes complications
- 2 Feel diabetes is taking up too much energy every day
- 3 Feel burnt out by diabetes self-management
- 4 Feel guilty about not self-managing “well enough”
- 5 Worry about hypoglycemia

Associations:



The findings underline the importance of addressing diabetes distress to improve the health of adults with type 1 diabetes.

Diabetes Care

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ARTICLE HIGHLIGHTS

• Why did we undertake this study?

This study reports diabetes distress data from a nationwide population-based registry study with responses from 10,186 adults with type 1 diabetes living in Norway.

• What is the specific question(s) we wanted to answer?

We wanted to identify the most commonly reported distress items and examine factors associated with diabetes distress.

• What did we find?

We identified the items from the 20-item Problem Areas in Diabetes scale endorsed by respondents as the most problematic. Factors associated with higher distress scores were female sex, younger age, shorter diabetes duration, minority background, primary education only, unemployment, daily smoking, continuous glucose monitoring use, higher HbA_{1c}, more symptomatic hypoglycemic events, having received retinopathy treatment, and reduced foot sensitivity.

• What are the implications of our findings?

The results highlight the importance of identifying and addressing diabetes distress in clinical follow-up.



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BRIEF REPORT

OBJECTIVE

To estimate diabetes distress prevalence and associations with demographic and clinical variables among adults with type 1 diabetes in Norway.

RESEARCH DESIGN AND METHODS

In this nationwide population-based registry study, the 20-item Problem Areas in Diabetes (PAID-20) questionnaire was sent to 16,255 adults with type 1 diabetes. Linear regression models examined associations of demographic and clinical variables with distress.

RESULTS

In total, 10,186 individuals (62.7%) completed the PAID-20, with a mean score of 25.4 (SD 18.4) and 21.7% reporting high distress. Respondents endorsed worrying about the future and complications as the most problematic item (23.0%). Female sex, younger age, non-European origin, primary education only, unemployment, smoking, continuous glucose monitoring use, more symptomatic hypoglycemia, reduced foot sensitivity, treated retinopathy, and higher HbA_{1c} were associated with higher distress.

CONCLUSIONS

Diabetes distress is common among adults with type 1 diabetes and associated with clinically relevant factors, underlining that regular care should include efforts to identify and address distress.

Diabetes distress reflects the emotional responses to the challenges of living with diabetes (1,2) and impacts on self-management (3). Consequently, routine diabetes distress monitoring is recommended in clinical guidelines (e.g., using the 20-item Problem Areas in Diabetes [PAID-20]) (4–6). However, we currently lack data from population-based studies regarding the prevalence of clinically significant diabetes distress that may require additional support, because existing estimates are derived from samples obtained in clinical studies (1,7). Therefore, in this nationwide population-based registry study, we aimed to 1) calculate PAID-20 scores and the proportion

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of respondents reporting high diabetes distress, 2) describe the distribution of PAID-20 item scores to identify the most reported problem areas, and 3) examine associations of demographic and clinical variables with PAID-20 scores.

RESEARCH DESIGN AND METHODS

We conducted a nationwide population-based study using data from the Norwegian Diabetes Register for Adults (NDR-A), which consists of data about adults (age ≥ 18 years) with diabetes who attend outpatient clinics. The Norwegian Regional Committee for Medical and Health Research Ethics (REK Vest 171685) and data protection officials approved the study.

In 2020, 21,484 adults with type 1 diabetes (from 51 of 52 diabetes clinics) were registered in the NDR-A. We included the 17,828 (83.0%) who attended consultations between October 2019 and December 2020 (Fig. 1). In May 2021, NDR-A administrators sent a digital questionnaire to 16,255 individuals reachable on national digital platforms, and 10,391 (63.9%) responded. Diabetes distress was assessed with the PAID-20, measuring common diabetes-related problems scored from 0 (not a problem) to 4 (serious problem) (8).

Scores are transformed to a 0–100 scale, where ≥ 40 is the established cut point for clinically significant high distress (1,7). Recently, moderate distress (score 17–39) was suggested (9). Furthermore, we extracted demographic variables (sex, age, ethnic origin, educational level, work, and cohabitation status), clinical process variables (diabetes duration, insulin regimen, continuous glucose monitoring [CGM], BMI, and smoking habits), and clinical outcome variables (hemoglobin A_{1c} [HbA_{1c}] and acute and long-term complications) from the NDR-A database.

Analyses

We conducted all statistical analyses using Stata SE (version 17.0). We calculated the PAID-20 total score, the proportion reporting high distress, and the distribution of the PAID-20 response options for all items. We identified the five items with the highest endorsement of “somewhat serious problem” or “serious problem” (score 3 or 4). Among PAID-20 completers (<50% missing items), we used person-mean substitution for missing item scores in 240 individuals (2.4%) (Supplementary Table 1).

We used linear regression models to examine associations of demographic and

clinical variables with distress scores. We imputed missing data using a chained equations algorithm and applied Rubin combinations rules in pooling β and B coefficients with 95% CIs across 100 imputed data sets. We report regression coefficients (B) with 95% CIs, signifying the change in PAID-20 score associated with a one-unit increase in the exposure variables, and standardized coefficients (β), indicating the strength and relative importance of each coefficient. We performed regression analyses, crude and with adjustment in a hierarchical manner, mutually adjusting the demographic variables for one another (model 1), the clinical process variables for one another and the demographics (model 2), and clinical outcome variables for one another, the demographic and clinical process variables (model 3). We interpreted the coefficients in models 1 to 3 block diagonally. Using Spearman, tetrachoric, and polychoric correlations and variance inflation factors, we found no collinearity.

Data and Resource Availability

Norwegian legislation prevents patient-level data sharing in public repositories. Data requestors must submit a proposal

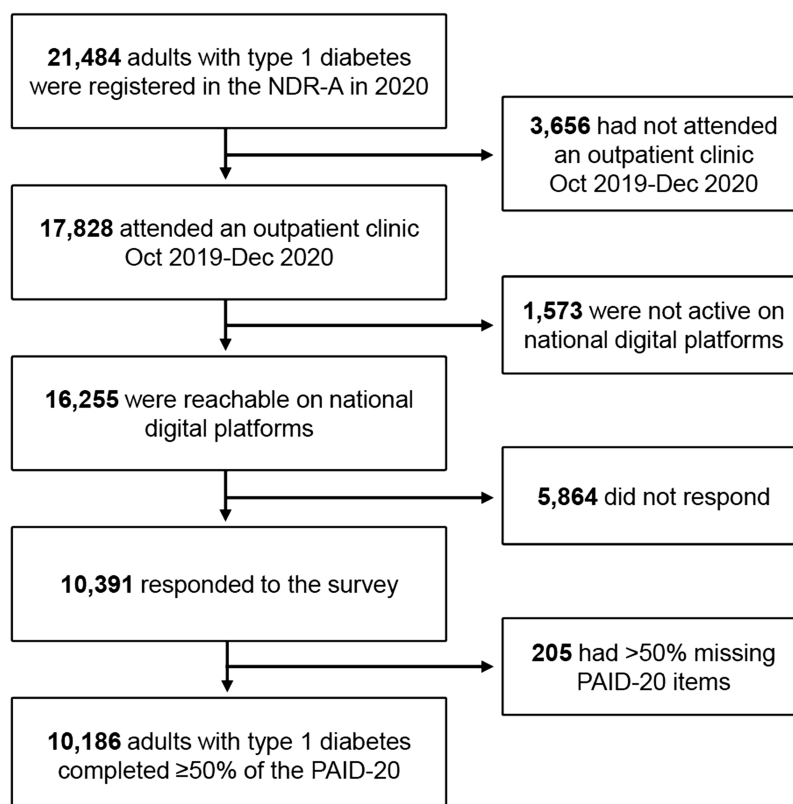


Figure 1—Flowchart for the cohort of study participants with type 1 diabetes from the NDR-A.

to the NDR-A (noklus@noklus.no), sign a data access agreement, and obtain necessary approvals to gain access.

RESULTS

We analyzed PAID-20 data from 10,186 participants (Fig. 1), of whom 54.0% were male (Table 1); mean age was 46.7 years (SD 15.3), mean diabetes duration was 22.9 years (SD 14.4), 35.6% received pump treatment, 69.7% used CGM, and mean was HbA_{1c} 59 mmol/mol (SD 12.7). Furthermore, 14.7% had treated

retinopathy, 12.9% had an elevated urine albumin-to-creatinine ratio, and 10.9% had reduced foot sensitivity.

The mean PAID-20 score was 25.4 (SD 18.4), and 21.7% reported high distress (Table 1). The 20-item score distribution is shown in Fig. 2 and Supplementary Table 2. The five items most endorsed as problematic were “worrying about the future and the possibility of serious complications” (23.0%), “feeling that diabetes is taking up too much of your mental and physical energy every day” (19.7%), “feeling burnt out by the constant effort needed to manage

diabetes” (18.7%), “feelings of guilt or anxiety when you get off track with your diabetes management” (17.4%), and “worrying about low blood sugar reactions” (13.0%). In total, 42.2% reported that at least one item was a somewhat serious or serious problem (Supplementary Table 3). Among participants with a PAID-20 score <40, this proportion was 20.9%.

In the fully adjusted regression (model 3), female sex, CGM use, daily smoking, symptomatic hypoglycemia, HbA_{1c} treated retinopathy, and reduced foot sensitivity were all associated with higher PAID-20 scores (Table 2), whereas older age, longer diabetes duration, European origin, university/college education, and working/studying were associated with lower PAID-20 scores. In examining these associations, sex displayed the largest effect (β) on PAID-20 scores, followed by age and HbA_{1c}. The associations observed for the demographic and clinical process variables remained consistent across the models, except for university/college education, which was attenuated in model 3.

CONCLUSIONS

In this large population-based cohort of adults with type 1 diabetes and PAID-20 data, we found that 21.7% of respondents reported high distress. The most common distress sources were concerns about complications, self-management burdens, and feelings of guilt or anxiety when self-management efforts fell short. Additionally, we identified associations between higher diabetes distress and sex, age, non-European origin, primary education only, not working/studying, shorter diabetes duration, CGM use, more symptomatic hypoglycemia, higher HbA_{1c}, retinopathy, reduced foot sensitivity, and smoking.

We found that one in five participants reported high distress, confirming results from smaller studies reporting 17% to 24% (7,9,10). The most endorsed problem areas related to worries about complications and diabetes self-management are consistent with previous research in health care settings (9,10). The associations of higher distress with female sex and younger age also confirm previous studies (7,9,11). Surprisingly, CGM use was associated with a higher PAID-20 score. One could assume that some choose CGM because of distress and that using CGM would positively affect and lower distress.

Table 1—Diabetes distress scores and characteristics of adults (age ≥ 18 years) with type 1 diabetes completing the PAID-20 scale (N = 10,186)

Variable	n*	Results†
PAID-20		
Score (0–100)	10,186	
Mean		25.4 \pm 18.4
Median		22.5 (0–100)
Score level	10,186	
0–16 (low)		3,970 (39.0)
17–39 (moderate)		4,002 (39.3)
≥ 40 (high)		2,214 (21.7)
Demographics		
Sex	10,186	
Male		5,502 (54.0)
Female		4,684 (46.0)
Age, years	10,186	46.7 \pm 15.3
European origin	9,491	9,258 (97.5)
Educational level	10,023	
Primary school		732 (7.3)
Secondary school		4,637 (46.3)
University/college		4,654 (46.4)
Working/studying	9,950	7,286 (73.2)
Living alone	10,025	1,949 (19.4)
Clinical processes		
Diabetes duration, years	10,175	22.9 \pm 14.4
CSII	10,005	3,558 (35.6)
CGM use	9,950	6,938 (69.7)
BMI, kg/m ²	7,847	27.1 \pm 5.0
Daily smoking	9,644	1,030 (10.7)
Clinical outcomes		
HbA _{1c} , %	10,055	7.6 \pm 1.2
HbA _{1c} , mmol/mol	10,055	59 \pm 12.7
Acute complications		
Symptomatic hypoglycemic events in previous month	8,609	7.9 \pm 9.6
History of severe hypoglycemia	8,749	4,041 (46.2)
History of DKA	8,454	1,857 (22.0)
Long-term complications		
Treated retinopathy	8,839	1,299 (14.7)
Reduced foot sensitivity	8,116	885 (10.9)
eGFR <60 mL/min/1.73 m ²	9,382	419 (4.5)
Urine ACR ≥ 3 mg/mmol	8,043	1,034 (12.9)
Stroke	8,747	187 (2.1)
Coronary heart disease	8,726	588 (6.7)
Two or more complications	9,220	822 (8.9)

ACR, albumin-to-creatinine ratio; CSII, continuous subcutaneous insulin infusion; DKA, diabetic ketoacidosis; eGFR, estimated glomerular filtration rate. *n of participants with available data for the variables. †Data are mean \pm SD, median (min–max), or n (%).

The PAID-20

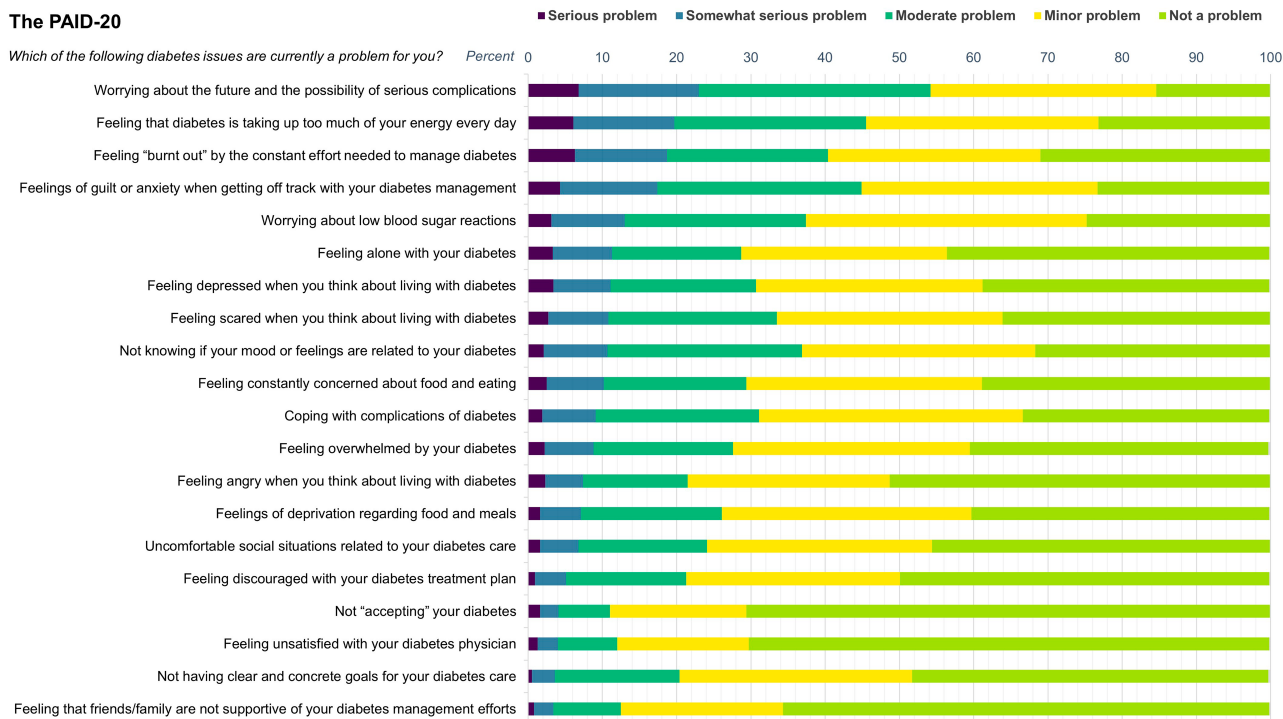


Figure 2—Score distribution of the 20 items in the PAID-20 scale among 10,186 adults with type 1 diabetes by problem areas endorsed as most problematic (i.e., the response options “somewhat serious problem” and “serious problem”).

However, in a recent review, only two of nine randomized controlled trials reported distress reduction after initiation of CGM (12), possibly explained by devices serving as constant reminders of disease or contributing to information overload. Prospective studies are needed to examine the CGM–distress mechanisms.

Our results support the relationship between poorer HbA_{1c} and higher distress (9,11,13). The association could be bidirectional, since previous studies have found that high distress is associated with higher HbA_{1c} (14,15). Not reaching the recommended glycemic target can be a potential source of diabetes distress, and distress can contribute to less effective self-management, typically increasing HbA_{1c} (3,16). However, individuals reaching target HbA_{1c} might also experience high distress, and distress sources may vary by HbA_{1c} level. Consequently, the link between HbA_{1c} and distress requires further investigation.

Diabetes distress is an expected part of living with diabetes that can arise from many sources (1,2,10). Elevated diabetes distress should be recognized as clinically important, since research indicates associations with psychological and somatic variables (1,2,9,12,14). If unaddressed, diabetes distress tends to increase or

persist (17,18). Therefore, clinicians should be able to address the multifaceted nature of living with diabetes in routine care (1,4,5). Individuals with diabetes typically want to talk to clinicians about their challenges (10,19). Discussing distress can reduce its impacts on living with diabetes, thereby improving self-management and glycemic control (2,3,7,10,18). Clinicians should pay particular attention to those who report feeling guilty or anxious about not succeeding with self-management, worrying about complications, and consequently feeling exhausted from everyday demands. Addressing specific problem areas with elevated scores is probably more relevant than examining total scores. However, many clinicians report lack of training, confidence, and resources to address distress (20). Health care services clearly need to allocate resources for this purpose. Diabetes teams should have access to assistance from behavioral health specialists and specialist follow-up of patients with very high distress.

Our population-based study contributes to an increased understanding of diabetes distress among adults with type 1 diabetes. Major strengths are the real-world setting, sample size (the largest reported to date), and high response rate. The national population-based data add

weight to smaller studies in health care settings that may have been biased by participant selection. Furthermore, we used the PAID-20, recommended for research and clinical settings (1,6). However, timing and technology literacy may have affected the response rate. Therefore, diabetes distress rates might have been underestimated. Also, the study design prohibits causal inference.

To conclude, diabetes distress is common among adults with type 1 diabetes in Norway and associated with clinically relevant factors, warranting greater attention in regular diabetes care, which should include efforts to identify and address diabetes distress. By doing so, we may help improve health outcomes for individuals with type 1 diabetes.

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Duality of Interest. No potential conflicts of interest relevant to this article were reported.

Author Contributions. I.H. wrote the initial draft of the manuscript, with assistance from J.G.C., R.M.N., T.C.S., R.B.S., M.M.I., M.G., K.F.L., T.V.M., S.S.L., D.A.R., G.Å.U., and A.H. I.H. and A.H. designed the study, with input from R.M.N., T.C.S., R.B.S., M.M.I., and M.G. I.H. and T.E.

Table 2—Associations of demographic, clinical process, and clinical outcome variables with PAID-20 scores in adults (age ≥18 years) with type 1 diabetes (N = 10,186)

Variable	Crude			Model 1			Model 2			Model 3					
	B	95% CI for B	P	B	95% CI for B	P	B	95% CI for B	P	B	95% CI for B	P			
Demographics*															
Female sex	7.6	6.9, 8.3	<0.001	7.3	6.6, 8.0	0.20	<0.001	7.0	6.3, 7.7	0.19	<0.001	7.0	6.3, 7.7	0.19	<0.001
Age, years	-0.2	-0.21, -0.16	<0.001	-0.2	-0.25, -0.20	-0.19	<0.001	-0.2	-0.21, -0.15	-0.15	<0.001	-0.2	-0.19, -0.13	-0.14	<0.001
European origin	-8.6	-11.0, 6.3	<0.001	-6.7	-9.0, -4.4	-0.06	<0.001	-6.8	-9.1, -4.5	-0.06	<0.001	-6.5	-8.7, -4.2	-0.05	<0.001
Living alone	1.7	0.8, 2.6	<0.001	1.4	0.5, 2.3	0.03	0.002	1.4	0.5, 2.3	0.03	0.002	1.1	0.2, 1.9	0.02	0.015
Educational level															
Secondary school	-1.9	-3.3, -0.5	0.01	-1.2	-2.5, 0.2	-0.03	0.10	-0.9	-2.3, 0.5	-0.02	0.21	-0.4	-1.7, 1.0	-0.10	0.59
University/college	-4.2	-5.7, -2.8	<0.001	-3.5	-4.9, -2.1	-0.10	<0.001	-3.0	-4.5, -1.6	-0.08	<0.001	-1.8	-3.2, -0.4	-0.05	0.013
Working or studying	-1.8	-2.6, -1.0	<0.001	-4.1	-5.0, -3.3	-0.10	<0.001	-4.1	-5.0, -3.2	-0.10	<0.001	-3.3	-4.2, -2.4	-0.08	<0.001
Clinical processes†															
Diabetes duration, years	-0.1	-0.16, -0.11	<0.001					-0.1	-0.10, -0.05	-0.06	<0.001	-0.1	-0.15, -0.08	-0.09	<0.001
CGM use	3.8	3.0, 4.5	<0.001					3.1	2.3, 3.9	0.08	<0.001	2.9	2.1, 3.7	0.07	<0.001
CSII	3.0	2.2, 3.7	<0.001					1.1	0.3, 1.9	0.03	0.005	0.8	0.1, 1.6	0.02	0.04
Daily smoking	3.4	2.2, 4.6	<0.001					2.7	1.5, 3.8	0.05	<0.001	1.6	0.5, 2.8	0.03	0.005
Clinical outcomes‡															
Symptomatic hypoglycemic events, n	0.1	0.08, 0.17	<0.001												
HbA _{1c} , mmol/mol	0.3	0.23, 0.28	<0.001												
History of DKA	4.0	3.1, 5.0	<0.001												
History of severe hypoglycemia	-0.6	-1.3, 0.2	0.15												
Treated retinopathy	0.8	-0.3, 1.8	0.17												
Reduced foot sensitivity	-0.4	-1.6, 0.9	0.59												
Reduced kidney functions§	0.5	-0.6, 1.6	0.33												
Coronary heart disease	-1.7	-3.2, -0.1	0.033												

CSII, continuous subcutaneous insulin infusion; DKA, diabetic ketoacidosis; eGFR, estimated glomerular filtration rate. *Male sex, non-European origin, not living alone, primary education, and not working/ studying. †Self-monitoring of blood glucose, insulin pen use, and nonsmoker. ‡No history of DKA, no retinopathy or nontreated retinopathy, normal foot sensitivity, normal kidney function (eGFR >60 mL/min/1.73 m² and urine albumin-to-creatinine ratio <3 mg/mmol), and no coronary heart disease. §Reduced kidney function defined as eGFR <60 mL/min/1.73 m² and urine albumin-to-creatinine ratio ≥3 mg/mmol.

conducted the statistical analyses, under the supervision of R.M.N. All authors contributed revisions to the paper and approved the final version. I.H. and A.H. are the guarantors of this work and, as such, had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Prior Presentation. This study was presented in part in poster form at the International Diabetes Federation World Diabetes Congress, Lisbon, Portugal, 5–8 December 2022.

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