Research: Educational and Psychological Issues

Diabetes Attitudes, Wishes and Needs second study (DAWN2™): Cross-national benchmarking of diabetes-related psychosocial outcomes for people with diabetes

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Abstract

Aims   The second Diabetes Attitudes, Wishes and Needs (DAWN2) study aimed to assess psychosocial outcomes in people with diabetes across countries for benchmarking.

Methods   Surveys included new and adapted questions from validated questionnaires that assess health-related quality of life, self-management, attitudes/beliefs, social support and priorities for improving diabetes care. Questionnaires were conducted online, by telephone or in person.

Results   Participants were 8596 adults with diabetes across 17 countries. There were significant between-country differences for all benchmarking indicators; no one country's outcomes were consistently better or worse than others. The proportion with likely depression [WHO-5 Well-Being Index (WHO-5) score ≤ 28] was 13.8% (country range 6.5–24.1%). Diabetes-related distress [Problem Areas in Diabetes Scale 5 (PAID-5) score ≥ 40] was reported by 44.6% of participants (17.2–67.6%). Overall quality of life was rated 'poor' or 'very poor' by 12.2% of participants (7.6–26.1%). Diabetes had a negative impact on all aspects investigated, ranging from 20.5% on relationship with family/friends to 62.2% on physical health. Approximately 40% of participants (18.6–64.9%) reported that their medication interfered with their ability to live a normal life. The availability of person-centred chronic illness care and support for active involvement was rated as low. Following self-care advice for medication and diet was most common, and least common for glucose monitoring and foot examination, with marked country variation. Only 48.8% of respondents had participated in diabetes educational programmes/activities to help manage their diabetes.

Conclusions   Cross-national benchmarking using psychometrically validated indicators can help identify areas for improvement and best practices to drive changes that improve outcomes for people with diabetes.

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Introduction

Despite new medical treatments and therapeutic options, most people with diabetes still do not achieve target blood glucose levels [1,2]. The lack of improved treatment outcomes may reflect suboptimal organization of chronic illness care and a deficiency of self-management and psychosocial sup-

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> **What's new?**
>
> - Diabetes impacts on physical, emotional, social and financial aspects of life across cultures and countries, yet gaps in care exist around psychosocial and self-management education and support.
>
> - The DAWN2 study highlights significant country variation in indicators of person-centred diabetes care and psychosocial outcomes of diabetes.
>
> - Most people with diabetes are not actively engaged by their healthcare professionals to take control of their condition; education and psychosocial care are often unavailable.
>
> - The DAWN2 study provides new insights from four continents that may help identify unmet needs and best practices to drive changes that improve outcomes for people with diabetes.

port [3]. In 2001, the global Diabetes, Attitudes, Wishes and Needs (DAWN) survey provided insights into the psychosocial challenges facing people with diabetes [4] and showed that psychosocial problems can be barriers to achieving adequate glycaemic control [5], that people with diabetes lack psychological support and that interdisciplinary care teams need to promote chronic illness care [6]. The DAWN 'Call to Action' [7] encouraged all stakeholders to implement person-centred diabetes care and actively involve the person with diabetes in self-management with support from an interdisciplinary team of healthcare professionals [3].

Despite the progress made since the initial DAWN study, the impact of the psychosocial burden of diabetes is still not fully recognized [3]. Healthcare systems are struggling to accommodate person-centred models of care and to encourage people with diabetes to self-manage their condition. Therefore, collaborative action across countries to improve self-management and psychological support and a deeper understanding of the psychosocial issues, unmet needs, barriers and facilitators to person-centred chronic care from the point of view of the different stakeholders is required.

The DAWN2 study [8] is a global partnership initiative between several established national and international organizations, including the International Diabetes Federation, the International Alliance of Patients' Organizations (IAPO) and the Steno Diabetes Center, and Novo Nordisk for the advancement of person-centred diabetes care, which aligns with the Global DAWN Call to Action [7], World Health Organization (WHO) frameworks for people-centred and innovative chronic illness care and the IAPO declaration for patient-centred health care [9]. The aims of the study are to: (1) improve our understanding of the unmet needs of people with diabetes and those who care for them; (2) facilitate dialogue and collaboration among all key stakeholders to

strengthen active patient involvement and self-management; and (3) establish a validated multinational survey system for assessing and benchmarking psychosocial and educational aspects of diabetes care delivery.

DAWN2 explores how people with diabetes, family members and healthcare professionals perceive diabetes care and a person-centred model that emphasizes the needs of the individual in the context of current chronic care, self-management education and psychological support. Here we present selected core descriptive results from the DAWN2 survey of people with diabetes, describing cross-national variation in quality of life and treatment burden, patient empowerment (as defined by Anderson and Funnell [10]) and self-care activities, healthcare provision and education, as well as societal support (i.e. patient-perceived support from different sources) and discrimination because of diabetes. These provide a set of key validated indicators of person-centred diabetes care, suitable for cross-national benchmarking (in which differences between countries can help identify country-specific needs and provide a baseline for future studies investigating changes in diabetes outcomes). This report is one of three linked papers within this edition of *Diabetic Medicine* that describe the core data for the three stakeholder groups surveyed in DAWN2 (people with diabetes, their family members and healthcare professionals); each report provides complementary data to the others.

Participants and methods

Design and study participants

The methodology of DAWN2 (UTN no: U1111-1123-7509; NCT01507116) has been published previously [8]. Briefly, DAWN2 is a multinational, interdisciplinary and multi-stakeholder study conducted in 17 countries from four continents: Algeria, Canada, China, Denmark, France, Germany, India, Italy, Japan, Mexico, the Netherlands, Poland, Russian Federation, Spain, Turkey, the UK and the USA. Each country's sample comprised 500 adults (≥ 18 years) with diabetes: 80 with Type 1 diabetes and 420 with Type 2 diabetes; those with Type 2 diabetes were stratified by treatment (100 diet/exercise only, 170 non-insulin medication and 150 insulin treated). Individuals with Type 1 diabetes were defined as those diagnosed aged < 30 years who started insulin treatment at diagnosis and continue to use insulin. Individuals with Type 2 diabetes were defined as those diagnosed aged ≥ 30 years and who did not start insulin treatment at diagnosis. Individuals aged < 18 years and/or diagnosed with diabetes for < 12 months and/or diagnosed with pregnancy-related diabetes were excluded.

Recruitment methodology

Internet, telephone and in-person methods relevant to each country's situation were applied while trying to maximize comparability of methodologies and survey populations

across countries (see Peyrot *et al.* [8]). In each country, the representativeness of the study population was enhanced by weighting the sample in comparison with the general population in terms of age, gender and level of education.

Questionnaires

Standardized instruments were incorporated into the questionnaires in original or shortened forms: the EuroQol-5D visual analogue scale (EQ-5D VAS), Problem Areas in Diabetes Scale 5 (PAID-5); Patient Assessment of Chronic Illness Care-DAWN Short Form (PACIC-DSF); Summary of Diabetes Self-Care Activities measure (SDSCA-6); WHOQOL-BREF Global Quality of Life item; and the WHO-5 Well-Being Index (WHO-5) [8]. Validation of the WHO-5 instrument in adolescents with Type 1 diabetes showed that a score of ≤ 28 was indicative of moderate to severe depression [11]. Other elements included: items from DAWN to assess changes in diabetes care over the past decade; newly developed questions to investigate the impact of diabetes on life dimensions, discrimination and the needs and preferences for better education and support; and open-ended questions to capture individual stories of living with diabetes. Some questions were developed with inspiration from, or adapted from, existing validated instruments, including the Diabetes Empowerment Scale-DAWN Short Form (DES-DSF) and the Health Care Climate DAWN Short Form (HCC-DSF) questionnaire. The various measures reported in this publication are described in the Supporting Information (Table S1).

To ensure the cultural relevance and appropriateness of all survey questions, the English version of the questionnaire was reviewed and approved by local diabetes healthcare professionals and/or patient representatives from each participating country. In addition, each country was given the opportunity to add country-specific questions to ensure that topics of local significance were included in their version of the questionnaire.

The questionnaire was pilot tested on people with diabetes to assess whether the content was unambiguous and understandable and to ensure face validity and acceptability [8]. For each participating country, the questionnaire was translated into the primary local language(s) then back translated and a harmonization process undertaken to ensure consistency with the original questionnaire [8].

Ethical considerations

DAWN2 was conducted in accordance with relevant ethical requirements, following regional/national/local guidelines relating to the conduct of non-interventional studies [8].

Statistical analysis

Descriptive data are summarized as mean ± standard deviation (SD; continuous variables) or percentages (categorical variables). Questionnaire scores, calculated on the entire study population (global score), are mean ± standard deviation for multi-item questions and number of respondents and percentages for single-item questions. Country scores are reported as median and range.

All the scale scores range from 0 to 100, with higher values indicating a higher level of the dimension measured. Country-level data were weighted separately, on age, gender, education and region in those countries where data were collected nationally, and on age, gender and education only in those countries where data were collected in selected cities. The internal consistency of multi-item questionnaires was measured with Cronbach's alpha coefficient (minimum accepted level of 0.7) and was estimated for each country and each language version, with median and range reported. To account for the hierarchical nature of the data (people with diabetes clustered within countries) and to estimate the proportion of residual variance attributable to country variation, we used multi-level regression models [12,13] with an unstructured correlation-type matrix [14].

Criteria to select indicators for benchmarking activities included acceptable reliability in all countries (according to Cronbach's alpha) and statistically significant between-country variation. The identical sampling design for each country allowed us to make comparisons without adjustment for differences in sample proportions.

Results

Overall, 8596 people participated (1368 and 7228 had Type 1 and Type 2 diabetes, respectively). Population characteristics are reported in Table 1. People with Type 1 diabetes were approximately 14 years younger, had a higher level of college education, twice the number of years of diabetes duration and similar rates of complications/co-morbidities, compared with people with Type 2 diabetes. The number of responders with data that permitted calculation of indicator scores exceeded 95% for all the indicators but PACIC (93%).

Descriptive findings for the key indicators investigated are summarized in Table 2. All the scales met the requirements for internal validity (Cronbach's alpha coefficient of ≥ 0.7), except for the DES-DSF in Japan (alpha = 0.68) and the general support scale in Russian Federation (alpha = 0.69) and China (alpha = 0.68). Finally, the SDSCA-6 composite score did not meet the minimum requirement in seven countries; individual items were thus considered for the analyses.

Cross-national comparisons

Between-country differences and percentage of variance explained by country (range 3–22%) were significant for all benchmarking indicators (*P* < 0.001) (Table 2).

Table S2 of the Supporting Information shows the ranking (scale 1 = highest/best to 17 = lowest/worst outcome) for each country for each indicator, and estimated means or proportions (%) with 95% confidence intervals, adjusted for

Table 1 Characteristics of people with diabetes

People with diabetes	Type 1 diabetes (n = 1368)	Type 2 diabetes (n = 7228)	Total (n = 8596)
Age (years), median (interquartile range)	41.0 (31–52)	59.0 (48–65)	57.0 (45–64)
Gender, n (%)			
Men	651 (47.6)	3872 (53.6)	4523 (52.6)
Women	717 (52.4)	3356 (46.4)	4073 (47.4)
BMI (kg/m²), median (interquartile range)	24.4 (22.0–27.6)	27.7 (24.5–31.9)	27.1 (23.9–31.2)
Diabetes duration (years), median (interquartile range)	21.5 (11.0–34.0)	8.0 (4.0–14.0)	9.0 (4.0–16.0)
Glucose-lowering treatment*, n (%)			
Diet and exercise	724 (52.9)	4588 (63.5)	5312 (61.8)
Alternative medicine	83 (6.1)	560 (7.8)	643 (7.5)
Oral hypoglycaemic agents	204 (14.9)	4038 (55.9)	4242 (49.4)
Insulin	1368 (100.0)	2591 (35.9)	3959 (46.1)
Other diabetes medication by injection	36 (2.6)	286 (4.0)	322 (3.8)
Other	23 (1.7)	170 (2.4)	193 (2.3)
None of these	0 (0.0)	123 (1.7)	123 (1.4)
Complications/co-morbidities*, n (%)			
Without complications/co-morbidities	387 (28.3)	1997 (27.6)	2384 (27.7)
With complications/co-morbidities	981 (71.7)	5231 (72.4)	6212 (72.3)
Stroke	102 (7.5)	504 (7.0)	606 (7.1)
Foot ulcers	180 (13.2)	595 (8.2)	775 (9.0)
Foot/leg amputation	26 (1.9)	108 (1.5)	134 (1.6)
Kidney disease	170 (12.4)	804 (11.1)	974 (11.3)
Eye damage	446 (32.6)	2170 (30.0)	2616 (30.4)
Nerve damage	244 (17.8)	1095 (15.2)	1339 (15.6)
Sexual dysfunction	187 (13.7)	1164 (16.1)	1351 (15.7)
Heart disease	148 (10.8)	1237 (17.1)	1385 (16.1)
Depression	438 (32.0)	1750 (24.2)	2188 (25.5)
Sleeping problems	514 (37.6)	2691 (37.2)	3205 (37.3)
Living situation*, n (%)			
With a spouse/partner	860 (62.9)	5012 (69.3)	5872 (68.3)
With son/daughter aged < 18 years	356 (26.0)	1138 (15.7)	1494 (17.4)
With son/daughter aged ≥ 18 years	200 (14.6)	1802 (24.9)	2002 (23.3)
With parents	255 (18.6)	434 (6.0)	689 (8.0)
With other adult relatives	87 (6.4)	354 (4.9)	441 (5.1)
With other non-relative adults	33 (2.4)	108 (1.5)	141 (1.6)
With other children aged < 18 years	46 (3.4)	170 (2.4)	216 (2.5)
Alone	174 (12.7)	1099 (15.2)	1273 (14.8)
Work situation, n (%)			
Full-time	630 (46.1)	2284 (31.6)	2914 (33.9)
Part-time	154 (11.3)	601 (8.3)	755 (8.8)
Not working full-time because of diabetes	145 (42.9)	283 (19.3)	428 (56.7)
Not working	580 (42.5)	4327 (60.0)	4907 (57.2)
Looking for work	65 (4.8)	277 (3.8)	342 (4.0)
Not looking for work	28 (2.1)	211 (2.9)	239 (2.8)
Unable to work	91 (6.7)	380 (5.3)	471 (5.5)
Retired	180 (13.2)	2612 (36.1)	2792 (32.5)
Student	76 (5.6)	46 (0.6)	122 (1.4)
Stay-at-home spouse or partner/housewife/husband	140 (10.2)	801 (11.1)	941 (11.0)
Living area, n (%)			
Large city	785 (57.4)	3756 (52.0)	4541 (52.8)
Small city or a large town	350 (25.6)	1835 (25.4)	2185 (25.4)
Suburban area	89 (6.5)	579 (8.0)	668 (7.8)
Village or rural area	144 (10.5)	1050 (14.5)	1194 (13.9)
Level of education, n (%)			
No college education	513 (39.9)	3729 (53.5)	4242 (51.4)
At least some college education	772 (60.1)	3245 (46.5)	4017 (48.6)

*Participants may have data in more than one category.

clustering and weighting, for each indicator by country, which also reflect the data in the figures (all country-specific references are based on these data). Countries ranked differently across the indicators; no individual country or region consistently appears to be better or worse than the others.

Quality of life and treatment burden

In DAWN2, the proportion of people with likely depression (WHO-5 score ≤ 28) was 13.8% (Table 2); the lowest and highest values being for Mexico and Algeria, respectively

Table 2 Key benchmarking indicators for people with diabetes

Categories Indicators	Global score, n (%)*	Country score, median (range)	% of total variance explained by country	Country alpha, median (range)
Self-reported health status				
EQ-5D VAS	69.3 ± 17.9*	65.8 (56.9–75.2)	9	NA
QoL/treatment burden				
WHOQOL-BREF: Global Quality of Life				
Composite score	58.0 ± 20.2*	59.5 (48.8–71.4)	8	NA
1: 'Poor'/'very poor'	1193 (12.2)	13.1 (7.6–26.1)		NA
2: 'Neither poor nor good'	3629 (47.6)	42.4 (19.7–71.3)	3	NA
3: 'Good'/'very good'	3774 (40.2)	45.5 (15.7–72.7)		NA
WHO-5: Psychological Well-Being				
Composite score	58.0 ± 23.4*	56.9 (48.9–71.4)	6	0.9 (0.88–0.95)
% with likely depression[†]	1285 (13.8)	13.7 (6.5–24.1)	3	NA
PAID-5: Diabetes Distress				
Composite score	35.2 ± 24.2*	34.5 (16.8–47.5)	13	0.9 (0.84–0.92)
% with high diabetes distress[‡]	3486 (44.6)	42.6 (17.2–67.6)	12	NA
DIDP				
Composite score	55.7 ± 16.7*	54.9 (52.0–64.7)	3	0.88 (0.83–0.94)
How does diabetes currently impact your…				
(% reporting a 'slightly negative' to 'very negative' impact):				
• Physical health	5174 (62.2)	60.6 (44.3–85.4)	6	NA
• Financial situation	3340 (44.0)	40.2 (26.9–65.4)	6	NA
• Relationship with your family, friends and peers	1712 (20.5)	19.2 (11.4–33.0)	4	NA
• Leisure activities	3107 (38.2)	37.4 (19.5–57.0)	4	NA
• Work or studies	2259 (35.4)	31.2 (16.7–50.7)	4	NA
• Emotional well-being	3808 (46.2)	42.5 (32.0–76.9)	6	NA
% reporting a positive impact of diabetes on at least one life dimension	2252 (27.7)	28.6 (14.4–38.6)	4	NA
'My diabetes medication routine interferes with my ability to live a normal life' (% who 'mainly' or 'fully' agree)	2589 (38.9)	32.6 (18.6–64.9)	13	NA
'I am very worried about the risk of hypoglycaemic events' (% who 'mainly' or 'fully' agree)	427 (55.5)	59.9 (24.8–83.1)	12	NA
'It is difficult to pay for the diabetes medications…' (% agreeing with statement)	1904 (27.4)	22.3 (3.3–45.2)	14	NA
Empowerment/involvement				
DES-DSF				
Composite score	42.1 ± 21.4*	36.0 (26.0–51.4)	13	0.76 (0.68–0.79)
Self-management				
SDSCA-6 (Composite score/single items)[§]				
On how many of the last 7 days…				
• Have you followed a healthy eating plan?	5.3 ± 2.2*	4.7 (3.9–5.9)	7	NA
• Did you participate in ≥ 30 min of physical activity?	3.8 ± 2.7*	3.4 (2.1–4.7)	9	NA
• Did you test your blood sugar?	3.4 ± 2.8*	3.7 (1.8–4.9)	11	NA
• Did you test your blood sugar the number of times recommended by your healthcare professional?	3.2 ± 2.8*	3.7 (1.8–4.5)	10	NA
• Did you check your feet?	3.2 ± 2.9*	3.7 (1.4–4.9)	10	NA
• Did you take all your diabetes medications exactly as agreed with your healthcare professional?	6.1 ± 1.8*	6.3 (5.6–6.6)	2	NA
Support for self-management				
DFSS: Support received by the person most involved in diabetes care	63.9 ± 21.6*	58.4 (43.8–75.9)	17	0.86 (0.78–0.91)
DSDSP				
Composite score	69.1 ± 26.5*	57.3 (39.0–77.2)	18	0.79 (0.68–0.89)
How supportive have the following people been in helping you… (% reporting 'somewhat' or 'very' supportive):				
• Your family	6803 (87.5)	79.2 (52.1–97.4)	22	NA
• Friends or people close to you	5222 (70.9)	58.9 (18.0–85.9)	16	NA
• People at work or school	2569 (33.5)	23.0 (6.3–47.0)	11	NA
• Healthcare team	7201 (85.5)	83.5 (60.3–94.9)	7	NA
• Other people in your community	2764 (42.8)	27.9 (4.4–72.7)	22	NA
Healthcare provision				
Tests/patient-reported quality indicators (clinical, feet, depression, diet, testing)				
In the past 12 months, did anyone from your healthcare team (% reporting 'yes'):				

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Table 2 (*Continued*)

Categories Indicators	Global score, n (%)*	Country score, median (range)	% of total variance explained by country	Country alpha, median (range)
• Measure your long-term blood sugar control level?	6479 (72.1)	75.3 (61.6–92.8)	8	NA
• Examine your feet?	4563 (45.3)	53.6 (14.8–81.8)	16	NA
• Ask if you have been anxious or depressed?	2868 (31.9)	32.5 (14.6–57.3)	6	NA
• Ask about the types of foods you have been getting?	3894 (48.5)	45.4 (26.6–63.8)	6	NA
PACIC-DSF				
Composite score	41.4 ± 24.3*	34.8 (21.0–55.9)	15	0.89 (0.83–0.91)
'I was asked how my diabetes affects my life' (% reporting 'most of the time' or 'always')	1576 (23.7)	15.2 (6.6–45.1)	11	NA
'I was satisfied that my care was well organized' (% reporting 'most of the time' or 'always')	4162 (47.3)	58.8 (18.5–67.6)	11	NA
HCC-DSF				
Composite score	48.6 ± 28.0*	47.6 (27.8–58.0)	7	0.81 (0.75–0.9)
Education				
% participating in any diabetes educational programmes/ activities¶	5155 (48.8)	59.2 (22.4–83.9)	20	NA
% reporting that education programmes attended were 'somewhat' or 'very' helpful	4070 (81.1)	79.1 (62.3–90.0)	4	NA
Community resources				
% who do not rely on any of the measured sources of education, information, or support¶	2503 (28.5)	27.3 (11.3–45.2)	6	NA
Society				
'I have been discriminated against because of diabetes' (% who 'mainly' or 'fully' agree)	1549 (19.2)	17.1 (9.6–30.3)	5	NA

*Unless otherwise stated as mean ± SD. Percentages given are weighted and do not reflect crude rates of respondents for each indicator; thus, crude numbers and percentages do not coincide.
†Scores of ≤ 28 on WHO-5 Well-Being Index (a score of ≤ 28 considered an indicator of likely depression).
‡Scores of 40–100 on PAID-5 (PAID-5 score of ≥ 40 considered an indicator of high diabetes-related distress).
§SDSCA-6 scores represent the mean number of days people with diabetes performed specific self-care activities in the past 7 days.
¶See Supporting Information (Table S1) for additional information.
DES-DSF, Diabetes Empowerment Scale-DAWN Short Form; DFSS, DAWN Family Support Scale; DIDP, DAWN Impact of Diabetes Profile; DSDSP, DAWN Support for Diabetes Self-Management Profile; EQ-5D VAS, EuroQol-5D visual analogue scale; HCC-DSF, Health Care Climate Questionnaire-DAWN Short Form; NA, not applicable indicates that no Cronbach alpha was computed because inter-item agreement cannot be assessed for single-item measures; PACIC-DSF, Patient Assessment of Chronic Illness Care-DAWN Short Form; PAID-5, Problem Areas in Diabetes Scale 5; QoL, quality of life; SDSCA-6, Summary of Diabetes Self-Care Activities-6; WHO-5, World Health Organization Well-Being Index 5; WHOQOL BREF, World Health Organization Quality of Life (an abbreviated version of the WHO-QOL-100).
Note: All questionnaire materials are copyrighted, either by Novo Nordisk or by an original copyright holder. The DAWN2 questionnaires, available in 22 different languages, can be obtained for local and cross-national diabetes research and quality improvement purposes. Guidelines and procedures for using or translating the DAWN2 questionnaires are available at www.dawnstudy.com.

(Fig. 1). A WHO-5 psychological well-being score below the overall mean was found in Italy, Poland, Russian Federation and Algeria, while the highest scores were in Mexico and Denmark (see Supporting Information, Table S2).

Self-reported health state (EQ-5D VAS) also varied between countries, being lower than the overall average in Russian Federation, Algeria and Turkey, and above the average in Mexico, USA, Canada, Denmark, China and Japan (see Supporting Information, Table S2).

High diabetes-related distress was reported by 44.6% of participants (Table 2); the lowest and highest values were for the Netherlands and Algeria, respectively (Fig. 2). Global quality of life (WHOQOL-BREF) was rated 'poor' or 'very poor' by 12.2% of participants, with wide between-country variation (range 7.6–26.1%; Table 2). Diabetes had a negative impact on all life dimensions investigated. A 'slightly' to 'very' negative impact on physical health was reported by 62.2% of

participants (Table 2); the lowest was reported in Japan and the highest in Russian Federation (see also Supporting Information, Fig. S1). Negative impact on emotional well-being and finances were reported by 46.2 and 44.0% of respondents, respectively (Table 2), with wide variation between countries (see also Supporting Information, Table S2). Notably, 27.7% of respondents reported a positive impact of diabetes on at least one aspect of their life (Table 2).

A high percentage of participants in all countries reported being worried about the risk of hypoglycaemic events (55.5%; Table 2, Fig. 3) or that their diabetes treatment interferes with their normal life (38.9%; Table 2).

Empowerment and self-care activities

The level of active patient engagement or empowerment (DES-DSF; 42.1 ± 21.4, Table 2) varied across countries,
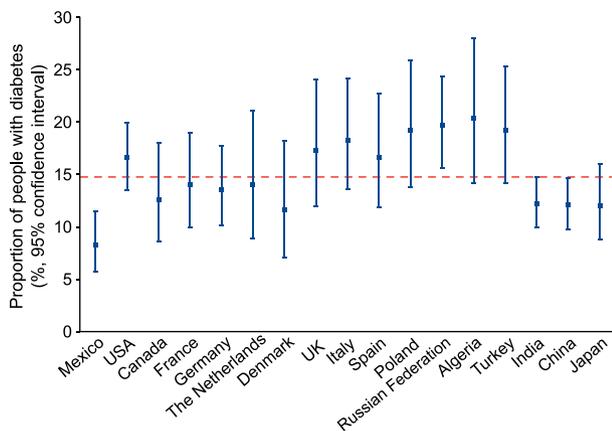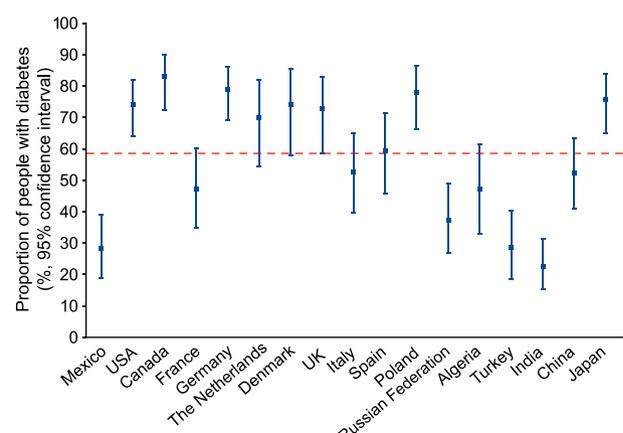
FIGURE 1 Proportion of people with diabetes with likely depression (WHO-5 ≤ 28), by country. Data are percentages with their 95% confidence intervals, adjusted for clustering, and weighted on age, gender, region and education to allow generalization from the sample to larger populations. Weights are based on population proportions for each country, as provided by each country's survey advisory group, and on publicly available epidemiological data. The dotted line represents the mean value relative to the entire sample of people with diabetes.
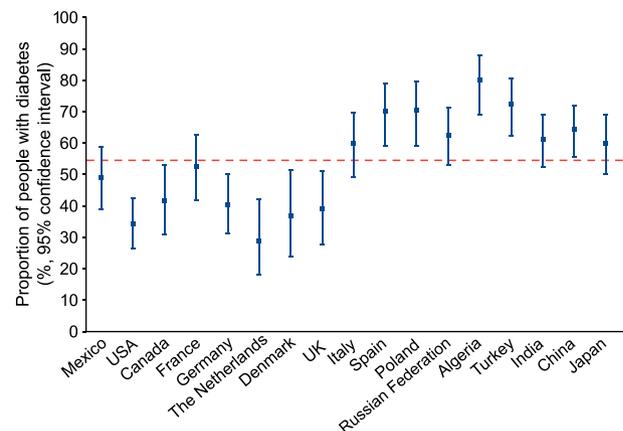
FIGURE 3 Proportion of people concerned about the risk of hypoglycaemia, by country. Data are percentages with their 95% confidence intervals, adjusted for clustering, and weighted on age, gender, region and education to allow generalization from the sample to larger populations. Weights are based on population proportions for each country, as provided by each country's survey advisory group, and on publicly available epidemiological data. The dotted line represents the mean value relative to the entire sample of people with diabetes.
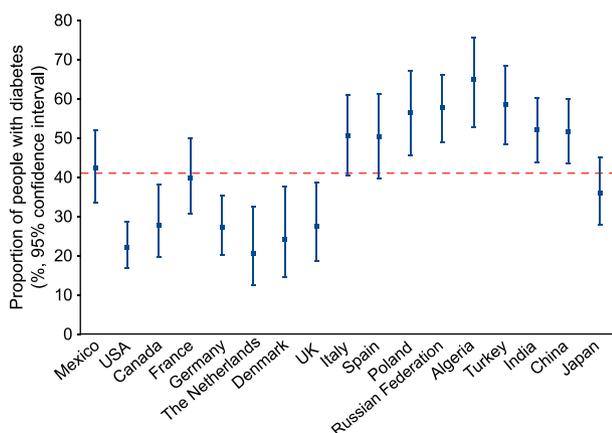
FIGURE 2 Proportion of people with high diabetes-related distress (PAID-5 ≥ 40), by country. Data are percentages with their 95% confidence intervals, adjusted for clustering, and weighted on age, gender, region and education to allow generalization from the sample to larger populations. Weights are based on population proportions for each country, as provided by each country's survey advisory group, and on publicly available epidemiological data. The dotted line represents the mean value relative to the entire sample of people with diabetes.

FIGURE 4 Proportion of people participating in any educational programme/activity, by country. Data are percentages with their 95% confidence intervals, adjusted for clustering, and weighted on age, gender, region and education to allow generalization from the sample to larger populations. Weights are based on population proportions for each country, as provided by each country's survey advisory group, and on publicly available epidemiological data. The dotted line represents the mean value relative to the entire sample of people with diabetes.

being lowest in Japan and highest in India (see also Supporting Information, Table S2). Following self-care advice was most common for medication and diet, and less common for glucose monitoring, physical activity and foot examination (Table 2), with wider country variation for the latter activities (see also Supporting Information, Table S2). Countries below the mean for physical activity included the USA, Algeria and Turkey, while those in Mexico, Turkey, India and Japan were less likely to undertake blood glucose self-monitoring, and foot self-examination was less likely in Turkey, India, China and Japan (see Supporting Information, Fig. S2).

Healthcare provision

Respondents reported varying levels of assessment by healthcare professionals. Measurement of long-term blood sugar control levels (HbA$_{1c}$) in the previous 12 months was reported by 72.1% of participants (Table 2), ranging from < 70% in Poland, Algeria, Turkey, India and China to > 85% in the USA, Denmark and Japan (see also Supporting Information, Table S2). Less than half of participants had received a foot examination (range 14.8–81.8%; Table 2),

while only one third (14.6–57.3%; Table 2) were evaluated in relation to their psychological well-being (Fig. S3 in the Supporting Information provides data by country).

Most respondents reported no access to person-centred chronic illness care (PACIC-DSF). Only 23.7% reported that their healthcare team asked them how diabetes impacted their life (Table 2). The perception of people with diabetes to having access to person-centred chronic illness care showed substantial between-country variation (PACIC-DSF score range 21.0–55.9%; HCC-DSF score range 27.8–58.0%; Table 2). Overall, 47.3% of respondents were satisfied that their care was well organized, but with wide variation between countries (range 18.5–67.6%; Table 2).

One quarter of the respondents reported difficulties in paying for diabetes medications (range 3.3–45.2%; Table 2), the lowest proportion being those from the UK and France, the highest from Mexico, Poland and China (see also Supporting Information, Table S2).

Education and information

Participation in education is a major problem in many countries. Less than half of respondents participated in any education programme, with wide cross-national variation (Table 2); India and Canada had the lowest and highest proportions, respectively (see also Supporting Information, Table S2 and Fig. 4). In all countries, the majority (81.1%) of those who had attended an education programme found it 'somewhat helpful' or 'very helpful' (Table 2).

Reliance on information from different sources (media, written material, etc.) varied markedly among the countries (Table 2). Notably, there was a large range (11.3–45.2%; Table 2) in the proportion of those who did not rely on any of the measured sources of education, information or support.

Family and societal support

Over 85% of participants received support from their family and the healthcare team (Table 2), with larger between-country variation for family support (see also Supporting Information, Fig. S4). Support from the community ranged widely (4.4–72.7%), with approximately one fifth of participants feeling that they had been discriminated against because of their diabetes (Table 2).

Discussion

DAWN2 reveals that diabetes is a significant physical and psychological burden for many individuals with diabetes in all 17 countries surveyed. Self-care activities remain suboptimal in most countries and need improvement. However, healthcare professionals report more encouragement of self-management than people with diabetes do [15].

Diabetes-related distress among people with diabetes is associated with suboptimal self-management [16,17], which may then lead to more complications and worse blood glucose control, compared with patients who are not distressed [17,18]. Necessary adjustments to daily life to help manage diabetes and long-term concerns can lead to people feeling that diabetes has a negative impact on many aspects of their daily life, which can impact on their emotional well-being [19]. Nevertheless, some people with diabetes have found that their condition has a positive effect on aspects of their lives.

Family involvement has a key role in the management of diabetes, with little or no support being associated with the lack of adherence to medication regimens and diabetes care behaviours [20]. DAWN2 confirmed that family support is available for most people with diabetes in all countries, while support from the broader community is scarce. Societal problems are underlined by the high proportion of individuals discriminated against because of their diabetes.

Poor coordination between organizations and healthcare professionals is an impediment to optimal diabetes management [21]. However, treating people with diabetes is often time-consuming and has a financial impact on healthcare systems [22,23]. In DAWN2, although people with diabetes found their healthcare teams to be supportive, many indicated that key aspects of their care had not been discussed, such as anxieties and diet; insufficient attention had been paid to psychological aspects of living with diabetes and the potential for individuals to take an active role in self-management. Notably, people with diabetes are less likely to report being asked about the impact of diabetes on their life than healthcare professionals are to report asking about this [15].

Only half of people with diabetes in DAWN2 reported having received some structured education. Access to educational information enables people with diabetes to gain the skills to self-manage their condition and live a healthy lifestyle [24]. Despite the availability of educational programmes in different settings (for example, individual vs. group, paper-based vs. electronic) and literature [25,26], many people with diabetes remain unaware of these services and are not actively taking up educational opportunities [27]. In addition, although many people with diabetes have been given access to self-management education, they refuse to receive it—possibly misunderstanding its importance, or for economic reasons [28]. This compromises efforts in self-care. Proactive and timely coordination of diabetes programmes and policies may help to raise awareness of the importance of education in assisting a healthier lifestyle for people with diabetes.

The DAWN2 study provides, for the first time, a platform for global monitoring and sharing of best practices for person-centred diabetes care that may help drive changes to improve outcomes. The range of indicators selected in DAWN2 may map onto the innovative chronic care model (WHO) and allow multidimensional evaluation of

patient-centred outcomes and, because of the substantial degree of between-country variation, they are suitable for comparing differences between countries. Furthermore, through validation of the multiple measurement instruments in DAWN2 involving assessment of psychometric properties of scales and the ability of measures to differentiate countries, each country can adopt the psychometrically validated indicators for local, regional or national quality improvement programmes.

With regard to benchmarking, further analyses are needed to explore potential determinants of cross-national differences. However, countries with findings above the average for the indicators assessed may represent a reference point to prompt positive changes and action to overcome existing barriers in other countries. The DAWN2 study includes multiple stakeholder surveys assessing similar dimensions of care as well as identification of national policies and programmes, and the ultimate use of the benchmarking data will be made by incorporating all these sources at the national level. As a new element, the DAWN2 survey highlights both positive and negative aspects of diabetes and thereby provides potential opportunities to learn from elements that are managed well and improve other areas.

The study methodology has a number of limitations, which have been described elsewhere [8]. The recruitment procedure could cause over-representation of the best-functioning group of patients, in countries where Internet access is limited. Mass invitations were used for the recruitment process and recruitment was closed when the required quotas were met; thus, not all eligible volunteers were able to participate and we do not know whether those who did not respond actually received the invitation or attempted to take part. The lack of data on number of persons who refused to participate raises questions about the representativeness of the samples. The different countries in the study represent very diverse socio-economic and cultural environments and it is beyond the scope of this report to discuss potential associations of country differences. Interpreting country differences will require further analyses, including consideration of national healthcare policies and systems for diabetes as mapped through the DAWN2 study.

Subsequent publications will combine results of DAWN2 for people with diabetes, family members and healthcare professionals to generate multi-perspective analyses of barriers and drivers for person-centred diabetes care in each country.

In conclusion, the DAWN2 study provides a first multi-national, multidisciplinary systematic framework for the comparison of unmet needs of people with diabetes and those who care for them in four continents. Its findings may facilitate innovative efforts by all stakeholders to improve self-management and psychosocial support in diabetes, thus improving acceptance of change, reducing the feeling of being overwhelmed and reducing the burden of disease in people with diabetes. Transforming study results into actions at the national level will represent one of the main activities of the DAWN2 initiative in the years to come.

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Figure S1. Proportion of people reporting a negative impact of diabetes on physical health, by country.
Figure S2. Average number of days a week people with diabetes checked their feet, by country.
Figure S3. Proportion of people who have received a psychological assessment by a healthcare professional in the previous 12 months, by country.
Figure S4. Proportion of people reporting that their family has been 'somewhat'/'very' supportive, by country.
Table S1. DAWN2 PWD Questionnaire Measures.
Table S2. The views and perceptions of people with diabetes on matters relating to diabetes care.