

Analysis of diabetes attitudes, wishes and needs in Switzerland, the Swiss DAWN2™ Study

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Summary

AIMS OF THE STUDY: Swiss DAWN2™ aimed to evaluate the difficulties and unmet needs of individuals with diabetes and stakeholders, based on the assessments of diabetes care and self-management: the individual burden of disease, the perception of the quality of medical care, and the treatment satisfaction of individuals with diabetes living in the Canton of Bern. The results of the Swiss cohort were analysed and compared with the global DAWN2™ results.

METHODS: 239 adult individuals with diabetes were enrolled in a cross-sectional study at the Department of Diabetes, Endocrinology, Nutritional Medicine and Metabolism at the University Hospital of Bern between 2015 and 2017. The participants completed validated online questionnaires regarding health-related quality of life (EQ-5D-3L) and emotional distress (PAID-5), diabetes self-care activities (SDSCA-6), treatment satisfaction (PACIC-DSF), and health-related wellbeing (WHO-5). Eligibility criteria were as follows: participants were aged >18 years, had a diagnosis of diabetes type 1 or 2 since at least 12 months and gave written informed for the participation in the present study.

RESULTS: When compared globally, the Swiss cohort reported a higher quality of life (77.28 ± 16.73 vs. 69.3 ± 17.9 EQ-5D-3L score, $p < 0.001$) and lower emotional distress (22.28 ± 20.94 vs. 35.2 ± 24.2 PAID-5 score, $p = 0.027$). Higher frequencies of self-measurement of blood glucose (6.43 ± 1.68 vs. 3.4 ± 2.8 SDSCA-6 score, $p < 0.001$) and physical activity (4.40 ± 2.04 vs. 3.8 ± 2.7 SDSCA-6 score, $p = 0.05$) were reported. PACIC-DSF revealed higher satisfaction concerning organisational aspects of patient care (60.3 ± 1.51 vs. 47.3 ± 24.3 , $p < 0.001$) and higher health-related well-being as compared to the global score (71.38 ± 23.31 vs. 58 ± 13.8 WHO-5 Well-Being Index, $p < 0.001$). HbA1c >7% correlated to emotional distress (PAID-5, 26.08 ± 23.37 vs. 18.80 ± 17.49 , $p = 0.024$), unfavourable eating habits (4.28 ± 2.22 vs. 4.99 ± 2.15 , $p = 0.034$) and decreased physical activity (3.95 ± 2.16 vs. 4.72 ± 1.92 , $p = 0.014$). Sleeping problems were most commonly reported (35.6%). In total, 28.8% of respondents completed diabetes-related educational programs.

CONCLUSION: In global comparison, Swiss DAWN2™ showed a lower burden of disease and yet a higher level of treatment satisfaction in patients who were treated in

Switzerland. Further studies are required to assess the quality of diabetes treatment and unmet needs in patients treated outside of a tertiary care center.

Introduction

The successful management of diabetes demands discipline, knowledge, and proper self-management from patients, family members, and caregivers. These requirements pose major challenges for patients and associates alike, leading to psychosocial distress and disease burden. According to a recent report, exposure to distress indirectly correlates to diabetes treatment success [1]. When left untreated, distress may contribute to decreased glycaemic control and increase the risk for glycaemic complications, which in turn may exacerbate psychological and mental health problems [2, 3]. Indeed, there is a higher-than-normal prevalence of mental health conditions in individuals with diabetes [4–7]. This is particularly true for depression, with a prevalence that is 2–3 times higher compared to the general population [8].

Treatment-associated distress is determined by the quality and structure of medical care, which, among other important aspects, comprise the successful acquisition and consideration of patients' wishes and needs [9]. To examine the interplay between psychosocial stress and treatment quality in individuals with diabetes, the Diabetes Attitudes, Wishes, and Needs Study (DAWN) was conducted in 2001. In a cross-national setup including 17 countries worldwide, DAWN was aimed at evaluating the psychosocial needs, views, and wishes of patients and stakeholders. It highlighted the link between psychosocial stress and the prevalence of diabetes-related complications [10, 11]. The authors identified psychosocial distress and inadequate support as determinants of poor diabetes management and highlighted the need to optimize psychosocial support in the treatment environment of diabetes [12]. In 2013, the international DAWN2™ study was conducted to illustrate the unmet needs of individuals with diabetes and also healthcare providers, in order to facilitate and strengthen joint treatment efforts [13]. DAWN2™ was performed by a multinational, multidisciplinary alliance of 17 countries worldwide. Its results enabled a better understanding of the priorities and psychosocial needs of individuals with diabetes. Thus, the present Swiss DAWN2™ study was designed to extend the existing knowledge by illustrating the burden of disease, the perception of medical

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care, and the treatment satisfaction of individuals with diabetes living in Switzerland. The study also provides a comparison of its results with the former studies conducted by the DAWN2™ consortium.

Methods

Between March 2015 and February 2017, patients were recruited from the outpatient clinics of the Department of Diabetes, Endocrinology, Nutritional Medicine, and Metabolism, a tertiary care center at the University Hospital of Bern. The inclusion criteria were: written informed consent, age >18 years and diagnosis of type 1 or type 2 diabetes ≥12 months before inclusion. The exclusion criteria were: diagnosis of gestational diabetes, concomitant terminal illness, and cognitive impairments interfering with the conduction of the study.

All participants received access to an online platform (Research Electronic Data Capture [RedCap]) hosted by an independent clinical trials unit at the University of Bern. They were asked to complete questionnaires having a cross-sectional design. These questionnaires comprised the European Quality of Life 5 Dimensions 3 level version (EQ-5D-3L), the Problem Areas in Diabetes Scale 5 (PAID-5), the Summary of Diabetes Self-Care Activities measure (SDSCA-6), the Patient Assessment of Chronic Illness Care-DAWN Short Form (PACIC-DSF), and the WHO-5 Well-Being Index (WHO-5) [14]. All surveys were reviewed and approved in the original English version and were translated into the primary languages of Switzerland (German, French, and Italian).

The EQ-5D-3L was used as a standardised measure of health status developed by the EuroQol Group, providing a simple, generic health measure for clinical and economic appraisal [15]. EQ-5D-3L enables a continuous assessment of the health-related quality of life and the self-reported health state using a scale ranging from 0 to 100.

The PAID-5 five-item short form of the Problem Areas in Diabetes Scale (question items 3, 6, 12, 16, 19) was used to identify diabetes-related distress using a scale with a range of 0–4. A total score ≥8 was deemed as warranting further assessments.

The SDSCA-6 questionnaire is a brief self-report measure. Using this questionnaire, diabetes self-care-related activities were assessed briefly, with the evaluation of specific self-care activities performed in the past seven days (0 = no implementation on any day of the week; 7 = implementation on every day of the week). An average score was obtained for each dimension in a range of 0 to 7, with a higher score suggesting better self-care. To be precise, activities such as eating habits, physical activities, self-measurement of blood glucose, compliance with recommended treatment strategies, and evaluation of diabetes-related health issues were assessed.

The PACIC-DSF was used to evaluate and quantify the patients' satisfactory states with regard to patient-centred care in the preceding six months. In general, this questionnaire includes 12 items evaluating the following: the effects of diabetes on life (item 1), diabetes medications and their effects (item 2), the patient's opinion on the diabetes treatment plan (item 3), the encouragement of patients to ask questions (item 4), the aspect of listening to patients

(item 5), the setting of specific goals to improve diabetes treatment (item 6), the setting of plans to achieve treatment goals (item 7), confidence conveyed by the diabetes expert in dealing with diabetes symptoms (item 8), the aid to patients so that they gather support from friends (item 9), the aspect of patients getting support from family or the community (item 10), the encouragement of patients to join groups to get help (item 11), and the task of contacting patients for information about treatment progress and their satisfaction with treatment organisation (item 12).

The effects of diabetes on people's personal lives and the patients' satisfaction with diabetes treatment organisation were highlighted and globally compared, in detail, in this study (items 1 and 12). The score on the form used in this study has a range of 1 to 5, with a higher score being indicative of a more patient-centred care.

The WHO-5 Well-Being index was used to indicate the presence of depressive episodes. A score ≤28 indicated an episode of psychological unrest and was likely associated with the development of depression.

Self-reported haemoglobin A1c (HbA1c) levels were separated in two groups: The first group "improvement required" (HbA1c >7%) and second group "no improvement required" (HbA1c <7%) were then used to evaluate the effects of HbA1c on parameters derived from questionnaires.

Participants and data collection

Recruitment was initiated by treating physicians in the outpatient clinics of the Department of Diabetes, Endocrinology, Nutritional Medicine, and Metabolism at the University Hospital of Bern. Type 1 diabetes was defined in terms of patient age ≤30 years, with the initial and ongoing requirement of insulin substitution at the time of diagnosis. Type 2 diabetes was defined by patient age >30, without initial insulin therapy. Patient demographics comprised age, sex, date, diabetes type, treatment type, treatment duration, education, and annual financial income. After providing written informed consent, the participants gained access to an online platform in order to complete the questionnaires. Missing, conflicting, and ambiguous chart elements were coded as missing data.

After the completion of all questions, the participants were able to announce the completeness of the data input. If missing data fields were observed, the respective participants were contacted by the study team and were asked to complete the missing items, if possible. Thereafter, data were pseudonymised and locked in the database. At the end of the recruitment period, automated data reports were created and used for analysis.

Statistical analysis

Mean and standard deviation were chosen to describe the central tendency and dispersion of continuous variables, while relative frequencies were indicated for categorical variables. Cronbach's Alpha was calculated to gauge scale reliability. Chi² and t-tests were conducted to determine the statistical significance of differences in the categorical and metric variables between diabetes types within the study. For the comparison of this Swiss study with the global study's mean values, one-sample t-tests were conducted for continuous measures. Exact binomial tests were also

used for the comparison of proportions. An α -level of 0.05 was chosen as the level of significance, and a two-sided test was used in all analyses. To test the distribution of systemic item variations across diabetes types, a comparison of mean values was done using Welch's t-test. The analysis was conducted using R version 4.2.0 [16].

Ethical considerations

All procedures performed in the present study involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments. All participants declared their consent in writing prior to any study-related activities. Moreover, the present study was approved by the Regional Ethics Committee of Bern under the project number 2014-03434 and was registered at <https://clinicaltrials.gov/> with the unique trial identifier number NCT02211742. The full trial protocol and an anonymised data report can be assessed on demand from the corresponding author.

Results

A total of 409 eligible patients were identified, of which 239 patients completed the online questionnaires. Of those included in the analysis, 115 participants had type 1 diabetes and 43 had type 2 diabetes. In 81 participants, the type of diabetes could not be assigned and was not reported. Table 1 reports the Swiss study sample, including sociodemographic data, diabetes duration, educational level and income range.

Table 2 reports the number of participants (n) who have completed the above-mentioned questionnaires and percentages of missing, conflicting or incomplete/ambiguous data.

Figures 1–3 illustrate the scores of completed questionnaires in the Swiss cohort and the comparison with the global average.

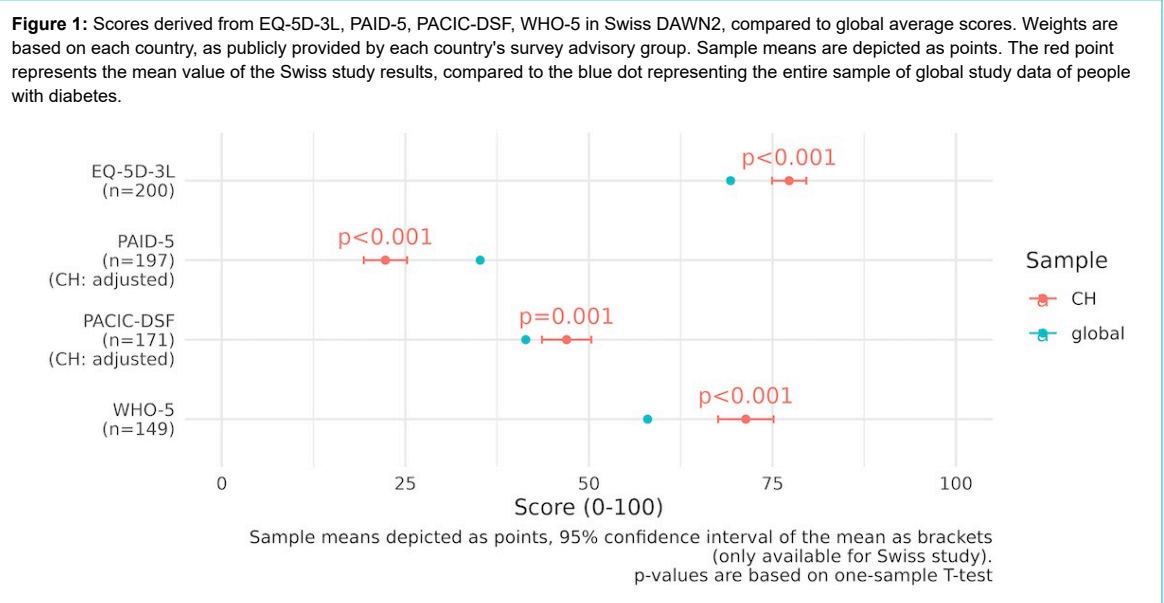
Figure 4 illustrates the effects of HbA1c on the scores of completed questionnaires.

Figure 5 illustrates the most commonly reported health concerns, figure 6 illustrates the distribution of the most

Table 1:
Baseline characteristics of the Swiss study cohort.

Parameter	Overall study cohort	Type 1 diabetes	Type 2 diabetes
Number of participants (n)	239	115	43
Age (years, \pm mean)	50.25 (16.08)	41.60 (13.69)	64.70 (9.74)
Men	120	43 (37.4)	32 (74.4)
Women	117	71 (61.7)	11 (25.6)
BMI (kg/m ²)	26.04 (4.83)	25.46 (4.21)	27.20 (5.52)
Diabetes duration in years	22.51	27.73	16.05
Education	No secondary education	57	26
	At least secondary education	145	77
Annual income in CHF	20.000–40.000	16	3
	40.000–80.000	70	12
	80.000–120.000	63	28
	120.000–160.000	17	10
	160.000–200.000	4	0
	>200.000 CHF	13	3
	N.A.	56	29

BMI = Body Mass Index, CHF = Swiss Francs



commonly reported health complications, and figure 7 illustrates the use of various types of diabetes self-management education (DSME) sources in patients with type 1 diabetes or type 2 diabetes.

The EQ-5D-3L questionnaire revealed a higher quality of life as compared to the global score (77.28 ± 16.73 vs. 69.3 ± 17.9 , $p < 0.001$, see figure 1). The PAID-5 questionnaire

indicated lower emotional distress in the Swiss study cohort as compared to the global study cohort (22.28 ± 20.94 vs. 35.2 ± 24.2 , $p < 0.001$, see figure 1). Hereby, patients with type 1 diabetes reported a higher percentage of distress compared to those with type 2 diabetes (18.3 vs. 4.7 , $p = 0.024$). PACIC-DSF illustrated higher treatment-related and organisational satisfaction in the Swiss study cohort as compared to the global study cohort (60.3 ± 1.51 vs. 47.3 ± 24.3 , $p = 0.001$, see figures 1 and 2). According to WHO-5, well-being was significantly higher in the participants of the Swiss DAWN2 as compared to the global score (71.38 ± 23.31 vs. 58 ± 13.8 , $p < 0.001$, see figure 1), yet, depressive episodes were reported significantly less frequent (8% vs. 13.8% , $p = 0.043$, see figure 2).

SDSCA-6 revealed higher frequencies regarding the implementation of physical activity (4.40 ± 2.04 vs. 3.8 ± 2.7 , $p < 0.001$), the self-measurement of blood glucose (6.43 ± 1.68 vs. 3.4 ± 2.8 , $p < 0.001$), and higher compliance with recommended treatment strategies (6.25 ± 1.92 vs. $3.2 \pm$

Table 2: Number of participants completing each questionnaire. Overall study cohort: n = 239.

Number of participants according to specific questionnaire	n	Missing, conflicting or incomplete/ambiguous data
EQ-5D-3L	200	16%
PAID-5	197	17%
PACIC-DSF	171	21%
PACIC-DSF Item 1	186	22%
PACIC-DSF Item 12	183	23%
WHO-5	149	38%
SDSCA-6	191	20%

Figure 2: Sub-scores were achieved from PAID-5, PACIC-DSF, and WHO-5 (percentage of participants suffering from depression, 8% vs. 13.8%) in Swiss DAWN2, compared to global average scores. Weights are based on each country, as publicly provided by each country's survey advisory group. Sample proportions are depicted as points. The red point represents the mean value of the Swiss study results, compared to the blue dot representing the entire sample of global study data of people with diabetes. PACIC-DSF Item 1: "I was asked how my diabetes affects my life", composite score PACIC-DSF Item 12: "I was satisfied that my care was well organised", composite score.

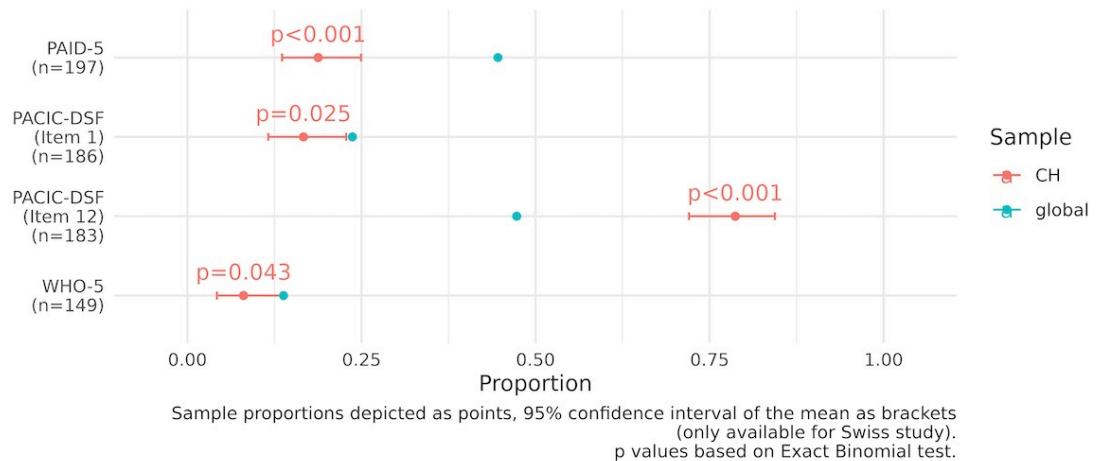
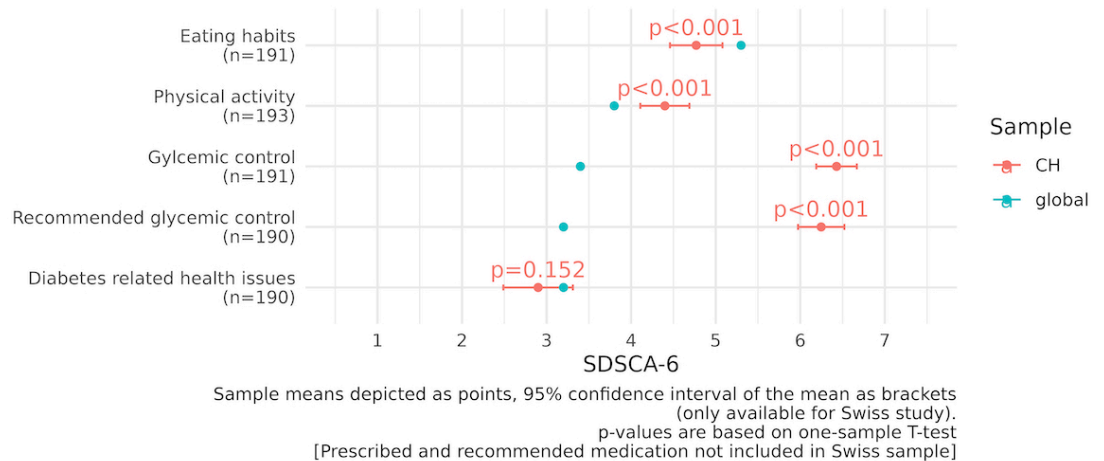


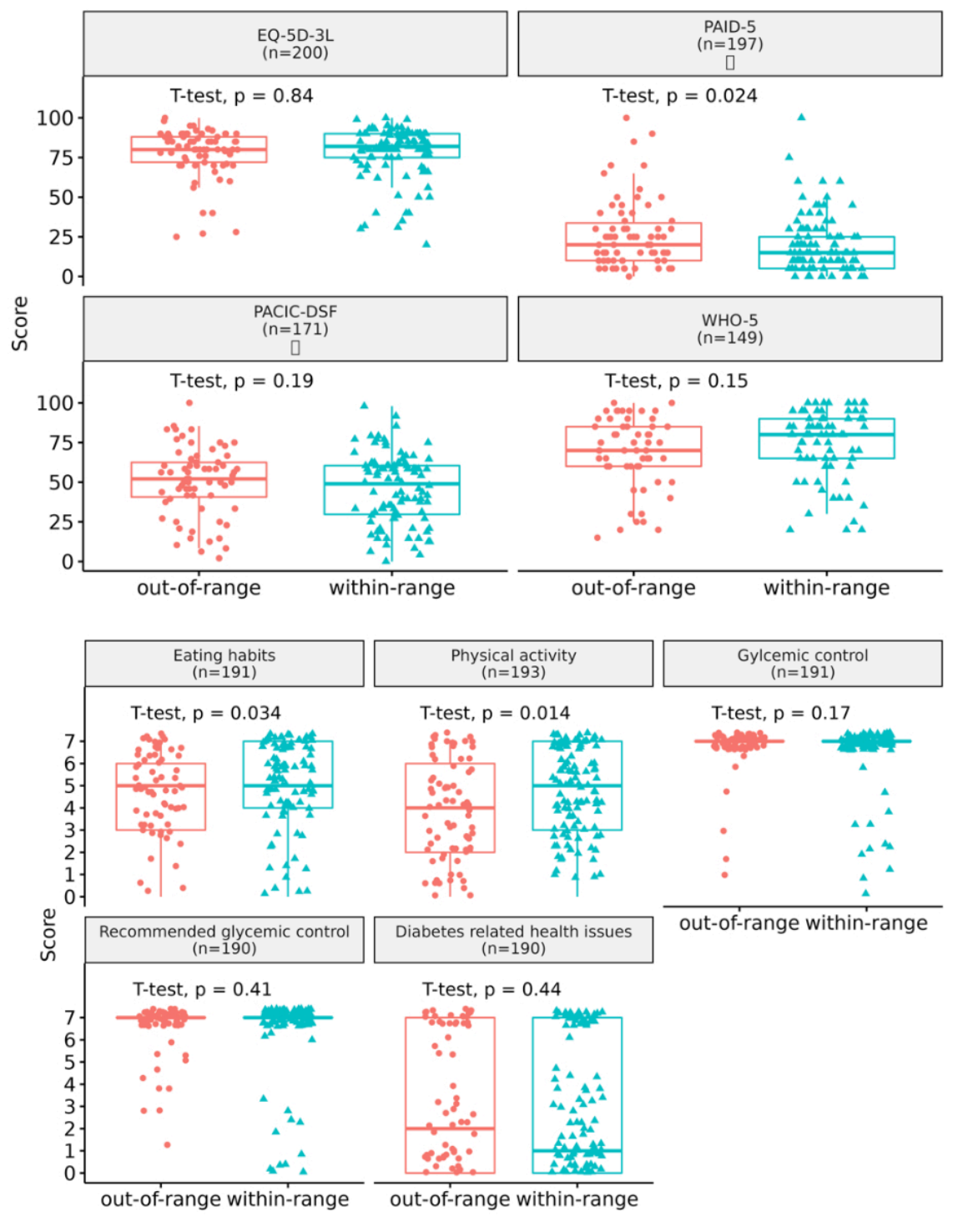
Figure 3: Scores achieved from SDSCA-6 in Swiss DAWN2, compared to global average scores. Weights are based on each country, as publicly provided by each country's survey advisory group. Sample means are depicted as points, 95% confidence interval of the mean in brackets. The red point represents the mean value of the Swiss study results, compared to the blue dot representing the entire sample of global study data of people with diabetes. Prescribed and recommended medication not included in Swiss sample.



2.8, $p < 0.001$, see figure 3) in participants of the Swiss DAWN2, compared to the global average. HbA1c $>7\%$ correlated to higher emotional distress (PAID-5, 26.08 ± 23.37 vs. 18.80 ± 17.49 , $p = 0.024$), less favourable diabetes-related eating habits (4.28 ± 2.22 vs. 4.99 ± 2.15 , $p = 0.034$) and lower frequencies of physical activity (3.95 ± 2.16 vs. 4.72 ± 1.92 , $p = 0.014$, see figure 4). A total of 47.2% of the Swiss DAWN2 participants expressed at least one concern related to their life with diabetes (see figure

5), including depressive mood swings, concerns regarding future serious health complications, cognitive and physical strength limitations, challenges in the management of health complications, as well as to feel overwhelmed by diabetes and therapeutic compliance, resulting in guilt. The most common concern among both diabetes types involved the fear of future serious health complications. Patients with type 1 diabetes reported a higher level of concern regarding treatment-compliance and guilt as compared to pa-

Figure 4: Scores achieved from EQ-5D-3L, PAID-5, SDSCA-6, PACIC-DSF, WHO-5 in Swiss DAWN2 depicting the effect of "within-range" HbA1c ($<7\%$) and "out-of-range" HbA1c ($\geq 7\%$) on parameters of the above mentioned questionnaires. A t-test has been used applying continuous variables in groups "within-range" and "out-of-range".



tients with type 2 diabetes (2.53 ± 1.14 vs 1.82 ± 0.90 , $p = 0.001$). The most commonly reported secondary complications related to diabetes were the following: sleeping problems (35.6%), vision impairment (34.1%), depression (25.5%), sexual impairment including erectile dysfunction (22.7%), and neurological damages (17.4%). Patients with

type 1 diabetes reported visual impairment (30.5%), while patients with type 2 diabetes reported sleeping problems/insomnia (46.3%) as the most common complication. In total, 69.9% of respondents reported having at least one health-related complication (see figure 6). A total of 28.8% of the Swiss DAWN2 participants had participated in

Figure 5: Most common concerns of patients with type 1 and type 2 diabetes .

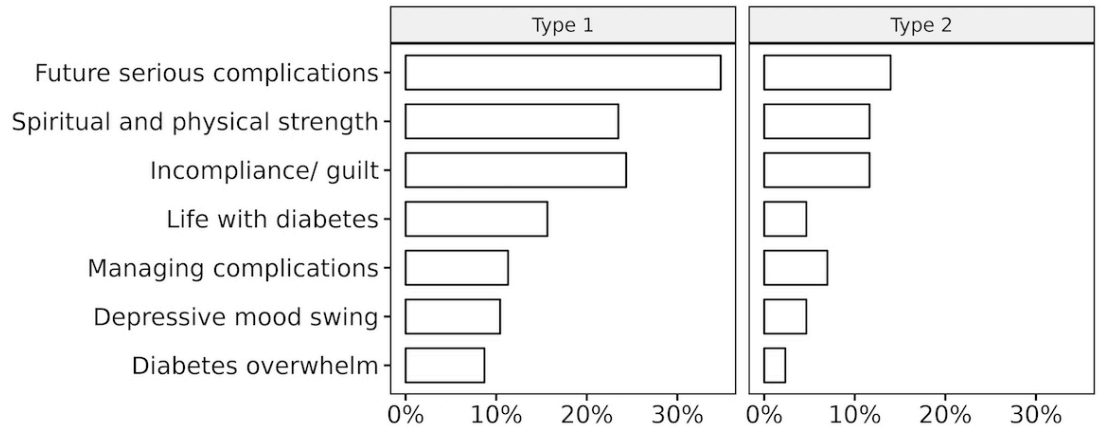


Figure 6: Most common health complications of patients with type 1 and type 2 diabetes .

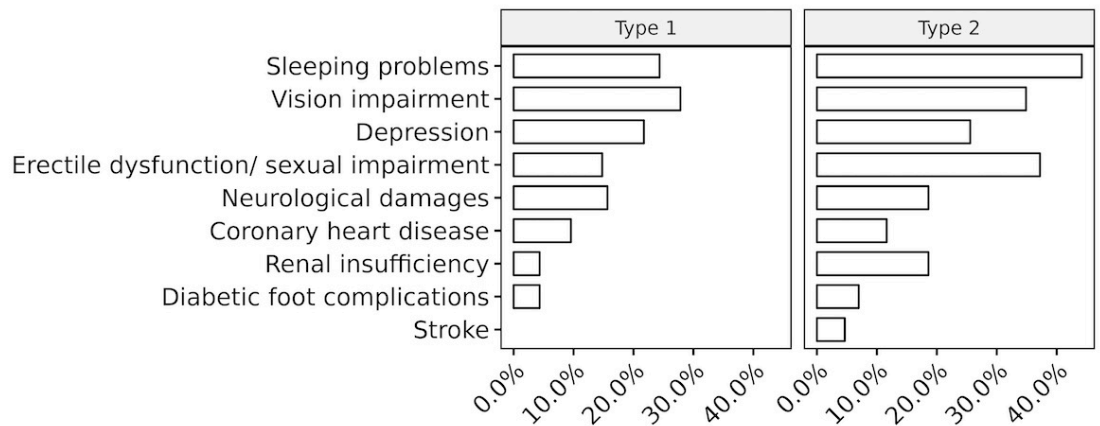
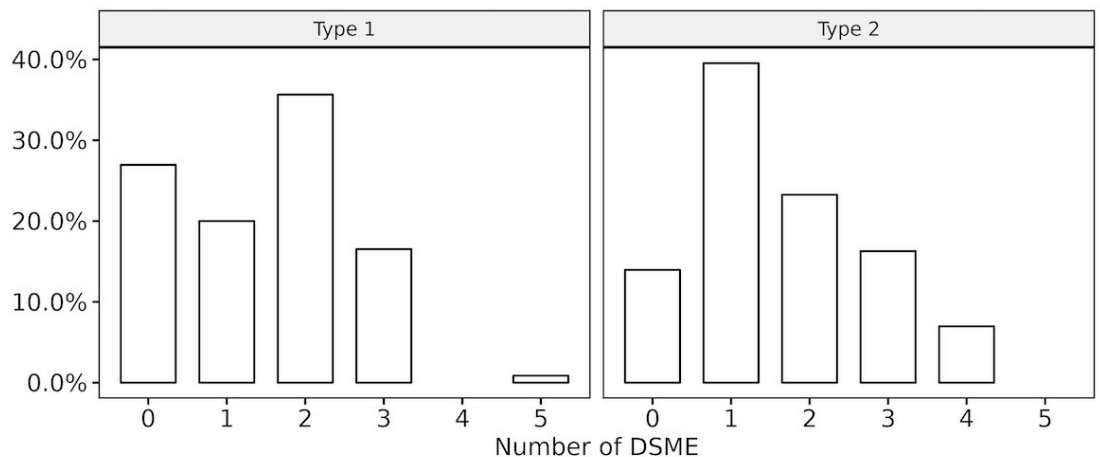


Figure 7: Number of DSME sources used by patients with type 1 and type 2 diabetes at any time prior to study inclusion.



DSME at any time prior to study inclusion. Of those, 73% of patients with type 1 diabetes reported using DSME sources compared to 86% of patients with type 2 diabetes (see figure 7). A total of 161 participants (67.4%) reported using DSME tools for diabetes-specific education, data management or physical training. A total of 85 participants (35.6%) had visited diabetes-specific group training, 37 participants (15.5%) had attended online diabetes programs and self-help support groups, 16 participants (6.7%) had interacted in weight loss or sports courses, and 46 participants (19.2%) had made use of regional offers provided by national diabetes associations.

Discussion

The Swiss DAWN2™ study illustrated higher scores for quality of life and treatment satisfaction in individuals with diabetes compared to the global average. Diabetes-related distress and the psychosocial burden of the disease were found to be lower in Switzerland as compared to the global study cohort. Also, the prevalence of depression was lower in the Swiss population.

As mentioned, a WHO-5 score ≤ 28 was associated with a higher probability of depression. In total, 13.8% of the global cohort suffered from depression. In this regard, country-specific comparisons, including the German and French study cohorts, reported values of 13.6% and 14%, respectively [17, 18]. The Swiss cohort, on the other hand, shows a lower prevalence of depression of only 8%. In addition, diabetes-related distress (PAID-5) was also lower in the Swiss study cohort as compared to the global and French samples.

Approximately 30% of patients with diabetes suffer at least once in their lifetime from clinically relevant depressive disorders, while 10% suffer from a major depressive disorder at least once. Depression has a tremendous impact on glycaemic control and significantly increases the risk for the acute and long-term complications of diabetes [19, 20]. Concurrent depression has a negative impact on the quality of life in patients with diabetes, reducing the implementation of physical activity and increasing the demand for medical care and supervision [21, 22].

Swiss DAWN2™ indicated an overall positive relationship between patients and healthcare experts in terms of support, organisational planning, and the acceptance of treatments proposed by healthcare experts [23]. Insufficient time management and inadequate organisational planning between health care professionals and patients may decrease glycaemic control and diabetes management and also increase the time and financial expenses required for successful treatment [24].

However, the present results also illustrate a potential to further support physical activity and nutrition education in patients with diabetes. This is in line with global observations indicating that the available single or group-based educational programs may not be sufficiently advertised, leading to lower compliance and acceptance rates for individuals with diabetes [25]. This situation may occur due to financial, time-wise, and personnel constraints, even though the present study design does not allow for the identification of factors leading to low perception rates.

Together, the original DAWN studies have shown that 48.8% of respondents participated in DSME programs at least once. Therapeutic successes are largely dependent on patient's self-management behaviour (SMB), consisting of medication adherence, regular blood glucose testing, behavioural adjustment, and treatment compliance [26]. Related research also shows that diabetes-specific knowledge positively correlates to adequate SMB, better glycaemic control, and improved HbA1c. In addition, structural DSME programs and their availability are critical elements related to education and awareness-raising in patients with diabetes [26].

As stated before, structured and unstructured DSME programs at the outpatient clinic of the University Hospital of Bern were made available to all the study participants. These programs intended to support patients with diabetes to adopt a healthy lifestyle, thus preventing the occurrence and progression of diabetes-specific complications. The long-term goals of diabetes rehabilitation programs are weight loss, healthier lifestyle, motivational training, and accessibility to self-help groups in the diabetic and cardiovascular field [27]. In this regard, 28.8% of the Swiss study cohort reported using DSME, including diabetes training participation, while 27.1% of the cohort in the neighbouring country of Germany reported using similar programs [17].

The present study is subject to certain limitations. First, the patient cohort was recruited at a tertiary care center, which might limit the generalisability of the present results. However, as the health care in Switzerland is coordinated nationwide, differences from other Cantons might be present but may not significantly inhibit access to diabetes care for patients and caregivers. Importantly, it is necessary to extend the obtained knowledge to patients treated outside of tertiary care centers. Second, eligibility was limited to patients speaking one of the three main languages spoken nationwide (German, Italian, and French). This inhibited the interpretation of the present results in patients with migration backgrounds from regions where other languages are used; future studies must consider this aspect. In summary, the present results cannot be generalised to the entire Swiss population. Moreover, the internet methodology may not be fully representative due to the possibility of systematic bias.

In summary, quality of life and treatment satisfaction were found to be favourable in Switzerland as compared to global cohorts. Further, the coordination between patients and health care providers seems sufficient, which strongly contributes to successful diabetes management [28]. Access to educational programs such as individual, group-based, or paper-based initiatives should be foregrounded to strengthen a diabetic patient's educational level and promote a stable and healthy lifestyle [29, 30].

The findings of this Swiss DAWN2™ study may help identify the unmet needs in the treatment of diabetes and may also facilitate better self-management and psychological support, ultimately reducing the disease burden on people with diabetes. Further studies in this field are essential, including but not limited to family members, general practitioners, and caregivers, in order to extend the present results' generalisability and comparability.

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Potential competing interests

All authors have completed and submitted the International Committee of Medical Journal Editors form for disclosure of potential conflicts of interest. No potential conflict of interest was disclosed.

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