

Attitudes, wishes, and needs of diabetes patients and their relatives: Turkish data from the DAWN2 study

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Background/aim: The DAWN2 (Diabetes Attitudes, Wishes, and Needs) study was conducted in order to ascertain the wishes, needs, and attitudes of diabetes patients, their relatives, and healthcare professionals. The study was conducted across 17 countries, including Turkey, and its objective was to introduce policies that could successfully meet these requirements. In this article, the needs, wishes, and attitudes of diabetes patients and their relatives in Turkey are compared with those from other countries.

Materials and methods: Eighty patients with type 1 diabetes, 426 patients with type 2 diabetes, and 126 relatives of patients with diabetes were included in the study.

Results: Depression was common in individuals suffering from diabetes and the quality of life was negatively affected. The primary concerns of diabetic individuals were general hypoglycemic attacks, nocturnal hypoglycemia, and gaining weight. Analysis of self-care activities showed that physical activity, foot care, and frequency of blood glucose measurement were below average in Turkey as compared to other countries.

Conclusion: DAWN2 is the first study of its kind. The problems and shortcomings related to diabetes care and management in Turkey are once again revealed with this study, and important data and opportunities to improve them are presented.

Key words: Diabetes mellitus, diabetes education, self-care behaviors

1. Introduction

In spite of significant advances in the field of diabetes diagnosis and treatment, the number of patients suffering from this disease is increasing rapidly. One of the major reasons why a vast majority of patients are unable to meet treatment targets is because an organized structure and approach, instrumental for mounting an effective response to chronic diseases such as diabetes, is lacking. As is true for all chronic diseases, also in diabetes self-care and psychosocial support are of paramount importance.

The first DAWN (Diabetes Attitudes, Wishes, and Needs) study, conducted in 2001 across 13 countries, revealed that the psychosocial difficulties encountered by diabetic patients negatively impacted the control of disease (1). The study also clearly demonstrated that maximal benefit was derived by patients when the treatment was conducted and managed by a multidisciplinary team. The results of DAWN emphasized that a patient-centered approach, one that incorporated all stakeholders and included self-care and patient education, was the cornerstone of the fight against diabetes.

Although significant advancements, in several aspects, were made as a result of the first DAWN study, the psychosocial dimension of diabetes was still being ignored and not given its due importance. To address this issue, the DAWN2 studies were initiated with the cooperation of several distinguished international institutions such as the International Diabetes Federation, International Alliance of Patients' Organizations, Steno Diabetes Center Group, and Novo Nordisk.

1.1. Objectives of the study

1- Identification of the requirements of diabetes patients and their caregivers.

2- Development of communication and collaboration between concerned stakeholders so as to facilitate active participation of patients in treatment as well as self-care.

3- Evaluation and comparison of diabetic care services on an international scale, especially from a psychosocial and educational point of view.

Turkey was a notable participant of the DAWN2 study and this article enumerates the insights revealed by this

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study regarding diabetes patients and their relatives. Comparisons to results obtained from other countries are also presented.

2. Materials and methods

DAWN2 was a multinational, interdisciplinary, and multistakeholder study that included the following countries: Algeria, Canada, China, Denmark, France, Germany, India, Italy, Japan, Mexico, Holland, Poland, Russia, Great Britain, Spain, the United States, and Turkey. From every country approximately 500 diabetes patients, 280 healthcare professionals working with diabetes, and 120 relatives of patients participated in the study. From Turkey, 506 patients (80 suffering from type 1 diabetes) and 126 family members living with the patients were part of the study. The questionnaire form was filled out after face-to-face interviews with the patients and their family members. Individuals from Adana, Ankara, Diyarbakır, İstanbul, İzmir, and Samsun were included in the study so as to provide uniform regional representation. Family members for the study were selected from among healthy, diabetes-free adult individuals who were living with an adult suffering from diabetes and who gave treatment-related support.

The study was approved by the Clinical Studies Ethics Committee of Kocaeli University and was conducted in accordance with the guidelines specified for the conduction of noninterventional studies. Separate questionnaire forms were developed for the patients and their relatives. The questionnaires were translated to Turkish and the accuracy and intercultural equivalences of the translations were evaluated and confirmed.

The EuroQoL5D Visual Analog Scale (EQ-5DVAS), Problem Areas in Diabetes Scale-5 (PAID-5), Patient Assessment of Chronic Illness Care-DAWN Start Form (PACIC-DSF), Summary of Diabetes Self Care Activities Measure (SDSCB-6), and WHOQoL-BREF (World Health Organization Quality of Life brief form questionnaire) were applied to diabetes patients included in the study. For the family members of the patients, the Problem Areas in Diabetes-DAWN family members (PAID-5DFM), DAWN Family Experience of Patient Involvement (DFEPI), and DIDP-FM (DAWN Impact of Diabetes Profile-Family Members) questionnaires were utilized.

2.1. Statistics

For continuous variables, descriptive values of results obtained for each country were expressed as mean \pm SD; for categorical variables, the descriptive values were expressed in terms of percentages. The descriptive values of the scale scores (global scores) belonging to the whole study population under study were calculated as mean \pm SD. The answers provided to the questions in the scales were described as percentage and figure frequencies. The

median, minimum, and maximum values of the scores belonging to individual countries were also calculated. All scale scores ranged between 0 and 100. The internal consistency or reliability of the scales was evaluated using Cronbach's alpha coefficient (a Cronbach's alpha coefficient of ≥ 0.7 was considered as an acceptable limit for internal consistency).

To assess if any part of independent variation (residual variation) could be explained by the differences between the countries, a multilevel regression model that used an unstructured correlation matrix type was employed. It was determined that a correction would not be needed for comparing the rates because the sampling design employed was consistent across different countries.

3. Results

From Turkey a total of 506 patients (80 patients with type 1 diabetes and 426 patients with type 2 diabetes) and 126 patient relatives were included in the DAWN2 studies. It was determined that patients with type 1 diabetes were younger and more educated as compared to patients suffering from type 2 diabetes. The demographic data of the patients are shown in the Table.

Results of the DAWN2 study revealed that, in Turkey, 19% of the patients suffering from diabetes also suffer from probable depression (WHO-5 score of < 28). In the other countries where this study was conducted, the median value for this result was 13.7%. According to the WHO-5 well-being index, the rate of probable depression in Turkey is on the rise. This increase is especially marked in the elderly and in patients with type 2 diabetes patients who are using insulin. Most of the patients (54%) studied in Turkey regarded diabetes as a problem (PAID-5 score of ≥ 40) (median: 42%) and this rate increased dramatically to 80% in patients who were using insulin. More than half (58%) of Turkish patients with type 2 diabetes who were undergoing insulin treatment stated that the quality of their life was low. The results from the study also demonstrated that there is an association between decline in quality of life and increase in age (> 60 years) as well as the duration of diabetes. The data obtained are congruent with results obtained on the global scale (2) (Figures 1 and 2).

In Turkey, 61% of the patient relatives enrolled in the study expressed serious concerns regarding health issues faced by their diabetic family member. This is significantly above the mean value of the study (30%) (3) (Figure 3).

The main health issues that caused concern to patients of type 1 and type 2 as well as their relatives were general hypoglycemic attack, nocturnal hypoglycemia, and fear of gaining weight. Many of the type 2 diabetes patients (65%) receiving insulin treatment thought that the continuous use of drugs prevented them from leading a normal life. More than 80% of the patients enrolled in the study stated

Table. Sex, age, occupation, and education profiles of the patients included in DAWN2 study.

		Type 1	Type 2
Sex	Male	48%	41%
	Female	53%	59%
Age (years)	18–39	44%	9%
	40–59	28%	56%
	60+	29%	35%
Occupational status	Full-time occupation	28%	27%
	Retired	33%	30%
	Student	4%	1%
	Spouse/partner at home	29%	34%
Education	Uneducated	4%	8%
	Primary school/left primary school	30%	42%
	Secondary school	11%	12%
	High school	36%	26%
	University	19%	10%

Baseline: All appropriate diabetes patients (T1: n = 80; T2: n = 426; T2 no treatment: n = 97; T2 noninsulin treatment: n = 170; T2 insulin treatment: n = 159).

that they knew what their drugs were used for and that complications could be prevented if they could control their diabetes well. The patients (53%) currently using noninsulin drugs stated that they would be willing to start insulin therapy if recommended by a healthcare provider. Among type 1 diabetes 59% of patients and among type 2 diabetes 79% of patients that were undergoing insulin therapy stated that they would be receptive to the idea of increasing their insulin injections if a healthcare provider recommended doing so. Upon analysis of self-care activities of diabetes patients in Turkey, it was observed that the mean values for physical activity, foot care, and frequency of blood glucose measurement were comparatively less than the global trend (Figure 4).

In Turkey, the majority of diabetic patients (89% for type 1, 67% for type 2) were evaluated by a specialist physician within the last 1 year. Eighty percent of type 1 diabetes patients and 61% of type 2 patients had undergone HbA1c measurement within the same duration. Some of the patients (40%) stated that their feet were examined in the last year and 25% stated that they were questioned if they appeared anxious or depressive. Only 4% of the patients stated that they were asked by the healthcare team if they need support (to determine specific needs to develop efficient diabetes management, etc.). However, the

participation of diabetes patients in educational activities in Turkey falls short of the global average (Figure 5).

Most of the family members (83%) stated that they had not participated in any diabetes education program in the past 1 year. It was observed that TV programs and printed information sources were used for the aim of education (Figure 6).

When queried, 66% of type 1 and 62% of type 2 diabetes patients in Turkey stated that there is an urgent need for development of early diagnosis and treatment methodologies. More than half of diabetes patients expressed the need for places from where they could procure healthy and inexpensive diabetic food. On a positive note, access to medications and reimbursement in Turkey were well above global values and the best scoring in this issue was secured by our country.

4. Discussion

According to TURDEP-2 data, Turkey has witnessed a 90% increase in the incidence of diabetes in the last 10 years; 13.7% of our population is now afflicted by the disease (4).

The DAWN2 studies once again demonstrated that diabetes constitutes a great physical and psychological burden for many patients. The self-care activities available are inadequate for the enormity of the challenges and need

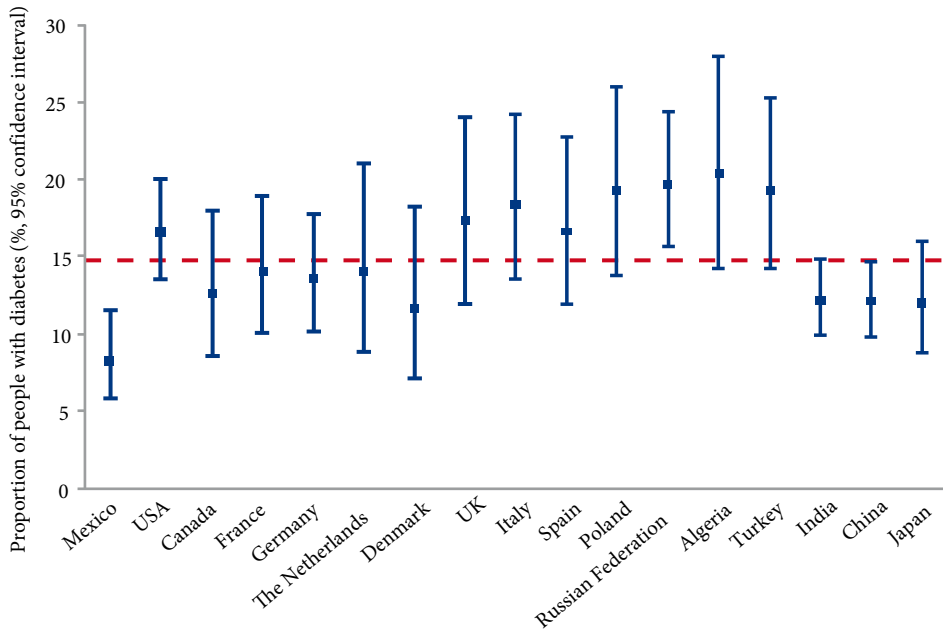


Figure 1. Proportion of diabetic people suffering from probable depression (WHO-5 ≤ 28): a country-wise representation. Data are presented in the form of percentages in their 95% confidence intervals. Results are adjusted for clustering and weighted on age, sex, region, and education so as to allow generalization from the sample to larger populations. Weights are based on population proportions for each country as provided by the respective country's survey advisory group and publicly available epidemiological data. The dotted line represents the mean value relative to the entire sample of people with diabetes (this graphic was adapted from Nicolucci et al. (2)).

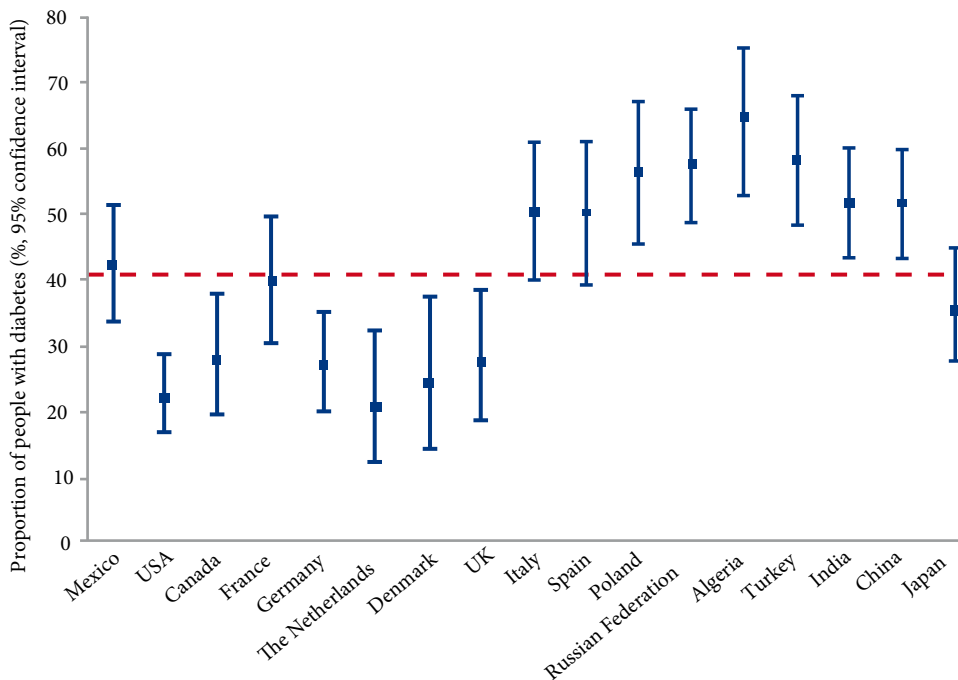


Figure 2. Proportion of diabetic people with high diabetes-related distress (PAID-5 ≥ 40): a country-wise representation. Data are presented in the form of percentages in their 95% confidence intervals. The results are adjusted for clustering and weighted on age, sex, region, and education so as to allow generalization from the sample to larger populations. Weights are based on population proportions for each country as provided by the respective country's survey advisory group and publicly available epidemiological data. The dotted line represents the mean value relative to the entire sample of people with diabetes (this graphic was adapted from Nicolucci et al. (2)).

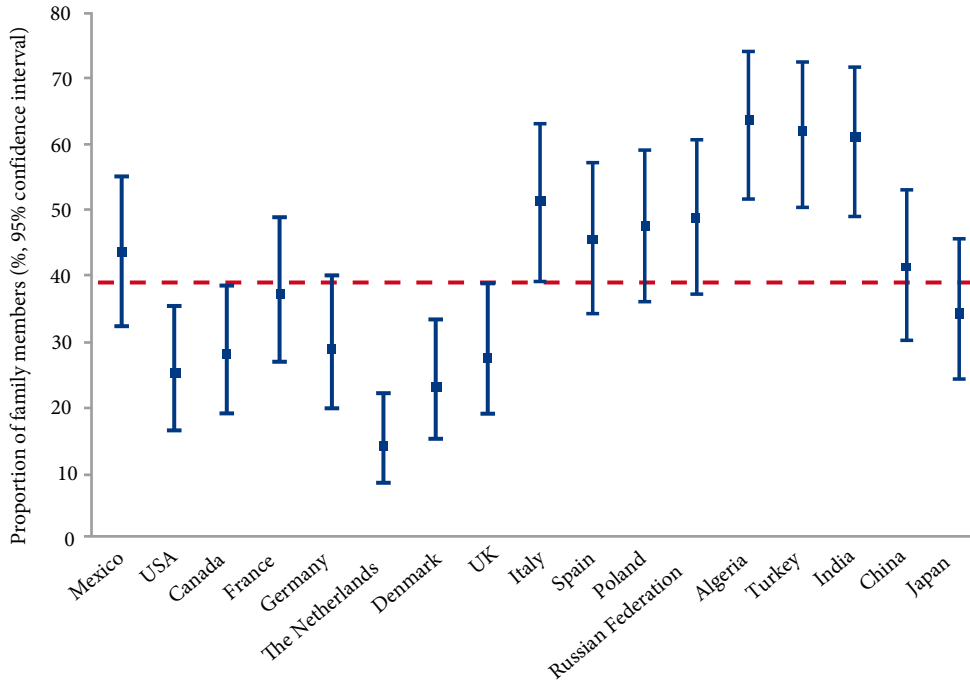
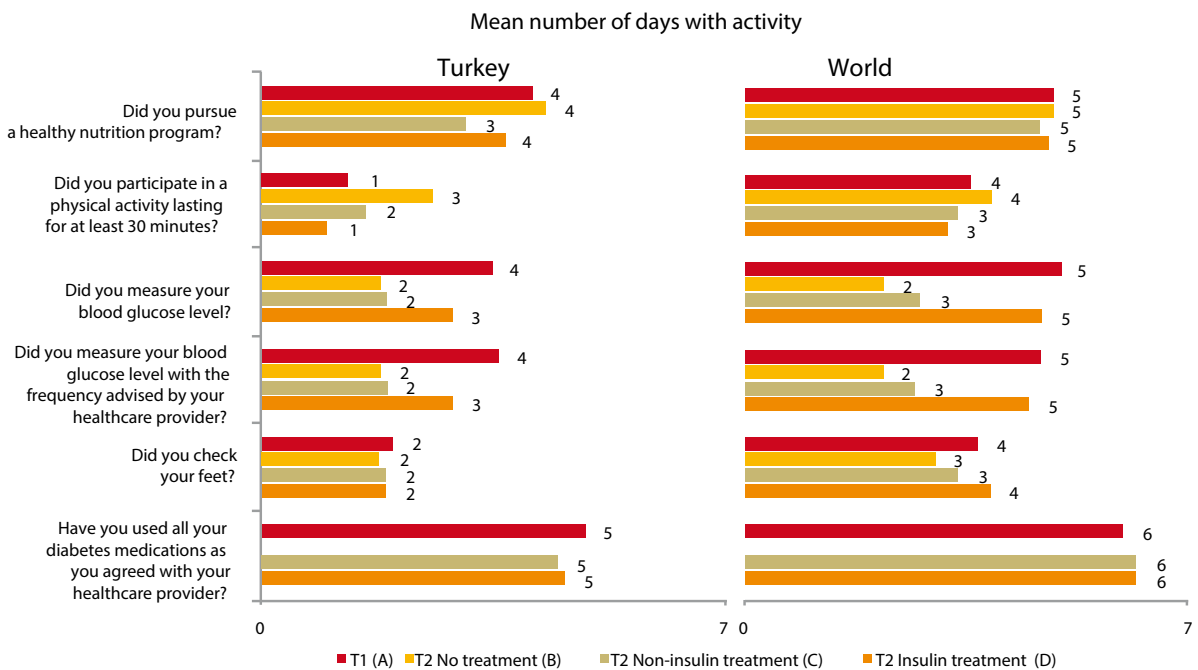


Figure 3. Proportion of family members who expressed serious concerns regarding health issues faced by their diabetic family member (this graphic was obtained from Kovacs Burns et al. (3)): a country-wise representation.

Self-care activities in the last 7 days



Baseline: All appropriate diabetes patients (T1: n=80; T2 No treatment: n=97; T2 Non-insulin treatment : n=170; T2 Insulin treatment: 159)

Figure 4. Patients were asked about their diabetes self-care activities and the duration of the activities that they performed in the last 7 days.

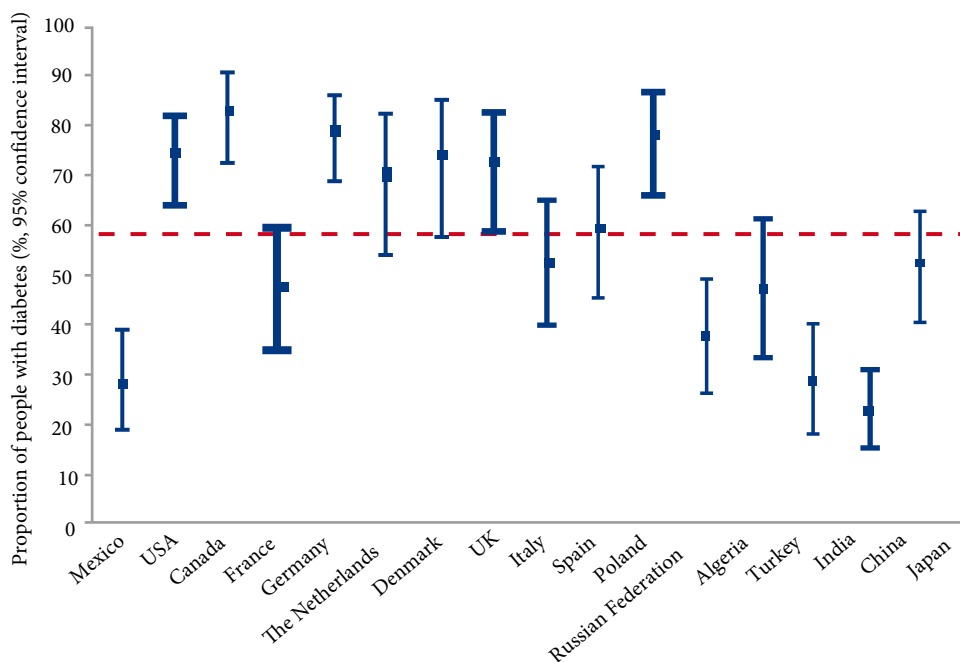


Figure 5. Proportion of people participating in any educational program/activity: a country-wise representation. Data are presented in the form of percentages in their 95% confidence intervals. The results are adjusted for clustering and weighted on age, sex, region, and education so as to allow generalization from the sample to larger populations. Weights are based on population proportions for each country as provided by the respective country's survey advisory group publicly available epidemiological data. The dotted line represents the mean value relative to the entire sample of people with diabetes (this graphic was adapted from Nicolucci et al. (2)).

to be significantly enhanced in many countries, including Turkey.

Psychological problems associated with diabetes further disrupt self-care, leading to a gradual worsening of blood glucose control and resulting in complications (5–7). These findings once again reinforce the need for persistent follow-up, evaluation, and appropriate treatment of the psychological states of diabetes patients as well as family members who assist in their care. Family support available for diabetes patients is considerably more in our country as compared to others. This can be attributed to the fact that the traditional family structure is still maintained in Turkey and families are genuinely concerned for members who are afflicted with this disease.

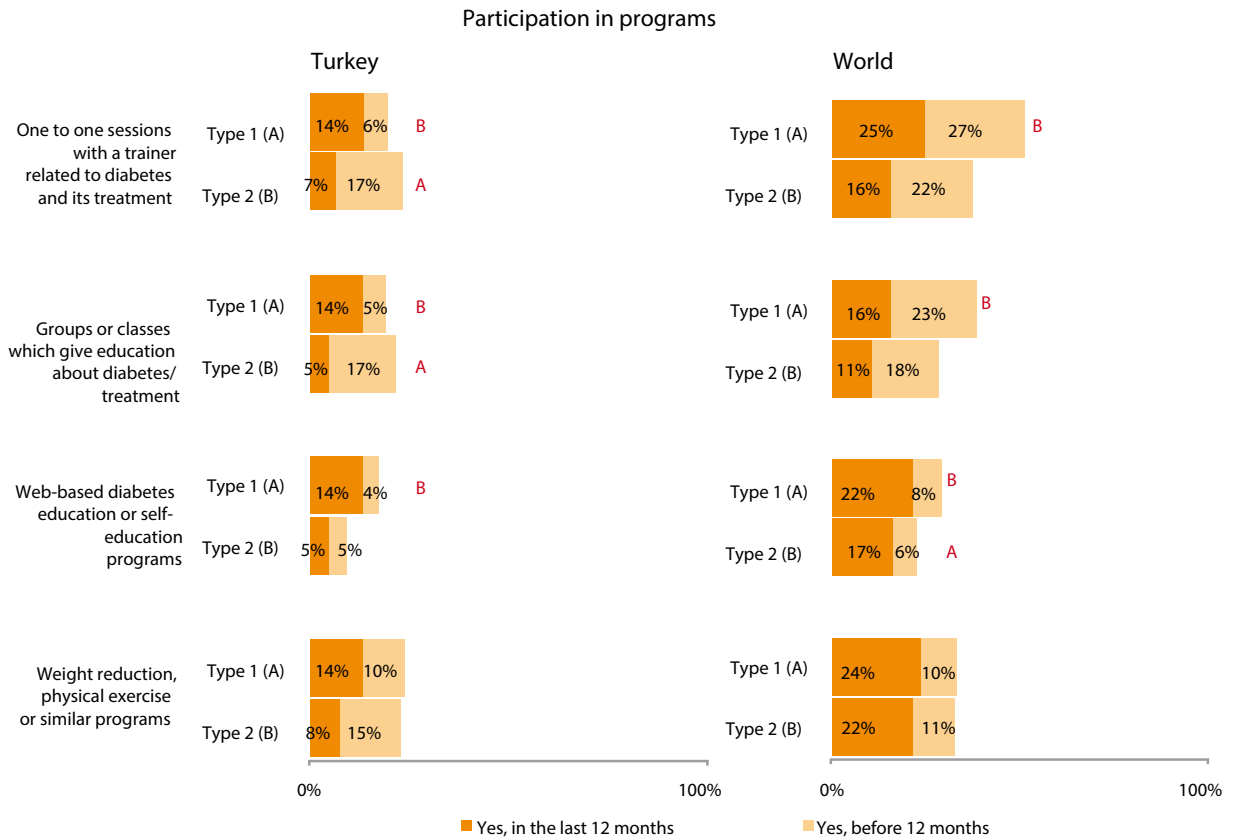
Although social discrimination against diabetes patients appears to be an issue in Turkey, the values are not drastically different from those obtained from other countries. In contrast to preconceived notions, diabetes patients in our country do not exhibit a serious resistance against initiation of insulin therapy or increase in insulin dosage. Nevertheless, a significant fraction of patients believe that insulin injections hurt and lead to weight gain.

Treatment of diabetes patients is a time-consuming and expensive burden for healthcare systems. In our country,

access to physicians has become easy due to the “Health Transformation Program” initiated in recent years. This study revealed that diabetes patients had no problems or issues related to access to physicians and all necessary investigations were performed as required. However, Turkey lags behind the global average in issues such as diabetic foot examinations, assessment of psychiatric problems, education regarding self-care, and patient participation in treatment. One possible explanation for this could be that these procedures are time-consuming and require close interaction with the patient and that the heavy work burden experienced by Turkish physicians leaves them with insufficient time to carry out the same. Also, diabetes teams in many centers are underutilized. Only 25% of diabetes patients in Turkey participated in educational programs about diabetes. Such educational programs have been shown to improve self-care and blood glucose control (8). TV health programs are attempting to remedy the deficiency in this aspect but the benefit of these programs, in terms of propagating accurate and beneficial information, is controversial.

The DAWN2 study is the first study of its kind to be focused on examining the wishes, needs, and attitudes of diabetes patients as well as their relatives and comparing

Educational activities/sources for patients



Baseline: All appropriate diabetes patients (Type 1: n=1368 ; Type 2: n=728)

Figure 6. Patients were asked to indicate whether they participated or not in educational activities regarding their diabetes.

them with those from other countries. Unfortunately, the study suffers from a few disadvantages: as a questionnaire-based study, the sample did not reflect the diabetic patient population of the whole country and the results were influenced by various international social, cultural,

healthcare service, and economic variables. Regardless, the study generated highly relevant data that were instrumental in identifying problems and deficiencies related to diabetes care and presented unique opportunities for the shortcomings to be corrected and improved.

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