

# Psychosocial problems and barriers to improved diabetes management: results of the Cross-National Diabetes Attitudes, Wishes and Needs (DAWN) Study

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## Abstract

**Aims** To examine patient- and provider-reported psychosocial problems and barriers to effective self-care and resources for dealing with those barriers.

**Methods** Cross-sectional study using face-to-face or telephone interviews with diabetic patients and health-care providers in 13 countries in Asia, Australia, Europe and North America. Participants were randomly selected adults ( $n = 5104$ ) with Type 1 or Type 2 diabetes, and providers ( $n = 3827$ ), including primary care physicians, diabetes specialist physicians and nurses.

**Results** Regimen adherence was poor, especially for diet and exercise; provider estimates of patient self-care were lower than patient reports for all behaviours. Diabetes-related worries were common among patients, and providers generally recognized these worries. Many patients (41%) had poor psychological well-being. Providers reported that most patients had psychological problems that affected diabetes self-care, yet providers often reported they did not have the resources to manage these problems, and few patients (10%) reported receiving psychological treatment.

**Conclusions** Psychosocial problems appear to be common among diabetic patients worldwide. Addressing these problems may improve diabetes outcomes, but providers often lack critical resources for doing so, particularly skill, time and adequate referral sources.

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**Keywords** adherence, cross-national, provider behaviour, psychological well-being

**Abbreviations** DAWN, Diabetes Attitudes, Wishes, and Needs

## Introduction

Although new and more efficacious diabetes medication and improved medication delivery systems have been developed, the majority of diabetic patients do not achieve optimal blood glucose control [1], leading to poor health outcomes [2,3]. Negative attitudes, coping difficulties and psychological problems such as depression, anxiety and eating disorders are

common in diabetes and can contribute to poor outcomes [4–6]. Research has indicated that patients and providers differ substantially in their perceptions and attitudes [7], which may lead to confusion and conflict and in turn to poor outcomes. However, we know little about providers' perception of the severity and consequences of patient problems and of the resources they have to deal with these problems. Better understanding of perceptions and attitudes among both patients and providers is needed to guide initiatives to improve the management of diabetes.

In this paper, we report the results of a large cross-national study, entitled Diabetes Attitudes, Wishes, and Needs (DAWN),

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examining the experiences of patients and providers in dealing with diabetes [8]. The objectives of this paper are to examine patient and provider reported psychosocial problems and barriers to effective self-care and resources for dealing with those barriers. We propose several hypotheses: (i) regimen adherence is poor, and providers are aware that this is a problem; (ii) persons with diabetes have diabetes-related psychological problems and poor psychological well-being, and providers are aware of these facts; (iii) providers believe that psychological problems interfere with regimen adherence and that patients need care for these problems; (iv) providers do not have adequate resources to deal with patients' psychological problems, and patients do not receive adequate psychological support.

## Participants and methods

### Design

The DAWN study was planned by a multidisciplinary international advisory group. The questionnaires were developed after review of a variety of diabetes-related instruments and several focus groups conducted with patients, providers and policy-makers in eight countries. The final patient questionnaire included the WHO-5 Well-being Index [9], and other questions were developed for this study. For non-English speaking populations, the questionnaires were professionally translated into the languages of each country, including several dialects for India.

The objectives of the larger DAWN study were to identify a broad set of attitudes, wishes and needs among patients and providers in order to lay the groundwork for efforts to improve diabetes care nationally and globally. The data collected in DAWN go well beyond those presented here. Patient data include sociocultural environment, life situation, initial adjustment to diabetes, diabetes history, health status, and attitudes toward treatment, as well as perceptions of access to care and quality of care. Providers (physicians and nurses) rated various aspects of their national health-care systems and reported their own practice behaviours and treatment-related attitudes. The unique feature of DAWN, beyond its cross-national scope, is the fact that patients and providers provide parallel responses on many study topics, such as regarding patient self-management and adjustment to diabetes.

Wirthlin, an international survey organization, was the prime contractor for the study and selected fieldwork firms in each country for sampling, questionnaire translation, interviewing and preparation of data files. All data are cross-sectional self-reports, gathered in mid-2001 by structured interviews conducted face to face or by telephone, depending on the countries' telephone penetration and recruitment strategy. Interview schedules were translated into the native language of each country, including five languages in India. Interviews took 30–50 min to complete. A variety of sampling frames were used in different countries to generate heterogeneous samples from the entire country (see below). A partial exception was India, where the sample was limited to five regions.

This research was conducted according to the Joint Guidelines on Pharmaceutical Research Practice of the British Healthcare Business Intelligence Alliance and the Association of the British Pharmaceutical Industry. Verbal informed consent was

obtained from all respondents and participation was voluntary. Ethical approval for use of these data was obtained from the Institutional Review Board at Loyola College in Maryland (The Human Subjects Research Committee).

### Participants

Interviews were conducted in 13 countries representing 11 regions: Australia, France, Germany, India, Japan, Netherlands, Poland, Scandinavia (Denmark, Norway, Sweden), Spain, UK and USA. The Scandinavian samples were evenly divided among the three countries.

The study was conducted with three independent samples. The first sample consisted of adults with diabetes mellitus, approximately 500 per region. Patient sampling frames included random-digit dialling, existing research panels, clinic and office practices, and diabetes association membership directories, and were supplemented by advertisements and snowball recruiting. Samples were selected to obtain roughly the same number of people with self-reported Type 1 and Type 2 diabetes. Later analyses revealed inaccuracy in self-reported type of diabetes, so for the analyses in this paper persons were classified as having Type 1 diabetes if diagnosed before age 40, and treated with insulin at diagnosis and at the time of the survey; others were classified as having Type 2 diabetes. Those who did not provide data adequate to classify type of diabetes were deleted from analyses, leaving a final total of 5104. Attrition due to missing data was highest in India (final sample = 404) and Japan (final sample = 387).

The provider samples were obtained from various professional directories and listings. The physician sample consisted of 2705 respondents, 250 per region, approximately 200 in primary care and 50 specialists (endocrinologists and diabetologists with 2 years' experience and treating more than 50 patients per month). The nurse sample consisted of 1122 respondents, approximately 100 per region, 50 specialists, treating 50+ persons with diabetes a month, and 50 generalists. Only those treating at least five persons with diabetes per month were included in the survey. Only one respondent was selected from any practice.

Tables 1 and 2 describe the participants. There are major differences among the countries in all groups. It is not clear the degree to which these represent differences in sampling strategies or differences in the populations from which these samples were drawn. One anomaly was that, in India, approximately half of the physicians (rather than the quota of 20%) were classified as diabetes specialists; however, this is because any physician in India who treated more than 50 diabetes patients a month, initiated insulin, and accepted diabetes referrals from other physicians was classified as a specialist. Another anomaly was that, in Japan, only 5% of patients had Type 1 diabetes; patient data regarding Type 1 diabetes in Japan therefore must be viewed with extreme caution.

### Measures

Main outcome measures included:

1. Patient and provider reports of whether patients were 'completely successful' in adhering to treatment recommendations for five domains (diet, exercise, medication, self-monitoring of

**Table 1** Physician/nurse characteristics\*

Country	Respondents (n)	Female (%)	Practice duration (mean years)	Practice site (% urban**)	Specialist (%)
Australia	248/100	19.8/92.0	18.7/11.8	51.6/41.0	20.2/46.0
France	251/112	27.9/85.7	15.6/11.9	87.6/93.8	20.3/50.9
Germany	250/100	37.2/96.0	13.0/12.0	81.2/70.0	20.0/52.0
India	251/103	17.5/99.0	12.7/7.9	78.5/88.3	54.6/63.1
Japan	252/100	7.9/98.0	19.7/6.8	73.8/76.0	21.8/19.0
Netherlands	249/104	20.9/90.4	15.0/6.8	53.8/55.8	20.5/70.2
Poland	250/100	72.4/100	13.7/11.7	88.0/83.0	20.0/50.0
Scandinavia	239/100	23.8/99.0	15.9/11.8	61.1/61.0	16.7/70.0
Spain	250/100	37.6/93.0	16.3/11.3	90.8/91.0	20.4/53.0
United Kingdom	249/102	17.3/97.1	17.1/11.6	55.8/43.1	20.1/62.8
United States	216/101	18.1/98.0	17.4/10.8	36.6/53.5	23.1/49.5
Total	2705/1122	27.4/95.2	15.9/10.6	69.5/69.0	23.5/53.4

\*Cell entries are physician/nurse data (physicians left of slash, nurses right of slash). All respondent characteristics are significantly different ( $P \leq 0.05$ ) by country and discipline by Chi-square or *F*-test. \*\*Urban does not include suburban.

**Table 2** Patient characteristics\*

Country	Respondents (n)	Age (mean years)	Female (%)	Residence (% urban**)	Education (median age at completion of formal education)	Duration of diabetes (mean years)
Australia	159/317	38.8/59.6	51.6/51.1	18.8/20.5	17/16	20.0/9.4
France	217/249	40.4/58.3	53.5/57.0	62.2/61.5	19/16	19.1/13.3
Germany	197/299	34.9/58.3	47.2/55.5	60.9/58.2	18/16	19.1/12.7
India	105/299	33.0/54.6	46.7/45.2	97.2/95.0	20/18	12.4/7.8
Japan	17/370	34.4/59.5	76.5/52.2	64.8/61.4	18/18	16.6/10.2
Netherlands	161/344	39.8/57.0	55.3/57.6	58.4/56.7	19/18	20.6/10.3
Poland	189/247	36.2/61.1	60.3/63.6	75.7/77.7	19/18	15.2/10.2
Scandinavia	185/300	38.2/59.0	52.4/44.3	62.7/56.4	19/19	21.8/11.1
Spain	212/264	31.6/60.3	52.8/60.6	86.4/83.3	18/14	13.8/12.6
United Kingdom	131/357	47.6/64.1	54.2/47.6	46.0/40.0	16/15	28.0/12.3
United States	99/386	45.4/59.8	59.6/63.5	26.3/31.0	20/18	28.3/13.2
Total	1672/3432	38.0/59.3	53.5/54.2	60.9/56.5	18/17	19.2/11.2

\*Cell entries are Type 1/Type 2 data (Type 1 left of slash, Type 2 right of slash). All measures are significantly different ( $P \leq 0.05$ ) by country (except number of respondents) by Chi-square or *F*-test.

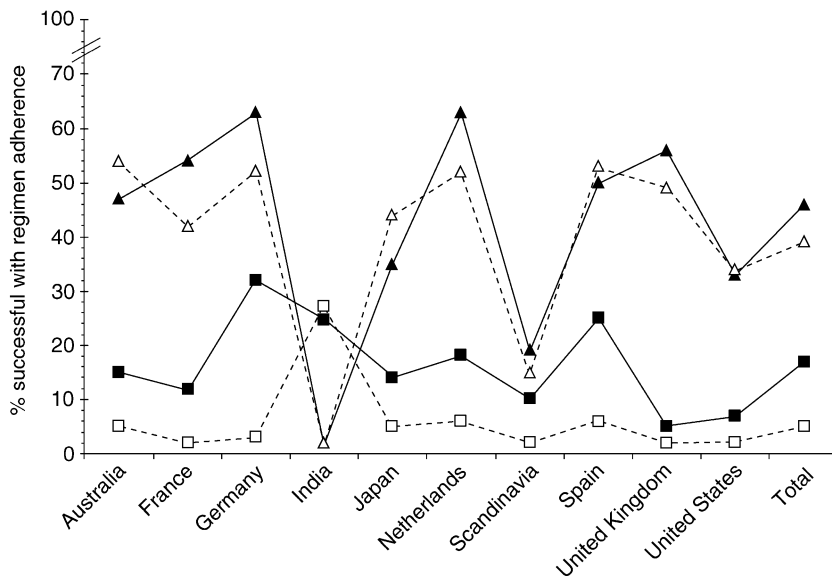
\*\*Urban does not include suburban.

blood glucose, appointment keeping). Patient and provider measures were created using different measurement strategies. For patients, the five adherence measures were combined into an overall index of adherence by identifying patients who reported ‘complete’ adherence with treatment recommendations in most (at least two-thirds) of the domains for which they reported receiving recommendations. Providers reported whether their ‘typical’ patients were ‘completely successful’ in following treatment recommendations in each of the five domains. For providers, the measure of overall treatment adherence was whether that provider’s typical patient was reported to be completely adherent in most (at least two-thirds) of the domains.

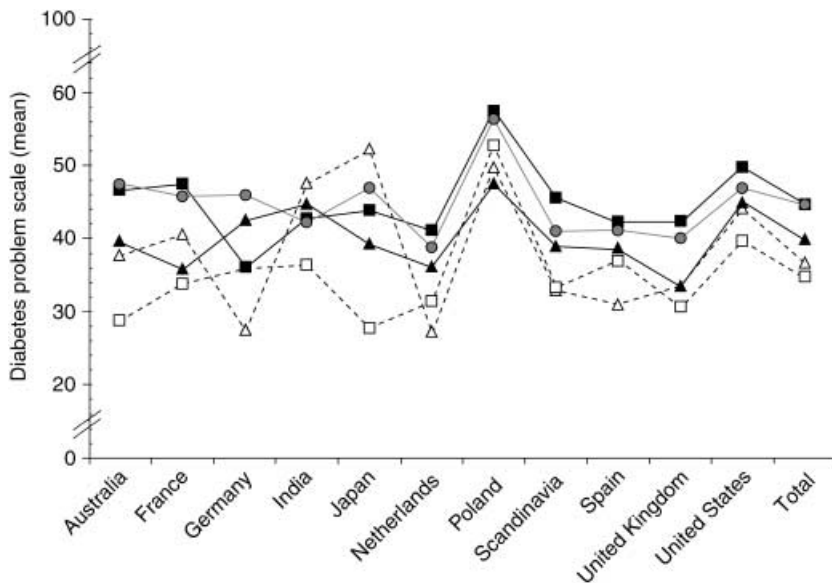
2. Patient and provider reports of diabetes-related distress (When I feel anxious and depressed I have no one to turn to; I am constantly afraid of my disease getting worse; I feel that diabetes is preventing me from doing what I want; I am worried about not being able to carry out my family responsibilities in

the future; My diabetes causes me worries about my financial future; I feel very anxious about my weight; I am very worried about the risk of hypoglycaemic events). Patients were asked if they would agree (agree = 100, disagree = 0); providers were asked how many of their patients would agree (most or all = 100, more than half = 66.7, less than half = 33.3, few or none = 0). Thus, the individual items represent actual prevalence (patients) or estimated prevalence (providers) of each problem. These items were combined into multi-item scales (one for patients, another for providers) by taking the mean of all items; the scales represent the average actual (patient) and estimated (provider) prevalence of the problems. These scales had acceptable reliability (patient alpha = 0.72; provider alpha = 0.74).

3. Patient reports of current psychological well-being based on the WHO-5-item well-being index [9], and recent treatment for psychological problems.



**Figure 1** Percentage of patients with good regimen adherence. Per cent of patients with Type 1 and Type 2 diabetes reported to be 'completely successful' in following their treatment recommendations for at least two-thirds of the treatment domains. Type 1 patients (▲), Type 1 health-care providers (■), Type 2 patients (△) and Type 2 health-care providers (□).



**Figure 2** Diabetes-related problems. Scores (range = 0–100) for diabetes-related problems by self-report (for patients) and proxy report (for providers). Type 1 patient (△), Type 2 patient (□), nurse (●), general physician (▲) and specialist physician (■).

4. Provider reports of the prevalence of psychological problems, their impact on self-care, and the resources available for managing these problems (see question wording in Table 3).

#### Statistical analysis

Differences among respondent groups were tested using chi-square or *F*-test. Statistical significance was set at  $P < 0.05$ . Significant differences obtained by *F*-tests were confirmed by the Mann–Whitney *U*-test if the assumptions of the *F*-test were not met; significant differences were reported only if confirmed. No adjustment was performed for multiple tests.

#### Results

Figure 1 shows that, although there was significant variation across countries, regimen adherence is less than optimal in all

countries. Only 46% of Type 1 patients (range of countries = 2–63%) and 39% of Type 2 patients (range of countries = 2–54%) achieved complete success in at least two-thirds of their self-care domains. Although methods for generating patient and provider estimates of adherence differed, provider-reported success in adherence was much lower than patient-reported success for both Type 1 (overall = 17%, range of countries = 5–32%) and Type 2 diabetes (overall = 5%, range of countries = 2–27%). The only exception to this pattern was India, where providers reported above-average adherence, while patients reported the lowest adherence levels of any country (this pattern was consistent across the different self-care domains). Patient-reported success was significantly higher for medication (overall Type 1/Type 2 = 83/78%), testing (70/64%), and appointment keeping (71/72%) than for diet (39/37%) and exercise (37/35%). Provider reports also

Table 3 Provider perceptions of psychological needs and resources

	Nurse	Primary care physician	Specialist physician
% of your Type 1 patients with psychological problems	72.1c	64.7†	70.4c
% of your Type 2 patients with psychological problems	72.0†	61.9†	66.5†
Psychological problems play only a small part in non-compliance (% disagree)	71.7c	65.2†	72.4c
I am able to identify and evaluate the patient's psychological needs (% agree)	49.0†	69.2†	62.2†
I am able to provide all the psychological support my patients need (% agree)	37.9†	61.0†	49.9†
I often refer diabetes patients to others for emotional or psychological support (% agree)	32.9c	20.0†	34.8c
Outside expertise in emotional and psychological matters is available to me if I need it (% agree)	51.2†	56.2†	65.2†

†Respondent group is significantly different from all other groups.

Letters in cells indicate from which groups the designated cell is significantly different (c = primary care).

Significant differences ( $P < 0.05$ ) determined by post hoc *F*-test, confirmed by Mann-Whitney *U*-test.

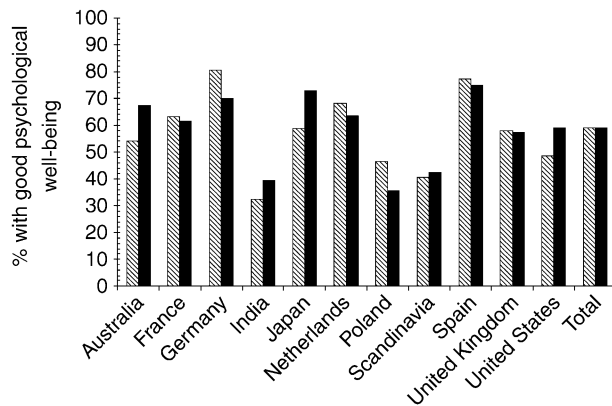


Figure 3 Percentage of patients with good psychological well-being. Bars show per cent of patients with Type 1 (▨) and Type 2 (■) diabetes that have scores above 50 (range = 0–100) on the WHO-5 Well-being Index [9].

indicated that adherence was significantly lower for lifestyle behaviours than for other self-care behaviours. While patient reports of adherence did not differ substantially by type of diabetes, providers reported significantly better adherence among their patients with Type 1 diabetes than those with Type 2 diabetes for most regimen domains (medication = 73/48%, testing = 44/24%, appointment keeping = 52/47%, diet = 21/8%, exercise = 15/6%).

Figure 2 shows that diabetes-related problems were significantly more common in Type 1 diabetes (mean = 36.6%, range of countries = 27.3–52.1%) than Type 2 diabetes (mean = 34.6%, range of countries = 27.6–52.8%). Providers were aware of these problems; in fact, although the methods for generating estimates were not identical, providers reported higher estimates than those obtained from patients. Primary care physicians (mean = 39.8%, range of countries = 33.4–47.4%) reported significantly fewer of their patients had problems than nurses (mean = 44.6%, range of countries = 38.6–56.4%) or specialists (mean = 44.6%, range of countries = 35.9–57.4%).

Figure 3 shows the distribution of psychological well-being by country according to WHO-5 criteria [9]. There was statistically significant variation across countries, but good

well-being was similar overall between patients with Type 1 (59.0%, range of countries = 32.4–80.7%) and Type 2 diabetes (59.1%, range of countries = 35.6–75.0%). Moreover, although 41% of patients experienced poor psychological well-being, only 9% (Type 1) and 12% (Type 2) of patients reported receiving psychological treatment in the past 5 years.

Table 3 shows that a substantial majority (61–72%) of providers reported that their diabetes patients had psychological problems (including depression, anxiety, stress and burnout) and 66–74% reported that psychological problems affected diabetes regimen adherence. Respondents felt more able to identify and evaluate psychological needs (49–69%) than to meet those needs (38–61%); only 42% were able to do both. Although a majority saw psychological problems as common and consequential, a minority referred their patients for psychological services. There were statistically significant differences by profession in provider reports of the need for treatment and the availability and use of resources to manage psychological problems. Primary care physicians reported the lowest level of problems and consequences, were most likely to report they could evaluate psychological problems and provide psychological support themselves, and least likely to refer their patients for outside psychological support. Specialists reported intermediate levels of personal ability to identify and treat psychological needs, but the highest availability of outside expertise.

## Discussion

The data reported here support the hypotheses which guided the analysis.

1. Patient-reported adherence to self-care recommendations is less than optimal, and providers are aware of this shortfall. In fact, they report much lower levels of estimated adherence than patients did for most self-care behaviours.
2. According to reports of both patients and providers, a majority of patients suffer from diabetes-related psychological problems and many have poor psychological well-being.
3. Providers believe that the shortfall in regimen adherence is in large part a consequence of their patients' psychological problems.

4. Many providers are not able to identify and evaluate psychological problems and provide the psychological support their patients need. In fact, almost half of those who agree they could assess and support their patients indicate only minimal agreement (4 on a scale of 1–6). Moreover, even though problems are perceived to be pervasive and important for diabetes self-care and many providers cannot manage these problems, few providers commonly refer patients to psychological services, and few patients receive those services.

Many differences are seen between countries in this study. Whether these differences are real differences in psychosocial problems and barriers or whether they are differences because of different expectations by patients and providers between different countries and cultures is not explored in this study. The important finding is that psychosocial problems and barriers are common in all countries.

Primary care providers consistently perceive fewer problems among their patients, feel better able to deal with the problems presented by their patients, and refer fewer patients for psychological services. This may reflect a difference in the patients seen by the different categories of providers. Nurses and specialists may see disproportionately more of the patients who are having trouble adjusting to diabetes and managing their care. Alternatively, primary care providers may be less sensitive to their patients' problems and therefore less likely to manage them effectively. Both are credible hypotheses, and both may contribute to the observed pattern; determining how much each contributes would require being able to link the perceptions of the different types of providers' to the actual psychological condition of their own patients, something which was not possible with the independent samples used in the present study. If primary care providers are less able to detect these problems and manage them alone or by referral, that does not bode well for diabetes patients, the majority of whom are managed by primary care providers.

This study has large and diverse samples, and the findings reported here have been collected across many cultures and health-care systems. We have confirmed the finding by others [10] that, in many countries, diabetes self-care is less than optimal, especially for lifestyle behaviours. Moreover, our multiconstituency design shows that providers report even lower levels of regimen adherence than patients, a pattern that has been observed for diseases other than diabetes [11]. This difference in perception can be a source of conflict between patients and providers [12] and may interfere with efforts to improve self-care, e.g. providers may not intensify care because they feel their patients are not complying with their current regimen and would not follow a more intensive regimen. Although patient and provider perceptions may not agree, each may have independent validity [13].

We have confirmed the finding that diabetes-related distress and psychological problems are common among people with diabetes [14,15]. Our research further demonstrates that most providers of the countries studied are aware of the level of patient distress. Moreover, most providers believe that psychological problems are associated with worse outcomes, a

belief which is consistent with published findings [6,16,17]. Yet, in spite of this general awareness, many providers in our study lack confidence in their ability to identify and evaluate psychological problems and to provide support for their patients who suffer from these problems. Thus, these factors remain key barriers to improving care and quality of life in diabetes. It is important that providers learn how to identify and manage the negative emotions that arise in living with diabetes; doing so can help patients overcome barriers to managing their diabetes more effectively [18].

### Limitations

Patients contributing to this study are likely to be more educated than the populations from which they were drawn, partly because of the sampling strategies (i.e. advertisements, snowball recruitment and using member lists of diabetes associations), and partly because of using telephone interviews. Because more educated persons have more personal and social resources, it is possible that this group exhibits higher levels of adherence and fewer psychological problems than exist in the corresponding populations. Also, while the survey did include many countries, most of these countries are highly developed, and few less-developed countries were included. This creates positive bias for all groups, e.g. patients and providers in these countries generally have more resources than in other, less-developed countries. Thus, in spite of the inadequacies in diabetes management identified in this study, the situation worldwide could be substantially worse.

Methodological heterogeneity (e.g. differences in sampling strategies) may have influenced country differences. In addition, telephone interviews, which were used in some countries more than others, may have generated more socially desirable and non-committal responses than the face-to-face interviews [19]. Finally, because providers did not report about the patients who participated in the survey, we had to use different measurement strategies to obtain parallel estimates; some of the differences between patient and provider responses may have been a result of the different strategies.

### Implications

Because psychological factors remain key barriers to improved outcomes, this study highlights the need for designing models of care that provide essential psychosocial services. We believe that research must be conducted to test interventions that target these psychological barriers [4,20]. For example, can providers be trained to recognize psychological problems, and either address them or refer to another service provider who can? While screening can be effective [21], evidence suggests that, even with training, providers do not do well in detecting problems such as depression [22]. Are some providers (e.g. nurses) more able or willing to assume this responsibility?

This study provides further evidence for the St Vincent Declaration's position that mental health services should be more

available for people with diabetes [23]. This will require increased training for providers to enhance their confidence and skill in managing these problems. Integrating mental health professionals into the diabetes care team could also help, especially if they receive training and experience in how to work with diabetic patients. As effective treatment options become more available, resolving patients' psychological issues will become more important in determining whether patients are able to achieve the best quality care for their diabetes.

This study establishes a baseline for examining changes over time in psychosocial problems and interventions. Future research is required to better understand the observed differences between countries and to determine which approaches and strategies may help improve the psychological care of diabetes patients within particular national contexts.

### Competing interests

TL has been reimbursed by Novo Nordisk for participation in scientific meetings and has received unrestricted research funds as well as fees for consulting. FJS has received fees for speaking at educational meetings. RR has been reimbursed by Novo Nordisk, the manufacturer of medications and insulin delivery devices for attending several conferences. He has also been paid by Novo Nordisk for speaking at meetings, organizing educational programmes, conducting research, and as a consultant. SES is employed by Novo Nordisk. MP has received grant funding, consulting fees, speaking honoraria and expense reimbursement from Novo Nordisk, sponsor of the DAWN Study.

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