Patient Preference and Adherence

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ORIGINAL RESEARCH

Patient perceptions of their glycemic control and its influence on type 2 diabetes outcomes: an international survey of online communities

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Purpose: This study aimed to assess awareness of glycated hemoglobin (A1C) testing and targets, perceived level of glycemic control and risk of complications, attitudes toward medications and self-management, and regimen-related distress in an international sample of patients with type 2 diabetes (T2D).

Methods: The descriptive study used a single time-point survey of adults in online health communities in the USA, Canada, the UK, Germany, Spain, and Mexico, who self-reported T2D diagnosed by a physician.

Results: In total, 661 patients participated. Awareness of their A1C value at last test varied considerably between countries (42%–89%), as did awareness of having an A1C target (26%–70%). Self-reported A1C values were similar across US, Canadian, and European respondents (mean, 6.8%–7.3%). Approximately two-thirds of respondents from these countries (66%–71%) reported that their T2D was very or fairly well controlled, and few (5%–15%) expected to experience serious complications within 1 year. However, many respondents expected to experience microvascular (rather than macrovascular) complications in this time frame (eg, nerve pain, 5%–47%). Self-reported adherence to oral medication was generally high, with most respondents (86%–98%) taking their pills or tablets as directed by their healthcare provider, although for insulin injections adherence was lower in the USA (71%) and Mexico (78%) than in the other countries (86%–95%). The majority of respondents across countries (71%–79%) reported that taking injectable medications was not at all or a little burdensome. Respondents across countries appeared to be reasonably confident that they could adequately manage their blood sugar levels; despite this, a sizeable minority (21%–35%) had clinically significant levels of regimen-related distress.

Conclusion: Limited patient awareness of their A1C value and the potential complications of poorly controlled T2D, particularly regarding cardiovascular complications, may be a widespread problem. Furthermore, greater patient support may be needed to improve self-management of T2D and to reduce regimen-related distress.

Keywords: diabetes mellitus, type 2, diabetes complications, glycated hemoglobin, self-management, surveys

Introduction

Adequate glycemic control is crucial to reducing the risk of complications from type 2 diabetes (T2D), which can include myocardial infarction, stroke, peripheral artery disease, lower limb amputation, vision loss, heart failure, nephropathy, retinopathy, and neuropathy.[1] Evidence-based guidelines for management of T2D recommend a combination of lifestyle changes and medication (insulin and oral hypoglycemic agents)

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to control blood glucose, as well as medication to control the cardiovascular disease risk and regular screening for early detection of complications.[1,2] These guidelines typically stipulate that patients with T2D should have an individualized glycated hemoglobin (A1C) target, often aiming for as low as 7.0% or 6.5%, depending on additional patient-specific factors such as age, duration of diabetes, comorbidities, and risk of hypoglycemia.[2–5] However, despite the availability of these guidelines, patients' glycemic control appears to remain suboptimal to various degrees worldwide,[6,7] including in both high-income[8,9] and low to medium-income countries.[10] In the MOSAIc study, for example, a multinational, longitudinal, observational study of adults with T2D using insulin, the mean participant A1C value across 18 countries at baseline was 8.2%, despite a mean target A1C of 6.9%.[7] This study also showed that there is considerable variation among countries in terms of patients' demographic characteristics, medical histories, drug treatment regimens, and self-reported knowledge of, and distress about, diabetes.[7]

Patient self-management is a critical aspect of T2D care. Patients' knowledge and perceptions of their glycemic control and T2D medication can impact treatment adherence and diabetes outcomes. Several studies have shown that limited numbers of patients are aware of their current and target A1C levels.[11–13] In addition, patients' adherence to their T2D medication can be limited by critical beliefs about their medications (such as perceived treatment inefficacy), and the perceived burden regarding obtaining and taking their medication (including treatment complexity, out-of-pocket costs, and hypoglycemia).[14,15] Patients with elevated A1C levels who display poor self-management behavior are less likely to receive treatment intensification,[16,17] thereby prolonging or exacerbating their inadequate glycemic control. However, it is not clear what patients perceive to be the consequences of poor glycemic control, or how this may vary between countries.

Online health communities aim to bring patients together to share their experiences and offer support for living with conditions such as diabetes. These communities offer an opportunity to exchange information outside of the clinic environment. The aims of this survey-based international study of patients with T2D in online health communities were to assess the level of patient awareness of A1C testing and targets, to uncover patient attitudes toward, and preferences for, T2D pharmacological treatments, and to determine patient-perceived consequences of poor glycemic control. Patients from Canada, Germany, Mexico, Spain, the UK, and the USA were surveyed. The prevalence of diabetes among adults in these countries ranges from 5.9% in the UK to 14.0% in Mexico (Table S1).[18] The general target A1C value for most adults with T2D stipulated by each country's national T2D management guidelines is 7.0% or below, with the exception of the German guidelines that recommend a target range of 6.5%–7.5% (Table S1), and all advise that the target should be tailored to the individual patient.[3,19–23]

Methods

Study population and conduct

Patients aged 18 years or older who resided in Canada, Germany, Mexico, Spain, the UK, or the USA and who self-reported that they had been diagnosed with T2D by a physician were eligible to participate in the study. Patients also had to be able to read and understand the language in which the survey was presented, which was the official language of the country (ie, English, German, or Spanish). Those patients who were diagnosed with T2D within the previous 6 months were excluded, because they may not have had sufficient experience of their diabetes to answer the questions in an informed manner.

Approval to field the survey in the USA and Canada was granted by the Western Institutional Review Board (Puyallup, WA, USA; Vancouver, BC, Canada) and was not required in the other countries. The appropriate regulatory bodies in the UK (Health Research Authority) and Spain (Agencia Española de Medicamentos y Productos Sanitarios), and local colleagues in Germany and Mexico, confirmed that approval was not required to field the survey in these countries. Participants gave their informed consent by completion of an online form before taking the survey.

Data source

Data for this descriptive study were obtained by surveying patients who were members of online health communities hosted by PatientsLikeMe (for patients resident in the USA and Canada), Carenity (for patients resident in Germany, Spain, and the UK), or HealthUnlocked (for patients resident in Mexico). Eligible members of the PatientsLikeMe platform were invited to participate through a private message sent to their account, directing them to the study on the PatientsLikeMe website. Users who did not complete the survey received up to three reminders. Eligible members of T2D communities hosted by Carenity and HealthUnlocked were sent pop-up invitations, weekly for Carenity members and once only for HealthUnlocked members, that directed them to internal landing pages for the study within the Carenity or HealthUnlocked platforms. Invitations were sent in members' native languages. The survey was fielded for

2 weeks, or until a sample of 100 respondents per country was achieved.

Survey instrument

The single time-point survey was designed to assess patient perceptions and attitudes about A1C and its impact on health outcomes (Appendix S1). The survey also included a series of questions on goal-setting, management of diabetes, treatments, and adherence, as well as demographic and health history information (Table S2).

Survey items were derived from the results of targeted literature reviews[6,7,11,14,24–26] and the relevant experience of the authors. Perceived diabetes control was assessed as in a previous cross-national study:[25] participants were asked whether they believed that their last A1C test result meant that they were doing well or poorly on a four-point Likert scale (very well, fairly well, fairly poorly, very poorly), or they could select "I don't know." In addition, participants were asked to rate the distress associated with taking their diabetes medication, using the Regimen-Related Distress domain of the Diabetes Distress Scale (DDS).[27]

The survey was prepared in English and translated into the official language of each country from which participants were drawn. A series of iterative survey language checks among investigators, and electronic pretesting for design elements, question ordering, and survey flow, were conducted before the survey launch.

Statistical analyses

All nonresponse options were treated as missing values and coded as null. Multisite data were aggregated and cleaned in RStudio version 1.0.143, with R version 3.0.0, utilizing the packages "dplyr" and "lubridate." Analyses were conducted using SAS Enterprise Guide version 7.13 (SAS Institute Inc., Cary, NC, USA). Descriptive statistics were generated for variables of interest.

Results

Participant demographics and characteristics

The response rate for the survey ranged from below 1% in Mexico to 39% in Canada (Table S3). In total, 661 respondents were included in the study (Table 1). There were slight differences between countries in the age of study participants, with German participants being older than American, Canadian, and Mexican participants. A slightly higher proportion of women than men participated in the study overall (53% vs 47%); the difference in proportions was most pronounced in the USA. The spread of responses for time since T2D diagnosis was similar across all countries, with most participants being diagnosed between 1 and 15 years previously. Respondents across countries typically saw a primary care physician/general practitioner for their T2D care, with other commonly seen healthcare providers (HCPs) being diabetologists for German respondents, endocrinologists for Spanish respondents, and nurse practitioners for UK respondents.

Awareness of diabetes tests, A1C test results, and A1C targets

There was variation between countries in the routine tests that respondents reported their HCPs performed regularly (Table 2). Most respondents across countries were aware that their A1C level had been assessed in the past. Respondents from Mexico and Spain reported the lowest rates of A1C testing on a regular basis, with 18% of Mexican respondents believing that their HCP had never tested their A1C level. By contrast, almost all US respondents were aware that their A1C level had been tested, and 97% reported regular testing.

Of respondents who reported having their A1C tested, the majority across countries reported that their most recent test occurred within the last 3 months (Table 2). Respondents' ability to recall their A1C value at last test varied considerably between countries, with more respondents from the USA, Germany, and Spain providing a response than those from Canada and the UK. The mean (SD) self-reported A1C value at last test was largely consistent across countries (6.8 [1.3]–7.3 [1.6]%), with over half of respondents (57%) reporting an A1C level of at least 7.0%. Two-thirds of respondents (68% overall) reported that their last A1C test result indicated that they were doing very or fairly well.

Approximately two-thirds of North American and German respondents reported that they had an A1C target, but this proportion was only 38% for Spanish respondents and 26% for UK respondents (Table 2). Of those respondents who reported having an A1C target, the highest mean value was reported by UK respondents (6.9 [1.0]%) and the lowest was reported by Spanish respondents (6.1 [1.4]%). The A1C test result that respondents felt would make them ask their HCP to change their treatment plan ranged from a mean of 7.6 (2.1)% for UK respondents to 8.6 (1.3)% for Canadian respondents.

Perceptions of diabetes control and complications

Respondents' perceptions of their level of diabetes control were fairly consistent across countries, with approximately

Table 1 Participant self-reported demographics and characteristics

	USA (n=148)	Canada (n=113)	Germany (n=100)	Mexico (n=100)	Spain (n=100)	UK (n=100)
Age (years), mean (SD)	58 (8.9)	58 (9.7)	62 (8.8)	56 (7.8)[a]	60 (9.2)	60 (8.0)
Sex, n (%)						
Female	99 (67)	62 (55)	45 (45)	49 (49)	42 (42)	55 (55)
Male	48 (32)	51 (45)	55 (55)	51 (51)	58 (58)	45 (45)
Prefer to skip	1 (1)	0	0	0	0	0
Education, n (%)						
High school graduate or less	23 (16)	35 (31)	75 (75)	42 (42)	48 (48)	41 (41)
Some college	55 (37)	45 (40)	4 (4)	12 (12)	22 (22)	33 (33)
College graduate or greater	70 (47)	33 (29)	21 (21)	46 (46)	30 (30)	26 (26)
Comorbidities, n (%)[b]						
Overweight/obesity	114 (81)	75 (70)	69 (69)	51 (51)	64 (64)	74 (74)
High blood pressure (hypertension)	105 (75)	69 (65)	73 (73)	47 (47)	57 (57)	73 (73)
High cholesterol (hypercholesterolemia)	94 (67)	67 (62)	45 (45)	42 (42)	47 (47)	69 (69)
Depression (MDD, dysthymia)	71 (51)	37 (35)	27 (27)	12 (12)	18 (18)	50 (50)
Neuropathy	61 (44)	32 (30)	31 (31)	28 (28)	13 (13)	25 (25)
Peripheral vascular disease	24 (17)	8 (7)	21 (21)	12 (12)	14 (14)	9 (9)
Retinopathy	19 (14)	17 (16)	9 (9)	13 (13)	11 (11)	13 (13)
Heart disease	23 (16)	9 (8)	18 (18)	2 (2)	9 (9)	7 (7)
Heart attack (myocardial infarction)	8 (6)	12 (11)	11 (11)	4 (4)	7 (7)	7 (7)
Chronic kidney disease	17 (12)	2 (2)	6 (6)	2 (2)	6 (6)	6 (6)
Stroke	5 (4)	3 (3)	5 (5)	1 (1)	5 (5)	1 (1)
Time since diagnosis, n (%)						
6 months to <1 year	11 (7)	12 (11)	0 (0)	4 (4)	5 (5)	0 (0)
1–5 years	37 (25)	30 (27)	29 (29)	27 (27)	28 (28)	25 (25)
6–10 years	33 (22)	33 (29)	28 (28)	29 (29)	30 (30)	27 (27)
11–15 years	29 (20)	18 (16)	22 (22)	23 (23)	23 (23)	29 (29)
16–20 years	23 (16)	13 (12)	8 (8)	11 (11)	7 (7)	12 (12)
>20 years	15 (10)	7 (6)	13 (13)	6 (6)	7 (7)	7 (7)
Symptoms, n (%)[c]						
Hypoglycemia	51 (34)	39 (35)	15 (15)	19 (19)	22 (22)	24 (24)
Fatigue	112 (76)	86 (76)	56 (56)	53 (53)	49 (49)	73 (73)
Insomnia or difficulty sleeping	90 (61)	72 (64)	47 (47)	39 (39)	41 (41)	59 (59)
Dizziness or fainting	50 (34)	42 (37)	18 (18)	12 (12)	15 (15)	34 (34)
Nerve pain	68 (46)	47 (42)	33 (33)	17 (17)	10 (10)	33 (33)
Problems concentrating	71 (48)	52 (46)	26 (26)	19 (19)	18 (18)	45 (45)
Joint stiffness	85 (57)	62 (55)	32 (32)	17 (17)	23 (23)	55 (55)
Frequent urination	72 (49)	63 (56)	52 (52)	34 (34)	39 (39)	48 (48)
Providers seen for T2D care, n (%)[d]						
PCP or GP	125 (84)	93 (82)	67 (67)	65 (65)	65 (65)	60 (60)
Endocrinologist	36 (24)	17 (15)	2 (2)	16 (16)	41 (41)	6 (6)
Diabetologist	2 (1)	10 (9)	55 (55)	24 (24)	7 (7)	15 (15)
Cardiologist	9 (6)	4 (4)	11 (11)	7 (7)	8 (8)	1 (1)
Pharmacist	12 (8)	20 (18)	3 (3)	0 (0)	4 (4)	4 (4)
Nurse practitioner	14 (9)	12 (11)	0 (0)	1 (1)	24 (24)	65 (65)
Certified diabetes educator	15 (10)	16 (14)	9 (9)	6 (6)	5 (5)	3 (3)
Podiatrist	17 (11)	10 (9)	20 (20)	4 (4)	9 (9)	18 (18)
Dietitian	5 (3)	20 (18)	1 (1)	16 (16)	3 (3)	10 (10)

Notes: [a]An additional three participants from Mexico were reported as being aged <1 year and were removed from the entire data set. [b]Comorbidities were chosen from a list of options. Study participants may have had other comorbidities not reported here. [c]Symptoms were selected from a list of common T2D symptoms. [d]A list of types of providers who may be involved in T2D care was presented. Response options were not mutually exclusive. Only providers seen by >10% of participants in any country are shown.

Abbreviations: GP, general practitioner; MDD, major depressive disorder; PCP, primary care physician; T2D, type 2 diabetes.

two-thirds (60%) of respondents, other than those in Mexico (43%), reporting that their diabetes was very well or fairly well controlled (Figure 1A). Spanish respondents were the most likely to indicate that, if they stayed at their current level of diabetes control, they did not expect any future diabetes-related complications (Figure 1B). Almost half of US and Canadian respondents expected complications within 5 years, compared with about one-quarter of respondents from the other countries.

Table 2 Participant-reported diabetes tests, A1C test results, and A1C targets

	USA (n=148)	Canada (n=113)	Germany (n=100)	Mexico (n=100)	Spain (n=100)	UK (n=100)
Which tests does your doctor normally do to check on your diabetes? n (%)						
A1C	144 (97)	87 (77)	85 (85)	23 (23)	44 (44)	82 (82)
Self-monitoring with a blood sugar meter at home	117 (79)	89 (79)	76 (76)	57 (57)	69 (69)	66 (66)
Fasting plasma glucose	73 (49)	73 (65)	55 (55)	70 (70)	67 (67)	33 (33)
Checking for sugar in urine	34 (23)	30 (27)	31 (31)	19 (19)	12 (12)	48 (48)
	(n=148)	(n=113)	(n=100)	(n=100)	(n=100)	(n=100)
Has your healthcare provider ever tested your A1C? n (%)						
Yes	147 (99)	96 (85)	88 (88)	72 (72)	75 (75)	82 (82)
No	0 (0)	2 (2)	1 (1)	18 (18)	4 (4)	3 (3)
I don't know	1 (1)	15 (13)	11 (11)	10 (10)	21 (21)	15 (15)
	(n=148)	(n=113)	(n=100)	(n=100)	(n=100)	(n=100)
When did you last have an A1C test? n (%)						
Within the last 3 months	105 (71)	62 (65)	77 (88)	43 (60)	38 (51)	40 (49)
Between 3 and 6 months	26 (18)	21 (22)	8 (9)	11 (15)	16 (21)	14 (17)
Between 6 months and 1 year	14 (10)	7 (7)	2 (2)	6 (8)	16 (21)	21 (26)
>1 year	1 (1)	5 (5)	1 (1)	12 (17)	5 (7)	6 (7)
I don't know	1 (1)	1 (1)	0 (0)	0 (0)	0 (0)	1 (1)
	(n=147)	(n=96)	(n=88)	(n=72)	(n=75)	(n=82)
What was your last measured % A1C value?[a]						
Mean (SD)	7.3 (1.6)	7.2 (1.2)	7.3 (1.4)	–	6.8 (1.3)	7.2 (1.5)
<6.0, n (%)	21 (16)	5 (9)	4 (5)	–	2 (4)	3 (7)
6.0–6.9, n (%)	46 (35)	18 (33)	18 (22)	–	26 (48)	14 (33)
7.0–7.9, n (%)	33 (25)	18 (33)	32 (40)	–	18 (33)	11 (26)
≥8.0, n (%)	32 (24)	14 (25)	27 (33)	–	8 (15)	14 (33)
	(n=132)	(n=55)	(n=81)	–	(n=54)	(n=42)
What do you think your last A1C test result means? n (%)						
Doing very well	36 (25)	18 (19)	7 (8)	13 (23)	10 (15)	13 (38)
Doing fairly well	62 (43)	45 (47)	57 (67)	15 (27)	36 (55)	16 (47)
Doing fairly poorly	36 (25)	23 (24)	14 (16)	18 (32)	8 (12)	0 (0)
Doing very poorly	12 (8)	4 (4)	5 (6)	7 (13)	5 (8)	3 (9)
I don't know	0 (0)	5 (5)	2 (2)	3 (5)	6 (9)	2 (6)
	(n=146)	(n=95)	(n=85)	(n=56)	(n=65)	(n=34)
Do you and your healthcare provider have a specific A1C target or goal? n (%)						
Yes	102 (70)	60 (63)	59 (59)	36 (64)	38 (38)	26 (26)
No	41 (28)	27 (28)	36 (36)	7 (13)	45 (45)	69 (69)
I don't know	3 (2)	8 (8)	5 (5)	13 (23)	17 (17)	5 (5)
	(n=146)	(n=95)	(n=100)	(n=56)	(n=100)	(n=100)
What is your % A1C goal or target? Mean (SD)[a]	6.4 (0.7)	6.4 (0.7)	6.4 (0.7)	–	6.1 (1.4)	6.9 (1.0)
	(n=95)	(n=44)	(n=54)	–	(n=54)	(n=20)
How high would your % A1C test result have to be for you to ask your doctor to do something about it, such as make a change to your treatment plan? Mean (SD)[a]	7.9 (1.6)	8.6 (1.3)	7.9 (1.1)	–	8.0 (1.3)	7.6 (2.1)
	(n=110)	(n=46)	(n=64)	–	(n=43)	(n=33)

Notes: [a]Data for Mexico have not been included owing to suspected confusion between A1C and glucose levels in participant responses. Additionally, data that did not fall between values of 4 and 14 were excluded, with the exception of values of 0.40–0.99 and 0.10–0.14; these were assumed to be in the decimal form and were multiplied by 10 or 100, respectively, and included.
Abbreviation: A1C, glycated hemoglobin.

North American respondents also anticipated a higher number of different complications, both within the next year and after 5 years, than European respondents, assuming that their diabetes remained at the same level of control (Figure 2A and B). Nerve pain, eye problems, sexual dysfunction, skin problems, and kidney problems were the most common complications that respondents reported they were likely to experience.

Diabetes medications and self-management

Overall, approximately two-thirds of respondents reported that they never missed medical appointments regarding their diabetes, although in Mexico this figure dropped to about half (Figure 3A). Participants across countries reported that they were frequently told by their doctor to take oral

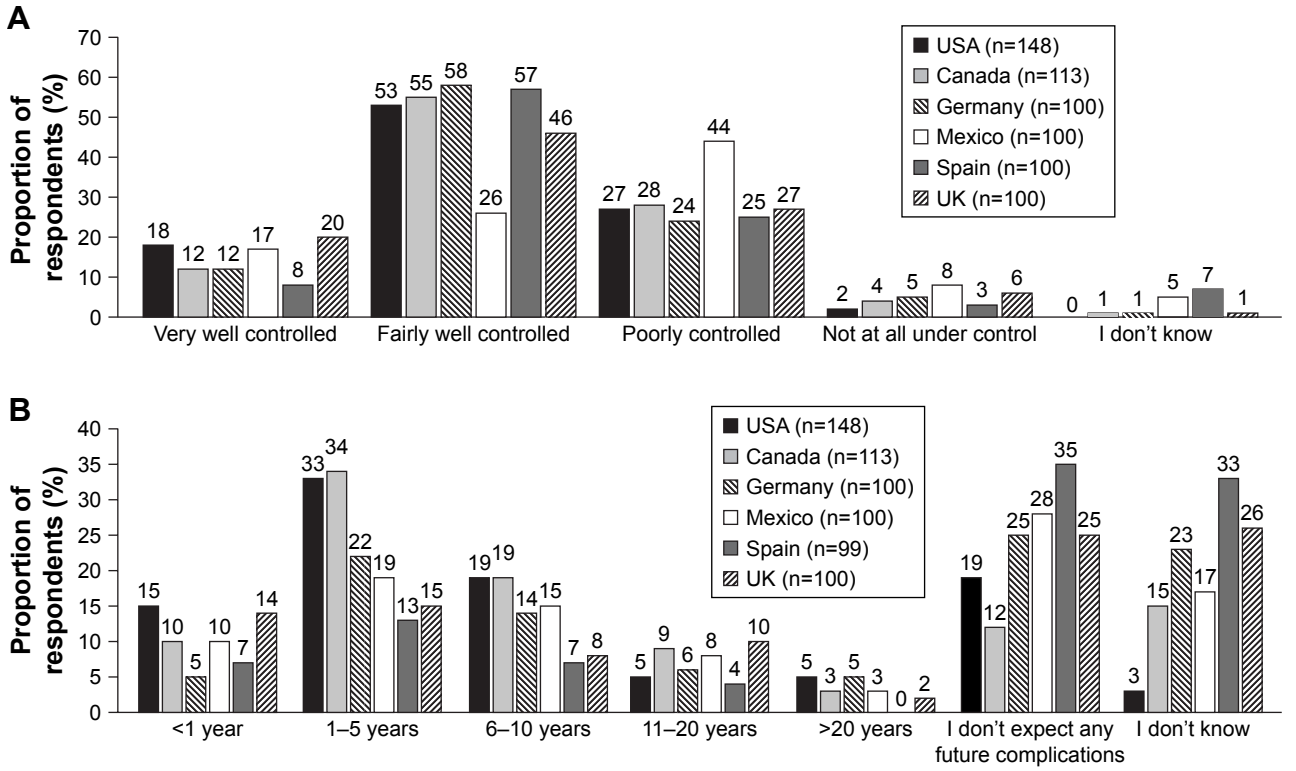

Figure 1 Participant perceptions of diabetes control and complications (part 1).
Notes: Responses to survey questions. (**A**) To what extent do you believe your diabetes is under control? (**B**) If you were to stay at your current level of diabetes control, for how long do you think you could avoid any serious complications due to your diabetes?

medications, to increase their levels of exercise, and to change their diet in order to improve their diabetes control (Figure 3B). Self-reported adherence to oral medication and insulin treatment was generally high, although adherence to insulin treatment appeared to be lower in the USA and Mexico than in the other countries (Figure 3C and D). The majority of respondents across countries reported that taking injectable medications was not at all burdensome or was a little burdensome (Figure 4A). When asked how important medications for T2D are in helping them achieve their diabetes goals, the vast majority (89%) of respondents across countries rated them as very important or important (Figure 4B); however, 27% of UK respondents said they were a very unimportant factor.

Regimen-related diabetes distress and attitudes toward diabetes self-management

Overall, approximately one-quarter to one-third of respondents' scores met or exceeded the clinical threshold for the Regimen-Related Distress domain of the DDS, with the highest proportion above the threshold being Canadian respondents and the lowest being German respondents (Table 3). The majority of respondents were confident that they could avoid serious problems due to low blood sugar when alone, and did not feel that worrying about the possibility of a low blood sugar episode interfered with their ability to do the things they wanted to do (Figure 5A and B). Responses across countries were similar regarding managing blood sugar to avoid hypoglycemic episodes, with approximately one-third of patients keeping their blood sugar levels higher than they should (Figure 5C).

Discussion

Individualized A1C targets, self-monitoring of blood glucose, and adherence to treatment are key pillars of T2D management guidelines. This survey-based study of patients with T2D in online health communities revealed several insights into patients' awareness of A1C testing and targets, their perceptions of their glycemic control, and their attitudes toward diabetes management.

Previous studies indicate that limited numbers of patients are aware of their current and target A1C levels.[11–13] The participants in our study who were aware of having an A1C target, approximately half of the total number, generally reported targets that were in line with national guidelines,[3,19–23]

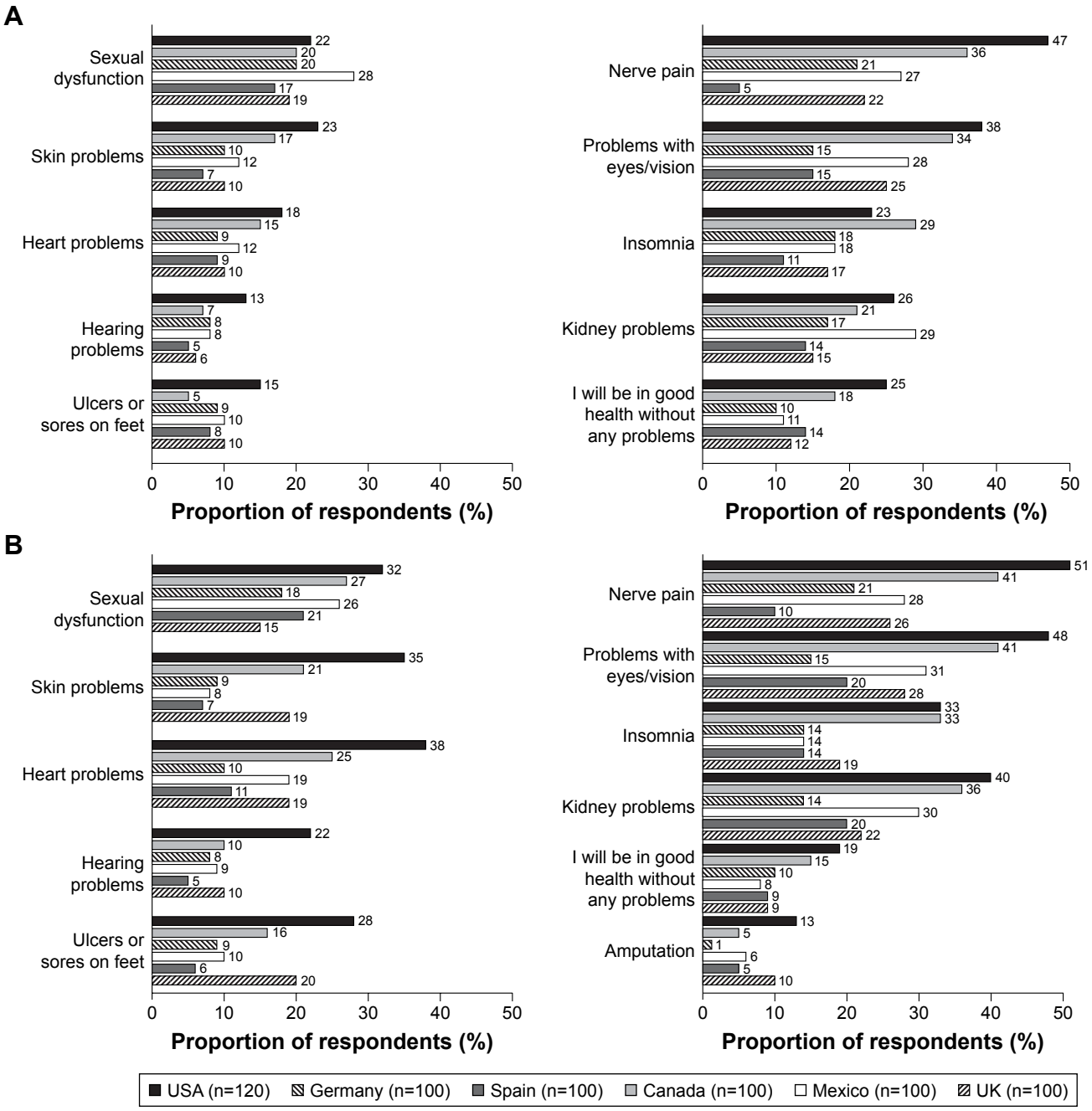

Figure 2 Participant perceptions of diabetes control and complications (part 2).
Notes: Responses to survey questions. (**A**) What do you think is likely to happen to you in the short term (within 1 year) if your diabetes stays at the same level of control? (**B**) What do you think is likely to happen to you in the long term (after 5 years) if your diabetes stays at the same level of control?

with a mean A1C value of 6.1%–6.9%. However, about half of participants who reported an A1C level at last test gave a value greater than 7.0%, generally considered to be a sign of uncontrolled glycemia,[2,3] although it should be noted that patient recollections of their last A1C test result may not be accurate.[11,12] Participant self-reported target A1C and last A1C test results were largely consistent between countries, suggesting that any slight differences between the national guidelines do not seem to have a great impact on patients' target and actual A1C values.

The majority of respondents across countries believed that their last test result indicated that they were doing very or fairly well, and that their diabetes was very or fairly well controlled. However, respondents did not feel that any change to their treatment plan was needed unless their A1C levels hit 7.6%–8.6% on average. This could suggest that patients

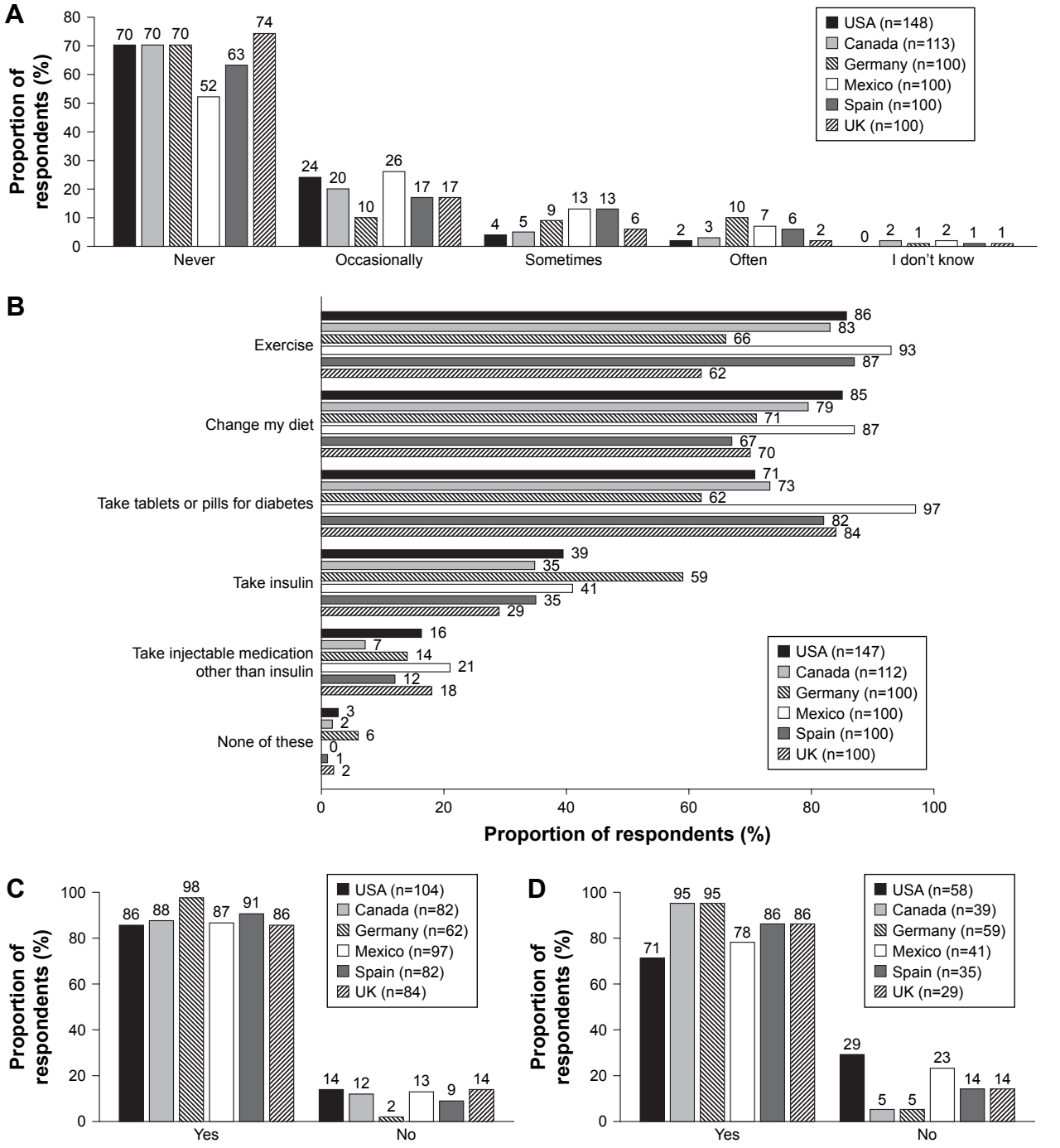

Figure 3 Participant behaviors relating to diabetes management.

Notes: Responses to survey questions. (**A**) How often do you miss or skip appointments, for any reason, with a healthcare provider to discuss or review your diabetes? (**B**) What has your doctor told you to do to manage/control your diabetes better? (**C**) Do you always take your pills or tablets as directed by your healthcare provider? (**D**) Do you always take your insulin as directed by your healthcare provider?

may overestimate the extent of their diabetes control, considering the A1C target set by their HCP to be an ideal target only and not feeling that action is required unless their A1C is considerably higher than this. Alternatively, HCPs may consider guideline A1C targets to be an ideal, with changes to patient treatment not being required until their A1C reaches a higher threshold.

Of further concern regarding patient adherence to A1C targets is that only about half of Canadian, Spanish, and UK respondents to our survey could recall their last A1C value, and only about one-third of UK and Spanish respondents were aware that they had an A1C target. In addition, the majority of respondents in Spain and Mexico did not think that their A1C levels were tested regularly by their HCP.

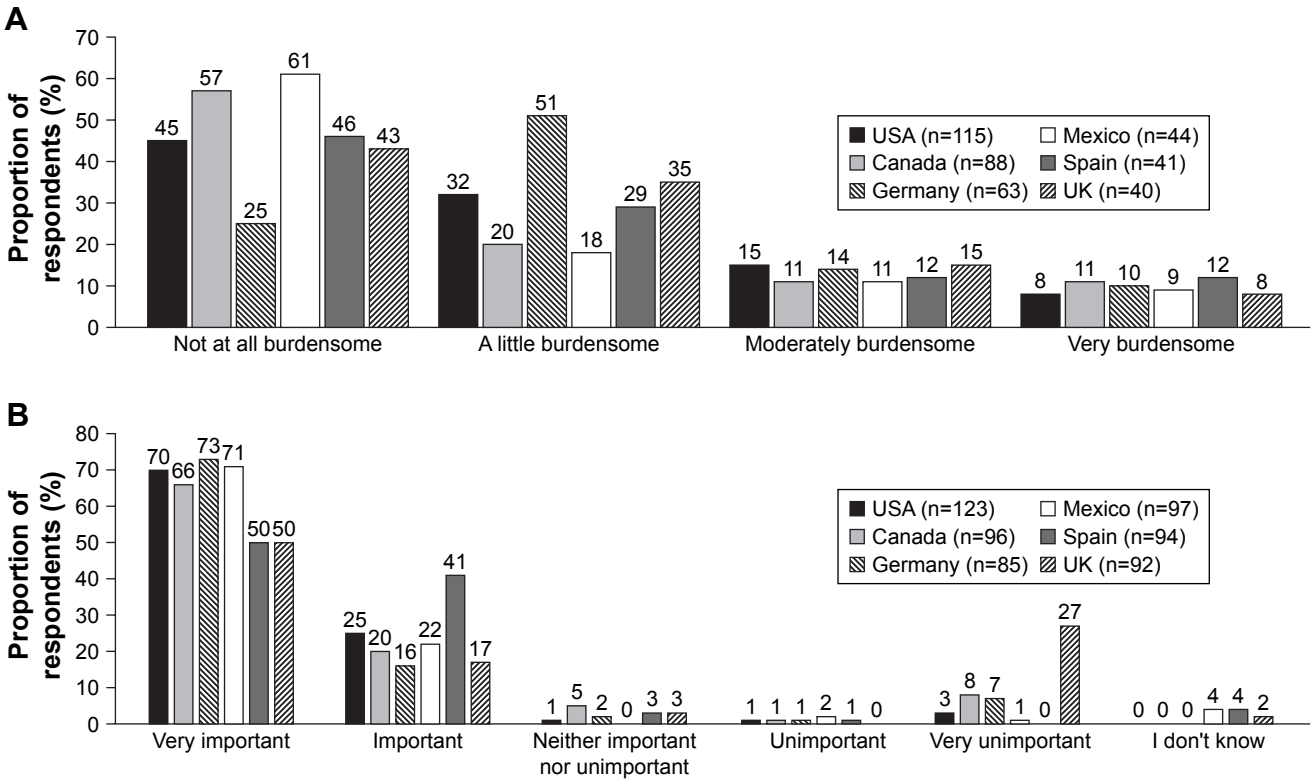

Figure 4 Participant perceptions of diabetes medications.
Notes: Responses to survey questions. (**A**) How burdensome would you say it is to take your injectable medication for your type 2 diabetes? (**B**) How important are medicines in helping you achieve your diabetes goals?

By contrast, almost all US respondents reported regular A1C testing, with almost 90% able to recall their last A1C value and over two-thirds aware that they had an A1C target. These findings suggest that A1C tests may be carried out more regularly in some countries than in others, which may be due to economic reasons, or that there may be variation in doctor–patient communication among these countries. In Spain and Mexico, for example, physicians may adopt a more paternalistic model of care than physicians in the USA, Canada, and northern Europe, and may therefore be less likely to communicate in detail about laboratory test results. Indeed, in a survey of patients in European countries, Spain had the lowest patient support for shared decision-making, favoring a doctor-led process;[28] while in Mexico, doctors are required only to give verbal (rather than written) summaries of medical records to patients.[29] By contrast, it has been the official policy of the US Department of Health and Human Services since 2014 to give patients direct access to their own test results;[30] this initiative seems to be reflected in our survey data. Our findings suggest that there is room for improvement in communication of A1C test results and targets between HCPs and patients in many countries. Patients' awareness of their A1C levels could also be improved by increased remote monitoring feedback via mobile devices and other telehealth technologies, as well as a broader implementation of continuous glucose monitoring with long-term sensors.

Table 3 Participant scores for the Regimen-Related Distress domain of the Diabetes Distress Scale

	USA (n=148)	Canada (n=113)	Germany (n=100)	Mexico (n=100)	Spain (n=100)	UK (n=100)
DDS – Regimen-Related Distress score, mean (SD)	12.4 (5.69)	13.1 (5.77)	11.1 (5.52)	11.9 (6.54)	10.9 (6.19)	11.2 (5.88)
Above DDS clinical threshold (≥3), % (n)	31.8 (47)	34.5 (39)	21.0 (21)	32.0 (32)	25.0 (25)	32.0 (32)

Notes: The Regimen-Related Distress domain of the DDS comprises five items, such as "how much has this problem bothered you during the last month: feeling that I am often failing with my diabetes regimen." Each item is assessed using a six-point Likert scale, ranging from "Not a problem" to "A very serious problem", scored from one to six. The item scores are summed to give the domain score. This is then divided by five to give a mean score, for which scores of three or higher are considered clinically significant.
Abbreviation: DDS, Diabetes Distress Scale.

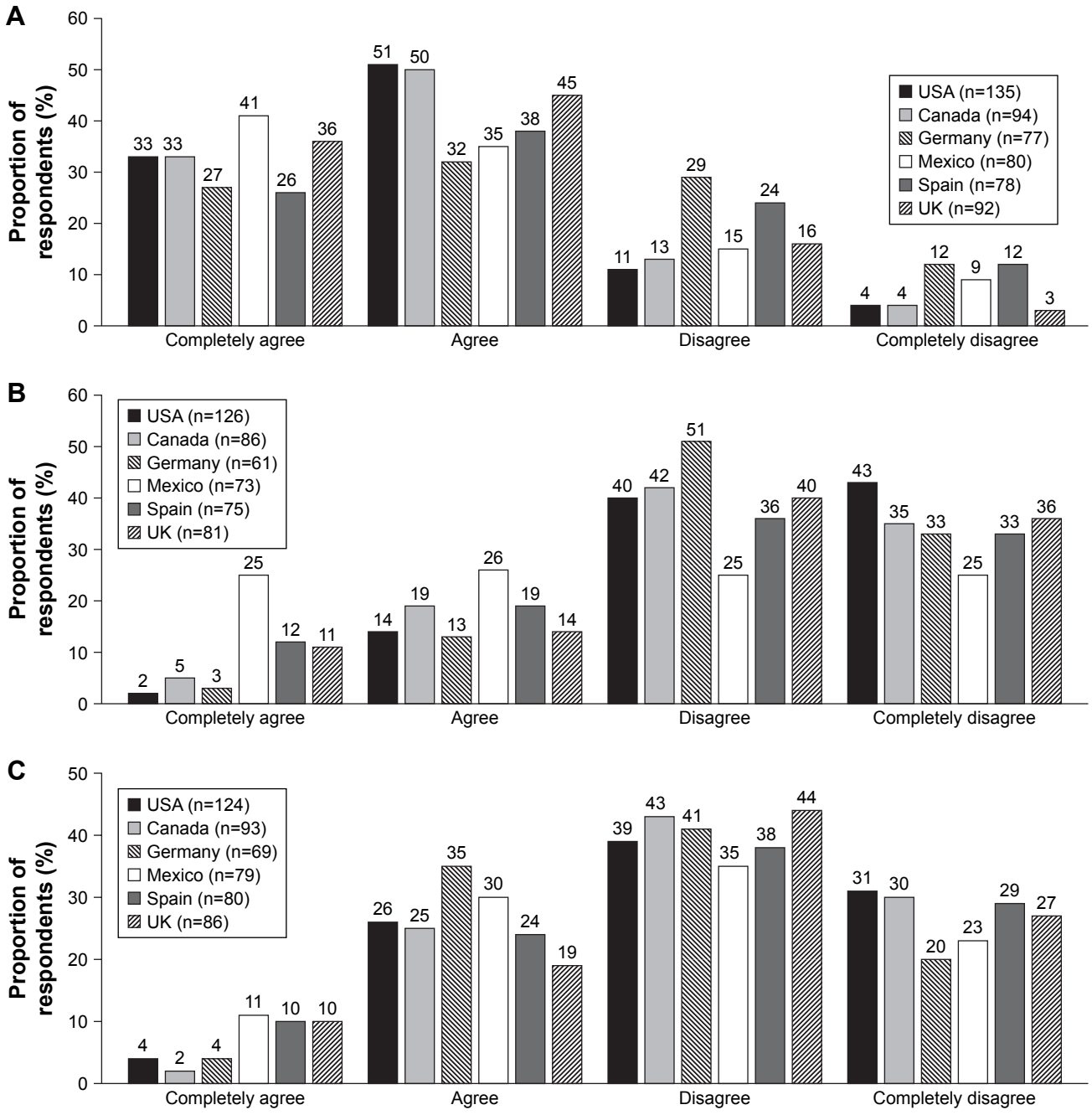

Figure 5 Participant attitudes toward diabetes self-management.
Notes: Responses to survey statements. (**A**) I am confident that I can avoid serious problems due to low blood sugar when I am alone. (**B**) I spend so much time worrying about the possibility of a low blood sugar episode that it interferes with my ability to do the things I really want to do. (**C**) To avoid serious problems with low blood sugar, I tend to keep my blood sugars higher than I probably should.

Although the majority of respondents across countries (other than in Mexico) had similar perceptions of their level of glycemic control, North American respondents expected to experience more diabetes-related complications in the future than their European counterparts, especially those from Spain. This finding may be explained by cultural and regulatory differences between North America and Europe. The high prevalence of T2D and widespread advertising of diabetes medication in North America is likely to increase awareness of T2D and its consequences.[31] Although few respondents expected to experience serious complications in general during the next year, when asked about specific complications many did expect to experience one or more of these in this time frame, particularly microvascular issues, such as neuropathy, retinopathy, sexual dysfunction, and skin problems, rather than cardiovascular issues. There are

several potential explanations for this response. It may be that patients do not perceive microvascular complications to be "serious," as was found in a telephone-based survey of patients with diabetes in the USA,[32] or that microvascular outcomes are more apparent in the shorter term. Alternatively, these patients may not associate diabetes with cardiovascular issues, as has been found in previous studies.[32,33] A recent systematic review of studies investigating the perceptions of diabetes-related complication risks in populations with T2D found that patients' perceptions are generally biased, characterized by optimism and low risk awareness.[34] In line with our findings, the review found that patients were less aware of their risk of experiencing macrovascular vs microvascular complications. Given that half of people with T2D die prematurely from cardiovascular disease,[35] it appears that patients may not be realistically evaluating their personal risk of developing macrovascular complications.

Patient-reported adherence to diabetes medications in the present study was generally high, albeit somewhat lower for insulin than for oral medications among respondents in the USA and Mexico, where patients may face higher out-of-pocket costs of treatment relative to income than in other countries.[36,37] Surprisingly, while the majority of respondents across countries believed that taking medications for T2D was an important or very important factor in achieving their diabetes goals, over one-quarter of respondents in the UK felt that it was very unimportant. This may suggest that, in comparison with their counterparts in other countries, UK physicians put more emphasis on lifestyle changes than on medication use when communicating with patients. When assessing self-management of their diabetes, respondents across countries appeared to be reasonably confident that they could adequately manage their blood sugar levels. Despite this confidence, a sizeable minority of respondents across countries had clinically significant levels of regimen-related distress. Diabetes distress has been linked with poor adherence and poor glycemic control;[38,39] however, greater levels of HCP support can decrease diabetes distress.[40,41] Improvement in HCP support for patients regarding their treatment, for instance by offering guidance on how often to test blood sugar levels and by providing, or referring patients to, nutrition support, may therefore reduce patient distress and improve diabetes outcomes.

Strengths and limitations

The major strength of this study is that it assessed data obtained directly from a network of patients with T2D in a real-world setting, offering context that cannot be observed in medical records. Use of an anonymous online survey may improve willingness to disclose sensitive information, such as medication nonadherence. Finally, direct access to patients through online communities enabled a potentially more diverse sample to be reached than could be reached through physicians' offices alone.

Several limitations of this work are noted, the first being sample generalizability and selection bias. The participants were a self-selecting population of patients who were concerned enough with their disease to become members of online health communities, therefore this group may overrepresent patient knowledge of T2D compared with the general T2D population. It may be expected that respondents to online surveys are likely to be younger, more computer-literate, and better educated than the general population. In addition, more participants in this study were female than male. These factors may also impact the generalizability of results to the general population of patients with T2D. A second limitation is that, because the study utilized a convenience sample, the populations from each country were not matched for variables such as age and duration of diabetes, and so were not homogeneously distributed, which may influence the interpretation of study results. A third limitation is that the accuracy of patients' perceptions could not be compared with their clinical data, introducing the possibility of recall bias. A fourth limitation is that participants may have had difficulties understanding the questions posed; some Mexican respondents appeared to conflate A1C and glucose levels when giving answers to A1C-based questions, providing responses that were clearly out of range for A1C tests, which led us to exclude these data. The questionnaire was not pretested in each country and we did not send a follow-up survey to assess comprehension.

Conclusion

Patients' knowledge of their glycemic control and targets, and the potential outcomes of poor control, varied between countries. Awareness of A1C testing and targets was high in the USA but considerably lower in Spain and the UK, and North American respondents anticipated a higher number of complications than European respondents. The majority of respondents across countries felt that their T2D was very or fairly well controlled, and few expected to experience serious complications within 1 year; however, many respondents expected to experience microvascular (rather than macrovascular) complications in this time frame. Our findings highlight the need for clear communication between HCPs and patients to ensure that the latter are aware of their

A1C levels and targets and to understand what is needed to achieve those targets. The potential consequences of poor glycemic control should also be communicated clearly to patients, including the possibility of macrovascular disease, of which they appear to be less aware. Furthermore, while patient self-reported adherence to medication was generally high and most respondents across countries felt that taking injectable medications was not overly burdensome, a sizeable minority still have regimen-related distress: HCPs should work with patients to support self-management, reduce distress, and improve diabetes outcomes.

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Author contributions

Kristina Simacek – conception and design of the study, acquisition and interpretation of data, and drafting and revising of the manuscript. Christopher Curran – conception and design of the study, acquisition and interpretation of data, and revising of the manuscript. Peter Fenici and Ricardo Garcia-Sanchez – conception and design of the study, interpretation of data, and revising of the manuscript. All authors gave final approval of the version to be published, and agree to be accountable for all aspects of the work.

Disclosure

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