

Contents lists available at [ScienceDirect](#)

Canadian Journal of Diabetes

journal homepage:
www.canadianjournalofdiabetes.com

Original Research

Diabetes Attitudes, Wishes and Needs Second Study (DAWN2): Understanding Diabetes-Related Psychosocial Outcomes for Canadians with Diabetes



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ARTICLE INFO

Article history:

Received 27 May 2015

Received in revised form

12 August 2015

Accepted 4 November 2015

Keywords:

DAWN

depression

diabetes

psychosocial

quality of life

support

Mots clés :

DAWN

dépression

diabète

psychosocial

qualité de vie

soutien

ABSTRACT

Objectives: DAWN2 assessed the psychosocial impact of diabetes on persons with diabetes (PWDs), family members and healthcare professionals (HCPs) across 17 countries. This article reports on the Canadian cohort of PWDs.

Methods: PWDs completed online, validated self-report scales assessing quality of life (QOL), self-management, beliefs, social support and priorities for improving diabetes care. Analyses used unweighted data.

Results: Of 500 participants (80 type 1, 420 type 2) positive self-reported QOL was common (64.6%) and likely depression less common (12.8%). Diabetes distress, however, was identified by almost half of PWDs with type 1 diabetes, and one-quarter of PWDs with type 2 (47.5% vs. 25.7% type 2; $p < 0.001$). Numerous life areas were negatively impacted, particularly finances, work and emotional well-being for those with type 1 diabetes ($p < 0.001$ vs. type 2). Most PWDs reported support from family, friends and HCPs, but few reported being asked by HCPs how diabetes affected their lives. Most PWDs participated in (type 1, 90.0%; type 2, 85.7%) and valued (type 1, 84.7%; type 2, 78.1%) diabetes education. Few PWDs relied on community supports (type 1, 17.5%; type 2, 26.9%), and discrimination was not uncommon for those with type 1 (33.8% vs. 12.4% for type 2; $p < 0.001$).

Conclusions: PWDs experience psychological challenges that should be addressed within diabetes management services.

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R É S U M É

Objectifs : L'étude DAWN2 évaluait les conséquences psychosociales du diabète sur les personnes atteintes du diabète (PAD), les membres de la famille et les professionnels de la santé (PS) de 17 pays. Le présent article rend compte d'une cohorte canadienne de PAD.

Méthodes : Les PAD remplissaient en ligne des échelles d'auto-évaluation validées sur la qualité de vie (QdV), la prise en charge autonome, les croyances, le soutien social et les priorités en vue d'améliorer les soins aux diabétiques. Les analyses utilisaient les données non pondérées.

Résultats : Les 500 participants diabétiques (80 de type 1, 420 de type 2) rapportaient fréquemment une QdV positive (64,6%) et moins fréquemment une dépression probable (12,8%). Cependant, presque la moitié des PAD de type 1 et le quart des PAD de type 2 (47,5% vs 25,7%; $p < 0,001$) rapportaient la détresse liée

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au diabète. De nombreuses sphères de la vie subissaient des conséquences négatives, particulièrement les finances, le travail et le bien-être émotionnel des PAD de type 1 ($p < 0,001$ vs PAD de type 2). La plupart des PAD rapportaient recevoir le soutien de leur famille, de leurs amis et des PS, mais peu rapportaient que les PS leur avaient demandé la manière dont le diabète affectait leur vie. La plupart des PAD y participaient (type 1, 90,0%; type 2, 85,7%) et valorisaient (type 1, 84,7%; type 2, 78,1%) l'enseignement du diabète. Peu de PAD comptaient sur le soutien communautaire (type 1, 17,5%; type 2, 26,9%). De plus, la discrimination n'était pas rare chez les PAD de type 1 par rapport aux PAD de type 2 (33,8% vs 12,4%; $p < 0,001$).

Conclusions : Les services de prise en charge du diabète devraient aborder les difficultés d'ordre psychologique auxquelles font face les PAD.

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Introduction

The psychosocial impact of living with diabetes has been an area of scientific study for some time (1). The evidence is clear that living with diabetes can affect one's emotional life, leading to increased risk for depression as well as other psychosocial problems (2–5). Further, the psychosocial impact of living with diabetes can negatively affect glycemic control. Therefore, managing psychosocial issues in diabetes might improve glycemic control (6–8). In Canada, the relevance of psychosocial factors in diabetes has been recognized for some time. The Canadian Diabetes Association (CDA) first included a chapter on psychological factors in diabetes in the 2003 Clinical Practice Guidelines (9). As well, the CDA actively endorses self-management and self-management support. The CDA website includes a number of interactive tools to assist healthcare professionals (HCPs) and persons with diabetes (PWDs) in addressing self-management issues (10).

As appreciation of the psychosocial impact of diabetes increases, a more thorough understanding of exactly what this means for PWDs is developing. The early literature in this area focused on a symptom approach to psychological experience. Instruments designed to detect levels of depressive or anxiety symptoms that would meet criteria for a mental health disorder diagnosis were used (4). More recently, there has been a focus on disease-specific psychosocial issues. In particular, diabetes distress (11,12), reluctance to start insulin (13,14), and fear of hypoglycemia (15,16) have been addressed. This research has been advanced significantly by a multinational survey called Diabetes Attitudes, Wishes and Needs (DAWN). In this first DAWN study, conducted in 13 countries, Canada did not participate (17). Results indicated that PWDs experienced significant emotional distress that interfered with diabetes outcomes (2,18). Despite the publication of these findings, the uptake of interventions to manage the psychosocial aspects of diabetes better remains a problem in Canada (19). Understanding the daily challenges of Canadians with diabetes would add to our understanding of the extent of psychosocial issues and what might be done about them. For instance, survey evidence suggests that intentional underdosing or avoidance of insulin is common among PWDs (20) and that fear of hypoglycemia is a significant concern for many PWDs (16,21). However, there are few resources in diabetes centres to address these psychosocial issues (22).

In the most recent Canadian Clinical Practice Guidelines, a distinction was made between depression as a mental disorder and diabetes distress (23). Diabetes distress is a construct in which the emotional burden is linked to the experience of living with diabetes (24,25). It can be assessed using the Problem Areas in Diabetes (PAID) (26) or the Diabetes Distress Scale (27). These scales are not symptom based but assess the extent to which the respondent experiences emotional burdens in living with diabetes, is distressed by the regimen activities of diabetes self-management, or experiences relationship distress (in relationships with HCPs or friends and family). This revision in understanding the role of psychological factors in diabetes, i.e. moving away from a symptom-based diagnostic model to a more descriptive diabetes-specific

psychosocial model, opens the door to better addressing the lived experience of those with diabetes. At the same time, it needs to be recognized that a full understanding of chronic disease should not be limited to the individuals with disease but should include the family (28) as well as the HCPs.

In recognition of the need to understand the psychosocial aspects of diabetes better, a second DAWN study, DAWN2, has recently been completed. DAWN2 is a global partnership (29) that aligns with the Global DAWN Call to Action (30), the World Health Organization (WHO) frameworks for people-centred and innovative chronic-illness care (31) and the International Alliance of Patients' Organizations (IAPO) declaration for patient-centred healthcare (32). Canada was a participant in DAWN2, along with 16 other countries on 4 continents.

The DAWN2 survey involved the assessment of people with diabetes (type 1 and type 2), family members providing support to those living with diabetes, and HCPs (general practitioners, endocrinologists, nurses and dietitians) providing diabetes care and treatment. Similar constructs were assessed in all 3 groups, allowing for a comparison among the groups. The overall aims of DAWN2 and initial global results have been published previously (29,33–35). In this article, results are presented for PWDs living in Canada, with a focus on quality of life (QOL) (likely depression and diabetes distress), treatment burden, empowerment, self-care management, healthcare provision and education as well as access to community resources and experiences of discrimination. The result of the HCP and family member groups have been published elsewhere (36,37).

Methods

Design and study participants

The DAWN2 methodology has been previously published (29). DAWN2 is a multinational, interdisciplinary and multistakeholder survey study undertaken in the following 17 countries: Algeria, Canada, China, Denmark, France, Germany, India, Italy, Japan, Mexico, the Netherlands, Poland, Russian Federation, Spain, Turkey, the United Kingdom and the United States (NCT01507116). Each country had a recruitment quota of 500 adults (≥ 18 years of age) with diabetes: 80 with type 1 and 420 with type 2 diabetes (100 persons using diet/exercise only, 170 using noninsulin medication and 150 treated with insulin). Type 1 diabetes was defined as diagnosis before 30 years, starting insulin treatment at diagnosis and continued use of insulin.

In the 11 DAWN2 countries with the highest Internet penetration (i.e. Canada, Denmark, France, Germany, Italy, Japan, the Netherlands, Poland, Spain, the United Kingdom and the United States), a hybrid recruitment method involving web-based and telephone recruitment was used. In Canada, all surveys were completed online between March and May 2012. Recruitment was done through a market research company (Harris Interactive, Rochester, New York, USA) that had access to multiple online patient panels. Citizens

signed up voluntarily to be part of such panels with the understanding that they would be asked to participate in surveys. Participants received reimbursement from these panels for participation as per the arrangement of the panel (reimbursement was on the order of \$10).

Instruments

The PWD survey included original DAWN questions as well as others from standardized or validated instruments in their original or shortened forms, including:

- The EuroQol-5D (38) visual analogue scale (EQ-5D VAS) to assess overall quality of health. Janssen (39) has recently published on the adequate psychometric properties of this scale.
- The WHOQOL-BREF Global Quality of Life (40) item, a single-item self-report measure of QOL that has been shown to have good psychometric properties (41,42)
- The WHO-5 Well-Being Index (WHO-5), which assesses QOL and incorporates a validated scoring algorithm to identify likely depression, with a score of ≤ 28 indicative of moderate to severe depression. It has been recently demonstrated to have good psychometric properties for use in diabetes (43).
- The Problem Areas in Diabetes Scale 5 (PAID-5) (44,45) to assess diabetes-specific distress, which has been demonstrated to have good psychometric properties as a short-form scale (46)
- Patient Assessment of Chronic Illness Care-DAWN Short Form (PACIC-DSF) (47,48), a modified version of the PACIC, which measures perceived self-management support. The psychometric properties of the short form have been verified by Goetz (49).
- Summary of Diabetes Self-Care Activities measure (SDSCA-6) (50) to assess self-reported diabetes self-care activities. The psychometric adequacy of this scale has been demonstrated with diabetes (51).
- Diabetes Empowerment Scale-DAWN Short Form (DES-DSF) (52) to assess self-efficacy. Anderson demonstrated the good psychometric properties of the short form (53).
- Health Care Climate DAWN Short Form 3 (HCC-DSF) (54) to assess the experience of being a patient in the healthcare system. The psychometric adequacy of this scale has been demonstrated recently by Rick (55).

The survey also included newly developed questions to investigate the impact of diabetes on life dimensions, levels of experienced discrimination and the needs or preferences for better education and support, and open-ended questions to capture individual experiences of living with diabetes.

In Canada, the survey was conducted in French or English, following the DAWN2 study approval by the Research Ethics Board of Capital Health in Halifax, Nova Scotia, Canada.

Statistical analyses

Descriptive data were summarized as means and standard deviations (SD) for continuous data and as percentages (%) for categorical data. All of the continuous measures were coded on a scale ranging from 0 to 100, with higher values indicating higher levels of the construct being measured. Differences between participants with type 1 and type 2 diabetes were tested using t tests for independent samples for the continuous measures and using the chi-square test for percentages. Results are presented as raw, unweighted data from the DAWN2 Canadian PWD sample.

Results

For the DAWN2 global study, each of the 17 countries recruited 500 PWDs. In Canada, the country recruitment quota of 80 persons

with type 1 diabetes and 420 with type 2 diabetes was met. Respondents were from all of the 10 provinces of Canada, and the distribution of participants matched the population distribution, i.e. the greatest number of participants were from Ontario (219), followed by Quebec (82), British Columbia (64), Alberta (43), Nova Scotia (30), Manitoba (25), New Brunswick (18), Newfoundland (8), Saskatchewan (5), Prince Edward Island (3) and the Northwest Territories (1). Provinces were collapsed into regions to allow for post hoc exploratory analysis of regional differences in selected measures. Regions were West (British Columbia, Alberta, Saskatchewan, Manitoba, Northwest Territories; $n=138$); Ontario ($n=219$); Quebec ($n=82$) and the Atlantic region ($n=59$). Due to the limited sample sizes and the fact that these were post hoc analyses, regional comparisons did not separate diabetes types.

The demographics of the Canadian sample are presented in Table 1. There was an even distribution for gender across both type 1 and type 2 diabetes populations. The majority of respondents reported diet and exercise as being key to their diabetes management, irrespective of diabetes type. In terms of complications and comorbidities, sleep disturbance and depression were common. PWDs with type 1 diabetes were significantly more likely to suffer from foot ulcers ($p<0.001$) but less likely to have heart disease ($p<0.05$) than were PWDs with type 2 diabetes. Just over one-half of respondents lived with a spouse or partner, but those with type 1 diabetes were more likely to live with a child under 18 years of age ($p<0.001$), with parents ($p<0.001$) or with other children under the age of 18 ($p<0.03$) than were those with type 2 diabetes. Individuals with type 1 diabetes were significantly more likely to be unable to work full time because of diabetes than were those with type 2 diabetes ($p<0.001$).

Quality of life and treatment burden

Table 2 presents the key psychosocial outcomes for PWDs in Canada. Respondents generally reported a positive QOL; 64.6% of respondents (67.5% with type 1; 64.0% with type 2) reported their QOL to be good or very good. Further, self-reported health status was rated in the upper range on a visual analogue scale where 0 is the worst health imaginable and 100 the best (71.16, 18.01). The percentages of respondents meeting the WHO criteria for likely depression were 7.5% for type 1 and 13.8% for type 2 diabetes.

In contrast to this generally positive picture of well-being, there was evidence of common diabetes-specific concerns. People with type 1 diabetes scored significantly higher on the PAID-5 scale for diabetes distress than did those with type 2 diabetes ($p<0.001$); 47.5% of those with type 1 and 25.7% of those with type 2 reported high diabetes distress ($p<0.001$). Furthermore, the impact of diabetes (DIDP scale) was higher in those with type 1 than type 2 diabetes ($p<0.04$). Diabetes had a negative impact on many aspects of daily life for PWDs, especially on their physical health (62.4%), emotional well-being (47.6%), finances (40.4%) and leisure (40.2%). More people with type 1 than with type 2 diabetes reported negative impacts of diabetes on their finances ($p<0.04$), leisure ($p<0.008$), work ($p<0.004$) and emotional functioning ($p<0.001$). A substantial percentage of respondents, particularly those with type 1 diabetes ($p<0.001$), reported that diabetes medications interfered with their ability to live life normally and expressed significant worry about hypoglycemia ($p<0.001$). Notably, in the context of the daily burden of living with diabetes, approximately one-quarter (26.6%) of the respondents overall reported that diabetes also had a positive impact on at least 1 life dimension. However, within any specific life dimension, no more than 15% of the sample reported positive experiences.

Regional differences in QOL and treatment burden were explored using 1-way ANOVAs for continuous measures and chi-square for dichotomous measures. No statistical comparisons resulted in

Table 1
Characteristics and demographics of persons with diabetes in Canada

PWD	Type 1 diabetes (n=80)	Type 2 diabetes (n=420)	Total (n=500)
Age mean (SD)	37.2 (13.89)	57.1 (11.27)	54.0 (13.82)
Gender, n (%)			
Men	44 (55.00)	216 (51.40)	260 (52.00)
Women	36 (45.00)	204 (48.60)	240 (48.00)
BMI (kg/m ²), mean (SD)	26.0 (6.92)	32.47 (8.36)	31.4 (8.47)
Diabetes duration, mean (SD)	20.86 (14.99)	11.18 (9.98)	12.73 (11.48)
Glucose-lowering treatment, n(%)			
Diet and exercise	59 (73.80)	299 (71.20)	358 (71.60)
Alternative medicine	7 (8.80)	19 (4.50)	26 (5.20)
Oral hypoglycemic agents	15 (18.80)	238 (56.70)	253 (50.60)
Insulin	80 (100.00)	150 (35.70)	230 (46.00)
Other diabetes medication by injection	3 (3.80)	13 (3.10)	16 (3.20)
Other	0 (0.00)	4 (1.00)	4 (0.80)
None of these	0 (0.00)	5 (1.20)	5 (1.00)
Without complications/comorbidities, n (%)	22 (27.5)	109 (26.0)	131 (26.2)
With complications/comorbidities, n (%)	58 (72.50)	311 (74.00)	369 (73.80)
Stroke	6 (7.50)	37 (8.80)	43 (8.60)
Foot ulcers	15 (18.80)	36 (8.60)	51 (10.20)
Foot/leg amputation	0 (0.00)	3 (0.70)	3 (0.60)
Kidney disease	9 (11.20)	37 (8.80)	46 (9.20)
Eye damage	18 (22.50)	81 (19.30)	99 (19.80)
Nerve damage	14 (17.50)	57 (13.60)	71 (14.20)
Sexual dysfunction	17 (21.20)	97 (23.10)	114 (22.80)
Heart disease	7 (8.80)	74 (17.60)	81 (16.20)
Depression	32 (40.00)	136 (32.40)	168 (33.60)
Sleeping problems	38 (47.5)	193 (46.0)	231 (46.2)
Living situation, n (%)			
With spouse/partner	47 (58.8)	271 (64.50)	318 (63.60)
With son/daughter aged <18 years	24 (30.00)	55 (13.10)	79 (15.80)
With son/daughter aged ≥18 years	9 (11.20)	59 (14.00)	68 (13.60)
With parents	17 (21.20)	17 (4.00)	34 (6.80)
With other adult relatives	4 (5.00)	23 (5.50)	27 (5.40)
With other non-relative adults	2 (2.50)	13 (3.10)	15 (3.00)
With other children aged <18 years	6 (7.50)	11 (2.60)	17 (3.40)
Alone	13 (16.20)	93 (22.10)	106 (21.20)
Work situation n (%)			
Full time	42 (52.50)	120 (28.60)	162 (32.40)
Part time	8 (10.00)	45 (10.70)	53 (10.60)
Not working full time because of diabetes	11 (64.70)	23 (18.70)	34 (24.30)
Not working	30 (37.50)	255 (60.70)	285 (57.00)
Looking for work	2 (2.50)	28 (6.70)	30 (6.00)
Not looking for work	0 (0.00)	5 (1.20)	5 (1.00)
Unable to work	7 (8.80)	45 (10.70)	52 (10.40)
Retired	7 (8.80)	157 (37.40)	164 (32.80)
Student	7 (8.80)	3 (0.30)	10 (2.00)
Stay-at-home spouse or partner/housewife/husband	7 (8.80)	17 (4.00)	24 (4.80)
Urban/nonurban setting, n (%)			
Large city	44 (55.00)	154 (36.70)	198 (39.60)
Small city or large town	15 (18.80)	130 (31.00)	145 (29.00)
Suburban area	14 (17.40)	58 (13.80)	72 (14.40)
Village or rural area	7 (8.80)	78 (18.60)	85 (17.00)
Level of education, n (%)			
Grad college/university	43 (53.80)	175 (41.70)	218 (43.60)
At least some college education	15 (18.80)	93 (22.10)	108 (21.60)
High school or less	22 (27.50)	151 (36.00)	173 (34.60)

BMI, body mass index; PWDs, persons with diabetes; SD, standard deviation.

Note: Data in bold indicate significant difference ($p < 0.05$) between those with type 1 and 2 diabetes.

significant differences between regions on any measure (all p values > 0.05).

Empowerment and self-care activities

Mean empowerment scores (DES-DSF scale) were higher for those with type 1 than with type 2 diabetes ($p < 0.001$) (Table 2). The activities least engaged in on a weekly basis were physical activity and checking feet (Table 2). Within these general results, people with type 1 diabetes were more likely to self-monitor blood glucose levels ($p < 0.001$).

Post hoc analysis of regional differences did not show any differences in empowerment scores, but differences were found in following healthy meal plans ($p < 0.01$) and self-monitoring blood

glucose levels ($p < 0.02$). Regional differences were seen between the West and Quebec; those in the West reported more strict adherence to healthful eating and less self-monitoring than those in Quebec.

Healthcare provision

The Canadian sample of respondents reported that HCPs were vigilant in measuring their long-term glucose control and commonly examined their feet but were less likely to ask about their diets or emotional functioning (anxiety or depression) (Table 2). Mean scores for patient-centred care were low overall (PACIC-DSF), but were significantly higher for people with type 1 than with type 2 diabetes ($p = 0.001$). Just over one half of respondents reported

Table 2
Views and perceptions of persons with diabetes from Canada on matters relating to diabetes care

People with diabetes	Type 1 diabetes (n=80)	Type 2 diabetes (n=420)	Total (n=500)
Self-reported health status			
EQ-5D VAS, mean (SD)	72.32 (15.20)	70.94 (18.51)	71.16 (18.01)
QOL/Treatment burden			
WHOQOL-BREF: Global Quality of Life			
Composite score N(%), mean (SD)	68.12 (23.18)	65.30 (24.05)	65.75 (23.91)
QOL rating, n (%)			
1. Poor/very poor	8 (10.00)	57 (13.50)	65 (13.00)
2. Neither poor nor good	18 (22.50)	94 (22.40)	112 (22.40)
3. Good/very good	54 (67.50)	269 (64.00)	323 (64.60)
WHO-5: Psychological well-being:			
Composite score, mean (SD)	58.60 (18.91)	58.09 (23.21)	58.17 (22.57)
% with likely depression, n (%)	6 (7.50)	58 (13.80)	64 (12.80)
PAID-5: Diabetes distress:			
Composite score, mean (SD)	38.00 (24.02)	26.31 (23.37)	28.18 (23.84)
% with high diabetes distress, n (%)	38 (47.50)	108 (25.70)	146 (29.20)
DIDP			
Composite score, mean (SD)	59.01 (14.66)	54.84 (16.41)	55.52 (16.20)
How does diabetes currently impact your... (% reporting "slightly negative" to "very negative" impact), n (%):			
Physical health	57 (71.20)	255 (60.70)	312 (62.40)
Financial situation	41 (51.20)	161 (38.30)	202 (40.40)
Relationships (family/friends/peers)	21 (26.20)	72 (17.10)	93 (18.60)
Leisure activities	43 (53.80)	158 (37.60)	210 (40.20)
Work or studies	33 (41.20)	106 (25.20)	139 (27.80)
Emotional well-being	53 (66.20)	185 (44.00)	238 (47.60)
% reporting a positive impact of diabetes on at least 1 life dimension, n (%)	23 (28.70)	108 (26.20)	131 (26.60)
"My diabetes medication routine interferes with my ability to live a normal life" (% mainly/fully agree), n (%)	31 (40.30)	80 (25.80)	111 (28.60)
"I am very worried about the risk of hypoglycemic events" (% mainly/fully agree), n (%)	50 (67.00)	148 (36.90)	198 (41.40)
"It is difficult to pay for the diabetes medication" (% mainly/fully agree), n (%)	20 (25.00)	106 (25.20)	126 (25.20)
Empowerment/involvement:			
DES-DSF			
Composite score, mean (SD)	48.37 (18.94)	38.94 (18.79)	40.45 (19.11)
Self-management			
SDSCA-6 (mean days per week [SD]): On how many of the last 7 days...			
Have you followed a healthy eating plan?	4.80 (1.93)	4.90 (2.15)	4.89 (2.11)
Did you participate in ≥30 min activity?	4.04 (2.03)	3.50 (2.37)	3.59 (2.32)
Did you test your blood sugar?	5.92 (1.97)	4.29 (2.86)	4.55 (2.80)
Did you test your blood sugar the number of times recommended by you HCP?	5.42 (2.13)	3.96 (2.96)	4.19 (2.90)
Did you check your feet?	4.26 (2.42)	3.75 (2.82)	3.84 (2.76)
Did you take all your diabetes medications exactly as agreed with your HCP?	6.11 (1.55)	6.28 (1.64)	6.24 (1.62)
Support for self-management			
DFSS: Support received from the person most involved in diabetes care			
DSDSAP:			
Composite score, mean (SD)	60.88 (19.80)	55.23 (22.63)	56.28 (22.22)
How supportive have the following people been in helping you... (% somewhat/very supportive), n (%):	70.77 (26.72)	67.40 (28.08)	67.95 (27.87)
Your family	70 (87.50)	331 (78.80)	401 (80.20)
Friends and people close to you	67 (83.80)	267 (63.60)	334 (66.80)
People at work or school	43 (53.80)	99 (23.60)	142 (28.40)
Healthcare team	76 (95.00)	371 (88.30)	447 (89.40)
Other people in your community	29 (36.20)	94 (22.40)	123 (24.60)
Healthcare provision			
Tests/patient-reported quality indicators			
In the past 12 months, did anyone from your healthcare team (% reporting yes), n (%):			
Measure your long-term blood sugar control level?	59 (73.80)	314 (74.80)	373 (74.60)
Examine your feet?	46 (57.50)	235 (56.00)	281 (56.20)
Ask if you have been anxious or depressed?	35 (43.80)	149 (35.5)	184 (36.80)
Ask about the types of foods you have been eating?	42 (52.50)	173 (41.20)	215 (43.00)
PACIC-DSF:			
Composite score, mean (SD)	43.56 (21.76)	33.72 (24.61)	35.27 (24.42)
"I was asked how my diabetes affects my life" (% reporting "most of the time"/"always"), n (%)	15 (18.80)	53 (12.60)	68 (13.60)
"I was satisfied that my care was well organized" (% reporting "most of the time"/"always"), n (%)	46 (57.50)	219 (52.10)	265 (53.00)
HCC-DSF:			
Composite score, mean (SD)	56.33 (28.96)	47.88 (32.65)	49.21 (32.22)
Education			
% participating in any diabetes educational programmes/activities, n (%)	72 (90.00)	360 (85.70)	432 (86.40)
% reporting that educational programmes attended were "somewhat"/"very" helpful, n (%)	61 (84.70)	281 (78.10)	342 (79.20)
Community resources			
% who do not rely on any of the measured sources of education, information or support, n (%)	14 (17.50)	113 (26.90)	127 (25.40)
Society			
"I have been discriminated against because of my diabetes" (% who "mainly"/"fully" agree), n (%)	25 (33.80)	49 (12.40)	74 (15.80)

DES-DSF, Diabetes Empowerment Scale-DAWN Short Form; DFSS, DAWN Family Support Scale; DIDP, DAWN Impact of Diabetes Profile; DSDSAP, DAWN Support for Diabetes Self-Management Profile; EQ-5D VAS, EuroQol-5D visual analogue scale; HCC-DSF, Health Care Climate Questionnaire-DAWN Short Form; NA, not applicable, indicates that no Cronbach alpha was computed because inter-item agreement could not be assessed for single-item measures; PACIC-DSF, Patient Assessment of Chronic Illness Care-DAWN Short Form; PAID-5, Problem Areas in Diabetes Scale 5; QOL, quality of life; SDSCA-6, Summary of Diabetes Self-Care Activities-6; WHO-5, World Health Organization Well-Being Index 5; WHOQOL BREF, World Health Organization Quality of Life (an abbreviated version of the WHO-QOL-100).

Note: Data in bold indicate significant difference ($p < 0.05$) between type 1 and 2 diabetes.

being satisfied that their healthcare was well organized most or all of the time, but only 13.6% reported that their HCPs asked about how diabetes affected their lives. Approximately one-quarter of the PWDs reported that they had difficulty paying for diabetes medications. Regional comparisons failed to show differences in patient-centred care, satisfaction with care or being asked about how diabetes affects their lives ($p>0.05$).

Education and information

A high proportion of PWDs affirmed that they had access to and valued diabetes education; 86.4% had attended diabetes education programmes or activities; and of these, 79.2% considered them to be somewhat or very helpful (Table 2). In the year prior to the study, nearly one-quarter (23.4%) of PWDs had attended 1-to-1 sessions with HCPs, and 12% had attended group-education sessions. When asked about education received more than 1 year before the study's start, an additional 45.8% of PWDs reported having participated in 1-to-1 sessions and 41.8% in group education.

Regional analyses found that the percentage of attendance at education was higher in the East than in the rest of the country ($p<0.01$), although the rates of satisfaction with education did not differ.

Family and societal support

In general, PWDs reported that family members, friends and HCPs were supportive, whereas fewer PWDs considered people at work and in the community to be supportive (Table 2). However, more of the people with type 1 than with type 2 diabetes reported friends ($p<0.001$), people at work ($p<0.001$) and people in the community ($p<0.009$) to be very supportive.

Although PWDs with both type 1 and type 2 diabetes experienced discrimination because of their diabetes, those with type 1 diabetes were significantly more likely to experience discrimination than those with type 2 diabetes ($p<0.001$). Regional analyses did not show differences in reports of discrimination ($p>0.05$) but did show differences in 2 of the measures of support: support from family ($p=0.005$) and from friends ($p<0.001$). In both cases, those from Quebec reported less support than those from the rest of Canada.

Discussion

The DAWN2 study aimed, in part, to understand the needs of PWDs and the effects that diabetes has on their lives and well-being. Canadians with diabetes from across the country participated in the survey that examined a wide range of psychosocial and diabetes-management issues. This study provides unique insights into the lives of PWDs.

The findings shed light on the psychological experiences of Canadians with diabetes. Reported rates of depressive symptoms were in keeping with those found in the general literature, suggesting that depressive experience in those with chronic diseases such as diabetes is approximately twice that of the general population. At a population level, however, overall risk for depressive symptoms remains low, and in those with type 2 diabetes, quite low (7.5%). In contrast, diabetes distress was alarmingly common, especially for those living with type 1 diabetes, where approximately 1 of 2 PWDs reports significant diabetes distress. Further, PWDs reported that diabetes negatively impacted virtually all aspects of life, including physical health, finances, work and leisure activities, relationships and emotional well-being. Based on the rates of diabetes distress and interference, one would predict that every second person with type 1 diabetes and every fourth person with type 2 diabetes seen in clinical practice experiences significant psychosocial

concerns related to their diabetes. Clearly, this is a call to action for providing services that directly address the issues of diabetes burden and daily function. In this context, screening for depression symptoms might be insufficient. We can use these findings to support diabetes professionals in assessing diabetes distress and the aspects of life impacted by diabetes. Tools such as the Problem Areas in Diabetes (PAID) (26) or the Diabetes Distress Scale (27) are available for such assessments. Further, disease-specific distress implies that integrating psychological resources into organized diabetes services would be preferable to the current standard of care, which is to refer PWDs identified as having psychosocial issues to an external mental health service. Many mental health services are unfamiliar with both diabetes and diabetes-related psychosocial issues. In a separate publication describing the responses of healthcare providers as part of the DAWN2 study, the results have helped us to understand that although they are sensitive to the importance of the psychological issues of those living with diabetes and are desirous of training to support PWDs, few have had access to such training (37).

Understanding the impact of diabetes on PWDs can help to devise more effective self-management plans. When one encounters significant burden, emotion-management interventions can be incorporated into the care plan. Similarly, problem-solving approaches commonly used to navigate diabetes management behaviours can be extended to address the issues of psychosocial interference. Strategies for supporting behaviour change in PWDs can empower HCPs to collaborate with PWDs and address complex issues. Communication skills, motivational interviewing and interventions promoting emotional health can help providers to expand their focus beyond the biomedical so as to adopt a whole-person approach (33,34). If this is not addressed, the psychosocial impact of living with diabetes might be akin to the "elephant in the room." As reflected in the Canadian Clinical Practice Guidelines, if psychological issues are addressed, it tends to take place in the context of screening for the presence of depressive symptoms (23). However, the DAWN2 findings from the Canadian cohort suggest that diabetes distress and interference with life tasks have the biggest impacts on PWDs. It is hoped that these findings will encourage clinicians to empower PWDs by assessing and promoting psychological resources and resiliency.

One of the strengths of the DAWN2 survey was the assessment not only of the negative aspects of living with diabetes but also of the aspects of the experience of diabetes that elicited coping skills and resilience (33). So, despite the fact that the emotional burdens were higher in those with type 1 than with type 2 diabetes, empowerment scores were also higher in those with type 1 diabetes. It may be that part of the experience of being burdened by diabetes is the elicitation of coping skills or resiliency. These results suggest that much can be learned by addressing the psychological experiences of PWDs. Diabetes is more than a biomedical disease.

Diabetes does not occur in a vacuum but in the context of the interpersonal world. PWDs in this study reported overall high levels of support from their immediate connections (family, friends, HCPs). Although family members were supportive of PWDs, in a separate publication concerning family members of PWDs, also part of the DAWN2 study, we reported that 33% of family members experienced high psychological distress related to the persons they lived with having diabetes (36). Other experiences of family members included emotional burdens as well as worry about how best to support the PWDs (36). It is interesting that although PWDs reported overall high rates of support from HCPs, they also reported low rates of interest by providers in assessing the impacts of diabetes on persons' lives. Given this positive climate, HCPs might be reassured that asking about how diabetes impacts persons' lives would be well received by PWDs. Consistent with this is the recent release of the Diabetes Charter by the CDA (56).

When the view outward toward the community and work environments is extended, the experience of support was found to be lower, especially for people with type 1 diabetes. This justifies a public education campaign to increase awareness of and support for people living with diabetes, particularly to clarify the differences between type 1 and type 2 diabetes. As the rate of diabetes increases across the globe, the importance of more public acceptance will also increase. Not only is the need for increased support justified, but the substantial report of discrimination experienced by those living with type 1 diabetes deserves to be addressed. More public awareness of type 1 diabetes may help to address this discrimination. Perhaps most important, the voices of individuals living with diabetes should be encouraged. Greater recognition and understanding of the lived experience of diabetes will be needed to combat discrimination.

Many of the respondents in this survey had participated in diabetes education services and had found them to be helpful. The most common form of delivery of service was in a 1-on-1 format. In the recent publication of the global DAWN2 results (33), Canada was the country with the highest participation in diabetes education. Cross-national comparisons of other measures generally show that Canada falls in the midrange of countries (33).

The Canadian DAWN2 results help to identify the strengths of the Canadian healthcare system, such as the provision of diabetes education and the management of diabetes. The results also highlight areas of weakness, such as the management of psychological aspects of diabetes, in which HCPs do not appear to address the psychosocial effects of diabetes. Regional comparisons of the survey results were preliminary, given that they were post hoc. Nonetheless, several regional differences were noted that are worth exploring further. Using the data collected, those living in Quebec reported less support from family and friends than did those living in the rest of Canada, and they were less likely to report healthful eating and more likely to report self-monitoring than those from the West. Also, attendance at diabetes education was higher in the East than in the rest of the country. No regional differences were found concerning quality of life or distress measures. Further research might examine the potential for regional harmony.

Although these findings are illustrative, they are not without limitations. First, the data are self-reported and, therefore, the questions were open to subjective interpretation by the individuals surveyed. In addition, the scales used, while validated, were generally short-form versions of the scales. This allowed the breadth of information obtained to be balanced with the need to offer a survey that could be completed in reasonable time frame. Full versions of the scales would have provided a more thorough understanding by enabling the examination of subscales. Second, this survey was conducted online, a method that was chosen partially to avoid clinic-based sampling. As a result, the sample of PWDs in this study is not representative of those who do not use the Internet.

In summary, these survey results identify several important areas for improvement in person-centred care in diabetes. First, these findings highlight the psychosocial impact of living with diabetes. In particular, it might be beneficial to look beyond measuring symptoms of depression to the concept of diabetes distress, as well as elucidating which aspects of life diabetes impacts. Further, assessing areas of resiliency and coping would be useful. Framing an assessment in this way is consistent with the perspective of self-management support. That is, rather than a reductionist and diagnostic approach, one can understand what diabetes means to people with respect to emotions (distress), impact (life roles) and coping resources. Second, these results suggest that the lack of acceptance of diabetes at the level of the community and, in particular, in the workplace is reason for concern. Third, Canadians appear to be open to diabetes education and to find it valuable. This is encouraging because it implies that our citizens would be open to novel

approaches to managing the whole person; i.e. a system more genuinely based on person-centred care.

Acknowledgements

The DAWN2 study is a global partnership of established organizations, including the International Diabetes Federation, the International Alliance of Patients' Organizations, the Steno Diabetes Center and Novo Nordisk. Novo Nordisk funded the DAWN2 study, which was overseen by the DAWN2 Study Group (www.dawnstudy.com). DAWN and DAWN2 are registered trademarks of Novo Nordisk. For more information, contact dawninfo@novonordisk.com. Editing support, funded by Novo Nordisk, was provided by Bioscript Medical, Macclesfield, Cheshire, United Kingdom.

Author Disclosures

MV is on an Ad Board for Novo Nordisk and Abbvie and receives speaking fees and travel expenses from Novo Nordisk, Abbvie, Merck, BD and Sanofi; KKB has received travel and expense reimbursement from Novo Nordisk for DAWN2 study meetings and related events; DH has received honoraria and travel expenses for an advisory meeting and presentation; JH is an employee of Novo Nordisk; SR has provided medical writing assistance to Novo Nordisk Canada.

Author Contributions

MV was lead author of the paper and, as such, contributed substantially to its design and content, including data analysis, results and presentation, tables and graphs and discussion and provided final approval; KKB contributed substantially to the design and content of the paper, including suggestions for data results and presentation, table and graphs and discussion; DH, SR and JH revised the drafts of this manuscript critically for important intellectual content.

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