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Research

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Psychosocial and Management Experiences of Canadian Family Members Living with People with Diabetes: The Second Diabetes Attitudes, Wishes and Needs Study (DAWN2™)

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Abstract

Aim: To explore the psychosocial impacts, needs and wishes of Canadian Family Members (FMs) of People With Diabetes (PWD), as part of the second global Diabetes Attitudes, Wishes and Needs (DAWN2™) study.

Methods: Over 2000 FMs including 121 Canadians participated in an online survey comprising various standardized, adapted, original DAWN, new and open-ended questions to determine and assess the lived experiences of FMs. The literature is void of such instruments specifically for FMs living with persons with chronic conditions such as diabetes. Criteria were set for FM recruitment. Data were weighted for descriptive quantitative and qualitative analysis.

Results: Many Canadian FMs reported a positive impact of diabetes (40%), good/very good quality of life (76%), and good well-being (78%). Negative aspects included high diabetes distress (33%), being very worried about hypoglycemic events (40%), "moderate" to "very large" burden (26%), and a negative impact on at least one aspect of life (58%), with the largest negative effect on emotional well-being (38%). About 40% of FMs indicated that they wanted to be more involved in the care of PWD, but were frustrated with not knowing how to help. Of the 37% of FMs who participated in diabetes educational programs, 64% said that the education was helpful. In addition, 34-37% of FMs indicated their desire for more diabetes care and support in their communities/area, more medical treatments available for PWD, and more general information about diabetes to help them better support PWD they live with.

Conclusions: In summary, diabetes has both negative and positive impacts on FMs of PWD. Gaps and needs in support and management were identified. The global including Canadian DAWN2 data provide benchmarking indicators of FMs' psychosocial and management needs that will help identify local level interventions, including education required to improve the lives of FMs and the PWD they care for.

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Introduction

People With Diabetes (PWD) are living with and managing a complex disease, requiring multiple therapeutic regimens, restricted diets, and regular physical activity to maintain glycemic control, prevent complications, and maintain a reasonably good Quality of Life (QoL) [1]. However, as with chronic diseases in general, PWD do not face their disease alone. First, their healthcare team provides them with the treatment and general advice they need to manage their diabetes, targeted primarily at maintaining appropriate glycemic levels. Unfortunately, Healthcare Professionals (HCPs) are often unable to provide the necessary frequency and duration of office visits and follow-up care to make substantial or sustained contributions to behavior changes, treatment adherence, or glycemic control [1]. As well, HCPs are challenged in providing emotional and practical support for PWD. Family Members (FMs), on the other hand, are in a position to influence and support the self-management of a person with diabetes who lives in their household [2–4]. FMs and PWD face many of the same emotions such as worries, depression, and distress concerning the disease and its long-term effects or outcomes [5, 6]. However, FMs also have the potential to motivate and share the responsibilities for effective adherence to treatment, maintenance of metabolic control, and self-management of PWD [3, 4, 7]. It is no wonder that diabetes is often considered a "family affair" [8]. The importance of FMs and the role they play in diabetes self-management of the PWD in their household has received increased attention in the discussion of family-oriented diabetes interventions, including more holistic family assessments, education, and other support [1, 4, 9].

The original Diabetes Attitudes, Wishes and Needs (DAWN) study (2001), involving 13 countries across four continents, was initiated as part of discussions between the International Diabetes Federation country members and Novo Nordisk, all concerned and interested in exploring what PWD experienced, psychosocially and with self-management, and what HCPs perceived as areas of healthcare which worked well with diabetes management and where improvements were needed. This study provided the perspectives of both PWD and HCPs, and generally confirmed gaps in diabetes management; including a lack of collaborative team-based care, less than optimal self-management compromised by untreated distress and other psychosocial issues, challenges with initiating and maintaining effective medication therapies, and ineffective metabolic and glycemic control [10, 11]. FMs were not included in this DAWN study. As a result of the findings from the DAWN study, there was a commitment to address the identified shortfalls in diabetes care and management through a set of goals and strategies targeted at HCPs and PWD at the country level. A "Call to Action" encouraged PWD, their families, HCPs, and policy decision makers to take the initiative with collaborative diabetes person-centered care, enhanced self-management support and practices, and improved interaction among PWD, FMs, and HCPs [12].

The second DAWN study (DAWN2) was initiated by multiple partners (International Diabetes Federation, International Alliance of Patient Organizations, Steno Diabetes Center, and Novo Nordisk) as a follow-up to the DAWN "Call to Action". DAWN2 involved 17 countries across four continents, and focused not only on PWD and HCPs, but also FMs. The inclusion of FMs was a significant enhancement from the previous study, and was considered essential for understanding the family dynamics in effective person-centered care and diabetes self-management [13]. The aims of DAWN2 were to: (1) improve our understanding of the unmet needs of PWD and those who care for them; (2) facilitate dialog and collaboration among all key stakeholders to strengthen active patient involvement and self-management; and (3) establish a cross-culturally validated multinational survey system for assessing and benchmarking psychosocial and educational aspects of diabetes-care delivery [13].

This paper focuses on the Canadian FMs who participated in the global DAWN2 study, and more specifically their perceptions of how diabetes impacts them, their involvement in caring for and supporting the PWD in their household, and their needs and wants for improved diabetes care and self-management. The intent of the global and Canadian portion of the study is to identify key benchmarking indicators for the FMs affected by and involved with supporting the PWD in their household. Hence, this paper is linked with the global DAWN2 study and its publications [13–16], as well as with other Canadian DAWN2 papers reporting the results concerning PWD and HCPs.

Participants and Methods

The following methodology is a brief overview of the full methodology of the DAWN2 study design and specific methods applied with FMs which is available in the first of the global series of DAWN2 articles previously published [13, 14].

Design and Study Participants

In brief, the DAWN2 study was a multinational, interdisciplinary, and multi-stakeholder survey undertaken across four continents in 17 countries, including Canada (NCT01507116). As with the original design of DAWN2, each country including Canada, was to recruit a minimum of 120 adult (aged ≥18 years) FMs of PWD to complete the survey online, over the telephone, or in person.

FMs who were recruited and participated in the study were not necessarily affiliated with corresponding PWD who responded to the survey. Although affiliations could exist, they were not considered in the analysis and reporting of results for this paper.

Instruments

In addition to the eligibility and screening questions, the survey comprised 36 questions relevant to FMs, some with multiple responses. FMs were asked about their personal considerations and their involvement in and concerns with the care and support of the PWD in their household. Specifically, questions were categorized as to “involvement/role of family member”, “diabetes profile”, “health/quality of life”, “care and support”, “diabetes education and information”, “future needs”, and “demographics”.

Some of the survey questions were taken from the original DAWN study; additional questions were adapted from standardized and validated instruments as described for DAWN2 [13], and further questions were modified specifically for FMs [14]. The adapted instruments, detailed in Table 1, include:

- The World Health Organization (WHO) 5-item Measure of Well-Being (WHO-5; Psychological Well-Being)
- The WHO Brief Quality of Life (QoL) Measure (WHOQOL–BREF, Global Quality of Life)
- The Problem Areas in Diabetes – DAWN Family Members Diabetes Distress (PAID-5-DFM)
- The DAWN Family Experience of Patient Involvement (DFEPI)
- The DAWN Impact of Diabetes Profile – Family Members (DIDP-FM)
- The DAWN Family Support Scale – Family Members (DFSS-FM).

In addition to these objective queries, the survey included open-ended questions inviting FMs to share their personal experiences of life with a person with diabetes. For example, one of these questions for FMs specifically explored what the impact of living with an adult with diabetes had on their lives, including quality of life dimensions (physical, psychologically, socially, work and others).

The survey was reviewed and approved in English and translated into French for Francophone Canadians. Ethical considerations for this Canadian component of the DAWN2 study were approved by the Research Ethics Board of Capital Health in Halifax, Nova Scotia, Canada.

Table 1: DAWN2 family member questionnaire measures* and response options.

CATEGORIES	INSTRUMENTS	RESPONSE OPTIONS
QOL/TREATMENT BURDEN		
WHOQOL-BREF (Global Quality of Life)		
	How would you rate your quality of life? Please choose the answer that appears most appropriate. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last 2 weeks.	• Very poor • Poor • Neither good nor poor • Good • Very good
WHO-5: PSYCHOLOGICAL WELL-BEING		
	Please indicate for each of the five statements, which is closest to how you have been feeling over the last 2 weeks. Example: If you have felt cheerful and in good spirits more than half of the time during the last 2 weeks, please select “more than half of the time”. Over the last 2 weeks… • I have felt cheerful and in good spirits • I have felt calm and relaxed • I have felt active and vigorous • I woke up feeling fresh and rested • My daily life has been filled with things that interest me	• All of the time • Most of the time • More than half of the time • Less than half of the time • Some of the time • At no time
With likely depression†	As above	Rather than %, Scores range from 0 to 100 Score ≥50 is indicator of good well-being Score between 29 and 49 is reduced well-being Scores of ≤28 on WHO-5 Well-being Index considered an indicator of likely depression
PAID-5-DFM (Family Members Diabetes Distress)		
	Which of the following diabetes issues are currently a problem for you, when you think about the diabetes of the person you live with? • Feeling scared when you think about the fact that the person you live with has diabetes • Feeling depressed when you think about the fact that the person you live with has diabetes	• [Not a problem] • Minor problem • Moderate problem • Somewhat serious problem • Serious problem

	• Worrying about the future and the possibility that the person you live with will get serious complications • Feeling overwhelmed by having to help the person you live with manage his/her diabetes • Feeling guilty or anxious about not helping the person you live with enough with his/her diabetes management	
With high diabetes distress[‡]	As above	Rather than %, Scores range from 0 to 100. Scores of ≥40 on PAID-5-DFM considered an indicator of high diabetes-related distress
DIDP-FM (DAWN Impact of Diabetes Profile – Family Members)		
	How does the diabetes of the person you live with impact the following aspects of your life? • Your physical health • Your financial situation • Your relationship with family, friends and peers • Your leisure activities • Your work or studies • Your emotional well-being • Your relationship with the person you live with who has diabetes • At least one of the above aspects of life DIDP – FM (reporting impact of diabetes on at least one life dimension)	• Very negative impact • Negative impact • Slightly negative impact • No impact • Slightly positive impact • Positive impact • Very positive impact • Not applicable
	Thinking of the person you live with who has diabetes, please rate to what extent you agree with the following statement related to diabetes • I am very worried about the risk of him/her having hypoglycemic (low blood sugar) events • His/her diabetes is well controlled • The way he/she lives with diabetes has been an inspiration • Learned to take care of own health because of person with diabetes in household	• Fully disagree • Mainly disagree • Mainly agree • Fully agree • Not sure
EMPOWERMENT/INVOLVEMENT Involvement in helping person with diabetes management with following: • Healthcare professional requested family involvement		

• Attend with the person to visits to healthcare professional • Wish person with diabetes would take greater responsibility • Confident person you live with can manage his/her diabetes		
DFEPI		
	How often does the person you live with do the following? • Lets you know how you can best support him/her in managing his/her diabetes • Asks for your support in helping manage his/her diabetes when he/she needs it • Gets annoyed when you try to help	• Never • Rarely • Sometimes • Often • Always
	In the future, how involved would you like to be in the following? • The diabetes care of the person you live with • Helping the person you live with deal with his/her feelings about diabetes	• Much less involved • Somewhat less involved • As involved as you are now • Somewhat more involved • Much more involved
FAMILY BURDEN		
	How much of a burden is it for you to help manage the diabetes of the person you live with?	• Very large burden • Large burden • Moderate burden • Slight burden • No burden
FAMILY SUPPORT¶ DFSS-FM		
	Now, we would like to understand in what ways you try to be supportive as you help the person you live with manage his/her diabetes. How often do you do the following? • Tell him/her when he/she is doing a good job of managing his/her diabetes • Tell him/her when he/she is not doing a good job of managing his/her diabetes • Listen to him/her if he/she talks about difficulties in living with diabetes • Tell him/her things he/she should or should not do to manage his/her diabetes • Assist with things he/she needs to do to manage his/her diabetes • Do things for him/her to manage his/her diabetes	• Never • Rarely • Sometimes • Often • Always

	• Do activities with him/her that he/she needs to do to manage his/her diabetes	
	Please indicate the extent to which you agree or disagree with this statement about your involvement in helping the person you live with manage his/her diabetes • You are frustrated that you don't know how to best help the person you live with manage his/her diabetes • You have good ways to help person take care of his/her diabetes • You take part in activities in the community to support families affected by diabetes	• Strongly disagree • Disagree somewhat • Neither agree nor disagree • Agree somewhat • Agree strongly
HEALTHCARE PROVISION		
Areas needing major improvement to help people with diabetes and their families in the community and society		
	Which of the following areas do you feel need major improvement in order to help people with diabetes and their families in your community and society? Please select all that apply • Earlier diagnosis and treatment of diabetes • Good medical care, including regular follow-up • Acceptance of people with diabetes as equal members of society • Convenient and safe places to participate in physical activity • Places to buy healthy and affordable food • Workplaces which make it easy for people to manage their diabetes • Public awareness of diabetes • Prevention of diabetes	Multiple response
EDUCATION		
	Please indicate if you have ever participated in a diabetes education program for people with diabetes and/or their families (e.g., group activities or one-on-one sessions about diabetes)	• Yes, in the past 12 months • Yes, more than 12 months ago • No, you have never participated • Not sure
	Overall, how helpful was/were the education program(s) you attended?	• Very unhelpful • Somewhat unhelpful • Neither helpful or unhelpful • Somewhat helpful • Very helpful
COMMUNITY RESOURCES		
	Which of the following sources of education, information and support do you currently rely on to help you or help support the person you live with who has diabetes? Please select all that apply	Multiple response

	• None of these • Do not want to rely on any resources over next 12 months • Support groups where you meet with other family members or friends of people with diabetes • Complementary or alternative health practitioners (e.g., herbal medicine, acupuncture, homeopathy) • People with diabetes in your community who work to coach or support people with diabetes and their families • Printed information such as brochures, newspapers, magazines, books • Educational programs about diabetes on TV, DVDs, or videos • On-going advice and support from the healthcare team of the person you live with • General health and diabetes websites • A personalized website, phone service, or home software that helps you track and improve the diabetes care of the person you live with • Social media websites where you can exchange information and share thoughts with other people with diabetes or their families • Canadian Diabetes Association website • Diabetes telephone help hotline	
SOCIETY		
	Thinking of the person you live with who has diabetes, please rate to what extent you agree with the following statement related to diabetes • The person I live with has been discriminated against because he/she has diabetes • Community family lives in is intolerant	• Fully disagree • Mainly disagree • Mainly agree • Fully agree • Not sure

*Only relevant questions reflecting the data are provided here. Where relevant, list of items providing context of reported item is provided.

[†] Scores of ≤28 on WHO-5 Well-Being Index.

[‡] Scores of 40–100 on PAID-5-DFM.

[¶] Reporting ways in which family members try to support an individual manage their diabetes.

[¤] None of these is a specific item and does not reflect a lack of response to the other items presented.

DAWN: Diabetes Attitudes, Wishes and Needs; DFEPI: DAWN Family Experience of Patient Involvement scale; DFSS-FM: DAWN Family Support Scale – Family Members; DIDP-FM: DAWN Impact of Diabetes Profile – Family Members; PAID-5-DFM: Problem Areas in Diabetes Distress 5 – DAWN Family Members; QoL: quality of life; WHO-5: World Health

Organization 5-item Well-Being Index; WHOQOL-BREF: World Health Organization Quality of Life (an abbreviated version of the WHO-QOL-100).

Note: All questionnaire materials are copyrighted, either by Novo Nordisk or by an original copyright holder. The DAWN2 questionnaires, available in 22 different languages, can be obtained for local and cross-national diabetes research and quality improvement purposes. Guidelines and procedures for using or translating the DAWN2 questionnaires are available at www.dawnstudy.com.

Statistical Analyses

The quantitative data for Canadian FMs were weighted and all measures were analyzed and reported descriptively as the number and percentage of FM respondents.

Results

Participants

In total, 121 FMs of adults with diabetes across Canada participated in the DAWN2 survey. The mean age of people with diabetes who lived with FMs was 54.0 and specifically 37.2 for Type 1 and 57.1 for Type 2. The results presented in this paper are based on the total number of FMs in Canada (n = 121) rather than on provincial results, where small sample sizes did not justify separate analyses.

More women FMs (73%) than men (27%) participated in the Canadian study, with an overall average age of 46 (range, 30–62) years. FMs lived with mostly male (61%) PWD living with type 2 diabetes (74%) and not using insulin (63%). All of the Canadian PWD was diagnosed more than 12 months prior to the survey. More than half of FMs (56%) were spouses; another 33% were children to parents living with diabetes. Over one-half of FMs (54%) were employed, and 8% of spouses reported not working and staying at home. Geographically, approximately equal proportions of FMs reported living in large urban centers (35%) or in suburban/rural settings (34%). Complete characteristics of the Canadian FMs participating in this study are presented in Table 2.

Table 2: Population characteristics of family members who took part in the survey (n = 121).

Family members of people with diabetes	**N (%)**
Gender	
Men	33 (27)
Women	88 (73)
Age (years)	46 ± 16*
18–45	53 (44)
46+	68 (55)
Level of education	
Completed high school	27 (22)
Some college/university	28 (23)
Completed college/university	49 (40)
Work situation	
Full-time	41 (34)
Part-time	21 (17)
Working part-time to help care for person with diabetes	1 (3)

Not working	
Looking for work	5 (4)
Not looking for work	3 (2)
Retired	30 (25)
Student	8 (7)
Stay-at-home spouse or partner/housewife/husband	10 (8)
Living area	
Large city	42 (35)
Small city or a large town	38 (31)
Suburban area	21 (17)
Village or rural area	20 (17)
Person with diabetes cared for	
Spouse/partner	68 (56)
Parent	40 (33)
Other adult relative	9 (7)
Age of the person with diabetes Diagnosed with diabetes <12 months ago Diagnosed with diabetes >12 months ago	59 ± 15* XX XX
Gender of person with diabetes	
Men	74 (61)
Women	47 (39)
Treatment of the person with diabetes	
No insulin	76 (63)
Insulin	45 (37)
Type of diabetes	
Type 1	18 (15)
Type 2	90 (74)
Not sure	13 (11)
Number of adults with diabetes in the family	
1	117 (97)
≥2	4 (3)

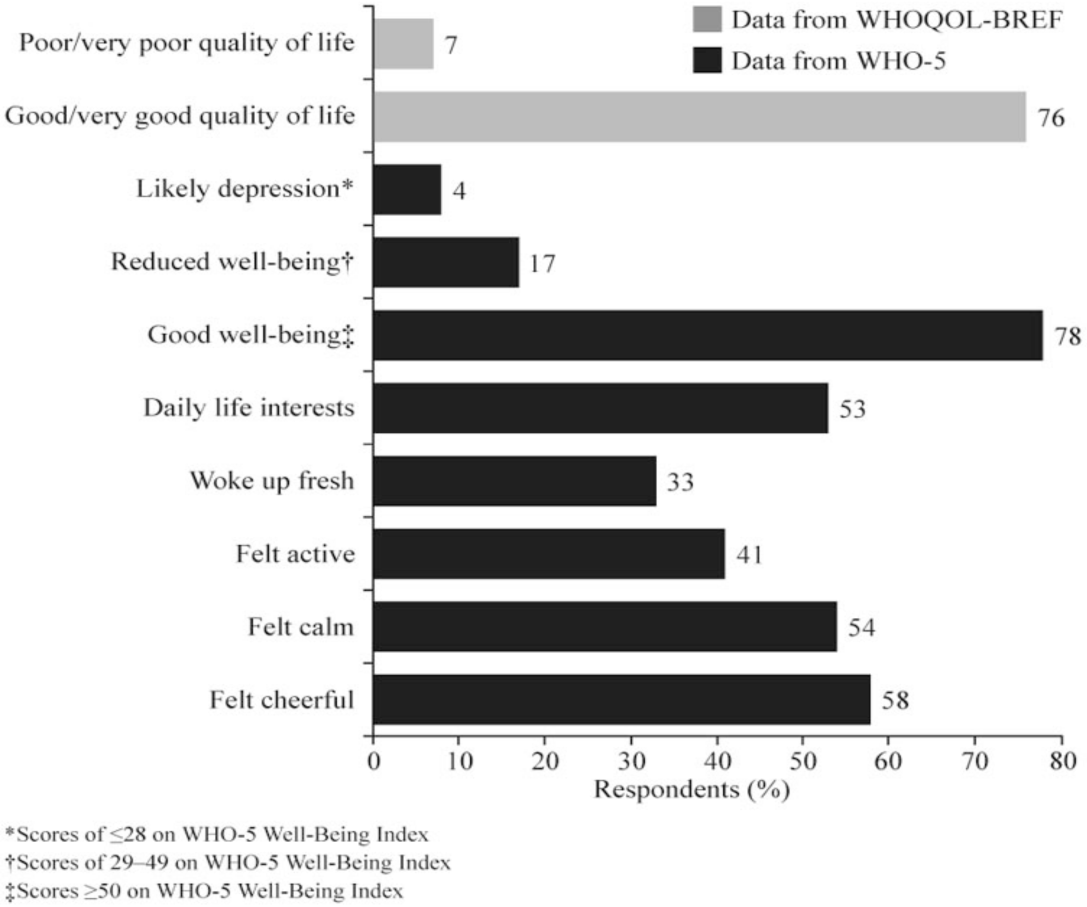
*Mean age ± standard deviation.

Key Psychosocial Indicators for Family Members

Total quantitative survey question responses for psychological, social, and other personal considerations and desires for improvements as reported by FMs living with and caring for PWD in their households have been captured. For this paper, some of the more noteworthy psychosocial and other related results are described in more detail. Qualitative responses are not included in this paper. Since there are only 121 Canadian FM responses in total, the results were weighted but reported with considerations for limitations in making any significant conclusions, and descriptions of results by province or region has not been done for this reason. However, these 121 Canadian responses are reflective of the global DAWN2 FM responses which were identified as key benchmarking indicators and provided baseline results which are useful for measuring positive and negative changes over time [14].

Quality of Life and the Impact and Burden of Diabetes. Over three-quarters (76%) of FM respondents indicated having a “good”/“very good” QoL, while 7% said that it was “poor”/“very poor” (Figure 1). A similar trend was noted when well-being was investigated using the WHO-5 instrument, with 78% of FMs indicating “good well-being”, 17% indicating “reduced well-being”, and 4% with “likely depression”. With other well-being measures, over half of FMs indicated that they felt cheerful and in good spirits, were calm and relaxed, and that their daily lives were filled with things that interested them “all” or “most of the time” (Figure 1).

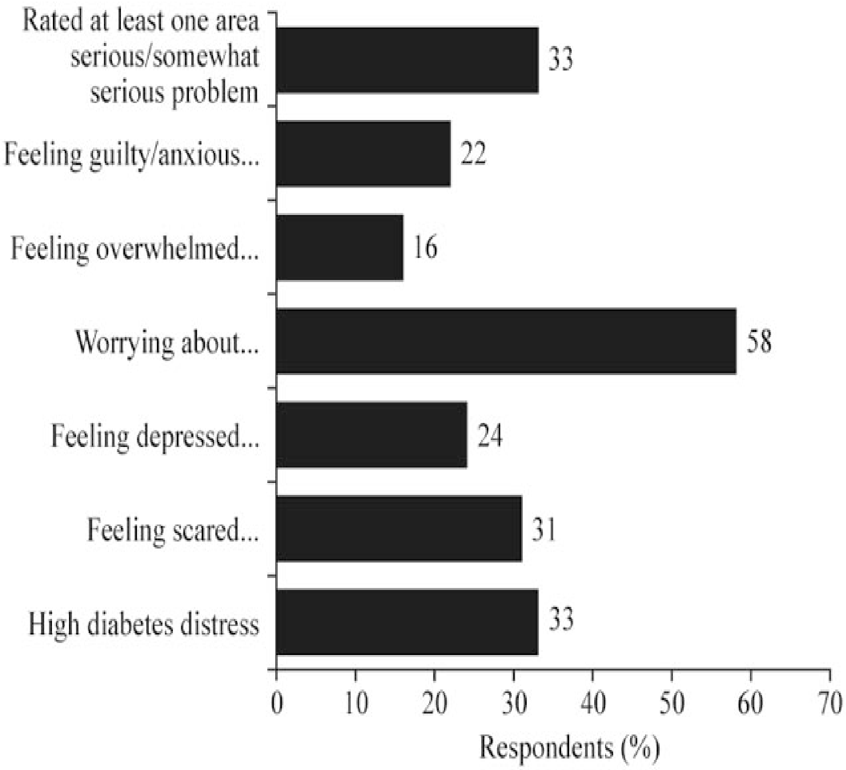
Figure 1: Percentage of family members reporting well-being scores (“all of the time”/“most of the time”)



WHO-5: World Health Organization 5-item Well-Being Index; WHOQOL-BREF: World Health Organization Quality of Life (an abbreviated version of the WHO-QOL-100).

Contrary to the two-thirds of FMs indicating "good"/"very good" QoL and "good" well-being, 33% reported experiencing high diabetes distress (Figure 2). High diabetes distress was identified among a number of responses to validated questions identifying diabetes issues which were currently a "serious", "somewhat serious", or "moderately serious" problem for FMs. Others related to feeling scared, depressed, overwhelmed, guilty or anxious; and to worrying about the future. At least one of these domains was rated as a "serious" or "somewhat serious" problem by one in three FMs.

Figure 2: Percentage of family members reporting distress related to diabetes issues they view as "serious"/"somewhat serious"/"moderately serious" problems.



Complete statements referred to in set of questions from PAID-5-DFM (Family Members Diabetes Distress) are as follows:

- Feeling scared when you think about person you live with has diabetes.
- Feeling depressed when you think about person you live with has diabetes.
- Worrying about the future and possibility of person you live with getting serious complications.
- Feeling overwhelmed by having to help person you live with manage his/her diabetes.
- Feeling guilty or anxious about not helping the person you live with enough with his/her diabetes management.

PAID-5-DFM: Problem Areas in Diabetes Distress 5 – DAWN Family Members.

The impact of diabetes on various aspects of FMs' lives (e.g., physical health, finances, work, or leisure activities) varied, with 40% reporting a positive impact of diabetes on at least one life dimension. As shown in Figure 3, "slightly negative" to "very negative" impact was also reported by FMs on emotional well-being, financial situation, leisure activities and their relationship with the person who has diabetes. Less than 20% of FMs indicated that the least negatively impacted life dimensions were physical health; relationship with family, friends, and peers; and work or studies.

Other questions measuring the impact of diabetes on FMs revealed that, four out of five FMs agreed that the persons they lived with had their diabetes well controlled. Even so, 40% were “very worried” about the person living with diabetes being at risk for hypoglycemic events (Figure 3). However, about the same number of FMs reported an overall positive impact of living with a PWD, and more specifically, two-thirds were inspired by the lifestyle of the person with diabetes in their household, and 80% said that they learned to take care of their own health from the person’s diabetes. This parallels with FM responses regarding the level of burden of diabetes - the majority of FMs (74%) reported that helping the PWD in their households manage their diabetes was a “slight” to “no” burden.

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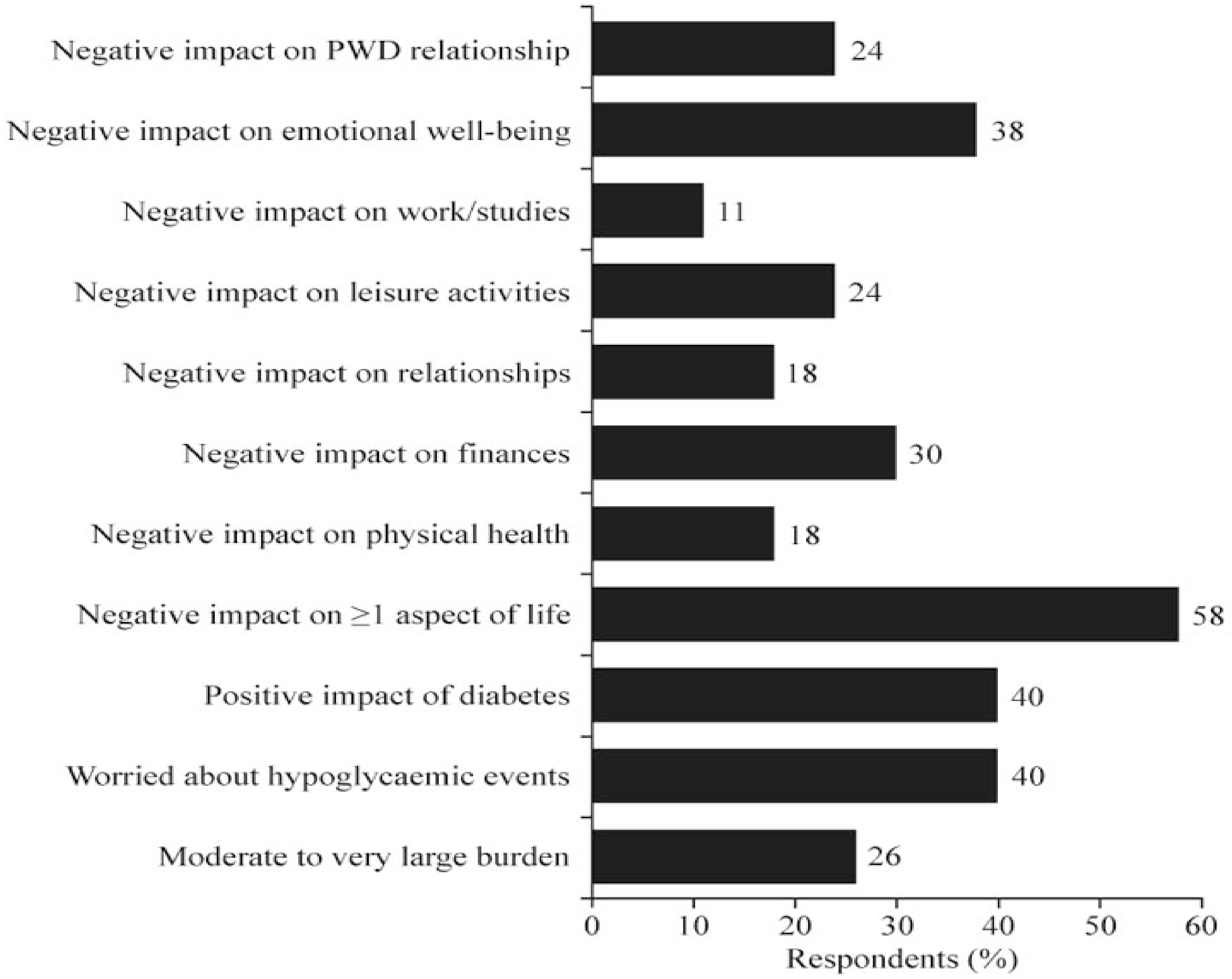
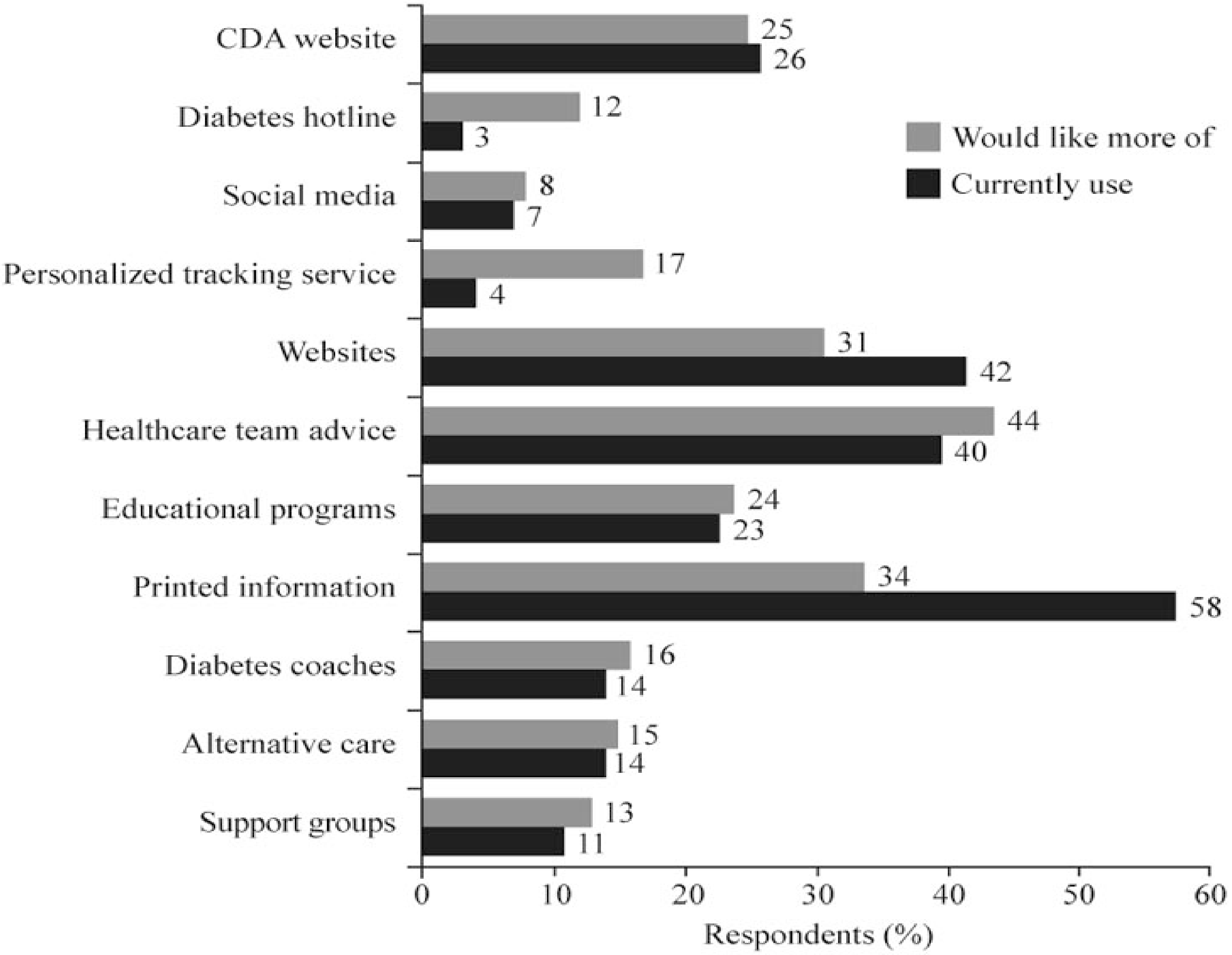
Figure 3: Percentage of family members experiencing a negative impact of diabetes on various life dimensions and positive impact overall.



PWD: person with diabetes

Family Involvement and Support for the Person with Diabetes. The survey response category of “Empowerment/Involvement” summarizes the results regarding FM involvement in helping the person in their household manage his/her diabetes. Nearly half of FMs (45%) said that HCPs had requested their involvement, and 48% of FMs accompanied the person with diabetes during their HCP visits. Many FMs (46%) wished that the PWD would take greater responsibility for managing their diabetes, supported by 51% of FMs who felt confident that the PWD were capable of managing their diabetes without help from the FM. Overall, 40% of FMs said that they wanted to be more involved in the diabetes care of the person with diabetes in their household. Of this group of FMs, 53% indicated they were frustrated (40.8% somewhat; 12.2% strongly) with not knowing how best to help the PWD they lived with to manage their diabetes. Specifically, 52% of FMs wanted to support the PWD more with managing their feelings about diabetes. One-third of FM respondents (30%) stated that the PWD had asked them for support and communicated how to best support them in managing their diabetes. However, 29% also said that the PWD had become annoyed when they had tried to help. Most FMs (69%) had found good ways to support the person in their household care for his/her diabetes; whereas few FMs (27%) had become involved in their community to support families affected by diabetes.

Figure 4: Percentage of community resources, information, and support family members used and wanted to have more of.



CDA: Canadian Diabetes Association.

Education, Community Resources, and Support

One-third of FMs (37%) had participated in diabetes educational programs or activities within 12 months prior to the survey, and 64% found them “somewhat” or “very” helpful. The sources of education, information, and support that FMs currently relied on or would like to use more are shown in

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Figure 4. Printed information, ongoing advice from the healthcare team of the PWD, and website were the most currently used by FMs. Fewer numbers of FMs accessed additional programs and resources including educational programs, support groups, or diabetes hotline. FMs indicated that they would like more access to these various resources and supports including websites, ongoing HCP advice and, to a lesser extent, diabetes coaches, alternative care, support groups, and social media. About one-third of FMs wanted more access to printed materials and websites.

Regarding societal support, 12% of FMs felt that the people they lived with were discriminated against because of their diabetes, and 17% felt their own community was intolerant of diabetes. These perceptions paralleled the perception of many FMs (34%) that public awareness of diabetes was an area needing major improvement.

Areas in Need of Improvement

Aside from improved public awareness of diabetes, FMs identified other key areas in diabetes care and management that required major improvement. Over half of FMs needed more places to buy healthy and affordable food (52%) and wanted to improve the prevention of diabetes (51%). Just under half of FMs felt that “good medical care, including regular follow-ups” (43%) and “earlier diagnosis and treatment of diabetes” (41%) needed major improvement.

Discussion

Although the number of studies with FMs of people living with chronic conditions has increased over the past 30 years [17, 18], literature specifically concerning families of adults with diabetes is limited (9). Most published studies found that people living with chronic conditions and their families face many challenges and concerns about managing the condition. With diabetes, most family studies have involved parents of children or adolescents with diabetes, rather than other FMs such as spouses, siblings, or children of adults living with diabetes [4, 19, 20].

The DAWN2 study has made an important contribution to this literature by including FMs of adults with diabetes and by using validated instruments to explore the effects of living with PWD on FMs. The effects studied included the burden and impact of diabetes on FMs; QoL issues; the involvement of FMs in the management of diabetes; and the needs of FMs in their efforts to help the PWD in their households manage their diabetes [13, 14]. As with the global DAWN2 results for FMs, the results reported in this paper on Canadian FMs confirm the importance of including them in studies and planning of interventions involving PWD, as the impact of diabetes is both negative and positive for FMs and has implications for their psychosocial needs as they care for PWD in their households.

Measuring the effects of living with a person with one or more chronic conditions on caregivers, who are often FMs, and assessing their needs is not new; but only in the past decade have validated instruments been used to assess and re-assess caregiver/FM use of interventions to assist them through their experiences. This information has been invaluable for determining what caregivers do or what interventions they use, which can become an important basis for helping caregivers manage their situation, including their mental and physical health [17]. The findings from studies such as DAWN2, with Canadian FMs in mind, will also be useful for determining the value of various instruments for assessing FM needs and for determining which interventions HCPs or communities should provide for caregivers such as FMs. This is of particular interest, since the number of caregivers, who are most likely FMs, is expected to grow as the population ages or more people are diagnosed with chronic conditions such as diabetes [17, 18, 21].

Most studies on diabetes and its impact on families have shown the burden, distress, and reduced QoL experienced by FMs; in addition to high levels of worry and fear about controlling diabetes and hypoglycemic events, and future outcomes for the PWDs [4, 5, 22, 23]. The global DAWN2 study found that there were as many positive effects of diabetes on FMs as there were negative ones, and that these findings needed to be viewed in the context of country-specific care and support [14] and supported by the global findings. The negative aspects of caregiving found in the global DAWN2 study must be acknowledged and interventions planned accordingly. It is not a slight matter that one-third of FMs in the global analysis felt a notable burden of diabetes of which about 40% experienced high levels of distress related to the person with diabetes in their household, and over 60% were worried about the risk of hypoglycemic events [14]. A similar trend was found for the Canadian cohort of the DAWN2 study, as presented in this paper. These findings, particularly those related to negative impact that were seen as "serious"/"somewhat serious" problems, reinforce the need to recognize these psychological experiences and negative effects of diabetes on FMs, and highlight the need for support for FMs to manage and reduce their overall burden and distress of caring for ill FMs [24, 25]. The literature points out that family interventions may be beneficial, not only for helping families to learn ways to better support the person with diabetes (4), but also for preventing detrimental outcomes, particularly regarding the risk of deteriorating mental and physical health, and eventual complications of diabetes [18, 25, 26]. The higher distress rating of 33% for Canadian FMs compared with other indicators, including "burden" (26%), "likely depression" (8%), "reduced well-being" (17%), and "poor"/"very poor" QoL (7%) warrants further exploration. For example, gender differences analyzed in some studies have shown that women have consistently higher levels of emotional distress when caregiving for a FM with a chronic disease [27]. In the Canadian DAWN2 study, 73% of respondents were women, but whether this has contributed to the greater proportions of FMs experiencing high distress, requires further examination.

It is equally important to acknowledge the positive impact that diabetes had on FMs, along with "good" well-being and "good"/"very good" QoL (Figures 1, 3). From the DAWN2 study, 35% of global and 40% of Canadian FMs experienced a positive impact on at least one life dimension. From the Canadian data, 80% of FMs also indicated that they had learned to care better for their own health because of the person with diabetes in their household. This, too, emphasizes the need for HCPs to include the whole family when discussing diabetes management and care [4], particularly as other studies have shown that FMs who have unmet needs or high burden and distress are less likely to support the PWD in their households. This, in turn, results in PWD receiving less support than they require from FMs and ineffectively managing their glycemic levels and diabetes overall [1, 21, 28]. Within the Canadian context, 48% of FMs accompanied the PWD on their visits and sat in the consultation room with them and their HCPs, which indicates that there is more willingness on the part of HCPs and PWD to have the FMs involved in the care discussion concerning the good news as well as issues, concerns and areas where the FMs may be able to become more involved and support the PWD in their diabetes management. In turn, FMs may also discuss some of their concerns and needs for supports. To identify and more effectively assist FMs with their needs so they are able to better support the PWD in their households, family or caregiver assessments [21] and interventions such as education have been proposed [4, 9, 29]. More research is needed in the area of family experiences with diabetes and intervention best practices, or into models for mobilizing family support [1]. This research also includes the use of validated instruments to assess caregivers, and the consideration of who is best trained to conduct these assessments, given the limited time most HCPs are able to spend with each person with diabetes, without consideration for additional time needed for FMs.

The DAWN2 approach with families intended to explore areas where improvements are needed, such as encouraging more family involvement in the self-management of PWD and communication or ongoing exchanges of advice between HCPs and FMs. It is particularly important that FMs are included in education sessions for PWD, particularly in those regarding self-management initiatives such as healthy eating, physical activity, and improved glycemic control. The literature suggests that family involvement in these educational initiatives contributes to improved outcomes in diabetes self-management [3, 7], as well as treatment adherence and metabolic control [30–32]. Within the Canadian sample of FMs, 37% had participated in diabetes education programs or activities and 64% found them helpful. This is worth exploring further to determine in which of the 10 Canadian provinces these 37% of

FMs reside and are able to be involved in diabetes education. Not all provinces currently offer diabetes education to PWD, let alone FMs. Support groups for FMs are also not available in every jurisdiction in Canada, which may account for only 13% of FMs taking part in these groups. However, FMs indicated their desire to have more access to both, education and support groups, as well as other resources and information.

Improved communication may also address family tensions and stress, and family overprotection or lack of support, all of which can impact PWD negatively [2, 3, 4, 33]. Supporting these areas of improvement and involvement for FMs is the Canadian Diabetes Association (CDA), with its principles and mission statements within the Diabetes Charter for Canada including “Enhance the health and quality of life for people who live with diabetes and their caregivers” [34].

Recognition by 12% of Canadian FMs and 22% of global FMs that discrimination still exists against PWD warrants ongoing awareness and education initiatives through diabetes associations and workplace health promotion. Although the national CDA has its 2014 Diabetes Charter for Canada [34], as well as specific guides and position papers regarding diabetes discrimination in the workplace [35], and the Canada Human Rights Act [36] to support PWD, other discrimination issues are managed case by case. Regional CDA advocacy initiatives could benefit from pursuing the inclusion of FMs to speak about their experiences with diabetes-related issues, including discrimination faced by the PWD in their households. With only 27% of FMs actively involved in community initiatives such as advocacy, in support of all families affected by diabetes, this number could be increased if the CDA or other community initiatives actively included and involved FMs along with PWD more directly.

The Canadian cohort of the DAWN2 study also contributes to the country-specific literature concerning the involvement and psychosocial indicators for FMs living with PWD. However, the recruitment process and resulting small sample size of 121 FMs limited the type of data analysis possible and the general conclusions that can be drawn from it [4, 13]. The small sample size made an analysis by diabetes type, age, gender, and other FM factors for each Canadian province impractical [37]. Further studies are needed in Canada involving greater numbers of FMs within each province to more specifically examine the key indicators identified and summarized in this Canadian DAWN2 study paper.

In conclusion, the key psychosocial indicators identified through the global DAWN2 study including the analysis of the Canadian cohort of FMs, PWD, and HCPs provides a baseline assessment on which future studies can build, at the national and provincial levels, to determine whether changes in psychosocial markers have occurred over time, as interventions have been implemented. The Canadian DAWN2 results for FMs confirm the global messages regarding identified issues, gaps in care and support, and areas requiring improvement. However, at the country and local levels, there are more possibilities for implementing interventions or actions within practice settings, educational organizations, communities, and homes. When one in three Canadian FMs experience high distress and more than half report a “slightly” to “very negative” impact on at least one aspect of life, HCPs must utilize this information as they support FMs in the care they provide to PWD, and health decision makers must consider funding more holistic family interventions for effective diabetes and chronic-disease self-management. Further analysis of the Canadian DAWN2 FM data, together with the data concerning PWD and HCPs, will establish baseline benchmarking indicators that can be used to plan or drive further broader studies in each province and align appropriate changes in family interventions, or policies regarding person-centered diabetes care and self-management.

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