**Original Article**

**Correlates of psychological outcomes among family members of people with diabetes in the second Diabetes Attitudes, Wishes and Needs (DAWN2TM) study**

**Running head:** DAWN2: correlates of psychological outcomes among family members

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# Bulleted novelty statement

        DAWN2, conducted in 17 countries across 4 continents, is the first study to identify key sociodemographic, treatment-related, psychosocial and behavioural factors associated with psychological outcomes for adult family members of adults with diabetes.

        Older age, not working due to diabetes, lower levels of school education, use of injectable medicine by the person with diabetes, worry about hypoglycaemia, high perceived severity of diabetes and experience of discrimination of the person with diabetes were associated with worse psychological outcomes among adult family members of people with diabetes.

        Family arguments about diabetes management, frustration with not knowing how best to help, and greater responsibility for diabetes management were associated with worse psychological outcomes for family members of people with diabetes.

        Knowing good ways to support, providing more support for diabetes and having access to more people to talk to about diabetes challenges were associated with better psychological outcomes.

        The study extends earlier evidence from the DAWN2 study highlighting the psychosocial impact of diabetes on family members and identifies globally important factors for psychological well-being of family members of adults with diabetes which need to be considered in future efforts to improve diabetes care.

# Abstract

**Aims** The second Diabetes Attitudes, Wishes and Needs (DAWN2TM) study examined the experiences of family members caring for adults with diabetes to identify correlates of family member psychological outcomes (generic psychological well-being; perceived quality of life; and diabetes-related burden, impact and distress).

**Methods** 2057 family members living with a person with diabetes and involved in their care participated in an online, telephone or in-person survey. Samples of 120 respondents were recruited in each of 17 countries. Significant (*P*<0.05) correlates of psychological outcomes were identified by multi-level multiple regression.

**Results** Outcomes were worse for family members not working due to diabetes or those who had other competing obligations. Outcomes were worse if the person with diabetes was not a partner or parent, used injected diabetes medication, or had more frequent hypoglycaemia. Outcomes were worse for family members who believed that diabetes was more severe, were more involved in diabetes care, had more conflict over diabetes care or were frustrated about not knowing how to help the person with diabetes. Outcomes were better for those who had greater support from others and felt they found good ways to help the person with diabetes. There were significant differences in outcomes among countries before and after adjustment for individual characteristics, and correlates of outcomes varied by country.

**Conclusions** Several modifiable risk and protective factors for family member psychological outcomes were identified in this study. Diabetes education and social support were associated with improved outcomes, especially if they were helpful in supporting people with diabetes.

# Introduction

Within the last decade, studies have focused increasingly on the role of family members and their impact on the quality of life or the clinical course of people with chronic diseases [1]. Few studies have explored the impact of chronic disease or various aspects of chronicity on family members and their lives. In the context of diabetes, studies have predominantly reported on the influence of caring for children or adolescents with diabetes on parents, and the effect of family on outcomes in youth [2-5]. Fewer studies have investigated the impact of diabetes on family members caring for adult people with diabetes and the effect of family members on the diabetes outcomes of these adults [6,7]. Diabetes is a lifelong journey that involves lifestyle changes for the person with diabetes that can affect the entire family. Therefore, it is vital to better understand how various characteristics of adult family members and the adults with diabetes with whom they live impact psychological outcomes of family members.

Recent studies have found that diabetes impacts family members, causing increased burden and worry, high levels of distress and reduced emotional well-being [8,9]. Conversely, diabetes can also have positive effects on the family, including improvements in the relationship with the person with diabetes and healthy changes in eating habits and lifestyle [10]. These findings were supported by results from the second multinational Diabetes, Attitudes, Wishes and Needs (DAWN2TM) study, which examined diabetes from the perspectives of family members [11], people with diabetes [12] and healthcare professionals [13], with particular focus on diabetes management, the impact of diabetes and aspects of diabetes care requiring improvement.

Here, we report DAWN2 data concerning the factors associated with good and poor psychological outcomes for family members. Knowing the risk and protective factors for psychological outcomes can help healthcare professionals anticipate the potential implications of diabetes for family members, and guide their provision of additional support, education and other programmes for family members. The objective of this paper is to identify potential risk factors for poor outcomes in family members caring for adults with diabetes, that could be ameliorated with appropriate care strategies. Companion publications describe associated findings from the DAWN2 study for people with diabetes [14] and for diabetes healthcare professionals [15].

# Methods

## Study design

DAWN2 is a multi-partner, multi-disciplinary and multi-stakeholder study conducted in 17 countries (Algeria, Canada, China, Denmark, France, Germany, India, Italy, Japan, Mexico, The Netherlands, Poland, the Russian Federation, Spain, Turkey, the UK and the USA) across four continents. Adults with diabetes, adult family members living with an adult with diabetes, and diabetes care professionals participated in DAWN2. The complete methodology of DAWN2 was previously published [11-13,16].

## Ethical considerations

DAWN2 was conducted in accordance with all applicable ethics guidelines. Ethics approval was obtained in accordance with requirements within each country.

## Participants

Each of the 17 countries aimed to recruit 120 family members living with people with diabetes, resulting in a final total sample of 2057. Participants were recruited and surveyed by internet, telephone or in-person methods. Participants in the study, defined in the broadest sense as family members, self-reported being ≥18 years of age, not themselves living with diabetes, having an adult with diabetes in their household and being involved as supporters in the care of the person with diabetes.

## Instruments and measures

The survey instruments and measures used in DAWN2 were detailed in previous papers [11,16]. All measures reported in this paper were obtained from family members who participated in the study. Questionnaires included questions from the original DAWN study and the DAWN2 study that were developed for people with diabetes and subsequently modified for family members, as well as new questions developed for the DAWN2 family member survey. Some items were adapted from validated instruments, and two established, validated instruments were utilised: the WHO-5 measure of psychological well-being [17], and the WHO brief QOL measure (WHOQOL-BREF) [18].

There were five outcome variables: well-being (WHO-5); quality of life (WHOQOL-BREF); diabetes impact (DIDP-FM); diabetes distress (PAID-5\_DFM); and, diabetes burden (single item rating on a 1 to 5 Likert scale). Measures used as predictors in the correlational analyses are described in Table 1. These potential correlates comprised measures in five categories: (1) family member demographic and socio-economic factors; (2) characteristics of the person with diabetes; (3) family member beliefs and perceptions; (4) family member involvement/experience in diabetes care and (5) social support resources.

## Analysis

Analyses were performed using data from the whole sample and by participating country. Descriptive data are summarised as global median values with country ranges (country minimum and country maximum). Questionnaire scores, calculated on the entire study population (global score) are expressed as means and standard deviations (SD) for multi-item questions or as numbers of respondents and percentages for single-item questions. All scale scores range from 0 to 100, with higher values indicating a higher level of the dimension measured.

In the comparison of psychosocial outcomes among countries, multilevel regression models [19,20] were utilised to account for the clustering of people within countries and to estimate the proportion of residual variance due to country. To evaluate the degree of variation between countries, the intraclass correlation coefficient (ICC) was calculated. Three models were estimated: in Model 0, country scores were adjusted only for clustering. In the other models, estimated marginal means for each country were adjusted for demographic and socio-economic factors (Model 1) or for all covariates (Model 2). To facilitate comparison among countries, the minimum clinically relevant difference was calculated, which requires an effect size of 0.5 standard deviations.

For the two-level multiple regression analyses, risk and protective factors were forced into the regression models according to their hypothesised causal order reflected in the five categories described above. Results are reported as beta values and *R*-squared for the between-subject variance explained by the variables in the model. Supplementary analyses tested the interaction of each risk or protective factor with country to assess variation in the strength of associations across different countries. A *P*-value of <0.05 was considered statistically significant. Data were analysed with SAS version 9.3 (SAS Institute, Inc., Cary, NC, USA).

# Results

The distribution of family member characteristics (except psychological outcomes) are reported in Table 2. Of the 2057 family members participating in the study, 65% were women, the median age was 43 years, 41% had low school education and 44% were not working. The person with diabetes cared for was most often a parent (32%) or spouse/partner (26%), was a woman in 47% of cases, had a median age of 59 years and was treated with insulin in half of the cases; 40% had experienced at least one severe hypoglycaemic episode in the last 12 months.

Before controlling for potential mediators, there were significant between-country disparities for each of the psychological outcomes considered (Table 3 – country-adjusted means of psychological outcomes are provided in the Model 0 column); the largest difference among countries was seen with respect to ‘family burden’ (ICC=0.14); the lowest difference among countries with respect to ‘well-being’ (ICC=0.05) and ‘diabetes impact’ (ICC=0.05). Controlling for potential mediators (as per Models 1 and 2) reduced between-country variation for all outcomes except for ‘well-being’ (remained at ICC=0.05) and ‘family burden’ (increased from ICC=0.14 to ICC=0.20). Therefore, these mediators contributed to the unadjusted country differences in all psychological outcomes except for ‘well-being’. Adjusted means (as per Model 2) for the five outcomes according to countries are shown in Fig. 1. Although there was some country-level covariation in outcomes, no single country consistently had the worst or best outcomes.

The associations of all factors with the five psychological outcomes from the regression models are provided in Table 4. Values reported in the ‘beta at entry’ column represent the total relationship with the outcome after all confounders (variables in the same or earlier categories) have been controlled. Coefficients reported in the ‘final beta’ column show the association between a potential risk or protective factor and an outcome that is not mediated by other variables in the analysis; it represents the ‘independent association’ or direct component of the total association.

Results in Table 4 indicate that every factor examined was significantly associated with one or more of the five psychological outcomes, except the gender of the person with diabetes. Controlling for mediators generally reduced associations (the ‘final beta’ was decreased relative to the ‘beta at entry’), indicating that the initial associations were, at least partly, a function of the potential mediators examined. The diabetes beliefs and perceptions of family members tended to have the strongest explanatory power (increase in *R*-squared) for the outcomes, ‘well-being’ and ‘diabetes-related distress’. Most of the variance for ‘quality of life’ and ‘diabetes burden’ was related to family member diabetes involvement. The characteristics of the person with diabetes generally showed little association with the incremental variance; they added explanatory power only to ‘diabetes distress’ and ‘diabetes burden’. Overall, the set of covariates tested accounted for 8% to 34% of incremental between-subject variance in psychological outcomes; demographic and socio-economic factors accounted for additional variance, representing 73% to 85% of the models’ explanatory power.

One or more outcome(s) were *worse* for family members who

* were women, older, less educated, not working due to diabetes, or had other competing obligations
* cared for a person with diabetes who was not a partner or parent, used injected diabetes medication, or had more frequent episodes of hypoglycaemia (including severe hypoglycaemia)
* believed that diabetes was more severe, worried about hypoglycaemia, were more involved in diabetes care, had more conflict over diabetes care, or were frustrated about helping the person with diabetes.

One or more outcome(s) were *better* for family members who received diabetes education and greater support from others, and found ways to help the person with diabetes.

A significant country-by-variable interaction in at least one outcome was found for all the covariates investigated (Table 4); the only exception was the gender of the person with diabetes. There were too many interactions to be described here, and no simple pattern could be identified. The main finding of this analysis was that some factors had more or less explanatory power within any given country for a particular outcome.

# Discussion

The DAWN2 study was developed to improve our understanding of the unmet needs of people with diabetes and those who cared for them. We previously reported that diabetes had a negative impact on family members of people with diabetes [11]. Rates of distress were high, with nearly two-thirds of family members worrying about hypoglycaemia. Many family members reported that diabetes had a negative effect on their emotional well-being. Conversely, over half of family members who participated in the DAWN2 study reported a ‘good’ or ‘very good’ quality of life. This suggests that diabetes can impact family members in different ways. Our analyses of DAWN2 data examined the underlying characteristics related to the psychosocial burden of diabetes in family members caring for adults with diabetes. Results showed that respondent demographic factors, beliefs and perceptions, their involvement in diabetes care and the level of support received were significantly associated with the psychological well-being and quality of life of family members caring for adults with diabetes.

Many factors associated with poor quality of life and well-being in most populations—including low educational achievement, unemployment, age and female gender—were also manifest in our study. This suggests that generic psychological outcomes among family members living with diabetes are a function of both generic and diabetes-specific factors. Approximately two-thirds of family members who participated in the survey were women and, as reported previously [21,22], these respondents report lower psychological well-being and higher distress than men. This may reflect the greater caring role of women generally and more specifically for certain chronic diseases in many societies. Notably, working full-time was associated with better well-being. Those not working because they took care of a person with diabetes and those with other obligations that prevented involvement in the care of the person with diabetes reported the highest diabetes burden. The former group may feel trapped by the diabetes while the latter may feel guilty for not looking after their relative as they might without their other commitments. In addition, this conflict could explain why people with other obligations also reported poor psychological well-being and high levels of diabetes impact and distress.

Family members caring for a spouse or partner with diabetes reported a better quality of life, those caring for a spouse or parent reported less perceived burden than family members caring for other relatives or non-related adults. This may be due to the closer bond with a spouse, partner or parent than with others. Given that the level of involvement is accounted for, this finding should be interpreted more appropriately in the context of expectations or willingness of family members to be involved.

The demands of diabetes clearly affected family members, with both the mode of treatment and side effects, notably hypoglycaemia, being important correlates: injectable therapies were associated with lower psychological well-being and higher perceived impact, frequency of symptomatic hypoglycaemia was correlated with higher burden, and severe hypoglycaemia was associated with poorer psychological well-being and quality of life. Worry about hypoglycaemia was related to poorer psychological well-being and quality of life, and higher diabetes distress and perceived burden; it had the largest association with diabetes distress. Health beliefs were also correlated with psychological outcomes in family members. As in earlier studies [1], the belief that diabetes is a severe condition was connected with lower levels of psychological well-being and quality of life and higher diabetes impact, distress, and diabetes burden. Perceived diabetes-related discrimination against the person with diabetes was associated with increased family member distress.

Family members who reported greater responsibility for the management of the diabetes showed poorer quality of life and reported higher levels of diabetes impact and perceived burden. Indeed, for family member impact and burden, the level of family member responsibility for the diabetes was the strongest correlate. Discord within the family about diabetes management was a correlate of poorer psychological well-being and quality of life, higher distress and higher perceived burden for family members. Diabetes-related disagreements resulting in frustration, in turn, were important predictors of poor psychological outcomes, particularly for diabetes distress. Conversely, the successful collaboration between family members and the person with diabetes was correlated to better psychological well-being and quality of life for family members, and with lower diabetes impact and perceived burden. Similar effects of diabetes-related discord or effective cooperation on family members have been reported in previous studies [5,23].

In this study, few family members (approximately 1 in 5) had received any diabetes education. Diabetes education was linked with increased burden and distress according to our findings; thus, it appears that family members bear a psychological cost in developing skills to care for the person with diabetes. However, other analyses have indicated an association of family member diabetes education and increased support willingness, confidence, responsibility, and efficacy [24]; this may be due to education being offered more to those with greater burden or may indicate that there is a psychological cost for family members related to thus the increased cost of caring may be offset by improved support for the person with diabetes.

Country disparities for psychological outcomes were noted in the original report of family member survey findings [11]. No country had the best results for all outcomes, indicating that there was room for improvement on one or more outcomes within each country. Controlling potential mediators resulted in less disparity between countries for several outcomes, suggesting that the mediators contributed to country differences. However, significant country differences existed in the adjusted analyses, indicating that factors not controlled in this analysis impacted between-country variation. Our findings suggest that each country deliberates carefully which known risk and protective factors may impact psychological outcomes when planning programmes and services for family members caring for adults with diabetes. Decision makers might consider the importance of the risk and protective factors identified here in our global analyses for their particular country.

One limitation of the DAWN2 study is the small number of family members recruited in each country [11]. Thus it was not possible to estimate separate models for each country, although we could identify factors that were differently associated with the outcomes in different countries. It also was not possible to link the data from family members with that from the person with diabetes whom they supported, or to objective characteristics (e.g., diabetes type and duration, complications, specific medications used, etc.). However, this problem is ameliorated when focusing on family member psychological outcomes because their perceptions of these factors are the potential drivers of their outcomes. As with all studies, caution should be used in generalising beyond the sample analysed in this study. Additional analyses of DAWN2 data should explore how qualitative research and relevant psychological theories might help to interpret these and other findings.

The findings of this study have important clinical implications for healthcare professionals and others who support family members of adults with diabetes. Where diabetes leads to social disadvantages, clinicians should be aware that this may be associated with distress not merely in people with diabetes but also in their family members. Clearly, there is a need for greater support of family members through appropriate educational programmes, and greater involvement of family members in the management of people with diabetes; both are positively related to the well-being of family members.

In conclusion, the results from this analysis have clarified the factors associated with either good or poor psychological outcomes in family members. These should be considered when determining how to best support adults with diabetes and their family members. Family members who could share worries and problems with the healthcare team and a wider circle of friends and relatives reported higher levels of perceived support, which was associated with better psychological well-being and quality of life. To a large extent, the perceived negative consequences of diabetes for family members could be prevented or ameliorated with social support from the healthcare team and other sources; being receptive to family member concerns as highlighted in the DAWN2 study may be an important role for healthcare professionals.

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**Table 1** Description of measures and outcomes assessed with DAWN2 questionnaires for family members caring for an adult with diabetes

| Measures | Description |
| --- | --- |
| Education | 1 = no college education; 0 = at least some college education |
| Other obligations | ‘You have other obligations (such as children, work, other family members) that prevent you from being as involved as you would like to be in his/her diabetes care’ (1 = somewhat/strongly agree, 0 = neither agree nor disagree or somewhat/strongly disagree) |
| PWD treated with injected diabetes medication | 1 = treated with diabetes drugs by injection, 0 = not treated by injections |
| Frequency of hypoglycaemia | Hypoglycaemia in last 12 months: 0 = none, 20 = less than monthly, 40 = monthly, 60 = several per month, 80 = weekly, 100 = daily |
| Frequency of severe hypoglycaemia | Natural log of the number of times in the last year that the person with diabetes had ‘severely low blood sugar such that he/she experienced problems with memory, language, thinking, or judgment and was unable to treat him/herself and needed help from someone to restore blood sugar levels’ (log taken after adding one to the number so that minimum value returned was zero) |
| Diabetes severity | ‘When you think of the word *diabetes*, what do you think of?’ (1 = a severe/very severe condition, 0 = a condition which can be severe, but is not always severe or a benign condition or no opinion) |
| Hypoglycaemia worry | ‘I am very worried about the risk of his/her hypoglycaemic events’ (1 = mainly/fully agree, 0 = mainly/fully disagree) |
| Diabetes-related discrimination | ‘Person you live with is discriminated against because of diabetes’ (0 = fully/mainly disagree, 1 = fully/mainly agree) [1] |
| Attend healthcare professional visits | ‘You usually attend his/her visits to healthcare professionals regarding his/her diabetes’ (1 = somewhat/fully agree, 0 = somewhat/strongly disagree or neither agree nor disagree) |
| Family member diabetes responsibility | ‘Thinking about yourself and the person you live with, please indicate who is responsible for each of the following related to his/her diabetes care’ Sum of 7 items (score 0 to 100) including: searching for useful information about diabetes; remembering to take his/her medications; measuring his/her blood sugar; injecting his/her medication; talking to healthcare professionals about his/her diabetes care; planning and cooking healthy meals; planning time for exercise or physical activity (from 4 = you are primarily responsible, to 0 = the person you live with is primarily responsible) |
| Dietary restrictions | ‘My ability to eat the way I want is restricted because of the diabetes of the person I live with’ (0 = fully/mainly disagree, 1 = fully/mainly agree) |
| Diabetes-related family arguments | ‘We argue about how he/she chooses to take care of his/her diabetes’ (0 = fully/mainly disagree, 1 = fully/mainly agree) |
| Frustrated about how to help the person with diabetes | ‘You are frustrated that you don’t know how to best help the person with diabetes you live with’ (0 = fully/mainly disagree, 1 = fully/mainly agree) |
| Diabetes education | ‘Please indicate if you have ever participated in a diabetes education programme for people with diabetes and/or their families’ (1 = yes, 0 = no or not sure) |

|  |  |
| --- | --- |
| Good ways to help the person with diabetes | ‘I have found good ways to help him/her take care of his/her diabetes’ (0 = fully/mainly disagree; 1 = fully/mainly agree) |
| Diabetes support network | Natural log of the number of people that a family member could talk to about living with someone with diabetes (log taken after adding one to the number so that minimum value returned was zero) |
| Diabetes support | DFSS-FM: Family Support Composite score. Scale derived from the sum of 7 items investigating in what ways the family member tries to be supportive (response options: never, rarely, sometimes, often, and always). Scale ranges from 0 (not supportive) to 100 (extremely supportive) |
| Outcomes |  |
| Well-being | WHO-5 Well-being Index, scored 0 to 100 [2] |
| Quality of life | WHO-QOL-BREF, scored 0-100 [3] |
| Diabetes impact | Mean of 7 DIDP-FM items (physical health, financial situation, relationship with family, friends, peers, leisure activities, work or studies, emotional well-being, relationship with the person who has diabetes); Scored 0 to 100 with the response options: very positive impact, positive impact, slightly positive impact, no impact, slightly negative impact, negative impact, very negative impact) [1] |
| Diabetes distress | PAID-5-DFM, 5-item scale, scored 0 to 100 [1] |
| Diabetes burden | ‘How much of a burden is it for you to help manage the diabetes of the person you live with’ (response options: very large burden, large burden, moderate burden, slight burden, no burden). Scored 0 to 100, with 100 = very large burden) |

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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; PWD: person with diabetes; 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).

**Table 2** Distribution of country values as reported by family members (N=2057) participating in the DAWN2 study

| Characteristics | Country median (min-max)\* | ICC |
| --- | --- | --- |
| FM demographic and socio-economic factors |  |  |
|  Female respondent | 65 (46.7-83.3) | 0.07 |
|  Age (years) | 43.2 (34.7-56.4) | 0.20 |
|  Low school education | 40.8 (5.0-86.5) | 0.26 |
|  Full-time work  | 40.7 (16.7-64.2) | 0.07 |
|  Part-time work  | 14.6 (1.6-25.8) | 0.13 |
|  Not working  | 43.8 (30.8-58.7) | 0.03 |
|  Not working - diabetes  | 1.6 (0.0-4.1) | 0.09 |
|  Other obligations  | 29.8 (9.8-54.8) | 0.11 |
| PWD characteristics |  |  |
|  Live with PWD spouse/partner | 26.2 (5.0-83.6) | 0.33 |
|  Live with PWD parent | 31.7 (1.6-52.5) | 0.16 |
|  Live with PWD other \*\* | 19.2 (6.4-38.8) | 0.10 |
|  Female PWD | 46.7 (25.4-60.0) | 0.05 |
|  PWD age | 59.1 (53.6-72.4) | 0.08 |
|  PWD treated with injected diabetes medication | 49.2 (25.8-60.0) | 0.02 |
|  Frequency symptomatichypoglycaemia | 12.3 (1.7-34.2) | 0.07 |
|  Severe hypoglycaemia | 40.2 (18.9-79.5) | 0.14 |
| FM diabetes beliefs/perceptions |  |  |
|  Diabetes severity | 39.4 (19.7-60.3) | 0.09 |
|  Hypoglycaemia worry | 63.6 (31.5-86.4) | 0.13 |
|  PWD discriminated against  | 20.0 (7.7-42.9) | 0.09 |
| FM diabetes involvement |  |  |
|  Attend healthcare professional visits for diabetes | 52.0 (27.1-77.1) | 0.08 |
|  FM diabetes responsibility  | 44.6 (27.5-55.0) | 0.09 |
|  Diet restricted by diabetes | 39.1 (17.4-67.5) | 0.10 |
|  Argue about diabetes management | 40.8 (15.0-78.6) | 0.14 |
|  Frustrated about how to help PWD  | 37.4 (17.5-53.0) | 0.06 |
|  Good ways to help PWD  | 72.7 (46.7-85.8) | 0.04 |
| FM support resources |  |  |
|  Diabetes education | 20.7 (9.4-43.3) | 0.07 |
|  Diabetes support network | 2.8 (1.7-7.3) | 0.22 |
|  Support Scale (DFSS-FM)  | 59.4 (49.4-73.8) | 0.14 |

\* Unadjusted value by country.

\*\* Includes PWD son/daughter, sibling, other adult relative, other non-related adult.

DFSS-FM: DAWN Family Support Scale–Family Members; FM: family member; ICC: intraclass correlation coefficient; min: minimum value; max: maximum value; PWD: person with diabetes.

**Table 3** Adjusted means of psychological outcomes for family member participants globally (N=2057) and in each of the 17 countries (n≈120)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Psychological outcome | Well-being (CRD = 10.6) | Quality of life (CRD = 10.3) | Diabetes impact (CRD = 7.2) | Diabetes distress (CRD = 11.4) | Diabetes burden (CRD = 13.4) |
|   | Model 0\* (ICC=0.05)  | Model 1\* (ICC=0.05) | Model 2\* (ICC=0.05)  | Model 0\* (ICC=0.11)  | Model 1\* (ICC=0.10)  | Model 2\* (ICC=0.07)  | Model 0\* (ICC=0.05) | Model 1\* (ICC=0.05)  | Model 2\* (ICC=0.03)  | Model 0\* (ICC=0.12)  | Model 1\* (ICC=0.10) | Model 2\*(ICC=0.02)  | Model 0\* (ICC=0.14)  | Model 1\*(ICC=0.14) | Model 2\*(ICC=0.20)  |
| Overall | 58.5 | 58.7 | 60.7 | 63.3 | 63.4 | 65.4 | 51.8 | 51.9 | 52.1 | 32.2 | 32.3 | 31.4 | 26.7 | 26.9 | 27.0 |
| Mexico | 66.2 | 68.4 | 69.3 | 52.0 | 54.4 | 55.9 | 50.1 | 49.4 | 49.2 | 33.8 | 32.1 | 30.1 | 8.4 | 6.1 | 3.9 |
| USA | 58.3 | 58.8 | 60.2 | 70.2 | 70.8 | 72.3 | 53.1 | 52.2 | 53.1 | 23.4 | 25.6 | 29.5 | 20.6 | 22.1 | 30.5 |
| Canada | 62.8 | 62.3 | 62.6 | 73.5 | 72.5 | 71.9 | 49.2 | 49.3 | 50.4 | 26.6 | 27.5 | 29.7 | 20.6 | 21.6 | 24.4 |
| France | 55.8 | 55.3 | 59.5 | 63.3 | 62.9 | 64.5 | 50.7 | 51.4 | 51.5 | 32.9 | 32.6 | 30.2 | 41.5 | 41.5 | 41.5 |
| Germany | 56.6 | 56.0 | 58.6 | 66.5 | 66.0 | 66.8 | 49.9 | 50.6 | 52.0 | 26.9 | 27.1 | 29.7 | 33.4 | 33.7 | 38.4 |
| Netherlands | 62.4 | 63.3 | 61.1 | 72.9 | 73.5 | 70.7 | 49.6 | 48.7 | 50.9 | 15.9 | 17.4 | 27.9 | 22.9 | 23.9 | 31.2 |
| Denmark | 64.5 | 64.1 | 64.3 | 73.0 | 72.1 | 69.6 | 51.7 | 51.1 | 51.9 | 22.4 | 24.5 | 32.6 | 22.7 | 25.0 | 31.6 |
| UK | 58.4 | 58.1 | 59.5 | 67.6 | 67.0 | 67.6 | 52.2 | 52.3 | 52.3 | 25.3 | 26.1 | 29.2 | 20.2 | 21.1 | 22.5 |
| Italy | 51.1 | 51.2 | 54.4 | 60.3 | 61.2 | 63.1 | 53.1 | 53.6 | 52.9 | 36.4 | 36.0 | 33.9 | 28.4 | 27.8 | 26.7 |
| Spain | 56.7 | 56.3 | 59.5 | 64.9 | 64.5 | 66.9 | 48.5 | 49.8 | 51.6 | 34.8 | 33.8 | 33.0 | 23.0 | 22.7 | 20.7 |
| Poland | 54.6 | 54.3 | 59.0 | 60.5 | 60.8 | 65.1 | 48.4 | 49.3 | 49.6 | 35.5 | 35.8 | 33.5 | 36.1 | 36.4 | 33.7 |
| Russian Fed. | 61.4 | 62.4 | 63.7 | 62.0 | 62.4 | 65.0 | 54.8 | 54.4 | 53.8 | 37.4 | 35.9 | 32.6 | 19.4 | 18.2 | 16.6 |
| Algeria | 53.7 | 55.0 | 54.4 | 54.9 | 56.2 | 63.2 | 47.5 | 48.7 | 50.0 | 45.5 | 44.1 | 33.3 | 38.1 | 37.2 | 28.7 |
| Turkey | 56.6 | 58.4 | 62.5 | 56.2 | 56.4 | 59.7 | 57.5 | 57.3 | 56.3 | 44.1 | 42.6 | 33.4 | 25.1 | 25.6 | 18.7 |
| India | 63.7 | 61.6 | 60.6 | 65.5 | 64.2 | 68.4 | 54.5 | 55.6 | 54.3 | 38.9 | 39.6 | 33.6 | 15.1 | 15.7 | 11.5 |
| China | 59.0 | 58.7 | 65.0 | 58.8 | 58.1 | 63.3 | 51.6 | 51.5 | 52.2 | 35.5 | 34.8 | 32.7 | 35.2 | 34.6 | 35.8 |
| Japan | 53.4 | 53.1 | 58.0 | 54.3 | 54.4 | 58.5 | 57.6 | 56.9 | 53.7 | 32.2 | 33.0 | 29.8 | 43.7 | 44.3 | 42.2 |

Model 0: multilevel model controlling country.

Model 1: multilevel model controlling country, diabetes type/treatment, diabetes duration, gender, age, education.

Model 2: multilevel model controlling variables in five categories: (1) family member demographic and socio-economic factors; (2) characteristics of the person with diabetes; (3) family member diabetes beliefs and perceptions; (4) family member involvement in diabetes care; and (5) family member support resources. A complete listing of variables within these categories is provided in Table 2.

\**P*<0.05 for country effect; CRD corresponding to an effect size of 0.5.

CRD: clinically relevant difference; ICC: intraclass correlation coefficient (higher values denote greater country effect).

**Table 4** Effect of various family characteristics on psychological outcomes of family members caring for people with diabetes (N=2057)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Characteristics | Well-being | Quality of life | Diabetes impact | Diabetes distress | Diabetes burden |
| Beta atentry | Final beta | Beta at entry | Final beta | Beta at entry | Final beta | Beta at entry | Final beta | Beta at entry | Final beta |
| FM demographic and socio-economic factors |  |
|  Female respondent a | -0.06\* | -0.09\* | 0.01 | -0.01 | -0.01 | 0.01 | 0.06\* | 0.05\* | 0.02 | 0.01 |
|  Age (years) a, b, d | -0.03 | -0.07 | -0.03 | -0.12\* | 0.12\* | 0.16\* | -0.05 | 0.03 | -0.01 | 0.02 |
|  Low education c | -0.06\* | -0.03 | -0.08\* | -0.09\* | 0.01 | 0.00 | 0.00 | -0.04 | 0.01 | 0.01 |
|  Full-time work@ b, e | 0.09 | 0.04\* | 0.03 | 0.01 | -0.02 | 0.02 | 0.02 | 0.02 | 0.04 | 0.04 |
|  Part-time work@ b, e | 0.04 | 0.03 | 0.00 | -0.04 | 0.02 | 0.03 | 0.02 | 0.02 | 0.09 | 0.09 |
|  Not working - diabetes  | -0.01 | 0.02 | -0.08\* | -0.04\* | 0.04 | 0.01 | 0.05\* | -0.01 | 0.08\* | 0.06\* |
|  Other obligations a, d | -0.10\* | -0.07\* | -0.08\* | -0.04 | 0.09\* | 0.07\* | 0.15\* | 0.05 | 0.14\* | 0.07\* |
|  *R-squared level 1* | 0.02 |  | 0.04 |  | 0.03 |  | 0.06 |  | 0.03 |  |
| PWD characteristics |  |
|  Live with PWD spouse/partner# d | -0.01 | -0.00 | 0.12 | 0.08 | 0.10 | 0.06 | -0.16\* | -0.09 | -0.24\* | -0.13\* |
|  Live with PWD parent# d | -0.13 | -0.03 | -0.05 | -0.02 | -0.04 | -0.09 | 0.10 | 0.01 | -0.11 | -0.13\* |
|  Female PWD | 0.00 | -0.02 | 0.00 | -0.03 | 0.00 | -0.01 | 0.03 | 0.04 | -0.02 | -0.01 |
|  PWD age d | 0.04 | 0.00 | 0.03 | 0.03 | 0.05 | 0.01 | -0.11\* | -0.07\* | 0.00 | 0.01 |
|  PWD treated with injected diabetes medication e | -0.03 | -0.04 | -0.05 | -0.06 | 0.08\* | 0.07\* | 0.03 | -0.01 | 0.02 | 0.01 |
|  Frequency symptomatichypoglycaemia a, b | 0.03 | 0.04 | -0.03 | 0.02 | 0.06\* | 0.04 | 0.15\* | 0.04 | 0.15\* | 0.07\* |
|  Severe hypoglycaemia a, c, d, e | -0.08\* | -0.06\* | -0.11\* | -0.09\* | 0.03 | -0.02 | 0.10\* | 0.03 | 0.17\* | 0.11\* |
|  *R-squared level 1* | 0.02 |  | 0.05 |  | 0.04 |  | 0.10 |  | 0.06 |  |
| FM diabetes beliefs/perceptions |  |
|  Diabetes severity a, d | -0.08\* | -0.08\* | -0.09\* | -0.08\* | 0.10\* | 0.13\* | 0.24\* | 0.21\* | 0.10\* | 0.10\* |
|  Hypoglycaemia worry a, b | -0.08\* | -0.06\* | -0.05 | -0.04 | 0.04 | 0.02 | 0.26\* | 0.24\* | 0.12\* | 0.07\* |
|  PWD discriminated against c  | 0.02 | 0.04 | -0.02 | 0.00 | -0.05\* | -0.04 | 0.07\* | 0.02 | 0.04 | 0.01 |
|  *R-squared level 1* | 0.07 |  | 0.09 |  | 0.07 |  | 0.29 |  | 0.11 |  |
| FM diabetes involvement |  |  |  |  |  |  |  |  |  |  |
|  Attend healthcare professional visits for diabetes b, e | -0.02 | -0.04 | 0.01 | -0.01 | -0.01 | -0.02 | 0.02 | 0.02 | -0.01 | -0.01 |
|  FM diabetes responsibility c, d  | -0.04 | -0.04 | -0.11\* | -0.12\* | 0.15\* | 0.16\* | 0.03 | 0.00 | 0.20\* | 0.20\* |
|  Diet restricted by diabetes b, c, e  | 0.02 | 0.00 | 0.09\* | -0.08\* | 0.02 | 0.03 | -0.05\* | -0.03\* | -0.13\* | -0.12\* |
|  Argue about diabetes management a, b, c, e | -0.09 | -0.06\* | -0.11\* | -0.10\* | 0.02 | 0.01 | 0.15\* | 0.14\* | 0.10\* | 0.08\* |
|  Frustrated about how to help PWD a, b, c, d, e | -0.10 | -0.09\* | -0.10\* | -0.09\* | 0.07\* | 0.07\* | 0.19\* | 0.18\* | 0.10\* | 0.08\* |
|  Good ways to help PWD e | 0.05 | 0.05 | 0.05 | 0.05 | -0.05 | -0.05 | 0.01 | 0.01 | -0.07\* | -0.07\* |
|  *R-squared level 1* | 0.09 |  | 0.15 |  | 0.10 |  | 0.37 |  | 0.17 |  |
| FM support resources |  |
|  Diabetes education c, e |  NA | 0.00 |  NA | -0.02 |  NA | -0.02 |  NA | 0.05\* |  NA | 0.06\* |
|  Diabetes support network b |  NA | 0.07\* |  NA | 0.10\* |  NA | 0.04 |  NA | -0.04 |  NA | -0.03 |
|  Support Scale DFSS-FM a, b, c, d, e |  NA | 0.07\* |  NA | 0.10\* |  NA | -0.07\* |  NA | 0.06\* |  NA | 0.05 |
|  *R-squared level 1* | 0.10 |  | 0.15 |  | 0.11 |  | 0.40 |  | 0.18 |  |

'Final beta' columns report regression coefficients for all variables in the model, with all variables entered into the model (i.e. the unconfounded and unmediated association).

R-squared is the proportion of between-subject variance explained by the set of covariates in the regression model. R-squared level 1 is the degree of between-subject variance explained when preceding variables have been entered.

@Reference group is ‘Not working’.

#Reference group is ‘Live with PWD other’.

Country-by-covariate interaction (*P*<0.05); awell-being bquality of life; cdiabetes impact; ddiabetes distress; ediabetes burden.

\**P*<0.05.

DFSS-FM: DAWN Family Support Scale–Family Members; FM: family member; PWD: person with diabetes.

**Figure Legends**

**Figure 1** Adjusted standard scores for family member psychological outcomes in the 17 countries represented in the DAWN2 study

Scores are calculated with a multilevel model (Model 2) controlling variables in five categories: (1) family member demographic and socio-economic factors; (2) characteristics of the person with diabetes; (3) family member diabetes beliefs and perceptions; (4) family member subjective burden; and (5) family member support resources. A complete listing of variables within these categories is provided in Table 2.