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Brief report

# The psychological impact of living with diabetes: Descriptive findings from the DAWN2 study in Denmark

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ABSTRACT

*Objective:* The descriptive findings from the Danish sample of the second Diabetes, Attitudes, Wishes, and Needs (DAWN2) study are presented, with specific focus on the psychological impact of living with diabetes and quality of life for people with diabetes and family members of people with diabetes.

*Method:* 502 people with diabetes over the age of 18 and 122 family members completed questionnaires online, by telephone or in person, including validated measures of diabetes-related distress, emotional well-being and quality of life as well as other measures of psychological well-being.

*Results:* People with diabetes reported that living with diabetes was a psychological burden, with individuals taking insulin medication or diagnosed with type 1 diabetes reporting the most distress. Half of all family members sampled reported that living with diabetes impacted them negatively.

*Conclusion:* The higher levels of emotional distress found in people taking insulin medication are likely due to greater disease severity and associated self-care burdens. Care and support programmes may need to be revised in order to better address these issues. Moreover, psychological support programmes may need to be extended to include family members that experience distress as a result of living with diabetes.

## 1. Introduction

Since the launch of the first global Diabetes, Attitudes, Wishes and Needs (DAWN) study over a decade ago [1–3], focus on diabetes prevention and care has increased, including an increased focus on the psychosocial and behavioural challenges facing people with diabetes. Despite improvements in health care provision and support programmes available to people with diabetes, living with diabetes, including the

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**Table 1 – Demographic data and continuous measures for PWD insulin medicated and non-insulin medicated and type 1 and type 2.**

| PWD | All PWD | Insulin treated | Non-insulin medication | Type 1 | Type 2 |
|---|---|---|---|---|---|
| Gender (% female) | 43.0% | 48.0% | 39.0% | 52.5% | 41.2% |
| Age | 59.7 (11.6) | 55.9 (12.8) | 63.0 (9.4) | 47.3 (14.0) | 62.1 (9.5) |
| Duration of diabetes | 14.3 (13.1) | 20.5 (13.97) | 9.0 (9.6) | 30.8 (15.2) | 11.1 (10.0) |
| PAID-5 score* | 21.2 (20.2) | 25.2 (21.5) | 17.7 (18.4) | 26.1 (21.9) | 20.2 (19.7) |
| WHO-5** | 67.9 (19.5) | 64.5 (21.0) | 70.7 (17.6) | 59.5 (20.4) | 69.5 (18.9) |
| WHO-QOL-BREF | 71.41 (21.42) | 66.63 (22.12) | 75.46 (19.97) | 64.69 (21.31) | 72.69 (21.22) |
| EQ-5D VAS | 74.56 (18.54) | 71.62 (19.81) | 77.05 (17.05) | 69.78 (20.36) | 75.47 (18.06) |
| DIDP | 52.13 (13.87) | 54.97 (14.68) | 49.64 (12.63) | 58.13 (14.71) | 50.97 (13.41) |
| N | 502 | 230 | 272 | 80 | 422 |

* Scores of ≥40 on PAID-5 (Problem Areas in Diabetes Scale) indicates high diabetes related stress.
** Scores ≤50 on well-being index indicates likely depression. A score of ≤28 indicates likely moderate to severe depression.

behavioural- and psychological-changes needed to manage diabetes effectively, remains an ongoing challenge to many people with diabetes [4–10]. The challenges of living with diabetes are not just confined to the person with diabetes. Family members of people with diabetes may also be at risk of experiencing distress due to worries about the consequences of the illness, or in some cases the added pressure of taking on the role of carer – which may in turn exacerbate the distress experienced by the person with diabetes [11,12].

One of the primary aims of the second Diabetes, Attitudes, Wishes, and Needs (DAWN2) study was to gain a better understanding of the unmet needs of people with diabetes (PWD) and family members of people with diabetes (FM) recruited from 17 participating countries (see Peyrot et al. [13] for a detailed description of the methods used). The descriptive findings from the Danish sample of the DAWN2 study are presented here, with specific focus on the psychological impact of living with diabetes and quality of life for PWD and FM.

## 2. Methods

### 2.1. Participants and procedure

A total of 502 PWD over the age of 18 and 122 FM were recruited using a combination of internet, telephone and in-person methods (the PWD and FM participant groups were recruited independently. In other words individuals in the PWD group were not necessarily related to individuals in the FM group). The mixed-mode recruitment method was chosen to ensure as representative a sample as possible. Utilising web-based recruitment alone in a Danish population may produce selection bias in people with type 2 diabetes, favouring younger and more highly educated respondents [14]. Online recruitment was carried out via multiple online sources including online panels and databases; telephone recruitment was carried out using a variety of sources including patient association lists, proprietary databases, etc. (see Peyrot et al. [13] for a detailed description of the recruitment methods used). Predetermined quotas of 80 people with type 1 diabetes, 150 insulin-medicated people with type 2 diabetes, 172 medicated (non-insulin) people with type 2 diabetes and 100 non-medicated people with type 2 diabetes were interviewed. Quotas also ensured gender, age, and geographic representation. The study was conducted in compliance with national ethical regulations and in accordance with the principles of the Declaration of Helsinki. Sample characteristics and other information are presented in Table 1.

### 2.2. Measures

Questionnaires were completed online, by telephone or in person and included validated measures of diabetes-related emotional distress (Problem Areas in Diabetes Scale 5 [PAID-5]), emotional well-being (WHO well-being index 5 [WHO-5]), quality of life (WHO quality of life assessment instrument [WHO-QOL-BREF]) and health status (EuroQol-5D visual analogue scale [EQ-5D VAS]), as well as bespoke measures of the psychological impact of diabetes (DAWN Impact of Diabetes Profile [DIDP]).

### 2.3. Descriptive results

The means and standard deviations for continuous and categorical measures are presented in Table 1 for PWD. All the scale scores were transformed to range from 0 to 100, with higher values indicating a higher level of the dimension measured. Frequencies and percentages for categorical (single item) measures of psychological well-being for PWD and FM are presented in Table 2.

Forty three percent of all respondents were female. Type 1 diagnosis was similar across genders, with marginally more men than women diagnosed with type 2 diabetes (58.8%). People diagnosed with type 2 diabetes were older as a group compared to type 1, and the duration of diabetes was longer in people diagnosed with type 1 compared with type 2 diabetes (see Table 1). Approximately 78% of family members sampled were female, with a mean age of 56.4 (10.7).

### 2.4. People with diabetes

PWD who take insulin reported higher levels of diabetes-related emotional distress, lower levels of emotional well-being, lower quality of life, and higher negative impact of living with diabetes compared to non-insulin users. The burden of living with diabetes, whilst challenging for people with type 2 diabetes, seems to have a greater psychological impact on

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