

Differential impact of type 1 and type 2 diabetes on families: a UK cross-sectional study using FROM-16

R. Shah ¹, A.Y. Finlay ¹, F.M. Ali ¹, K. Otwombe ², S. Nixon ³, J.R. Ingram ¹, M.S. Salek ⁴

¹ Division of Infection and Immunity, School of Medicine, Cardiff University, Cardiff, UK. ² Faculty of Health Sciences, University of the Witwatersrand, South Africa.

³ Patient Research Partner, Cardiff, UK. ⁴ School of Health, Medicine and Life Sciences, University of Hertfordshire, Hatfield, UK.

Introduction

A person's diabetes affects the quality of life (QoL) of family members. However, how the family impact varies across Type 1 (T1D) and Type 2 diabetes mellitus (T2D) was unknown.

Aims

The study aimed to measure the impact of T1D and T2D on the QoL of family members/partners and assess whether there is any difference in family impact.

Methods

- A cross-sectional study, recruited online through Patient Support Groups: Diabetes UK, Juvenile Diabetes Research Foundation (JDRF), Healthwise Wales (HWW) and Social Services Departments in Wales.
- The study involved UK family members/partners of people with diabetes completing the **Family Reported Outcome Measure-16 (FROM-16)**.

FROM-16

The FROM-16 is an extensively validated generic family QoL questionnaire which measures the impact of any disease, across all medical specialities, on the QoL of family members or partners of patients of any age [1-5].

The FROM-16 comprises 16 items, each with three response options: 'Not at All' (scoring 0), 'A Little' (scoring 1) and 'A Lot.' The lowest possible score of FROM-16 is 0, and the highest is 32. The higher the score, the greater the negative impact on the family member's QoL.

Results

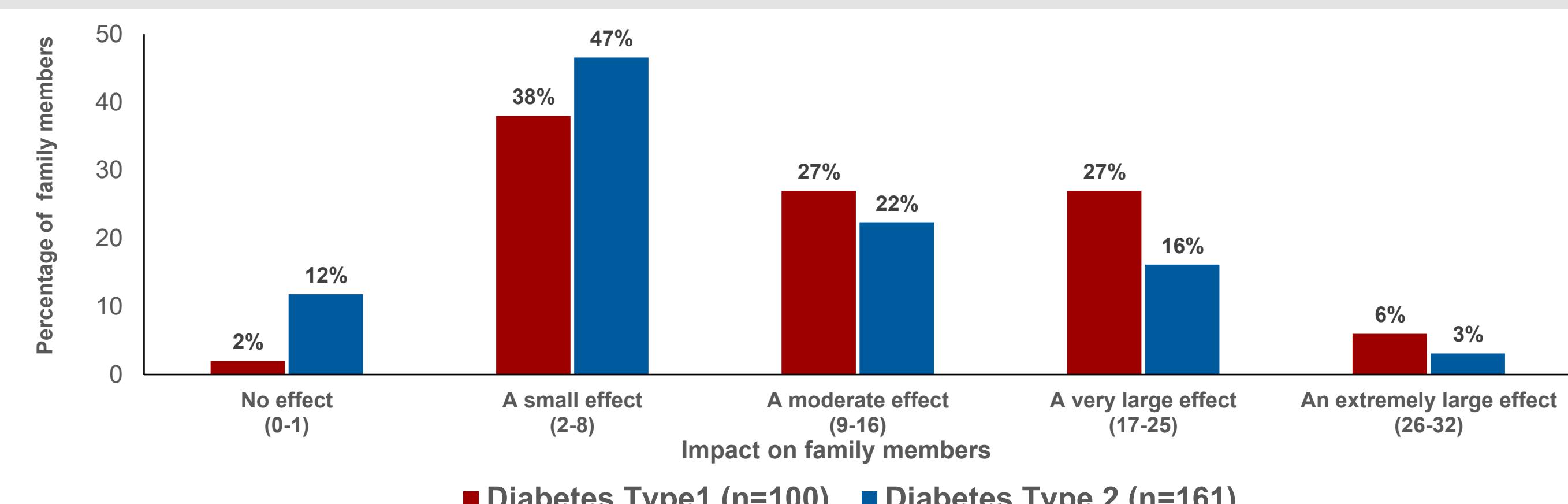
- 261 family members/partners (mean age=57.9 years, SD=13.8; females=68.2%) of people with diabetes (mean age=57.7, SD=20.6; females=38.3%; T1D n=100; T2D n=161) completed the FROM-16.
- The family members were mostly spouses/partners (67%), followed by Parents (15%), Adult children (13%), and Siblings (5%).
- The overall FROM-16 mean score was 10.5, SD=7.8, meaning a 'moderate effect' on the QoL of family members of people with diabetes.
- 25% of family members experienced a "very large effect" or 'extremely large effect' on their QoL (FROM-16 score ≥ 17) (Table 1).

Table 1 FROM-16 severity score banding describing the impact of a person's diabetes on family members/partners (n=261) [3].

FROM-16 score banding	Number of family members	% of family members
No effect (0-1)	21	8.1
A little effect (2-8)	113	43.3
A moderate effect (9-16)	63	24.1
A very large effect (17-25)	53	20.3
An extremely large effect (26-32)	11	4.2
Total	261	100

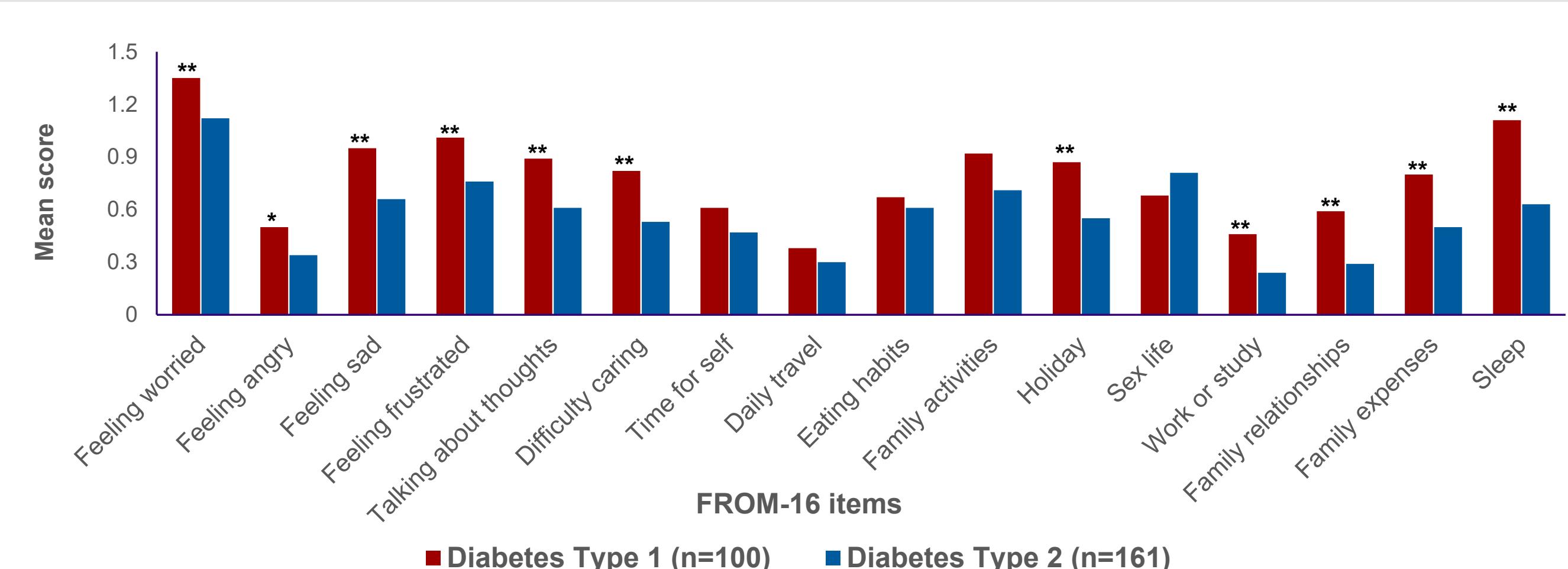
- The family impact of T1D (mean FROM-16=12.6, SD=7.9) was greater than that of T2D (mean FROM-16=9.2, SD=7.5, $p<0.01$).
- The family members of people with T1D were more impacted (33% having FROM-16 ≥ 17) than the family members of people with T2D (19% FROM-16 scores ≥ 17) (Figure 1).

Figure 1 Impact on Quality of life of family members/partners of people with diabetes Type 1 and Type 2 [3].



- The difference in impact between the family members of T1D and T2D was also noticed at the **individual item level**.
- T1D family members** had significantly **higher mean scores** for feeling **worried**, feeling **sad**, feeling **angry**, feeling **frustrated**, talking about **thoughts**, having **difficulty caring** for their relative, effect on **work or study**, effect on **holidays**, effect on **family relationships**, effect on **family expenses**, and effect on **sleep** ($p<0.05$) (Figure 2).

Figure 2 Family impact of diabetes Type 1 and Type 2 across individual FROM-16 items (max=2, min=0).



*significance level p-value <0.05; ** significance level p-value <0.01

- Being "**female**" and "**parents** of children and adolescents" were significant predictors of greater impact.
- Family members of people with **T2D** had a **lower risk** of experiencing a **high family impact** (FROM-16 score ≥ 17) compared with family members of people with **T1D** (RR: 0.561, 95% CI: 0.371-0.849).

Conclusions

- The family members of people with T1D, particularly **females** and those caring for **children and adolescents**, experience a greater impact on their QoL compared to those with T2D.
- These findings have **clinical and resource implications**, indicating a need to assess this impact as a part of routine diabetes care to support impacted family members.
- The **FROM-16 could assess this impact in routine practice** and facilitate appropriate support to families.

Acknowledgements

- We are grateful to the people with diabetes and family members/partners for their participation in this study.
- We are thankful to Diabetes UK, JDRF, HWW and Social Services Departments in Wales for their support with participant recruitment.

References

1. FROM-16 website, Cardiff University, <https://www.cardiff.ac.uk/medicine/resources/quality-of-life-questionnaires/family-reported-outcome-measure>.
2. Golics, C. J., Basra, M. K. A., Finlay, A. Y., & Salek, S. The development and validation of the Family Reported Outcome Measure (FROM-16) to assess the impact of disease on the partner or family member. *Qual Life Res.* 2014 Feb;23(1):317-26. doi: 10.1007/s11136-013-0457-y.
3. Shah R, Finlay AY, Salek SM, et al. Meaning of Family Reported Outcome Measure (FROM-16) severity score bands: a cross-sectional online study in the UK. *BMJ Open* 2023; 13: e066168. 2023/03/24. DOI: 10.1136/bmjopen-2022-066168.
4. Shah R, Finlay AY, Salek MS, Allen H, Nixon SJ, Nixon M, Otwombe K, Ali FM, Ingram JR. Responsiveness and minimal important change of the Family Reported Outcome Measure (FROM-16). *J Patient Rep Outcomes* 8, 38 2024. <https://doi.org/10.1186/s41687-024-00703-1>.
5. Shah R, Salek S, Finlay A, et al. Mapping of Family Reported Outcome Measure (FROM-16) scores to EQ-5D: algorithm to calculate utility values. *Quality of Life Research* 2024; 1-13. DOI: 10.1007/s11136-023-03590-z.

 [Read the full paper here](#)



Contact Author: Shahr45@cardiff.ac.uk