



Spouses' educational needs and perceptions of health in partners with type 2 diabetes

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Introduction

The proportions of people with diabetes who meet the recommended goals for glycaemia, blood pressure (BP) and cholesterol parameters are as low as approximately 10%.^{1,2} Since these parameters are well known risk factors for microvascular and macrovascular complications,³ quality improvement strategies for diabetes care are of utmost importance. One such strategy for type 2 diabetes mellitus (T2DM) is the implementation of a cross-specialty team approach to patient care, *ie* the diabetes team model.^{2,4} However, since diabetes management is influenced by several psychosocial factors, such as characteristics of patients and healthcare providers, social environment (including support systems, especially family support) and care provider-patient relationships,⁵

Abstract

Background: The importance of spousal support in type 2 diabetes mellitus (T2DM) patient management is often neglected. We prospectively investigated spouses' needs for T2DM information, and whether their perceptions of health changes in their diabetic partners correlated with changes in objective and subjective health parameters for the partners.

Methods: Spouses and partners with T2DM (n=52 per group) were followed for two years. Questionnaires on T2DM information/education and general health perception of themselves and their partners were given to spouses at start and end of study. Perceived changes in partners' health were compared with changes in objective (10-year Framingham coronary heart disease risk) and subjective (health-related quality-of-life [EuroQoL]) measures.

Results: Spouses' (mean age±SD 58±10 years, n=42 females) self-reported needs for T2DM information/education were high at both assessments (61.5%/76.7%; 46.2%/63.0%, respectively). General health of diabetic partners (mean age 60±8 years, n=42 males) was perceived as improved by 10%, worsened by 27% and unchanged by 63% of spouses. Significant correlations were observed between spouses who perceived improvements in partners' health, and subjective and objective parameters of partners' health (EuroQoL scores increased by 18; Framingham risk reduced by 2.0±3.0%); similar correlations were observed in spouses who perceived worsening of partners' health (EuroQoL scores decreased by 7±15; Framingham risk increased by 1.7±4.1%). Spouses' results showed moderate sensitivity for capturing health worsening in relation to increase in Framingham risk (57%); specificity in relation to no change or reduction in Framingham risk was high (74%).

Conclusion: Spouses' needs for T2DM information/education were high. Perceived changes in partners' health significantly correlated with subjective and objective outcome data. Further studies should investigate whether spouses' perceptions of negative changes could be used to trigger more intensive T2DM management strategies.

Key words

Type 2 diabetes; education; spouse

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spouses' involvement may represent an important resource for patients' self-management and education.⁶⁻⁸

Nevertheless, experience shows that: (a) spouses are seldom integrated in T2DM patient care or education strategies, despite research suggesting that the majority want to be involved;⁹ (b) spouses do not feel that the healthcare system provides adequate support in T2DM care.⁹ However, and perhaps most importantly, interventions that include spousal education could also improve patients' glycaemic control.¹⁰ Further evidence in favour

of strategies that loosely support spouses' involvement in T2DM education and care lie in the fact that improved illness adaptation and health-related quality-of-life (HRQoL) are observed in the presence of enhanced family support and/or less family conflict.^{6,7,11}

To date, however, sparse data are available and little is known prospectively about spouses' self-reported needs for education about T2DM in their partners. Similarly, there are few reports of spouses' perceptions of health changes in partners with T2DM, and how well such percep-



tions reflect objective and subjective patient outcomes. The present study aimed to prospectively evaluate spouses' self-reported educational needs for the care of their partners with T2DM, and the applicability of using spouses as a source for assessing the standard of health among these patients.

This is a follow-up of a cross-sectional study that compared HRQoL in patients with T2DM with that of their spouses.⁹ The primary objectives were to assess, over a two-year disease trajectory, spouses' changes in self-reported needs for diabetes education, and associations between perceived changes in the general health of their diabetic partners and changes in objective and subjective parameters. Secondly, the aim was to characterise spouses and their diabetic partners in relation to perceived health changes.

Methods

The study, which was conducted at Vestre Viken, Asker and Bærum Hospital Trust in southern Norway, was initiated in 2002. Recruitment of study participants to this two-year study ended in 2004, hence by 2006 the last included subjects had completed follow-up. All participants gave written informed consent for study participation, and the study was conducted in accordance with the Helsinki Declaration and approved by the Regional Ethics Committee and the Norwegian Data Inspectorate.

Study flow

Of the 73 couples forming the initial cross-sectional study group who were eligible to participate in this follow-up analysis, separation/divorce affected two couples, and in four couples either the partner or their spouse died or suffered from a medical condition that prevented further participation (*eg* stroke,

Alzheimer's disease). This left 67 eligible couples. Spouses received sealed envelopes containing questionnaires at study initiation and at two-year follow-up, via the patients with T2DM, and completed questionnaires were returned either by mail or by personal delivery. If the questionnaire was not returned within two weeks, one reminder was sent by post.

During the two-year follow-up period, the partners with T2DM participated in an open, parallel-group, randomised controlled study investigating the effect of structured intensive care versus standard care;¹² they were seen at three-monthly intervals either at the outpatient clinic or by their general practitioner. Treatment was administered according to international and national treatment guidelines.^{13,14} Inclusion/exclusion criteria and recruitment procedures for this trial have been described previously.^{9,12}

Data collection

In addition to collecting general background information (age, gender, education level, employee status, presence of chronic disease), the spouses' questionnaire included seven questions, all self-administered and previously used.¹⁰ Potential replies for three questions were of multiple-choice format:

- Q1: "How do you interpret your own health?" (reply choices: Poor, Average, Good or Excellent).
 - Q2: "How do you interpret the health of your partner who has T2DM?" (Poor, Average, Good or Excellent).
 - Q3: "Is your daily life affected by your partner's T2DM?" (Not at all, Very modestly, Some or Very much).
- Four questions were formatted for "Yes" or "No" responses:
- Q4: "Are you in need of more

information about T2DM?"

- Q5: "Do you want to participate in a formal education programme for spouses of patients with T2DM?"
- Q6: "Do you feel that adequate support is given by the healthcare system with respect to T2DM?"
- Q7: "Have you ever received information about T2DM from professional healthcare providers?"

Spouses' perceptions of partners' health change were classified as improved if responses to Q2 changed from: poor to average; poor to good or excellent; average to good or excellent; or good to excellent. Perceptions were considered to be worsened if the reversed patterns were seen. If health classifications at baseline remained identical after the two-year follow-up period, perception was recorded as unchanged.

Assessment of objective measures of health

Handling and analysis of the cardiovascular (CV) risk factors evaluated in this study (glycaemic control, lipid levels, weight, BP, antidiabetic medication use) have been described.¹² CV risk was evaluated by estimating each patient's 10-year absolute risk for coronary heart disease (CHD), using the adult treatment panel's risk estimator from the Framingham heart study.¹⁵ This model is based on an epidemiological study and incorporates several isolated CV risk factors (age, gender, total cholesterol, high-density lipoprotein cholesterol, tobacco use and systolic BP) to predict patients' 10-year absolute risk for CHD; it has been validated for use in people with T2DM.¹⁶ Changes in CV risk, calculated using the Framingham CV risk score, were then related to whether spouses perceived health as improved, worsened or unchanged.



Evaluating HRQoL in T2DM patients' partners

To compare how well each spouse's perceptions of changes in their partner's health correlated with the partner's own assessment of HRQoL, two sets of questionnaires were administered to patients: the Short-Form HRQoL (SF-36) and the EuroQol visual-analogue scale (EQ-VAS).

The EQ-VAS categorises current overall health by a single number on a scale from 0 (worst imaginable state of health) to 100 (best imaginable state of health)¹⁷ and has acceptable reliability and validity in patients with CHD.^{18,19}

The SF-36 health survey questionnaire, Norwegian version 1.2²⁰ (which is self-administered and has been validated for use in Norway²¹) contains 36 questions that measure function and capacity/limitation across eight conceptual domains. The eight domains are: mental health (MH), vitality (VT), bodily pain (BP), general health perceptions (GH), social functioning (SF), physical functioning (PF), role limitations – emotional (RE), and role limitations – physical (RP). Scales of 0–100 are used for each domain, with higher scores indicating good HRQoL.

Statistical analysis

Since T2DM is usually a progressive disease, our clinical hypothesis was that 30% of the spouses would state that the general health of their partners with T2DM worsened during the two-year disease trajectory. With our null hypothesis being that no changes should occur, in order to capture proportional changes at a value of 0.05 and to have reasonable power (80%) in this study, at least 42 couples needed to be evaluated.

Data are presented as the mean, with standard deviation (SD) as a measure of variance for non-

categorical data and proportion (or %) for categorical data. Between-group comparisons of the three categories were conducted using analysis of variance. Fisher Least Significant Difference *post hoc* tests were used to evaluate which means differed for continuous parameters; was used for categorical data.² Specificity, sensitivity, and positive and negative predictive values of spouses' perceptions of changes in health (dichotomised as improved, no change or worsened) were calculated using changes in Framingham CV risk scores (dichotomised as ≤ 0 or > 0) as the gold standard. SPSS statistical software version 16.0 for Windows (SPSS Inc. Chicago, USA) was used for calculations, and the level of statistical significance was set at $p \leq 0.05$.

Results

Of the 67 couples eligible for analysis, seven spouses explicitly stated that they did not want to participate in the two-year follow-up study. Six couples did not respond, despite reminders, and two couples answered the questionnaires incompletely, leaving a total of 52 couples (77.6%) utilised for the final analysis.

Participants' baseline characteristics are given in Table 1; the baseline characteristics of those who did not participate did not differ significantly from those who did (data not shown). Of note is the relative predominance of couples where the spouse was female and the patient was male ($n=42$), and that among the spouses, 51.9% ($n=27$) reported that they suffered from a chronic disease, osteoarthritis being predominant ($n=10$, 19.2%).

Over the two-year period, nine (24.3%), 18 (48.6%) and 10 (27%) spouses reported that their own health improved, did not change or worsened, respectively; correspon-

ding replies concerning their partners with T2DM were five (9.6%), 33 (66.5%) and 14 (26.9%), respectively.

Of the spouses, at baseline 61.5% reported a need for more information about T2DM; after two years, this increased to 76.7%. At two years, 63% expressed a desire to participate in a formal educational programme about T2DM, and 30.8% reported having received information about T2DM: both percentages were slightly higher than baseline levels (46.2% and 25%, respectively). A minority of respondents (26.9%) felt adequately supported by the healthcare system at baseline, rising to 37.0% at two years, but most spouses reported that their daily lives were 'not at all' (13.5%) or 'very modestly' (46.2%) affected by their partner's T2DM at baseline, compared with 45.6% and 12.3% respectively at two years. In fact, few respondents reported that their daily lives were affected 'very much' by their partner's condition (5.8% at baseline and 5.5% at two years).

Table 2 illustrates changes in objective measures of health (glycosylated haemoglobin [HbA_{1c}], fasting glucose, lipid levels, weight, BP, antidiabetic medication use, Framingham risk score). When patients' EQ-VAS and SF-36 scores were compared with perceived health changes reported by spouses ('improved', 'no change' or 'worsened'), significant correlations were observed for Framingham risk results (Table 2), and EQ-VAS scores (Figure 1). EQ-VAS scores increased significantly (by 18 ± 36) in patients whose spouses perceived improvements in their partner's health, compared with reductions of -7 ± 15 in patients whose spouses perceived that their partner's health had worsened ($p=0.012$). As expected, EQ-VAS scores were unchanged in those who perceived



no change in their partner's health.

Regarding the Framingham risk scores, significant changes were seen in people with T2DM, both for

those whose spouses reported improved health in their diabetic partners and those whose spouses reported no change, compared

with spouses who perceived worsened status (Table 2). No significant associations were seen for other objective (Table 3) or

	People with T2DM	Spouses
Baseline couple characteristics		
Age, y \pm SD	59.8 \pm 8.2	58.4 \pm 10.2
Gender (F/M) n (%)	10/42 (19/81)	42/10 (81/19)
Education level, n (%)		
\geq 4 y at university	12 (23)	12 (23)
1–3y at university	13 (25)	14 (26.9)
College	20 (38.5)	17 (32.7)
No higher education	7 (13.5)	9 (17.3)
Working status, n (%)		
Employed full-time	27 (51.9)	25 (48.1)
Employed part-time or unemployed	6 (11.5)	11 (21.1)
Retired	13 (25.0)	10 (19.2)
Disabled	6 (11.5)	4 (7.7)
Specific questions asked of spouses		
Q1) How do you interpret your own health?		n (%)
Poor		1 (2)
Average		13 (26)
Good		26 (60)
Excellent		7 (12)
Q2) How do you interpret the health of your partner who has T2DM?		n (%)
Poor		6 (11.5)
Average		16 (30.8)
Good		28 (58.3)
Excellent		2 (3.8)
Specific evaluations administered to people with T2DM		
EQ-VAS 0–100, score \pm SD	72 \pm 20	
Baseline 10y CHD risk, % \pm SD	9.2 \pm 5.2	
Medications taken, n \pm SD (%)	3.2 \pm 1.8 (0.8)	
Oral hypoglycaemic drugs, n \pm SD (%)	1.0 \pm 0.8 (0.3)	
T2DM treatment by diet alone, n (%)	16 (30.8)	
Any insulin therapy, n (%)	7 (13.5)	
HbA _{1c} , % \pm SD	7.5 \pm 1.5	
Fasting plasma glucose, mmol/l \pm SD	9.2 \pm 2.9	
Weight, kg/BMI, kg/m ² \pm SD	92 \pm 18/29.5 \pm 5.3	
Smoking habits, n (%):		
Never/Previous use/Current daily use	18/30/4 (35/58/7)	
Previous CV disease, n (%)	10 (19)	
Hypertension, n (%)	39 (75)	
Premature CHD in family, n (%)	32 (61.5)	
Previous CV disease, n (%)	10 (19)	
Abbreviations: EQ-VAS, EuroQoL visual-analog scale; CHD, coronary heart disease; HbA _{1c} , glycosylated haemoglobin; BMI, body mass index; CV, cardiovascular		

Table 1. Baseline characteristics of people with type 2 diabetes mellitus (T2DM) and their spouses



subjective measures, such as the SF-36 instrument (Figure 1), although similar trends were observed in spouses who perceived that their partner's health status had worsened.

A moderate sensitivity (0.57, 95%CI confidence intervals: 0.30, 0.81), a positive predictive value (0.44) with high specificity (0.74, 95%CI: 0.57, 0.86) and a high negative predictive value (0.82) were found in relation to spouses' perceived ability to capture true worsening, or no change in health status, when utilising the Framingham risk score as the gold standard.

When improvements in the patients' health were reported by their spouse, the following parameters were noted:

- The patient's general levels of education tended to be higher.
- The patient's tended to have a shorter duration of T2DM.
- The couples tended to be younger (Table 3).
- Insulin treatment was not initiated during the two-year follow-up period.

Discussion

In the present two-year follow-up study, spouses' levels of interest in learning about T2DM and their willingness to participate in educational programmes were high. In addition, changes in objective (as measured by Framingham CV risk) and subjective (HRQoL) parameters of the health of their diabetic partners correlated with spouses' perceptions of health changes. These results suggest that methodologies that utilise spouses to assess and evaluate health changes, including capture of CV risk progression, are of moderate sensitivity; they also suggest a high specificity (for no change or improvement in CV risk) when the Framingham CV risk is used as the gold standard.

	Level of change		
	Worsened (n=14)	No change (n=33)	Improved (n=5)
Changes in biological parameters			
HbA1c, %±SD	-0.38±1.20	-0.14±1.07	-0.66±2.40
Fasting plasma glucose, mmol/l±SD	-0.82±2.50	-1.20±3.16	0.34±3.88
Total cholesterol, mmol/l±SD	0.07±1.07	-0.51±0.93	-0.91±0.41
LDL-cholesterol, mmol/l±SD	-0.12±0.98	-0.53±0.84	-0.64±0.73
HDL-cholesterol, mmol/l±SD	0.07±0.44	0.02±0.18	0.02±0.13
Triglycerides, mmol/l±SD	0.03±0.55	-0.07±0.94	-0.60±1.00
Weight, kg±SD	0.09±3.03	-0.32±5.14	-0.14±4.81
Changes in 24h arterial BP measurement			
Mean systolic BP, mmHg±SD	4±19	-5±17	-14±19
Mean diastolic BP, mmHg±SD	-3±6	-3±9	-9±10
Changes in 10y absolute risk for CHD			
Framingham risk, %±SD	1.7±4.1	-0.3±2.7*	-2.0±3.0†
Changes in antidiabetes medication use			
Number of OGDs, n±SD	0.1±0.9	0.2±0.8	0.2±0.8
Intensified/initiated insulin treatment, n (%)	1 (7.1)	4 (12.1)	0 (0)
Abbreviations: HbA _{1c} , glycosylated haemoglobin; LDL, low-density lipoprotein; HDL, high-density lipoprotein; BP, blood pressure; OGDs, oral glucose-lowering drugs a <i>p</i> =0.049 for overall analysis of variance; * <i>p</i> =0.048 vs Worsened; † <i>p</i> = 0.029 vs Worsened			

Table 2. Two-year changes in cardiovascular (CV) risk factors, risk for coronary heart disease (CHD) and use of medication in patients with type 2 diabetes mellitus (T2DM), compared with spouses' perceived changes in partners' health

The findings of increased interest in, and willingness to learn more about, T2DM among spouses is interesting and merits further consideration, given the potential for improved patient outcomes through enhanced spousal participation in T2DM care programmes.¹² Conversely, increasing the focus on including the spouse might result in a spouse becoming overprotective, which might impact negatively on the patient's self-management of his or her diabetes.²² The present study and a previous report highlight the need for providing patients and their families with appropriate, practical information about T2DM.²³ Our results therefore underscore the fact that there are unmet educational

needs for spouses, although we cannot answer how such needs are best met. However, our results clearly indicate that the current model for T2DM care does not adequately address such needs, as reflected by the low proportion of spouses who had received information about T2DM from healthcare providers (30.8% after two years).

Although our sample is relatively small, an interesting finding is that spouses are sensitive to changes in the health of their partners with T2DM, regardless of whether subjective or objective assessment parameters are considered. This also suggests that further studies are needed regarding spouses' evaluation of changes in



health status, especially if they perceive worsening health. Such results could then be used to develop criteria for selecting patients who perhaps should receive more intensive, rather than conventional, risk management. The moderate sensitivity in this setting is defensible, since the most important intervention from a societal view would be to capture and intervene in high-risk groups, for example, those most at risk for worsening health status.

Although this ability among spouses depends on many factors that were not addressed in the present study (for example, the quality of couples' relationships, which was previously shown to have an impact on diabetes control and HRQoL²³), we found that where the partner's health improved, the couple's average age tended to be lower and the education level among patients was higher. In addition, no insulin therapy was initiated in those who perceived health improvements, whereas other studies have associated insulin therapy initiation with the perception of more 'serious' disease.²⁴

The strengths of this study are its length of follow-up and the lack of change in marital status during the total study period, such changes can significantly influence health perception in longitudinal analyses.²⁵ Study limitations include the low number of study subjects, the use of a single study centre, the involvement of only Caucasian heterosexual subjects, and the unequal numbers of male and female spouses, all of which may have affected the results. Furthermore, 51.9% of the spouses reported having chronic diseases themselves. This is a variable that may adversely impact perceived health,²⁶ and one for which we did not control. Similarly, we did not

	Spouses' perceptions		
	Worsened (n=14)	No change (n=33)	Improved (n=5)
Years of partnership, mean±SD	32±12	28±14	28±15
Spouses' characteristics			
Age, y, mean±SD	61±6	58±11	54±16
Working status (%)			
Full-time	50	42	80
Part-time/unemployed	14.3	27.3	0
Retired	21.4	18.2	20
Disabled	0	12.1	0
Educational level (%)			
≥4y at university	30	21.1	22.2
1–3y at university	20	50	30
College	50	36.8	0
No higher education	0	15.8	44.4
Patients' characteristics			
Age, y, mean±SD	60±8	60±8	57±9
Diabetes duration, y, mean±SD	7±4	7±8	4±4
Working status (%)			
Full-time	50	54.6	40
Part-time or unemployed	7.1	12.1	20
Retired	35.7	21.2	20
Disabled	7.1	12.1	20
Educational level (%)			
≥4y at university	38.1	15.2	60
1–3y at university	42.9	21.2	0
College	7.1	48.5	20
No higher education	21.4	15.2	20

Table 3. Baseline characteristics of couples, spouses and patients with type 2 diabetes mellitus (T2DM) according to spouses' perceived changes in patients' health. There were no significant between-group differences

control for differences in insulin therapy initiation during the two-year study period.

Conclusion

The continued need for educational programmes for spouses of patients with T2DM seems to be high and should be considered for all, although further research is needed to evaluate how this can best be administered to leverage patient reduction in CV risk. Furthermore, since perceived changes (improvement or worsening)

of partners' health significantly correlate with subjective and objective patient-outcome data, future studies should investigate whether spouse's perceptions of negative changes in their partners' health could be used as a trigger for more intensive patient management.

Conflicts of interest

E Orvik and L Ribu report no conflicts of interest. OE Johansen is an associated post-doctoral researcher at Vestre

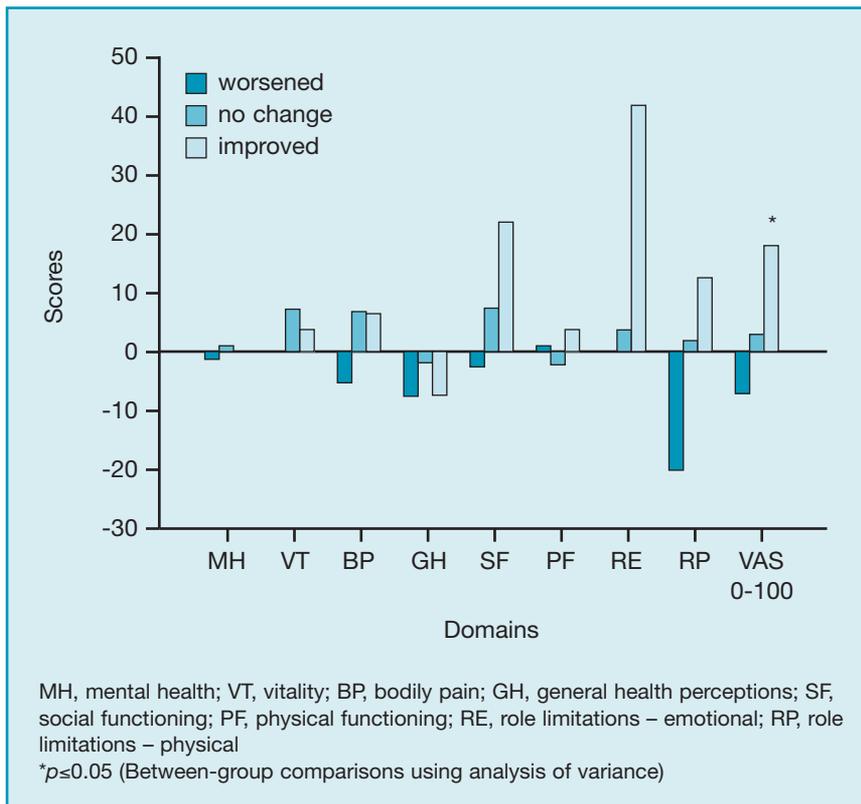


Figure 1. Two-year changes (compared with baseline) in short form-36 quality-of-life and EuroQol visual-analog scale (VAS 0–100) scores, according to spouses' assessments of the health of patients with type 2 diabetes mellitus

Viken, Asker and Baerum Hospital Trust, but is a senior research physician at a pharmaceutical company (Boehringer Ingelheim) that develops compounds for the treatment of diabetes mellitus.

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