Patients' expectations:

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CHAPTER 8

Illness perceptions and health outcomes in newly diagnosed diabetes patients

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Abstract

Objective
The aim of this study is to explore illness perceptions of type 2 diabetes patients (T2DM) and to examine the contribution these perceptions in predicting changes in health related quality of life (HRQOL) and HbA1c in a longitudinal way.

Research design and methods
This was a prospective cohort study of 228 T2DM patients diagnosed < 3 years ago. The illness perceptions questionnaire-revised (IPQ-R) was used to measure illness perceptions at baseline (T0) and 1 month (T1). Outcomes were changes in physical and mental HRQOL between baseline and 4 months (T2) measured by the SF-12, and changes in HbA1c between baseline and one year (T3). Changes in illness perceptions between T0 and T1 were analyzed with paired samples t-tests. Hierarchical linear regression analyses were performed to investigate the contribution of these changes in illness perceptions to the variance in changes in the outcomes, above and beyond a set of medical, demographic and psychological covariates. Regression models were repeated with baseline illness perceptions instead of changes in illness perceptions.

Results
Mean changes in illness perceptions between T0 and T1 were small. Regression analyses showed that only changes in perceptions about consequences of T2DM contributed significantly to the variance in changes in physical HRQOL. Changes in other dimension and baseline illness perceptions did not contribute to the variance in changes in outcomes.

Conclusions
We conclude that perceptions about the health consequences of T2DM are most promising for future research. They may have the potential to act as a possible target to enhance physical HRQOL in an intervention.

Introduction

Diabetes mellitus type 2 (T2DM) is an important cause of mortality and morbidity worldwide and the prevalence is rising globally[1, 2]. Treatment of T2DM is aimed at normalizing blood glucose levels (HbA1c <7.0%) in order to prevent serious complications[3].

In order to reach the treatment goals of normalizing blood glucose levels and preventing serious complications patients are advised to adopt a healthy lifestyle with regular physical activity and a heathy diet, proper medication intake, and other self-management activities [4-6]. These complex behavioral tasks may place a large burden on patients. Consequently, a significant proportion of T2DM patients reports that their illness intervenes with their ability to live a normal life[7] and evidence shows that health related quality of life may decrease after getting diagnosed with T2DM[8].
Psychological factors like the beliefs and perceptions of a patient about its illness and treatment may play an important role in the motivation and ability of a patient to engage in the behaviors mentioned above and thereby also may affect treatment outcome[9]. For instance patients who belief that T2DM does not seriously influence their future health may not be motivated to change their lifestyle which may result in poor glycemic control.

A theoretical model often used to describe and explain how illness perceptions and beliefs may influence health outcomes is Leventhals' common sense model[10-12]. This model hypothesizes that persons who experience a health threat like getting diagnosed with T2DM, will develop perceptions about the illness they have, for instance about how long the illness will last, perceptions about how the course of symptoms will be, perceptions about the health consequences of T2DM, perceptions about personal control and perceptions about treatment and treatment outcomes.

Illness perceptions influence how patients cope with their illness and engage in the behavior necessary to manage their illness which subsequently influences illness outcomes like HbA1c levels and health related quality of life (HRQOL). Leventhal conceptualizes illness perceptions as dynamic constructs that may change over the course of the disease.

A recent systematic review primarily based on cross-sectional studies showed that illness perceptions of diabetes are associated with levels of HbA1c[13] and one study included in this review found this effect remained after adjusting for important clinical variables[14]. Another study[15] found a negative association with both mental and physical HRQOL. For any of the reported significant associations in these cross sectional studies however, reverse causality is plausible, that is, health status may also influence the perceptions of a person. Longitudinal studies are currently scarce, but may provide better understanding of the dynamics of illness perceptions over time and the specific role that illness perceptions play in T2DM patients and their treatment.

We were able to perform a longitudinal study in recently diagnosed T2DM patients (<3 years) getting usual care in the Netherlands. These patients were informed and educated by a diabetes nurse or dietician about the consequences of diabetes, the management of their blood glucose and lifestyle advices. Although the education was not specifically aimed to influence patients' illness perceptions, some patients may do so. This provides a population to appropriately investigate the influence of several types of illness perceptions and change in illness perceptions on changes in HB1Ac and HRQOL. More specifically we aimed to:

- Describe the illness perceptions of T2DM patients
- Study the changes in these illness perceptions
- Study the contribution of these changes to the proportion of variance explained in changes in HRQOL and HbA1c and the contribution of baseline illness perceptions, above and beyond other relevant clinical, demographic and psychological variables.

Research design and methods

Design and setting

This longitudinal cohort study was conducted within the Diabetes Care System West Friesland (DCS) which is extensively described elsewhere[16]. In short, the DCS organizes managed diabetes care with contracted health care providers in the region of West-Friesland in the Netherlands, a region with about 200,000 inhabitants, representative of a Caucasian population. Diabetes care provided by the system encompasses the care provided by a primary care provider (PCP), according to Dutch treatment guidelines for T2DM, the annual assessment as organized centrally by the DCS, for annual review and patient education by the diabetes nurse and dietician. Results of the assessment and protocol-driven therapeutic advice are provided to the patients PCP. The DCS maintains anonymized computer records and the patients were informed of the use of these records for research purposes

Participants and procedures

Between September 2011 and February 2012, consecutive patients diagnosed with diabetes less than three years ago and treated at the DCS were invited to participate in this study. An information letter about the study procedure and purpose was sent to all eligible patients together with the invitation for their annual physical examination. At their visit to the DCS for the physical examination, a research nurse gave additional information about study procedures when necessary, and patients were asked consent to participate. Subsequently, written informed consent was obtained from the participants. This study was approved by the Medical Ethical Committee of the VU Medical Center in Amsterdam, identification nr 2011/347.

Assessment

Demographic data (date of diagnosis (dichotomous: <3 months and 3 months – 3 years) age, gender, education level (low, medium, high) were extracted from the computer records of the DCS. Disease characteristics (Hba1c, fasting glucose, Body Mass Index (BMI) and comorbidities (dichotomous ≤1 and > 2) were extracted from the reports of the routine annual physical assessment at baseline (T0). To be able to measure change in the outcome HbA1c over time, HbA1c levels were again extracted from the routine physical assessment data one year after baseline (T4).

Self-reported questionnaire data were collected at the visit for the physical examination (T0), one month after baseline (T1) and four months after baseline (T2). In between T0 and T1 patient education by a diabetes nurse and/or dietician took place. The participating patients completed the baseline questionnaire in the waiting room and then returned them to the research assistants. The second and third questionnaire was sent to their home address together with a pre-stamped and addressed envelope. Questionnaires consisted of the illness perception questionnaire revised (IPQ-R), the Hope Scale, the life orientation test revised (LOT-R) and the hospital anxiety and depression scale (HADS) and the Short Form Health Survey (SF-12).

Questionnaires

Illness perceptions

The Dutch version of the IPQ-R17 for diabetes patients was used to collect data on illness beliefs and perceptions. The IPQ-R consists of 7 subscales with 4 to 6 items each, 5 of these subscales were used in this study namely: timeline acute chronic (beliefs about how long the illness will last), consequences (beliefs about the health consequences of T2DM), personal control (beliefs about control over self-management), treatment control (beliefs about treatment outcomes) and timeline cyclical (beliefs about how the course of symptoms will be). Items are answered on a 5 point Likert-type scale ranging from strongly disagree to strongly agree.

A high score on the timeline acute/chronic, timeline cyclical and consequences subscales represent more negative beliefs. A high score on the personal control and treatment control subscales represent more positive beliefs.

Changes in illness perceptions between T0 and T1 were calculated by subtracting the scores on T1 from the scores on T0. Hence, a positive change score therefore indicates a change towards more positive illness perceptions for the timeline acute chronic, timeline cyclical and consequences dimensions. While a positive change score indicates a change towards more negative illness perceptions for the personal control and treatment control dimensions.

Health Related Quality Of Life

Health Related Quality Of Life (HRQOL) was measured by the 12-Item Short Form Health Survey (SF-12) 18. The SF-12 is a self-reported questionnaire which consists of two summary measures: the physical component summary (PCS) and the mental component summary (MCS). Items were scored and weighted to produce a standardized score from

0 to 100 for each summary measure, in which a score of 50 on a summary measure represents a healthy adult population. Changes in HRQOL between baseline and T2 were calculated by subtracting the scores on T2 from the scores on T0. A negative change score therefore indicates a change towards more HRQOL.

Optimism
Optimism was measured with the Life Orientation Test- Revised (LOT-R)[19, 20] which is a 10 item self-reported questionnaire. The questionnaire consists of 3 positively formulated items (e.g. I'm always optimistic about my future), 3 negatively formulated items (e.g. I rarely count on good things happening to me) and 4 filler items (e.g. It's easy for me to relax). Patients can indicate their agreement with the items on an 5-point likert-type scale ranging from 'I totally disagree' to 'I totally agree'. A total score ranging from 5 to 30 was derived by summing the positively formulated items and the reverse scored negatively formulated items.

Hope
Hope was measured with the Hope Scale[21;22] which consists of 12 items. 4 items measure 'pathways' (e.g. There are lots of ways around the problem) and 4 items measure 'agency' (e.g. I meet the goals that I have set for myself) and 4 are filler items (e.g. I worry about my health). Patients can indicate their agreement with the items on an 8-point Likert-type scale ranging from 'I totally disagree' to 'I totally agree'. A total score ranging from 8 to 64 was derived by summing the scores on the 4 agency and the 4 pathway items.

Anxiety and depression
Anxiety and depression was measured by the hospital anxiety and depression scale (HADS)[23], which consists of two 7 items scales that measure states of anxiety and depression. The two subscales together represent the construct emotional distress. Items were answered on a 4 point Likert-type scale and scored from 0-3 points. Both positively and negatively formulated items were present, the negatively formulated items were reverse scored and a total score from 0 to 42 points was derived by summing the scores on each item. A higher score indicates more emotional distress.

Statistical analysis
Baseline characteristics of participants are presented as mean ± SD or percentage. Missing data were first explored using the missing value analysis procedure in SPSS 20 which indicated missing questionnaire data were probably missing at random (MAR). Missing data on the item level were explored handled by multiple imputation by chained equations with predictive mean matching[24]. The number of imputations was set to 25 and the number of iterations to 100 in order to achieve proper convergence. When more than one missing item was observed in a multi-item questionnaire (sub)scale, items were imputed at the item level, otherwise the multiple imputation was performed at the scale score level[25]. The imputation model for item level imputation was specified so that the item scores of each (sub)scale (e.g. 'timeline acute chronic' of the cognitive illness scale) were imputed using the item scores of this subscale at all three time-points and the scale scores of the other questionnaires, along with the other model variables of interest. That way item level information was incorporated to handle missing data without including too many variables in the imputation model. Between each iteration, scale scores were updated using the imputed items from the previous iteration. Multiple imputation was performed by the MICE package[24] of R statistical software[26].

To analyze changes in illness perceptions between T0 and T1 paired samples t-tests were performed.

To investigate whether these changes in illness perceptions are related to changes in health outcomes between T0 and T2 (HRQOL) and 1 year after T0 (HbA1c) regression analyses were performed. Independent variables were entered into the regression analysis in steps to determine the contribution of the change in cognitive illness perceptions above and beyond relevant medical and demographic variables (Step 1: BMI, comorbidities, diabetes duration, gender, age and education level). At step 2 the change scores of the illness perceptions dimensions were added (separate models for each dimension). Additionally, effect modification by diabetes duration was investigated by adding an interaction term between diabetes duration and illness perceptions to all regression models. Unstandardized Beta (B) values and 95% confidence intervals for the pooled analysis (25 multiple imputation datasets) were examined and R2 was inspected as a measure of the variance accounted for by the complete models, the R2 change between step 1 and 2 in the analyses shows the additional explained variance by the change in illness perceptions.

To investigate the influence of other psychological variables (optimism, hope and emotional distress) on the variance explained by each of the illness perception dimensions analysis were then repeated with at step 2 the psychological characteristics optimism, hope, emotional distress and at step 3 the illness perceptions dimensions.

Further, as illness perceptions have found to be interrelated[27], it may be that all illness perception dimensions together explain more variance in outcome than separate illness perception dimensions. Therefore final models were made with all 5 illness perception dimensions together in step 2.
To investigate whether baseline illness perceptions are associated with changes in HRQOL and HbA1c the analyses above were repeated with the T0 score of the illness perceptions dimensions instead of the change score between T0 and T1.

Table 1 demographic characteristics, clinical characteristics and baseline questionnaire scores

	Total sample (N=228)	Diagnosis <3 months ago (N=68)	Diagnosis 3 months-3 years ago (N=160)	Non-participants (N=145)
Age	62.9 (10.9)	61.5 (10.5)	63.5 (11.1)	63.3 (10.3)
Gender (%female)	41.7%	35.3%	44.4%	49.4%
Education level				-
Lower level	41.4%	37.3%	43.4%	
Medium level	37.2%	38.8%	36.5%	
Higher level	21.2%	23.9%	20.1%	
Comorbidities				-
≤1	50.9%	52.9%	50%	
>1	49.1%	47.1%	50%	
BMI (SD)	30.5 (5.5)	31.8 (6.3)	30.0 (5.0)	30.3 (5.6)
Treatment				-
Advise only	37.7%	33.8%	39.4%	
Blood glucose lowering medication	58.8%	61.8%	57.5%	
Insulin subcutaneous	3.5%	4.4%	3.1%	
HbA1c 2012 % ; mmol/mol (SD)	6.6 (0.8);48.9 (8.6)	7.3 (1.5) ;56.1 (16.6)	6.3 (0.6);45.8 (6.3)	-
HbA1c 2013 % ; moml/mol (SD)	6.4 (0.7);46.7 (7.1)	6.4 (0.6);46.1 (6.6)	6.4(0.7) ;46.9 (7.3)	6.4 (1.0) ;46.2 (11.0)
HRQOL mental (SF-12 MCS) (range 0-100	6.7 (0.9);49.6 (9.4)	6.5 (0.9) ;47.9 (10.1)	6.8 (0.8) ;50.4 (9.1)	-
HRQOL physical (SF-12 PCS) (range 0-100)	46.3 (9.5)	45.6 (9.3)	46.5 (9.6)	-
Optimism (LOT-R (range 6-30)	21.0 (3.5)	21.3 (3.6)	20.8 (3.4)	-
Hope (the hope scale) (range 8-64)	49.2 (8.9)	49.0 (9.4)	49.3 (8.7)	-
Emotional distress (HADS) (range 0-42)	8.5 (6.1)	8.9 (6.1)	8.3 (6.1)	-

Results

Patient characteristics

228 out of 373 eligible patients agreed to participate in the study and completed the T0 questionnaire, 68 patients were diagnosed with diabetes <3 months ago and 160 patients were diagnosed 3 months – 3 years ago. Patients were on average 63 years old and 42% was female.

At T1 16% of patients did not return their questionnaire and at T2 24%. On the item level 1.8% to 8.8% of the scores were missing at T0, 1.6% to 7.5% of the scores were missing on T1 and 2.3% to 8.8% on T2. Baseline clinical and demographic characteristics of the sample as well as the eligible non-participants, and baseline scores on the questionnaires for the participants are shown in table 1. No relevant differences in available baseline characteristics (i.e. age, gender, BMI and HbA1C) were found between participants and eligible non-participants.

Description of illness perceptions and changes in illness perceptions between T0 and T1

Table 2 shows the T0 and T1 scores for the illness perception dimensions and the p-value of the paired sample t-tests for the mean changes between T0 and T1. Patients held strong beliefs about the chronicity of their disease though did not perceive the disease to have severe consequences. Patients also believed their disease was stable rather than fluctuating of nature. Patients further held positive beliefs about their own ability to control their disease (personal control) and about the treatment and advice (treatment control). No relevant differences were observed between patients that were diagnosed very recently and who visited the DCS for the first time (<3 months ago) and those that were diagnosed somewhat longer ago (3 months – 3 years ago). The mean changes in illness perceptions between baseline and one month follow-up (after the educational intervention) were small for all illness perception dimensions and none of the mean differences were statistically significant, though there was substantial variance in change scores indicating that some patients showed changes towards more positive perceptions whilst others showed changes towards more negative perceptions.

The additional proportion of variance in change in outcomes (HbA1c, SF-12 MCS, SF-12 PCS) explained by the change in illness perceptions

The results of the regression models for the change in the 5 dimensions of illness perceptions between T0 and T1 and the health outcomes are shown in table 3a. None of the individual changes illness perception dimensions were significantly associated with change in HbA1c and the illness perceptions dimensions did not significantly contribute to the explained variance in the changes in HbA1c. The change in the illness perception dimension consequences was significantly associated with the change in SF-12 PCS and added 3.2% to the explained variance in change in SF-12 PCS indicating that a change towards the perception that T2DM has less serious consequences leads to an improvement in QOL. The other illness perceptions dimensions were not significantly

Table 2. Mean scores and paired sample t-test for the illness perceptions dimensions at baseline and T1 (pooled results for 25 imputed datasets)

		Complete sample			Diagnosis < 3months ago			Diagnosis 3 months-3 years ago		
	Range of scores	T0 score (SD)	T1 score (SD)	p value for paired t-test*	T0 score (SD)	T1 score (SD)	p value for paired t-test*	T0 score (SD)	T1 score (SD)	p value for paired t- test*
IPQ-R timeline acute chronic	6-30	22.4 (4.6)	22.5 (4.6)	0.65	21.9 (4.9)	22.5 (4.8)	0.36	22.5 (4.4)	22.5 (4.5)	0.77
IPQ-R consequences	6-30	15.5 (3.8)	15.8 (3.8)	0.37	15.6 (3.8)	15.6 (3.9)	0.99	15.5 (3.8)	15.8 (3.8)	0.29
IPQ-R personal control	6-30	23.0 (3.5)	23.3 (3.2)	0.25	23.3 (3.3)	23.9 (3.3)	0.16	22.9 (3.5)	23.1 (3.1)	0.53
IPQ-R treatment control	5-25	19.3 (2.6)	19.1 (2.1)	0.31	19.2 (2.6)	19.3 (2.2)	0.82	19.4 (2.6)	19.1 (2.1)	0.18
IPQ-R timeline cyclical	4-20	10.0 (3.3)	9.9 (3.1)	0.77	10.3 (2.8)	9.9 (2.8)	0.33	9.8 (3.5)	9.9 (3.2)	0.75

*p-value for the paired t-test on the mean change between T0 and T1.

associated with SF-12 PCS. Further none of the changes in illness perceptions significantly contributed to the variance explained in changes in SF-12 MCS. Adding psychological factors optimism, psychological distress and hope in step 3 of all models and the illness perception dimensions in step 4, did not significantly change the added value of illness perceptions, nor the total amount of explained variance of each of the models (data not shown, available upon request).

The additional proportion of variance in outcomes (HbA1c, SF-12 MCS, SF-12PCS) explained by baseline (T0) illness perceptions

The results of the regression models for the T0 illness perceptions and change in health outcomes are shown in table 3b. None of the T0 illness perception dimensions were significantly associated with change any of the changes in outcomes (HbA1c, SF-12 PCS and SF-12 MCS). Hence, the variance in change explained by the T0 illness perception dimensions was small and non-significant. Adding psychological factors optimism, psychological distress and hope in step 3 of all models and the illness perception dimensions in step 4, did not significantly change the added value of illness perceptions, nor the total amount of explained variance of each of the models (data not shown, available upon request).

Table 3a. Added value of change in cognitive illness perceptions in predicting change in HbA1c and change in Sf-12PCS and MCS

	Outcomes		
Models with individual illness perceptions dimension in step 2	ΔHbA1c *	ΔSF-12 PCS	ΔSF-12 MCS
Δ Timeline acute chronic, B (95% CI)	-0.027 (-0.067;0.013)	-0.027 (-0.067;0.013)	-0.014(-0.317;0.288)
Total R^2	0.229	0.070	0.036
R^2 change	0.009	0.002	0.003
Δ Consequences, B (95% CI)	-0.012 (-0.052;0.028)	-0.384 (-0.696;-0.071)*	-0.289 (-0.634;0.057)
Total R^2	0.221	0.100	0.055
R^2 change	0.002	0.032*	0.021
Δ Personal control, B (95% CI)	0.021 (-0.030;0.071)	0.303 (-0.115;0.722)	-0.075 (-0.485;0.334)
Total R^2	0.224	0.086	0.037
R^2 change	0.004	0.018	0.004
ΔTreatment control, B (95% CI)	0.010 (-0.054;0.073)	-0.076(-0.596;0.444)	0.227 (-0.263;0.716)
Total R^2	0.221	0.072	0.041
R^2 change	0.002	0.003	0.008
ΔTimeline cyclical, B (95% CI)	0.007 (-0.043;0.058)	-0.313 (-0.694;0.069)	-0.020 (-0.423;0.384)
Total R^2	0.221	0.084	0.035
R^2 change	0.001	0.015	0.002
Model with all illness perceptions dimensions in step 2			
ΔTimeline acute chronic,B (95% CI)	-0.029 (-0.071;0.012)	-0.050 (-0.355;0.254)	0.061 (-0.246;0.0368)
ΔConsequences,B (95% CI)	-0.013 (-0.055;0.029)	-0.426 (-0.739;-0.114)*	-0.261 (-0.613;0.091)
ΔPersonal control ,B (95% CI)	0.024 (-0.028;0.075)	0.367 (-0.045;0.779)	-0.121 (-0.530;0.288)
ΔTreatment control, B (95% CI)	-0.005 (-0.073;.063)	-0.359(-0.885;0.165)	0.175 (-0.325;0.676)
ΔTimeline cyclical, B (95% CI)	0.010 (-0.040;0.060	-0.299(-0.670;0.072)	-0.001 (-0.410;0.407)
Total R^2	0.239	0.145	0.067
R^2 change	0.019	0.077*	0.034

* HbA1c in %. B= unstandardized beta coefficient of the illness perception dimension. Total R^2 : explained variance of the total model (step 1 and 2), R^2 change= the change in explained variance between step 1 and step 2
* p <0.05

Table 3a. Added value of change in cognitive illness perceptions in predicting change in HbA1c and change in Sf-12PCS and MCS

	Outcomes		
Models with individual illness perceptions dimension in step 2	ΔHbA1c *	ΔSF-12 PCS	ΔSF-12 MCS
Δ Timeline acute chronic, B (95% CI)	-0.005 (-0.038;0.028)	0.129 (-0.116;0.374)	-0.009 (-0.245;0.227)
Total R^2	0.220	0.075	0.034
R^2 change	0.002	0.007	0.001
Δ Consequences, B (95% CI)	0.013 (-0.025;0.051)	-0.149 (-0.439;0.140)	0.012 (-0.286;0.310)
Total R^2	0.222	0.074	0.035
R^2 change	0.002	0.006	0.001
Δ Personal control, B (95% CI)	0.027 (-0.015;0.070)	0.213 (-0.106;0.532)	0.085 (-0.262;0.432)
Total R^2	0.223	0.078	0.037
R^2 change	0.004	0.010	0.003
ΔTreatment control, B (95% CI)	-0.003 (-0.056;0.051)	-0.160 (-0.590;0.270)	0.052(-0.417;0.521)
Total R^2	0.220	0.072	0.036
R^2 change	0.000	0.004	0.003
ΔTimeline cyclical, B (95% CI)	0.030 (-0.016;0.076)	-0.061 (-0.401;0.279)	0.005 (-0.333;0.343)
Total R^2	0.227	0.070	0.034
R^2 change	0.007	0.001	0.001
Model with all illness perceptions dimensions in step 2			
ΔTimeline acute chronic,B (95% CI)	- 0.004 (-0.037;0.029)	0.112 (-0.134;0.359)	-0.008(-0.249;0.232)
ΔConsequences,B (95% CI)	0.006 (-0.032;0.045)	-0.175(-0.471;0.121)	0.008 (-0.292;0.308)
ΔPersonal control ,B (95% CI)	0.039(-0.011;0.088)	0.383 (0.018;0.749	0.086 (-0.295;0.468)
ΔTreatment control, B (95% CI)	- 0.021(-0.085;0.044)	-0.427(-0.925;0.710)	-0.003 (-0.529;0.523)
ΔTimeline cyclical, B (95% CI)	0.029 (-0.020;0.078)	-0.033 (-0.390;0.323)	0.012 (-0.335;0.359)
Total R^2	0.239	0.109	0.041
R^2 change	0.020	0.040	0.008

*HbA1c in %, B= unstandardized beta coefficient of the illness perception dimension, Total R 2 = explained variance of the total model (step 1 and 2), R 2 change= the change in explained variance between step 1 and step 2

Discussion

The aim of this study was to investigate the role of illness perceptions in T2DM patients in a longitudinal way. Results show that at T0, very recently diagnosed (<3 months ago) as well as patients diagnosed somewhat longer ago (<3 y) perceive their illness as chronic. Patients had relatively low scores on the consequences domain indicating they do not belief that T2DM can have serious consequences for their health. Furthermore, patients in this study did perceive their own ability to control their disease as high and also had positive perceptions of the effectiveness of treatment. In our study mean changes in illness perceptions between T0 and T1 were very small, though the variance in these changes was substantial, indicating inter-individual differences were present. Hierarchical linear regression analysis showed that none of the baseline illness perceptions dimensions or changes in illness perception dimensions explained a significant amount of variance in outcomes, except for the change in the illness perception dimension consequences, which was significantly associated with the change in physical HRQOL (SF-12 PCS) (B= - 0.384) and added 3.2% to the explained variance in the changes in physical HRQOL. Although the influence of a change of 1 point in perceived consequences on HRQOL is small, it may be that patients with a large change (e.g. > 13 points on a scale from 6-30) towards the belief that the consequences of T2DM will have a less serious impact on their life, show clinically relevant increases in physical HRQOL (5-8 points corresponding to a moderate effect size of 0.5-0.8)[28,29].

Our results are in line with previous descriptive or qualitative studies that suggest that patients T2DM are not or only slightly worried about the consequences of their illness for future health and well-being and perceive their ability to control their illness as high[30, 31]. These previous studies have suggested that these beliefs may have negative implications for the motivation to engage in behavior necessary for successful self-management, which consequently affects treatment outcomes negatively. However, our results indicate another direction of the effect namely that the perception of less severe consequences contributed to higher physical HRQOL. Other cross sectional and prospective studies[14, 15,32,33] have suggested a similar direction of the effect. This implies that positive beliefs about consequences may be most beneficial.

In contrast to our study, many of the previous cross sectional and some of the prospective studies also found that besides the dimension consequences also other illness perceptions dimensions were related to outcomes. Further many of those studies not only found significant relationships with HRQOL, but also with HbA1c. A recent review by Mc Sharry[13] identified the dimension timeline cyclical as having the strongest relationship with HbA1c, and further identified the cognitive dimensions personal control and consequences and two more emotional dimensions to be related to HbA1c. The differences in results between those studies and ours may be due to differences in study design. For instance, cross-sectional studies such as the ones included in a recent systematic review[13] compare differences between patients instead of changes within patients but temporal relationships cannot be established from these studies.

To our knowledge our study is the first to assess both the relationship between baseline illness perceptions and changes in outcomes as well as the relationship between changes in illness perceptions and changes in outcomes for newly diagnosed patients as well as patients diagnosed with T2DM longer ago. The largest prospective study until now was a randomized controlled trial evaluating an educational program which was developed using the common sense model of illness perceptions, for newly diagnosed T2DM patients[32, 34, 35]. This trial found positive effects of the intervention on changing illness perceptions, patients were for instance more likely to agree they can affect the course of their diabetes and to agree that T2DM will have less impact on their daily life. In concordance with our study, changes in perceptions in this were related to changes in HRQOL, but not to changes in HBA1C.

Our results further confirm recent work[15, 36, 37] that suggests that medical variables (like comorbidities and type of treatment) are more important for glycaemic control (HbA1c) then psychological variables like illness perceptions, but psychological variables may contribute more to HRQOL outcomes. In our study all changes illness perception dimensions together explained 1.9% in the variance of changes in HbA1c, 3.4% of changes in mental HRQOL, and 7.7% of changes in physical HRQOL. This suggests that (changes in) perceptions about diabetes are more important for changes in (physical) quality of life then for metabolic control.

The results of this study have to be seen in the light of some important methodological considerations. First, during the study period (in between T0 and T1) all patients received education by a diabetes nurse and/or dietician as part of usual care, however because of the observational character of this study this intervention was not specifically targeted at changing illness perceptions. We hypothesized however, that specifically the patients that were newly diagnosed (<3 months ago) would change their expectations during the study period. This hypothesis was based Leventhal's common sense model[12], which proposes that illness perceptions are cyclical of nature and not static, and on a recent study concluding that illness perceptions of diabetes patients were formed quickly after diagnosis[35]. Our study did not confirm this hypothesis, though; changes in illness perceptions may possibly be larger when perceptions are specifically targeted.

Second, because of co-linearity with duration of disease it was not possible to include the HbA1c value of previous physical examinations in the model (patients diagnosed <3 months ago did not have these data) which is an important predictor of future outcome. Though repeating the analyses without duration of disease in the model, but with HbA1c of the year before the start of the study did not change our results, the variance explained by illness perceptions stayed relatively similar (data not shown).

Third, despite the effort put into contacting patients by phone and sending reminders drop out and missing data were present in this study. This limits power and may introduce bias. Missing value analysis indicated that data were (partly) missing at random; therefore advanced multiple imputation techniques were used to overcome these limitations[25].

Fourth, it may be possible that we have missed some important variables to be included in the models in this study. The variance in outcome explained by our complete models was rather low and including other variables like complications, and more accurate measures of comorbidity (now dichotomous) may have increased this.

In conclusion our study suggests perceptions about the health consequences of T2DM are most promising for future research, as a positive change in this dimension added significantly to the variance in changes in physical HRQOL. Therefore this dimension may have the potential to act as a possible target to enhance physical HRQOL in T2DM in an intervention, specifically when targeted at the patients with extremely negative perceptions at baseline.

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