



Expectations and fear of diabetes-related long-term complications in people with type 2 diabetes at primary care level

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Abstract

Aims The quality report of patients enrolled in the disease management programmes of North Rhine Westphalia 2016 showed prevalence of long-term complications in diabetes type 2: neuropathy 24.2%, nephropathy 12.5%, retinopathy 8.2%. The aim of this study was to assess expectations and fear of diabetes-related long-term complications in people with diabetes type 2.

Methods We assessed expectations and fear of diabetes-related complications in 104 people with diabetes type 2 (age 67.0J, diabetes duration 6.6J, HbA1c 6.6%/48.6 mmol/mol, neuropathy 20.2%, nephropathy 11.5%, retinopathy 1.9%) in an outpatient healthcare centre at primary care level. Fear of diabetes-related complications was assessed using the “Fear of Complications Questionnaire” (FCQ) with a range of 0–45 points (≥ 30 means clinically meaningful fear, higher scores imply higher level of fear). Furthermore, study participants estimated general and personal risk of suffering from diabetes-related long-term complications after 10 years of diabetes duration on a scale of 0–100%.

Results Mean FCQ score was 22.9 ± 11.5 . 34/104 participants (32.7%) scored ≥ 30 points and thus had great fear. Participants estimated general risk of suffering from diabetes-related complications after 10 years of diabetes duration on 55.1% and personal risk on 46.0%. Risk of diabetes-related complications scoring highest was impaired circulation of lower limb (62.1%), eye complications (57.3%) and kidney complications (54.7%).

Conclusion Prevalence of diabetes-related long-term complications was overestimated in people with diabetes type 2. Approximately one third of the participants showed even great fear. Patient expectation and fear about diabetes-associated complications did not correspond with data on clinical reality.

Keywords Diabetes-related complications · Fear of complications · FCQ

Abbreviations

| | |
|-------|-------------------------------------|
| BMI | Body mass index |
| DMP | Disease management programmes |
| FCQ | Fear of complications questionnaire |
| HbA1c | Glycated haemoglobin |

Introduction

The German guideline for the treatment of people with diabetes type 2 recommends that all individuals should be informed about benefit and harm regarding their diabetes therapy and especially about possible long-term organ-associated complications (e.g. blindness, amputation) [1]. Nowadays, diabetes-related long-term complications are one of the most important diabetes-related worries in people with diabetes type 1 and type 2 [2, 3]. There are several studies showing that people with diabetes suffer from fears concerning long-term diabetes complications [4–6].

Quality reports about the laboratory and clinical data of the patients enrolled in the disease management programmes (DMP) of North Rhine Westphalia were annually published. The quality report 2016 showed the following prevalence of long-term complications in people with diabetes type 2: neuropathy 24.2%, nephropathy 12.5%, retinopathy 8.2%, amputation 0.7%, dialysis 0.6%

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and blindness 0.4% [7]. A study by Heller et al. confirmed this prevalence [8].

Already in 1998, Hendricks et al. suggested that diabetes educators should address patients' fear of long-term complications directly and effectively [5]. This paper claimed that patients need accurate information about acute and chronic diabetes complications. Within the currently available diabetes treatment and education programmes in Germany, the patients are taught about possible diabetes-related complications. However, prevalence and risk is not communicated though fear of long-term organ-associated complications is the most important diabetes-related worries in people with diabetes [2, 3]. A reason for great fear might be lack of knowledge about the real risk suffering from diabetes-related complications.

Therefore, the aim of this study was to assess expectations and fear of diabetes-related long-term complications in people with diabetes type 2. We hypothesised that people with diabetes type 2 overestimated their risk of diabetes-related long-term complications and fear is overrepresented.

Methods

Participants and study design

We assessed expectations and fear of diabetes-related long-term complications [neuropathy, nephropathy, retinopathy, amputation, dialysis, blindness, stroke, coronary sclerosis (cardiovascular disease, myocardial infarction, angina pectoris) and impaired circulation of lower limb] in 104 people with diabetes type 2 in an outpatient healthcare centre at primary care level over three months (baseline characteristics are shown in Table 1). All participants with type 2 diabetes attending the outpatient healthcare centre for medical consultation during the investigation period were interviewed. All people who were not able to answer the questionnaire by themselves (e.g. due to cognitive limitations or dementia) were excluded. Further reasons for exclusion were language barrier and unwillingness to give written consent to the study.

The study was approved by the Medical association of Thuringia. All study participants signed an informed consent.

All procedures followed were in accordance with the ethical standards of the responsible committee on human

Table 1 Characteristics of the study participants

| | All (<i>n</i> = 104) | People with FCQ score < 30 (<i>n</i> = 70) | People with FCQ score ≥ 30 (<i>n</i> = 34) | <i>p</i> value* |
|---|-----------------------|---|---|-------------------|
| Female <i>n</i> (%) | 48 (46.2) | 27 (38.6) | 21 (61.8) | 0.036 |
| Age (years) | 67.0 ± 11.1 | 67.4 ± 11.6 | 66.2 ± 10.2 | 0.597 |
| Diabetes duration (years) | 6.6 ± 6.4 | 6.5 ± 6.9 | 6.6 ± 5.4 | 0.982 |
| HbA1c (%) | 6.59 ± 0.83 | 6.59 ± 0.84 | 6.62 ± 0.83 | 0.798 |
| HbA1c (mmol/mol) | 48.6 ± 9.1 | 48.4 ± 9.2 | 48.9 ± 9.1 | 0.798 |
| BMI (kg/m ²) | 31.1 ± 5.7 | 30.9 ± 5.3 | 31.6 ± 6.5 | 0.579 |
| RR systolic (mmHg) | 133.9 ± 15.2 | 132.4 ± 14.9 | 137.1 ± 15.7 | 0.141 |
| RR diastolic (mmHg) | 80.5 ± 9.7 | 78.9 ± 9.8 | 83.8 ± 8.7 | 0.014 |
| Diabetes medication <i>n</i> (%) | | | | |
| Without | 48 (46.2) | 33 (47.1) | 15 (44.1) | |
| Oral/GLP-1 | 37 (35.5) | 25 (35.7) | 12 (35.3) | |
| Insulin | 19 (18.3) | 12 (17.2) | 7 (20.6) | 0.907 |
| Participation in an education programme <i>n</i> (%) | 65 (62.5) | 41 (58.6) | 24 (70.6) | 0.284 |
| Diabetes-related long-term complications <i>n</i> (%) | | | | |
| Diagnosed | 30 (28.8) | 20 (28.6) | 10 (29.4) | 0.552 |
| Assumed by patient | 17 (16.3) | 7 (10.0) | 10 (29.4) | 0.033 |
| DTSQ (0–36) | 30.3 ± 5.6 | 30.5 ± 5.5 | 29.8 ± 5.8 | 0.539 |
| WHO-5 (0–25) | 16.2 ± 5.2 | 17.0 ± 4.7 | 14.6 ± 5.7 | 0.021 |
| FCQ score (0–45) | 22.9 ± 11.5 | 16.7 ± 7.8 | 35.9 ± 5.1 | < 0.001 |

BMI body mass index, *DTSQ* Diabetes Treatment Satisfaction questionnaire, *FCQ* Fear of Complications questionnaire, *GLP-1* Glucagon-like Peptide 1, *RR* blood pressure, *WHO-5* World Health Organisation 5 questionnaire

*Between people with FCQ score < 30 and ≥ 30. Bold values are statistically significant

experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2008 (5).

Data collection and questionnaires

Laboratory and clinical data were drawn from the digital patient record of each participant and were collected on the day of the survey of the respective patient.

Fear and worries about diabetes-related long-term complications were assessed using the validated “Fear of Complications Questionnaire” (FCQ) [9]. The FCQ is a self-report inventory to quantify fear of diabetes-related complications in people with diabetes type 1 and type 2. The questionnaire was developed by Taylor et al. [9]. The German translation and adaptation was created in 2014 by Schmitt & Reimer at the Research Institute of the Diabetes Academy Mergentheim [10]. A pilot study was used for the first version of the questionnaire (30-item-scale). Afterwards, an evaluation study was initiated to verify the scale including 15 items. The German version of the FCQ is a validated and reliable instrument with a Cronbach’s alpha of 0.94–0.96 [10]. The questionnaire includes 15 items of which each item is score by the following values: 0 (“no fear”), 1 (“minor fear”), 2 (“moderate fear”), and 3 points (“greatest fear”). All 15 scores are added up resulting in a total score of 0–45 points. Higher scores imply higher level of fear. A score ≥ 30 (cut-off) is considered as clinically meaningful and relevant fear. An empirically justified cut-off has not been developed so far. However, a relevant level of fear could be assumed from an item value of 2 (i.e. “moderate fear”). Consequently, based on the 15 items, a cut-off of ≥ 30 points was defined.

People were asked to indicate whether they already suffer from one or more diabetes-related complications within a structured interview. This was verified with digital patient record by documented diagnosis. In addition, they were asked whether they have ever participated in a structured diabetes treatment and education programme.

In addition, participants were asked to estimate how many patients with diabetes suffer from diabetes-related complications after 10 years of diabetes duration (general risk) on a scale from 0% representing “none” to 100% representing “everybody”. Following this, the individuals should estimate their own risk of suffering from a diabetes-related complication (personal risk) on a scale from 0% representing “no risk” to 100% representing “I definitely suffer from a long-term diabetes complication”.

We assessed associations between fear of diabetes-related complications and satisfaction of diabetes treatment as well as well-being. Satisfaction with diabetes treatment was evaluated by the Diabetes Treatment Satisfaction Questionnaire status (DTSQs; score range: 0–36; higher scores indicating greater treatment satisfaction) [11]. Current well-being was

assessed using the WHO-5 questionnaire. This questionnaire is composed of five questions. Each item has to be scored from 0 to 5 points resulting in a total score of 0–25. Higher scores indicated higher well-being [12].

Statistical analysis

All continuous data are presented as mean \pm standard deviation (SD). Categorical data are described by absolute and relative frequencies. Inter-group differences were examined subject to the type of scale using either Fisher’s test or *t* test. Regression analysis was used to assess association between covariates and FCQ score. Significance was defined at the 0.05 level. Statistical analysis was performed using the Statistical Package IBM SPSS Statistics 21 (IBM Corporation Armonk, USA).

Results

203 patients attended the outpatient healthcare centre for medical consultation during the investigation period. 99 individuals were excluded from study. Thus, 104 individuals gave written consent and were included. The characteristics of the 104 study participants are shown in Table 1.

30 of 104 (28.8%) participants had at least one diagnosed diabetes-related long-term complication [20.2% neuropathy (21/104), 11.5% nephropathy (12/104), 1.9% retinopathy (2/104)], of whom only 30.0% (9/30) indicated to have such a disease by structured interview. Overall, only 42.4% of patients correctly judged their presence or absence of diabetic long-term complications (Table 2, $p=0.033$).

Participants estimated general risk of suffering from diabetes-related complications after 10 years of diabetes duration on 55.1%. Risk of specific diabetes-related complications after 10 years of diabetes duration were estimated as follows: impaired circulation of lower limb 62.1%, retinopathy 57.3%, nephropathy 54.7%, myocardial infarction

Table 2 Comparison of assumed and diagnosed diabetes-related complications

| | Diagnosed diabetes-related complication | |
|---|---|----------------------|
| | No (5) | Yes (%) |
| Assumption to have at least one diabetes-related complication | | |
| No | 35 (33.7) ^a | 14 (13.4) |
| Yes | 8 (7.7) | 9 (8.7) ^a |
| N/A | 31 (29.8) | 7 (6.7) |

^a42.4% correctly judged their presence or absence of diabetic long-term complications ($p=0.033$)

52.8%, neuropathy 51.9% and stroke 51.9%. Personal risk was estimated on 46.0%.

Mean FCQ score was 22.9 ± 11.5 . 34 of 104 participants (32.7%) scored ≥ 30 points. The items scoring highest were (in descending order): worries about health in the future (mean FCQ score 2.0 ± 0.9 of a maximum of 3.0), impaired circulation (1.8 ± 0.9) and stroke (1.7 ± 0.9). Items on rare but severe complications as losing the eyesight (1.3 ± 1.1), kidney dialysis (1.1 ± 1.1) and kidney transplantation (1.0 ± 1.0) were scored quite high compared to items regarding frequent but mostly mild complications as eye problems (1.7 ± 1.0) feet problems (1.6 ± 1.0) and kidney problems (1.5 ± 1.0).

Study participants with FCQ score ≥ 30 were more often female in comparison to those with FCQ score < 30 (61.8% vs. 38.6%, $p = 0.036$; Table 1). In addition, individuals assumed to have at least one diabetic long-term complication scored higher ($n = 17$, 31.5 ± 10.2) than those indicating to have no complications ($n = 49$, 19.6 ± 11.4 , $p < 0.001$). People with participation in a treatment and education programme had a non-significant, but numeric higher FCQ score ($n = 65$, 24.2 ± 10.6) than those without participation ($n = 39$, 20.9 ± 12.7 , $p = 0.149$). Similarly, people with FCQ score ≥ 30 participated more often in a treatment and education programme than those scored < 30 (29.4% vs. 10.0%, $p = 0.033$; Table 1).

People with FCQ score ≥ 30 had lower level of well-being than those scoring < 30 (14.6 ± 5.7 vs. 17.0 ± 4.7 , $p = 0.021$). After adjustment for age and diabetes duration, FCQ score had a significant effect on well-being ($\beta = -0.1$, $p = 0.031$).

Discussion

Our study showed that prevalence and risk of diabetes-related long-term complications were overestimated in people with diabetes type 2. Approximately one third of the participants showed even clinically meaningful fear (FCQ score ≥ 30). Individuals with clinically relevant fear (FCQ score ≥ 30) showed lower level of well-being than those with less fear.

Taylor et al. [9] developed the first inventory to assess systematically fear of complications. Another instrument is the “Fear of Progression Questionnaire” (FoP-Q) by Herschbach et al. [13]. However, this questionnaire measures only fear of progression of complications that means fear of the progression of a disease in general (items are not diabetes-specific).

Diabetes-related long-term complications are one of the most important diabetes-related worries in people with diabetes type 1 and type 2 [2, 3]. Already in 1990, Pramming et al. investigated worries of people with type 1 diabetes. The highest fears were severe hypoglycaemia, blindness, and

in women, kidney complications [4]. Another study showed that fears of diabetes-related long-term complications concerned especially with amputation, cardiovascular disease, nephropathy, neuropathy, retinopathy, and stroke [5]. The study suggested that diabetes educators may need to address patients’ fears of long-term complications directly and effectively. The trial by Janzen Claude et al. using also the FCQ showed a mean FCQ score of 18.9 in people with diabetes type 1 and type 2 which is equal to our study [14]. The study showed a strong correlation between health anxiety and fear of diabetes complications. Within a structured interview the study by Quandt et al. showed that older people with diabetes had fears concerning amputation, blindness, coma, and disease progression [6].

Only 42.4% of our study participants judged correctly their presence or absence of diabetic long-term complications. General risk suffering from diabetes-related long-term complications after 10 years of diabetes duration was hugely overestimated. These are indications that individuals with diabetes type 2 were not adequately informed about general and own risk as well as prevalence of diabetic long-term complications. Knowing current prevalence of diabetes-related complications as a part of informed shared decision making (SDM) might help patients to reduce their worries and fear. “Informed shared decision making” is also strongly recommended in the recent national treatment guideline for type 2 diabetes in Germany [1].

However, why could only 42.4% of our study participants correctly state if they suffer from diabetes-related complication or not? Maybe there is a problem of communication between physician and patient. Patients do not know that they suffer from diabetes-related complications. Reason for that could be that the physician may not communicate this. Another reason could be that these patients have no restrictions caused by the complication concerned. Thus, they think they have no complication.

In general, the absolute risk of diabetes-related complications is not communicated and therefore often overestimated by patients and public health media, as well as health care professionals. Quarterly visits during the consultation by physician can be used to inform patients about their real risk. However, health care professionals communicated prevalence of diabetes complications partly in a suboptimal way, sometimes due to lack of information or they used risk of complications as an intended motivator for better diabetes self-care of the patients. The issue “long term complications” is discussed within all currently available treatment and education programmes for people with diabetes type 1 as well as type 2. However, specific information on prevalence and risk, respectively, to suffer from serious complications are not content though data are available. Quality reports of DMPs and insurance companies annually publish data about prevalence of diabetes-related complications in Germany [7, 8]. Prevalence

of “mild” complications in people with diabetes type 2 after 7–10 years of duration of diabetes are low: neuropathy 20.7%, nephropathy 9.7% and retinopathy 10.9% [15]. However, our study participants overestimated this prevalence to a considerable extent (neuropathy 51.9%, nephropathy 54.7% and retinopathy 57.3%). Furthermore, though severe complications such as blindness (0.3%), amputation (0.6%) or kidney dialysis (0.4%) are very rare events in people with type 2 diabetes nowadays [15], the FCQ items on severe complications as losing the eyesight, kidney dialysis or transplantation were scored quite high compared to items regarding frequent but mostly mild complications as eye, kidney or feet problems. Nowadays, diabetes duration is no longer recorded in the DMP, hence published prevalence is related to the whole population of people with diabetes. However, the data showed similar numbers [7].

People with participation in a treatment and education programme had a numeric higher FCQ score than those without participation (24.2 vs. 20.9 on a scale of 0–45). This is a further indication that patients were not informed by education programmes to a sufficient extent that long-term complications are possible but rare events. As a result, patients develop more fear and worries. A study by Kuniss et al. showed that the item “worries about the future and the possibility of serious complications” of the “Problem Area in Diabetes” (PAID) questionnaire was one of the most important diabetes-related burdens before and also after participation in a treatment and education programme [16]. These worries could not reduce by such an education programme. In conclusion, editing all currently available treatment and education programmes by adding information about prevalence of long-term diabetic complications could probably reduce excessive fear and worries. However, this must be investigated in a randomised, controlled trial.

A limitation of our trial is the study design which does not allow any causal relationships. Unfortunately, there is no data regarding prevalence of diabetes-related complications for Thuringia. In Germany, there is no diabetes register. Only the DMP North Rhine Westphalia provides annual data about the patients of this region. Thus, we could only compare the results of our study to the data of patients enrolled in the DMP in North Rhine Westphalia. However, our study has also some strength. This trial is a study of a well-characterised group from primary care level. Fear of diabetic long-term complications was measured with a standardised questionnaire (“Fear of Complications questionnaire”).

Conclusions

Prevalence of diabetes-related long-term complications is overestimated in people with diabetes type 2. Approximately one third of the participants showed even clinically

meaningful fear. Patient expectation and fear about diabetes-associated complications did not correspond with data on clinical reality. Knowing current prevalence of diabetes-related complications as a part of informed shared decision making (SDM) might help patients to reduce their worries and fear.

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Compliance with ethical standards

Conflict of interest None. All authors declare that they have no competing interests.

Ethical standard The study was conducted in accordance with the ethical standards laid down in an appropriate version of the 1964 Declaration of Helsinki.

Human and animal rights All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2008 (5).

Informed consent Informed consent was obtained from all patients for being included in the study.

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