What are disease perceptions and subjective treatment goals of insulin treated diabetic patients?

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Background: Despite increasing importance of patient self-management, little is known about their own perceptions and treatment goals.

Objectives: The aim of this explorative study was to examine what diabetic patients perceive as most concerning and what their own treatment goals are.

Methods: A 23-item anonymous questionnaire was distributed among type 1 diabetic patients treated with and without an insulin pump and insulin treated type 2 diabetic patients in the outpatient clinic of a University Hospital. 86% of the questionnaires were returned (n = 124).

Results: In open-ended questions, patients in all three groups together felt mostly restricted by their loss of freedom (24%), the dietary restrictions (17%) and the need to measure blood glucose (17%). Patients treated with an insulin pump worried more about hypoglycaemia and less about dietary restrictions. In closed-ended questions, patients were mostly concerned about hypoglycaemia and developing complications. However, the main treatment goal of both groups together was long-term good blood glucose control (63%). Further patient goals were the prevention of complications (27%) and the preservation of a good quality of life. Quality of life was a more important goal for type 1 diabetic patients (29%) than for type 2 diabetic patients (0%). Patients thought that blood glucose control was more important for their physicians (main treatment goal for 86%) than for themselves.

Conclusion: Insulin treated patients with diabetes spontaneously express concerns about their actual quality of life and daily hassles and mention long-term worries after explicit questioning. For their main treatment goals they choose mainly long-term goals. According to the patients, physicians tend to overestimate blood glucose control.

Key words: diabetes mellitus; perception; goals; quality of life; patients

Introduction

Diabetes mellitus affects more than 170 million people worldwide. The psychological burden of this disease is substantial and quality of life can be markedly reduced in affected subjects [1, 2]. Insulin treatment seems to further influence the impact of the disease on quality of life [2]. On the other side, patient empowerment and self-management can increase their satisfaction and quality of life [3, 4] as well as metabolic control [5–7]. Therefore, diabetes care is moving towards more patient-centred care. Individual tailoring of the treatment goals to patients’ own goals potentiates this autonomy [8]. The patient-driven implementations of their own treatment goals are influenced by their disease perception and their attitude towards the disease, which are both necessary components for a behavioural change [9, 10]. Unfortunately, little is known about patients’ subjective disease perception and diabetes-related concerns, eg which components of their disease bother them. The available diabetes-specific questionnaires like the Diabetes Illness Representation Questionnaire (and its generic form, the Illness Perception Questionnaire), the Personal Model of Diabetes Interview, the Problem Areas in Diabetes Scale, the Diabetes Quality of Life Questionnaire and the Diabetes-specific Quality-of-Life Scale) cover disease perceptions to some extent, but focus more on illness representation, illness beliefs, quality of life and perceived health consequences and less on the question which aspect of the disease or its management patients perceive as most
Disease perceptions and treatment goals of diabetic patients

and then, in open-ended questions, which components of asked whether their diabetes impairs their quality of life and treatment goals and to diminish pleasing bias. We first able to include a maximal range of patients’ perceptions tionnaire [11]. The questions were tested among 5 patients tions were used from the Diabetes Quality of Life Ques- questionnaire for its reliability. Wherever possible, ques- this study, we added some own questions and assessed the est included patients’ disease perception, their treatment of diabetic complications. The three main areas of inter- metabolic control and the eventual presence and number aments according to the blood glucose values) and in- sulin treated type 2 diabetic patients. None of the type 2 diabetes in the outpatient clinic of the University Hos- al within a four-week period. Anonymity was ensured. 86% of the questionnaires were answered and re- turned in a prestamped envelope addressed to the primary investigator. The demographic characteristics of the patients are described in table 1. The majority of these patients have type 1 diabetes (n = 102) and most of them underwent a group-training course where they learn to adjust insulin dosage to food intake and daily activity (Course in Functional Insulin Therapy [FIT]). Thus, it is assumed that they are knowledgeable about their meta- bolic control and/or the presence of complications.

Investigating in closed-ended questions the influence of diabetes on their life and their concerns using a 5-point scale ranging from 0 (“does not concern me at all”) to 4 (“concerns me very much”) or “always concerns me”) for the following diabetes-related categories: dietary restrictions, measuring blood glucose, insulin injections, fear of hypoglycaemia, fear of complications, worries about loss of efficiency, need for discipline, need to carry around utensils or dependence on foreign body (patients with insulin pumps), general stress, mental stress, general health.

Regarding treatment goals, the following question was asked: “What is your most important goal regarding your diabetes?” Patients could mention up to two treatment goals. Furthermore, they were asked to state the main treatment goals they thought that their physicians had. If two treatment goals were mentioned, both of them were included in the analysis. Subsequently all answers were categorised as follows: good glucose control, prevention of complications, preservation of quality of life, avoidance of hypoglycaemia, discipline, independence, self-efficiency, good medical care, weight reduction.

Provider satisfaction

The following items regarding the physicians’ role in patient-centred care were investigated in closed-ended questions, where patients could answer yes, no or partly: “Does your physician know your treatment goals and is he/she responsive to them? Does your physician answer your questions and spend enough time with you? Are you generally satisfied with your physician?”

Statistical analysis

Data are expressed as means (SD) unless indicated otherwise. Principal component analyses with subsequent varimax-rotation were used to assess the structure of the questionnaire. Cronbach’s α was computed as a reliability measure. However, the reduction of all perceptions to one or two single factors would result in a loss of necessary

**Patients and methods**

**Patients**

A self-report questionnaire was distributed to all Ger- man-speaking patients with type 1 and insulin treated type 2 diabetes in the outpatient clinic of the University Hos- pital of Basel within a four-week period. Anonymity was ensured. 86% of the questionnaires were answered and re- turned in a prestamped envelope addressed to the primary investigator. The demographic characteristics of the patients are described in table 1. The majority of these patients have type 1 diabetes (n = 102) and most of them underwent a group-training course where they learn to adjust insulin dosage to food intake and daily activity (Course in Functional Insulin Therapy [FIT]). Thus, it is assumed that they are knowledgeable about their meta- bolic control and/or the presence of complications.

Patients were divided in three groups: type 1 diabetic patients treated with an insulin pump, type 1 diabetic pa- tients treated without an insulin pump (practicing FIT or basis-bolus therapy, ie basal/mealtime insulin with dose- adjustments according to the blood glucose values) and in- sulin treated type 2 diabetic patients. None of the type 2 diabetics were satisfied with their medical care in an Outpa- tient Clinic of a University Hospital in Switzerland and whether there is a discrepancy between their own and their physicians’ treatment goals.
clinical information. Therefore, all single items were used for further analyses.

As this was an explorative study and we were not testing hypotheses, a sample size calculation was not appropriate and no p-values are reported. The frequencies of the mentioned perceptions and treatment goals of patients with type 1 and type 2 diabetes in answer to open-ended questions are shown in figure 1. The results of the closed-ended questions regarding disease perceptions for type 1 and type 2 diabetic patients were shown as median and interquartile ranges in table 2.

Results were analysed using Intercooled STATA (version 8, StataCorp LP, Texas) and Statistica for Windows (version 6.0, StatSoft, Inc., Tulsa, OK, USA).

Results

Disease perceptions

The principal component analysis revealed a one-dimensional solution. The reliability of the single factor could be considered as high ($\alpha = 0.78$).

In 74% of all patients, the quality of life was partially or totally impaired by diabetes. This effect was more pronounced in patients with type 2 diabetes (89%) than in patients with type 1 diabetes (overall frequency of type 1 diabetic patients 70%, table 1).

As described above, patients were divided in the following three groups: type 1 diabetic patients treated with an insulin pump, type 1 diabetic patients treated without an insulin pump and insulin treated type 2 diabetic patients.

In the open-ended questions, patients in all three groups together were mostly concerned about their loss of freedom (frequency of all respondents 24%), dietary restrictions (17%), the need to measure blood glucose (17%) and about hypoglycaemia (15%), followed by worries about loss of efficiency (12%), need for discipline (12%) and the need to carry around utensils or dependence on a foreign body (12%, figure 1). Women (data not shown) and patients with insulin pumps worried especially about hypoglycaemia. Interestingly, none of all patients worried about hyperglycemias. Patients treated with insulin pumps worried very little about dietary restrictions, but a fourth of them were bothered by their dependence on a foreign body or their need to carry around utensils. Patients with type 2 diabetes did not list the need to measure blood glucose or the fear of hypoglycaemia as their concerns.

In the closed-ended questions (table 2), patients in all three groups together felt mostly concerned about the fear of hypoglycaemia (median [interquartile range]; 2 [1–4]) and the fear of developing complications (2 [1.5–3.5]). Patients with type 1 diabetes, and especially patients treated with an insulin pump, worried a lot about hypoglycaemia. Subjects with type 2 diabetes worried more about dietary restrictions and the need to lose weight than subjects with type 1 diabetes (median [interquartile range] 2 [2–3] in type 2 diabetes vs 1 (0–2) in type 1 diabetes and 1.5 (1–3) vs 0 (0–1), respectively). The results were not different when only the patients who answered to the open-ended questions are shown in figure 1. The results of the closed-ended questions regarding disease perceptions for type 1 and type 2 diabetic patients were shown as median and interquartile ranges in table 2.

Results were analysed using Intercooled STATA (version 8, StataCorp LP, Texas) and Statistica for Windows (version 6.0, StatSoft, Inc., Tulsa, OK, USA).

Figure 1

Patients’ perceptions and concerns given in answer to an open-ended question. The perceptions and concerns of type 1 diabetic patients treated without (type 1 “no pump”) and with an insulin pump (type 1 “pump”) and insulin treated type 2 diabetic patients are shown in descending order from left to right.

Table 1

Demographics of study population.

<table>
<thead>
<tr>
<th></th>
<th>type 1 diabetes (no insulin pump)</th>
<th>type 1 diabetes (insulin pump)</th>
<th>type 2 diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients</td>
<td>60</td>
<td>42</td>
<td>22</td>
</tr>
<tr>
<td>Gender (m/f)</td>
<td>35/24</td>
<td>15/28</td>
<td>13/9</td>
</tr>
<tr>
<td>Age (y)</td>
<td>44 (14)</td>
<td>45 (14)</td>
<td>65 (10)</td>
</tr>
<tr>
<td>Diabetes duration (y)</td>
<td>19 (14)</td>
<td>20 (13)</td>
<td>17 (9)</td>
</tr>
<tr>
<td>Diabetic complications (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No complications</td>
<td>71</td>
<td>61</td>
<td>32</td>
</tr>
<tr>
<td>1 complication</td>
<td>15</td>
<td>17</td>
<td>23</td>
</tr>
<tr>
<td>2 complications</td>
<td>9</td>
<td>11</td>
<td>23</td>
</tr>
<tr>
<td>3 complications</td>
<td>3</td>
<td>11</td>
<td>9</td>
</tr>
<tr>
<td>4 complications</td>
<td>2</td>
<td>0</td>
<td>13</td>
</tr>
<tr>
<td>Quality of life totally impaired by diabetes (%)</td>
<td>17</td>
<td>20</td>
<td>42</td>
</tr>
<tr>
<td>Quality of life partially impaired by diabetes (%)</td>
<td>48</td>
<td>58</td>
<td>47</td>
</tr>
</tbody>
</table>

Data are shown as means (SD)
Disease perceptions and treatment goals of diabetic patients

The main treatment goal of both type 1 and type 2 diabetic patients together consisted of keeping a good blood glucose control (frequency of all respondents: 63%, figure 2A). A less important goal was the prevention of complications (frequency of all respondents: 27%). Patients treated with and without insulin pumps had very similar treatment goals. In contrast, none of the patients with type 2 diabetes mentioned quality of life or avoidance of hypoglycaemia as their treatment goal, while this goal was stated by 29% and 8% of the patients with type 1 diabetes, respectively. The following items were mentioned by all respondents in less than 5% of the cases, and thus are not shown in figure 2A: own control over the disease, acceptance of diabetes, medical care, discipline, knowledge, flexibility, independence, avoidance of injections, nutritional freedom.

Both type 1 and in type 2 diabetic patients thought their physicians had goals that were similar to their own goals (figure 2B). This was especially apparent in the prevention of complications or hypoglycaemia. Interestingly, patients with type 2 diabetes thought that their physicians cared more about their quality of life than they did themselves. However, patients and physicians judged the importance of good glucose control differently; according to the whole group of patients this aspect was more important for their physicians (frequency of all respondents: 86%) than for themselves.

Provider satisfaction
Satisfaction with medical care was high. 95% of all respondents were completely satisfied with their physicians. 84% of the patients thought that their physicians knew their treatment goals. 98% thought that their physicians were responsive to their needs, 95% that their physicians seemed to answer their questions, and 97% were convinced that their physician spent enough time with them.

Table 2
Patients’ perceptions and concerns given in answer to closed-ended questions.

<table>
<thead>
<tr>
<th></th>
<th>type 1 diabetes</th>
<th>type 2 diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>“no insulin pump”</td>
<td>“insulin pump”</td>
</tr>
<tr>
<td>Hypoglycaemia</td>
<td>2 (1–3)</td>
<td>3 (1–4)</td>
</tr>
<tr>
<td>Fear of complications</td>
<td>2 (1–4)</td>
<td>2 (1.25–3)</td>
</tr>
<tr>
<td>Measuring glucose</td>
<td>2 (1–2.25)</td>
<td>2 (0.25–2.75)</td>
</tr>
<tr>
<td>Injections</td>
<td>2 (0.25–2)</td>
<td>1 (0–2)</td>
</tr>
<tr>
<td>Personal relations</td>
<td>0 (0–2)</td>
<td>2 (1–2)</td>
</tr>
<tr>
<td>Dietary restriction</td>
<td>1 (0–2)</td>
<td>2 (0–2)</td>
</tr>
<tr>
<td>Need to lose weight</td>
<td>0 (0–0)</td>
<td>0 (0–1)</td>
</tr>
<tr>
<td>Physical activity</td>
<td>0 (0–2)</td>
<td>0 (0–2)</td>
</tr>
<tr>
<td>Financial concerns</td>
<td>1 (0–2)</td>
<td>1 (0–2)</td>
</tr>
</tbody>
</table>

Concerns are listed in descending order of overall importance for type 1 diabetic patients treated without (type 1 diabetes “no pump”) and with an insulin pump (type 1 diabetes “pump”) and insulin treated type 2 diabetic patients. The scale ranges from 0 (“does not concern me at all” or “never concerns me”) to 4 (“concerns me very much” or “always concerns me”). Data are shown as median (interquartile range).
Discussion

This study identified disease perceptions and treatment goals of type 1 diabetic patients treated with and without an insulin pump and insulin treated type 2 diabetic patients. We were also interested whether patients mentioned different concerns when they are generally asked what their concerns are, or whether they are guided through by answering to closed-ended questions and whether these perceived concerns differed from their treatment goals. We also wanted to find out whether patients think that their own treatment goals differ from those of their physicians.

When being asked what they perceived generally as most concerning, type 1 and 2 diabetic patients mentioned the loss of freedom, the dietary restrictions and the need to measure blood glucose. When given a list of items, patients were especially concerned about hypoglycaemia and the development of complications. In general, dietary restriction and loss of freedom were less and the fear of hypoglycaemia was more concerning for type 1 diabetic patients treated with an insulin pump. Thus, in open-ended questions, patients spontaneously worry about their restriction in their actual quality of life and daily hassles and mention worries regarding long-term control or side effects of their treatment after explicit questioning. The main treatment goals of type 1 and type 2 diabetic patients focused on long-term goals like keeping a good blood glucose control. Further goals were prevention of complications and in type 1 diabetic subjects, but not in type 2 diabetic patients, the preservation of a good quality of life. Although hypoglycaemia was of substantial concern for patients, less than half of the type 1 diabetic patients that were concerned about hypoglycaemia and none of the type 2 diabetic patients mentioned the prevention of hypoglycaemia as one of their main treatment goals. Similarly, patients felt somewhat restricted by their diet, but nutritional freedom was mentioned in less than 5% as a treatment goal. On the other side, patients chose good glucose control as their main goal, but none of them was concerned by the presence of hyperglycemia. Patients thought that blood glucose control was more important for the physicians than for themselves.

As we did not find in the literature any validated questionnaire covering especially treatment goals or all aspects of disease perceptions, we added our own questions. The fact that we used open questions in several items, which were categorised afterwards could be regarded as a methodological limitation of the study. However, at the same time this gave us the possibility to gather more textual information. Another limitation of our study is that, due to the small sample size of patients with type 2 diabetes, we cannot make extensive statements on the differences in perceptions or goals of patients with type 1 and type 2 diabetes. There probably also exists a selection bias in our type 2 diabetic patients who had a relatively long duration of illness and suffered from many complications. In addition, a larger study should clarify the impact of confounders like age, sex, level of education, diabetes duration, number of complications on disease perceptions and treatment goals in patients with diabetes.

Disease perceptions

Of specific interest is the finding in our study that asking an open-ended question yielded different results than presenting a list of possible answers. Asked open-ended, patients spontaneously were more concerned about the restriction of actual quality of life and daily hassles. Upon more explicit questioning, patients chose long-term concerns like the fear of complications as well as side effects of their treatment like the fear of hypoglycaemia as their main concerns. Possibly these concerns are more in accordance with physicians’ views. These concerns expressed as answers to closed-ended questions were similar to the results of other studies that also investigated this topic with closed-ended questions; a previous survey performed in patients with type 1 diabetes showed that 20% of them perceived hypoglycaemia as worrisome [17]. In another study, type 1 and insulin treated type 2 diabetic patients were reported to worry predominantly about the development of complications, and less about hypoglycaemia [16]. In our study, the fear of hypoglycaemia was particularly pronounced in the patients treated with an insulin pump. This is most likely a selection bias, as frequent and especially severe events of hypoglycaemia are among the main indications for therapy with an insulin pump in our institution. Unfortunately, we did not collect information about the prevalence of mild or severe hypoglycaemia, as this probably influenced disease perceptions.

Dietary restrictions impaired our participating subjects consisting of mainly type 1 diabetics only moderately and even less those type 1 diabetic patients that were treated with an insulin pump. Most of our type 1 diabetic patients and all patients treated with insulin pumps practiced intensified insulin therapy using meal-adapted multiple injections, and thus have a more liberalised diet. This might explain why patients in other studies and our patients with type 2 diabetes felt their diet restriction to be of greater concern [2, 17].

Treatment goals

The main treatment goals of type 1 and type 2 diabetic patients focused on long-term goals like keeping a good blood glucose control and preventing complications. Previous data obtained in patients with type 1 diabetes demonstrated that stable and low glucose values as well as avoidance
Relationship between disease perception and treatment goals

The majority of patients stated that their main treatment priority was to achieve a good blood glucose control. Despite this, none of them mentioned hyperglycaemia as concerning. Hypoglycaemia was perceived as being very concerning, and yet, its prevention was only mentioned in 8% as a treatment goal. Why this discrepancy?

Even when they are told, many patients might not realise the correlation between poor day-to-day glycaemic control and long-term complications of the disease. This is all the more difficult, as diabetes is a silent disease for a long time.

Both perceptions and concerns are emotional terms, relate to daily life and rather short-term decisions, while treatment goals relate to the more cognitive aspects of managing life as a diabetic person, probably also over a longer period of time. Treatment goals include rather general aspects of care and are more influenced by health care provider priorities [22]. Set treatment goals might also be unrealistic or patients may mention exclusively those goals, which they consider to be able to actively influence. For example, many patients feel helpless in avoiding mild hypoglycaemia, as it is influenced by many uncontrollable minor factors.

In general, highly individualised goals that are in concordance with the patients’ own goals and short-term behaviour targets are most successful [23]. To achieve their goals, patients can increase self-care behaviour to a certain extent by themselves [24] and improve glucose control [25]. However, even when physicians and other health educators encourage their patients to set their own treatment goals, this by itself is often not sufficient to implement most of the behavioural changes that are necessary to achieve these goals.

Additional factors like perceptions and concerns influence the attitude and the feeling of responsibility towards certain behaviour. Together with motivation and successful coping with stress situations, they need to be strong enough to overcome the inconvenience and discomfort that such behavioural changes involve [9, 26, 27]. Perceptions may also represent barriers and inhibit the achievement of goals [27]. An example for this situation might be that as long as a patient is concerned about hypoglycaemia, he will avoid low normal glucose values, even when good glucose control truly represents this patient’s main treatment goal. Thus, it is necessary to incorporate perceptions to be able to successfully implement the patients’ treatment goals [16].

Our results regarding perceptions, goals and differences between patients’ and physicians’ goals are overall in accordance with other published studies. Nevertheless, our findings should be replicated in larger samples including also diabetic patients treated in private practices.

In summary, the present exploratory study identifies the disease perceptions and treatment
goals of type 1 diabetic patients treated with and without an insulin pump and insulin treated type 2 diabetic patients. In open-ended questions, patients spontaneously express concerns about their actual quality of life and daily hassles and mention concerns regarding long-term control or side effects of their treatment after explicit questioning. For their main treatment goals they choose mainly long-term goals like glucose control, but still think that physicians overestimate the importance of glucose control.

Thus, this study demonstrates that disease perceptions might differ depending on how they are investigated and that they can differ from patients’ treatment goals. Based on our results, we propose that both, disease perceptions and treatment goals should be actively searched for in individual patients. They should be supported to bridge the gap between daily concerns and long-term treatment goals, such as a high quality of life and good blood glucose control.

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