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

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Summary

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

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concerning or restricting [11–15]. In addition, these questionnaires use closed-ended questions. One study that examined patients' perceptions showed that over 80% of patients worried about developing complications, while about a third worried about the occurrence of hypoglycaemic events. Gender and the presence of complications influenced these perceptions [16]. Regarding patients' own treatment goals, there is hardly any published data. It is also unclear if treatment goals differ from disease perceptions. One study demonstrated that patients found good glucose control, flexibility, avoidance of late complications as well as of severe hypoglycaemia to be very important goals [12]. In this study, almost all queried items were given a high priority, and causes that influenced these goals or differences in gender or type of diabetes were not investigated. Secondly, the questionnaire was not anonymous, and thus more vulnerable to biases such as social desirability.

We therefore performed this explorative study to learn about the subjective disease-related perceptions, concerns and treatment goals of type 1 diabetic patients treated with and without an insulin pump and insulin treated type 2 diabetic patients. We also were interested whether patients are satisfied with their medical care in an Outpatient Clinic of a University Hospital in Switzerland and whether there is a discrepancy between their own and their physicians' treatment goals.

Patients and methods

Patients

A self-report questionnaire was distributed to all German-speaking patients with type 1 and insulin treated type 2 diabetes in the outpatient clinic of the University Hospital of Basel within a four-week period. Anonymity was ensured. 86% of the questionnaires were answered and returned 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 metabolic 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 patients 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 insulin treated type 2 diabetic patients. None of the type 2 diabetic patients was treated with an insulin pump.

The human research ethics committee of the University of Basel approved the study.

Questionnaire development

A 23-item questionnaire was devised to obtain routine sociodemographic information about the age, sex and level of education of the patients as well as information about their type of diabetes, their disease duration, their metabolic control and the eventual presence and number of diabetic complications. The three main areas of interest included patients' disease perception, their treatment goals and provider satisfaction. As it was difficult to find validated measures that covered all factors of interest for this study, we added some own questions and assessed the questionnaire for its reliability. Wherever possible, questions were used from the Diabetes Quality of Life Questionnaire [11]. The questions were tested among 5 patients and three diabetes educators prior to being used and were found to be comprehensible.

Disease perceptions

We specifically included open-ended questions to be able to include a maximal range of patients' perceptions and treatment goals and to diminish pleasing bias. We first asked whether their diabetes impairs their quality of life and then, in open-ended questions, which components of their diabetes concern them mostly or impair their quality of life. Subsequently all answers were categorised as follows: loss of freedom, 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.

We investigated 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" or "never concerns me") 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, influence of diabetes on personal relations, need to lose weight, need to be physically active and financial concerns.

Treatment goals

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 physicans' 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

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.

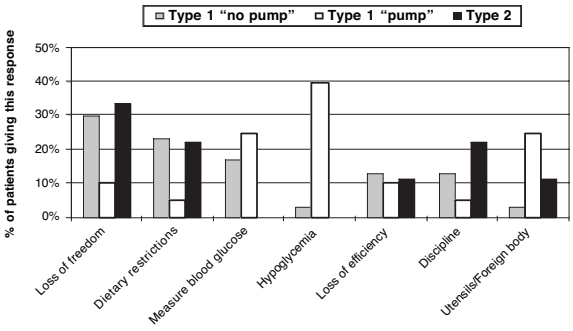


Figure 1

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.

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

Table 1

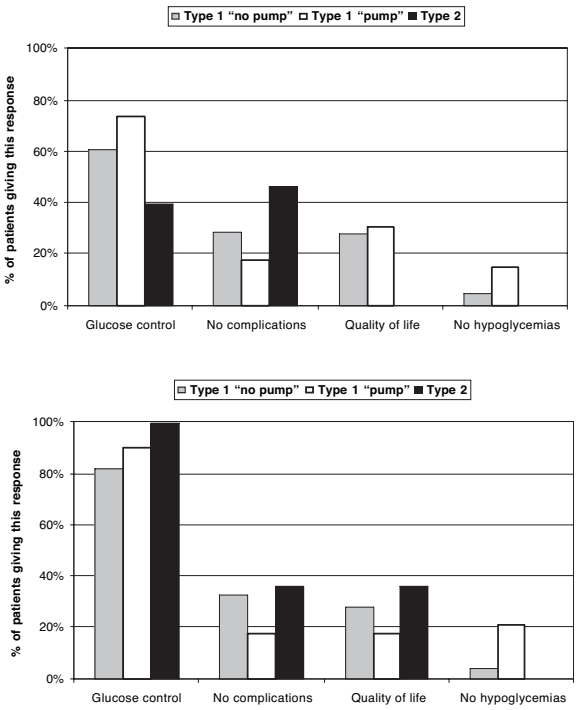
Demographics of study population.

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

Data are shown as means (SD)

Figure 2

Patients' treatment goals (A) and their perception of their physicians' goals (B). The treatment goals 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 and of their physicians are shown in descending order from left to right.



questions regarding disease perceptions were included.

Treatment goals

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.

	type 1 diabetes		type 2 diabetes
	"no insulin pump"	"insulin pump"	
Hypoglycaemia	2 (1–3)	3 (1–4)	2 (2–2)
Fear of complications	2 (1–4)	2 (1.25–3)	2 (2–4)
Measuring glucose	2 (1–2.25)	2 (0.25–2.75)	2 (2–2)
Injections	2 (0.25–2)	1 (0–2)	2 (1–3)
Personal relations	0 (0–2)	2 (1–2)	2 (0.5–3.5)
Dietary restriction	1 (0–2)	2 (0–2)	2 (2–3)
Need to lose weight	0 (0–0)	0 (0–1)	1.5 (1–3)
Physical activity	0 (0–2)	0 (0–2)	1 (0–1)
Financial concerns	1 (0–2)	1 (0–2)	0.5 (0–4)

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 hyperglycemias. 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

of late complications were scored as being very important, along with flexibility (both dietary flexibility and flexibility in their leisure time), physical fitness and avoidance of severe hypoglycaemia [12]. To our knowledge, there are no other published studies focusing mainly on the treatment goals of insulin treated diabetic patients. The few other studies with an interest in treatment goals in diabetes do not focus on patients' treatment goals, but rather on the differences between doctors' and patients' goals [18, 19]. We found that patients with type 1 diabetes judged good quality of life to be more important than patients with type 2 diabetes did. This is possibly due to the more dramatic impact of diabetes on their daily life as well as their younger age, as we showed that the importance of quality of life as a treatment goal appeared to increase with younger age.

Patients' estimates of physicians' treatment goals

There is considerable evidence that the type and quality of the patient-doctor relationship play essential roles in achieving set treatment goals [20]. In our study, patient satisfaction was very high and patients thought that their physicians knew and respected their goals and were responsive to their needs. According to the patients, physicians had treatment goals that were similar to their own goals. This was particularly apparent in the goals regarding prevention of complications or hypoglycaemia. Despite this, patients thought that their physicians valued glucose control more than they did themselves. Physicians generally tend to overvalue metabolic control [8, 21], and the agreement between patients' and physicians' goals is generally rather low [18, 19]. Why would physicians overestimate the importance of glucose control? One possibility is that patients as compared to physicians have more additional, possibly more short-term goals like the actual quality of life. The physicians' original long-term goal is probably the prevention of complications. However, this issue is hard to address and is accompanied by a significant burden like fear about the patient's reaction. Moreover, such a discussion is time-consuming. Glucose control or especially HbA1c has become a surrogate goal marker for preventing complications in daily practice, as it is easier and faster to talk about. However, according to our results, it is tempting to speculate that for many patients, glucose control as a goal has become too detached from the original long-term goal. As management of type 1 and type 2 diabetes is largely relinquished to the patients in their individual life, their treatment goals are necessary to be set and known [9]. The differences between patients' and presumed physicians' goals that we and others [19] found stress the need to actively investigate the patients' own treatment goals.

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 hyperglycemias 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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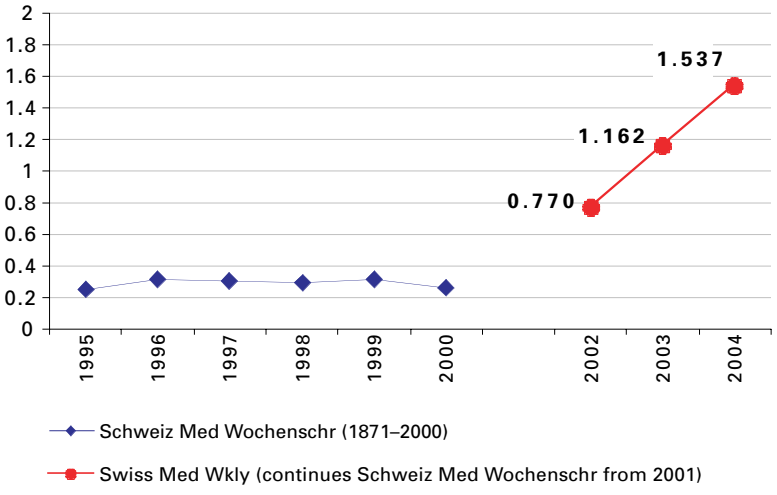

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