

How patients with insulin-treated Type 1 and Type 2 diabetes view their own and their physician's treatment goals

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Summary

Objectives: To investigate the subjective treatment goals of insulin-treated diabetic patients

Methods: 297 type 1 and 205 type 2 diabetic patients, representative of the North-western Swiss population, filled out a self report questionnaire focusing on their own treatment goals using standardized measures wherever available. Factor analysis of the 16 items reflecting their treatment goals revealed four subscales (Cronbach's alpha): High actual quality of life (0.73), weight reduction/maintenance and daily hassles (0.68), good medical care and knowledge (0.64) and good long term glucose control (0.71).

Results: Good long term glucose control was the single most important main treatment goal for most patients (type 1: 60.2%, type 2: 49.7%, $p = 0.025$). However, both type 1 and type 2 diabetic patients believed that this goal – especially the value of HbA1c – was overestimated (both $p < 0.0001$), while high actual quality of life was underestimated ($p = 0.003$ and $p = 0.05$, respectively)

by their physicians compared to their own assessment. Good long term glucose control (OR 1.63, $p = 0.003$) and high actual quality of life (OR 2.17, $p < 0.0001$) were more important and weight reduction/maintenance and coping with daily hassles (OR 0.75, $p = 0.07$) were slightly less important treatment goals for type 1 than for type 2 diabetic patients. These differences in goals were best associated with the mode of insulin therapy, self-monitoring, and with the extent of diabetes education.

Conclusions: Patients believe that physicians overestimate the importance of long term glucose control and underestimate the importance of actual quality of life. Diabetes education and self management have the largest impact on patients' own treatment goals.

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

Introduction

Quality of life is affected in patients with diabetes [1, 2] and insulin treatment further influences the impact of the disease on quality of life [2]. On the other side, patient empowerment and self-management can increase quality of life and patient satisfaction [3, 4] as well as metabolic control [5–7]. Patients' autonomy is further potentiated when treatment goals are tailored to their own treatment goals [8]. Despite this, there are hardly any published data on patients' own treatment goals, and it is generally assumed to be in the patient's interest that certain goals are achieved [9]. One study demonstrated that type 1 diabetic patients found good glucose control, flexibility, avoidance of late complications as well as absence

of severe hypoglycaemia to be very important goals [10] and almost all queried items were given a high priority. Furthermore, the questionnaire was not anonymous, and thus more vulnerable to biases such as social desirability.

In an exploratory pilot study, we investigated the main treatment goals of insulin-treated diabetic patients [11]. The results indicated that long term blood glucose control and actual quality of life were more important for type 1 than for type 2 diabetic patients. These patients also believed that their physicians overestimated the importance of long term glucose control [11]. In the current study, we asked the following questions: Is long term glucose control indeed the single most im-

portant main treatment goal of insulin-treated diabetic patients? Do patients believe that their physicians have different treatment goals compared to themselves? Can we confirm that there

are differences in treatment goals between insulin-treated type 1 and type 2 diabetic patients and what factors determine these differences?

Subject and methods

Patients

This study examined a sample of 509 German speaking insulin-treated diabetic patients (297 type 1 and 205 type 2 diabetic patients) that are representative of the North-western Swiss population. They were recruited from the diabetes outpatient clinic of the University of Basel Hospital (n = 203), the other 5 regional hospitals in this area (n = 135), 13 of 14 specialist practices (n = 107) and 15 randomly selected general practitioner practices (n = 64). Each general practitioner and each specialist distributed the questionnaire consecutively to 6–10 patients respectively within a time period of 2 months. The questionnaires were sent to all insulin-treated diabetic patients in our outpatient clinic. Anonymity was ensured. Overall, 636 questionnaires were distributed and 80% were answered and returned. The characteristics of the patients are presented in Table 1. The human research ethics committee of the University of Basel approved the study.

Development of the questionnaire

Our 83-item self report questionnaire was developed through a three-step procedure. First, the authors reviewed existing questionnaires and articles and a self report questionnaire was distributed to 124 patients with insulin-treated diabetes in a qualitative pilot study investigating *patients' treatment goals for diabetes-related behaviour, diabetes-related worries and satisfaction with medical care* [11], with questions from the Diabetes Quality of Life (DQOL) Questionnaire [12]. Based on this information, we constructed a set of items for these three scales and obtained feedback from diabetes specialists, diabetes educators and psychologists. Wherever possible we used scales from other validated questionnaires. To be able to better compare both types of diabetes, the same questionnaire was used for patients with type 1 and with type 2 diabetes. This German-speaking questionnaire is available on the website of the Swiss Medical Weekly: http://www.smw.ch/dfe/set_archiv.asp → Archive → issue 35-36, 2006.

Measures

In addition to sociodemographic questions, the questionnaire asked about the type of diabetes, weight and height, the mode of insulin therapy (conventional, basal-bolus or functional insulin therapy), self-monitoring (frequency of blood glucose measurements and insulin injections) and the extent of diabetes education, glucose control (diabetes duration, HbA1c, number of mild and severe hypoglycaemic events) and diabetic complications (Table 1). Severe hypoglycaemic events were defined as in the Diabetes Controls and Complications Trial [13].

Quality of life

Quality of life was assessed using the validated German translation of the two overview items (quality of life per se and impact of diabetes on quality of life) of the Audit of Diabetes-Dependent Quality of Life (ADDQoL) questionnaire [2], where we slightly modified the explanatory introducing sentence. The overview item of quality of life has been shown to be useful in the DAFNE trial [14].

Internality

Internality was assessed using the scale *internality* from the IPC diabetes questionnaire consisting of 8 items [15].

Treatment goals for diabetes-related behaviour

Questions were generated to evaluate the importance of 16 different treatment goals incorporating questions from previous questionnaires [10, 11, 16]. However, we did not find any published validation of these cited questions.

Main treatment goals

Patients were asked to mention their single most important main treatment goal among the 16 goals (below) as well as the main treatment goal they thought that their physicians had. These two responses were used to address a potential discrepancy between patients' main goals and the perceived physicians' main goals.

Treatment goals

Patients rated all 16 goals on a scale ranging from 1 (totally unimportant) to 6 (very important). No items were eliminated. The following four subscales were derived from the principal component analysis with subsequent varimax rotation:

1. *High actual quality of life* (Eigenvalue = 5.7, Cronbach's α 0.73): Importance of good quality of life, flexible diet, flexible life, physical efficiency, self efficiency, discipline
2. *Weight reduction/maintenance and avoidance of daily hassles* (Eigenvalue = 1.7, Cronbach's α 0.68): Importance of weight reduction/maintenance or of avoidance of either blood glucose monitoring or of insulin injections
3. *Good medical care and knowledge* (Eigenvalue = 1.6, Cronbach's α 0.64): Importance of medical therapy, knowledge, avoidance of hypoglycaemia
4. *Good long term glucose control* (Eigenvalue = 1.1, Cronbach's α 0.71): Importance of good HbA1c, avoidance of complications, avoidance of blood glucose fluctuations, disease acceptance

Diabetes-related worries

Questions were generated to evaluate the impact of 10 different worries, 8 of them having been previously used in the DQOL and/or the diabetes-specific quality-of-life scale (DSQOLS) questionnaire (10, 12). In analogy with the DQOL, we used a five-point scale for each question ranging from 1 ("never worries, restricts or exhausts me") to 5 ("always worries, restricts or exhausts me"). No items were eliminated.

The following two subscales were derived from the principal component analysis with subsequent varimax rotation:

1. *Diabetes-related physical complaints and worries about dietary restriction* (Eigenvalue 4.2, Cronbach's α 0.74): Exhaustion or lack of energy due to either diabetes or high blood glucose, restriction by diet
2. *General diabetes-related worries* (Eigenvalue 1.3, Cronbach's α 0.73): Restriction in flexibility or in physical activity, worries about complications, hypoglycaemia,

hyperglycaemia, weight reduction, impact of diabetes on social life

Satisfaction with medical care

Six questions were generated to assess the patient-physician relationship, rated on a scale ranging from 1 ("never") to 4 ("always"). The following single subscale was derived from the principal component analysis:

Satisfaction with medical care (Cronbach's α 0.76): Telling physician everything about diabetes, physician accepts the way patients handle their diabetes, satisfaction with medical care, patients' questions adequately answered by their physician, sufficient time spent with their

physician during consultation and being able to contact their physician as needed.

One question was added rating the importance of a diabetes team (physician, diabetes educators, psychologists) in their diabetes treatment.

Statistical analysis

We estimated our sample size based on the differences in their most important treatment goal (glucose control, 67% vs 40%) between the type 1 and type 2 diabetic patients and between patients and their physicians' estimate (63 vs 86%) found in our pilot study [11]. Assuming a type I error rate of 5% and a type II error rate of 10%

Table 1

Demographic characteristics of insulin-treated type 1 and type 2 diabetic patients.

	Type 1 diabetic patients (n = 297)	Type 2 diabetic patients (n = 205)	P
Age (yrs)	45.4 ± 17.9	63.0 ± 9.9	<0.001
Sex (m/f) (%)	46/54	63/37	<0.0001
Married (%)	53	71	<0.0001
Level of education (%)			0.03
Up to 9th grade	26	30	
10–12th grade	40	47	
Over 12th grade	34	23	
Employment status (% employed)	45	23	<0.0001
Region of origin (Central Europe, Mediterranean [Italy, Turkey], other) (%)	87/9/4	92/5/3	0.25
Exertional physical activity (times/week)	2 (1–2)	2 (1–7)	0.96
BMI (kg/m ²)	23.4 (21.3–26.0)	29.9 (26.5–33.5)	<0.001
Diabetes duration (yrs)	17.0 (7.5–29.0)	11.0 (7.0–16.0)	<0.0001
Over 6 diabetes education sessions (%)	76.3	50	<0.0001
Course in functional insulin therapy (%)	54.7	7.5	<0.0001
Mode of insulin therapy (%)			<0.0001
Conventional insulin therapy (fixed insulin doses)	4	31	
Basis-bolus insulin therapy (blood glucose adapted insulin doses)	32	57	
Functional insulin therapy (insulin doses adapted to blood glucose, carbohydrate intake and physical activity)	64	12	
Continuous subcutaneous insulin infusion (insulin pump) (%)	20.8	1.5	<0.0001
Number of injections/day	4 (4–4)	3 (2–4)	<0.001
Skipping injections/week	0.04 (0–0.04)	0 (0–0.04)	0.13
Number of blood glucose measurements/day	4 (3–5)	3 (2–4)	<0.0001
Mild hypoglycaemia/day	0.15 (0.03–0.3)	0.02 (0–0.03)	<0.001
Severe hypoglycaemia/year	0 (0–1)	0 (0–0)	0.007
HbA _{1c} (%)	7.3 ± 1.0	7.7 ± 1.1	<0.0001
Total diabetic complications (n)	0.4 ± 0.8	0.6 ± 0.9	0.007
Single complications (%):			
Sensory polyneuropathy	11	15	0.14
Retinopathy without visual impairment	7	18	<0.0001
Retinopathy with visual impairment	14	19	0.21
Cerebrovascular disease	1	4	0.11
Coronary heart disease	4	10	0.02
Nephropathy	7	6	0.52
Lower limb amputation	1	2	0.58
General quality of life	1.2 ± 1.0	0.7 ± 1.1	<0.0001
Impact of diabetes on quality of life	–1.4 ± 1.0	–1.5 ± 1.0	0.22
Internality	40 (34–44)	42 (38–45)	<0.001
Treatment facility (generalist/specialist/hospital) (%)	5/26/69	23/15/62	<0.0001
Satisfaction with medical care	3.7 (3.3–3.8)	3.7 (3.5–3.8)	0.56

(i.e. 90% power), the maximal sample size calculated to 237 patients in both groups together.

Data are shown as means ± SD for normally distributed variables and as median and interquartile ranges for not normally distributed variables, respectively. Variables with a skewed distribution were log-transformed. The differences in demographic characteristics between type 1 and type 2 diabetic patients were compared by unpaired t-test, Mann-Whitney U test or by χ^2 analysis, as appropriate. The main treatment priorities and goals were compared by χ^2 analysis.

The influence of the type of diabetes on patients'

treatment goals was assessed by ordinal logistic regression analysis both unadjusted and after controlling for four groups: 1) sociodemographic variables, 2) glucose control and diabetic complications, 3) mode of insulin therapy, self-monitoring and extent of diabetes education and 4) psychological variables. We also analysed if allocation of patients to our outpatient clinic (94% response rate, almost no selection bias) vs all other treatment facilities had an effect on treatment goals. All the analyses were performed using Intercooled STATA (version 8, StataCorp LP, Texas). Two-tailed p values <0.05 were considered statistically significant.

Results

The demographic characteristics of the patients are shown in table 1.

Main treatment goals: Differences between type 1 and type 2 diabetic patients, and between their own goals and their beliefs about their physicians' goals

Overall, type 1 and insulin-treated type 2 diabetic patients had significantly different main treatment goals (p = 0.001) and their main treatment goals were significantly different from what they felt their physicians' main goals were (type 1, p <0.0001; type 2, p = 0.001, respectively, figure 1A). This difference was noted despite a high satisfaction with medical care (table 1).

Good long term glucose control was the single most important main treatment goal for 56% of the patients, and its importance as a main treatment goal differed both between type 1 and type 2 diabetic patients (p = 0.025) as well as between their own and their estimate of their physicians goals (type 1, p = 0.0001; type 2, p = 0.001, respec-

tively). Breaking the subscale 'good long term glucose control' into single elements demonstrated that patients thought that the value of HbA_{1c} was much more important for their physicians than for themselves (type 1, p <0.0001; type 2, p <0.0001, figure 1B).

High actual quality of life was the second most important treatment goal for 24% of the patients (figure 1A). Patients believed that their quality of life was more important for them than for their physicians (type 1, p = 0.003; type 2, p = 0.05, respectively).

Differences in treatment goals between type 1 and type 2 diabetic patients

Good long term glucose control and high actual quality of life were more important for type 1 than for type 2 diabetic patients, while weight reduction/maintenance and avoidance of daily hassles, such as avoidance of frequent blood glucose monitoring or of reducing the number of insulin injections, were slightly more important for pa-

Figure 1

Main treatment goals of type 1 and insulin-treated type 2 diabetic patients and their perception of their physicians' goals. A: Overall, main treatment goals differed between type 1 and insulin-treated diabetic patients as well as between their own goals and their perception of their physicians' goals (type 1, <0.0001; type 2, p = 0.001, respectively).

Differences in the importance of long term glucose control as a main treatment goal:

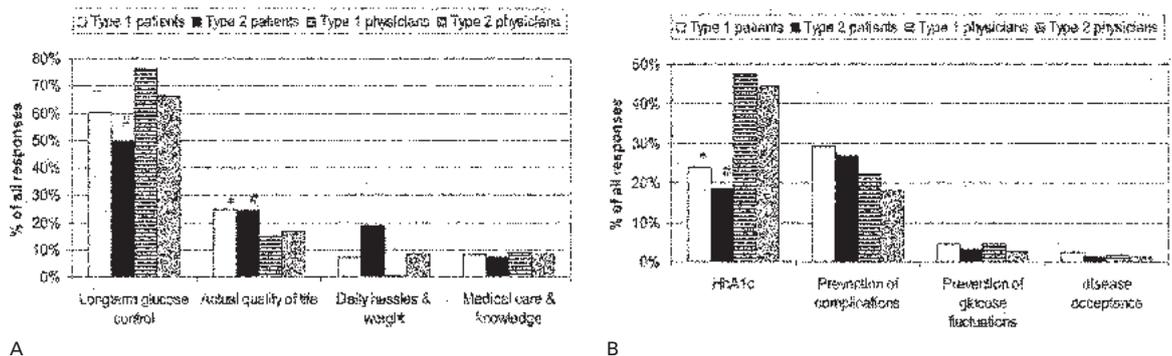
- + p <0.025 between type 1 and type 2 diabetic patients
- * p = 0.0001 between type 1 diabetic patients and their physicians
- # p = 0.001 between type 2 diabetic patients and their physicians

Differences in the importance of actual quality of life as a main treatment goal:

- * p = 0.003 between type 1 diabetic patients and their physicians
- # p = 0.05 between type 2 diabetic patients and their physicians

B: Subanalysis of the main treatment goal subscale "long term glucose control"

- Differences in the importance of HbA_{1c}
- * p <0.0001 between type 1 diabetic patients and their physicians
- # p <0.0001 type 2 diabetic patients and their physicians



tients with type 2 diabetes (table 2). Adjusting for *sociodemographic variables* or for the *variables related to glucose control and diabetic complications* did not eliminate these differences. However, after adjusting for *mode of insulin therapy, self-monitoring and extent of diabetes education* (treatment allocation [generalist, specialist, hospital], number of diabetes education sessions, completion of a course in functional insulin therapy, mode of insulin therapy, use of an insulin pump, frequency of blood glucose measurements and insulin injections), the differences between type 1 and type 2 diabetes regarding these three treatment goals were completely abolished. The same effect on these treatment goals was observed when the variables of the mode of insulin therapy, frequency of self-monitoring and extent of diabetes education were analyzed separately (data not shown). Similarly, removing variables that almost exclusively belong to type 1 diabetic patients such as "use of an insulin pump" and "completion of a course in functional insulin therapy" did not alter these results (data not shown). Adjusting for *psychological variables* slightly reduced the differences between the two diabetes types for the goal "good long term glucose control", but had no or almost no effect on the goal

of attaining or maintaining a "high quality of life" or the goal "weight reduction/maintenance and avoidance of daily hassles". Good medical care and knowledge was more important for type 1 than for type 2 diabetic patients, but only after adjustment for sociodemographic variables. Thus, differences in mode of insulin therapy, self-monitoring and/or the extent of diabetes education between patients with type 1 and type 2 diabetes were best associated with the differences in treatment goals.

Physical activity, skipping insulin injections, general treatment allocation (generalist, specialist, hospital) or allocation of patients to our outpatient clinic vs all other treatment facilities did not alter the differences in all four treatment goals between type 1 and type 2 diabetic patients (data not shown). Adjusting for BMI slightly reduced the difference in the treatment goal "weight reduction/maintenance and avoidance of daily hassles". Independent of variables related to the mode of insulin therapy, self-monitoring and extent of diabetes education, all four treatment goals were much more important for patients who felt that a team approach was very important for their diabetes care (data not shown).

Table 2

Differences between Type 1 vs Type 2 patients regarding their treatment goals both unadjusted and adjusted in a multiple ordinal regression analysis.

Treatment goals	Odds Ratio	95% confidence interval	P value
Good long term glucose control			
Crude	1.63	1.18–2.25	0.003
Sociodemographic model	1.68	1.13–2.51	0.01
Glucose control & complications model	1.63	1.08–2.47	0.02
Diabetes therapy & education model	1.09	0.69–1.70	0.71
Psychological model	1.38	0.95–1.99	0.09
High actual quality of life			
Crude	2.17	1.47–3.22	<0.0001
Sociodemographic model	2.00	1.37–2.94	<0.0001
Glucose control & complications model	1.87	1.25–2.80	0.002
Diabetes therapy & education model	1.22	0.79–1.87	0.37
Psychological model	1.93	1.34–2.77	<0.0001
Weight reduction and daily hassles			
Crude	0.75	0.55–1.02	0.07
Sociodemographic model	0.73	0.49–1.07	0.11
Glucose control & complications model	0.70	0.47–1.04	0.07
Diabetes therapy & education model	0.88	0.57–1.34	0.55
Psychological model	0.77	0.54–1.09	0.14
Good medical care and knowledge			
Crude	1.01	0.74–1.39	0.95
Sociodemographic model	1.71	1.15–2.55	0.008
Glucose control & complications model	0.97	0.65–1.44	0.88
Diabetes therapy & education model	0.81	0.52–1.26	0.41
Psychological model	0.87	0.61–1.25	0.35

Sociodemographic model: Adjusting for sociodemographic variables (age, sex, level of education, region of origin, employment and marital status).

Glucose control & complications model: Adjusting for glucose control and diabetic complications (diabetes duration, HbA_{1c}, number of mild and severe hypoglycaemic events, diabetic complications).

Diabetes therapy & education model: Adjusting for mode of insulin therapy, self-monitoring and extent of diabetes education (treatment allocation [generalist, specialist, hospital], number of diabetes education sessions, completion of a course in functional insulin therapy, mode of insulin therapy, use of an insulin pump, frequency of blood glucose measurements and insulin injections).

Psychological model: Adjusting for psychological variables (diabetes-related worries, internality, quality of life).

Discussion

This is the first study to provide extended information on subjective treatment goals of insulin-treated type 1 and type 2 diabetic patients. Good long term glucose control was the single most important main goal for most patients, but was more important for subjects with type 1 than type 2 diabetes. However, both type 1 and type 2 diabetic patients believed that long term glucose control – especially the value of HbA_{1c} – was overemphasized, while the actual quality of life was underestimated by their physicians compared to themselves. Good long term glucose control and high actual quality of life were more important general goals, and weight reduction/maintenance and avoidance of daily hassles were slightly less important goals for type 1 compared to type 2 diabetic patients. These differences were best explained by the mode of insulin therapy, self-monitoring and the extent of diabetes education.

We demonstrated that for insulin-treated patients, long term glucose control and quality of life are the most important treatment goals. However, the patients in this study also thought that their doctors overemphasized the disease and its long term complications (good long term glucose controls, value of HbA_{1c}), while neglecting their present every-day life (actual quality of life). As the questionnaire was in part handed out by the care providers, this could have oriented the results towards even more “physician oriented” treatment goals (bias of social desirability). One previous study examining exclusively type 2 diabetic patients found that normal glucose levels and avoidance of long term complications were the most important goals for patients and their providers [16]. However, the same study also revealed that the agreement between patients’ and physicians’ goals was rather low. Similarly, two other studies reported that physicians overvalued the importance of metabolic control [16, 17]. Why is there this difference in therapeutic objectives? Physicians are trained to treat or prevent diseases. However, in chronic diseases, the personal everyday life and the present quality of life have to be weighted against the impact of the demanded efforts to maintain a future good quality of life. Often, these personal impacts, the individual perceptions and understanding of the disease are not known or not comprehensible to the physicians. In additions, HbA_{1c} has become a surrogate marker for prevention of complications in physicians’ daily practice, as it is easier to talk about this than to discuss complications. For many patients, however, HbA_{1c} is not a measure of long-term glucose control and personal risk for complications, but rather a measure of poor behaviour. Indeed, our patients believed that prevention of complications was at least as important for themselves as it was for their physicians, while the value of HbA_{1c} was only half as important. What could be done to improve these

differences? Knowing the patients’ personal settings and their goals and engaging them actively in setting the common goals, helps to specifically address their individual perceptions, improve their understanding, but also to adjust the providers’ goals. Patient-centred therapeutic groups such as functional insulin therapy group courses are an ideal environment to address these questions. Regarding the HbA_{1c}, physicians could try to enhance their patients’ understanding of this value as a measure of long-term glucose control, and not a measure of poor performance.

Knowing the patients’ goals and promoting a greater *agreement* on treatment goals and strategies on both sides, can improve the patient-provider collaboration and lead to improved outcomes [8, 16, 18–21]. *Actively engaging patients* in setting treatment goals encourages patient understanding and motivation to follow treatment plans, increases self-management and provides a reference against which success can be measured [8, 16, 18, 20–28]. Even if some discrepancy in treatment goals persists, the role of the provider in a patient-centred environment is also to provide patients with the necessary knowledge so that they can define and reach their own goals.

Patients with type 1 diabetes chose “good long term glucose control” more often as their single most important main treatment goal than patients with type 2 diabetes. For patients with type 2 diabetes, the management of other cardiovascular risk factors or the reduction in weight might be at least as important as glycaemia control. As we studied both type 1 and type 2 diabetic patients and focused on insulin therapy, we only used one questionnaire for both types of diabetes and unfortunately did not list other cardiovascular risk factors as treatment goals in this questionnaire. Another limitation of this anonymous study is that the data are self-reported. This could be relevant for some of the variables like the number of diabetic complications or the value of HbA_{1c}.

For patients with type 1 diabetes, “good long term glucose control” and “high actual quality of life” were more important treatment goals and “weight reduction/maintenance and avoiding daily hassles” were slightly less important goals compared to the goals of type 2 diabetic patients. These differences were best associated with the mode of insulin therapy, self-monitoring and extent of diabetes education. Based on these data, we hypothesize that subjects who undergo more extensive diabetes education and subjects who are more engaged with their diabetes learn to better define, understand and weigh their goals, and may choose those goals that agree with those of their providers. Potentially, patients with more extensive diabetes education might be more biased by what they have been told by their providers. There could also be another bias, as those patients who are primarily

interested in attaining a good long term glucose control are also interested in having more diabetes education sessions and agree to inject insulin and measure blood glucose more frequently.

In conclusion, we could demonstrate that for insulin-treated type 1 and type 2 diabetic patients long term glucose control is the single most important main treatment goal. Nevertheless, patients believed that physicians overestimate the importance of long term glucose control, especially the value of HbA_{1c}, and underestimate the importance of the actual quality of life. Differences in treatment goals between type 1 and type 2 diabetic patients were best associated with the extent of diabetes education and differences in self-management. This leads us to believe that diabetes education and self-management have a major influence on assisting the patient to set their own treatment goals, increase the mutual patient-provider agreement on goals and subsequently improve outcome. Future studies will show us the value of incorporating patients' treatment goals in diabetes

care in improving metabolic control, quality of life and satisfaction with medical care in patients with diabetes.

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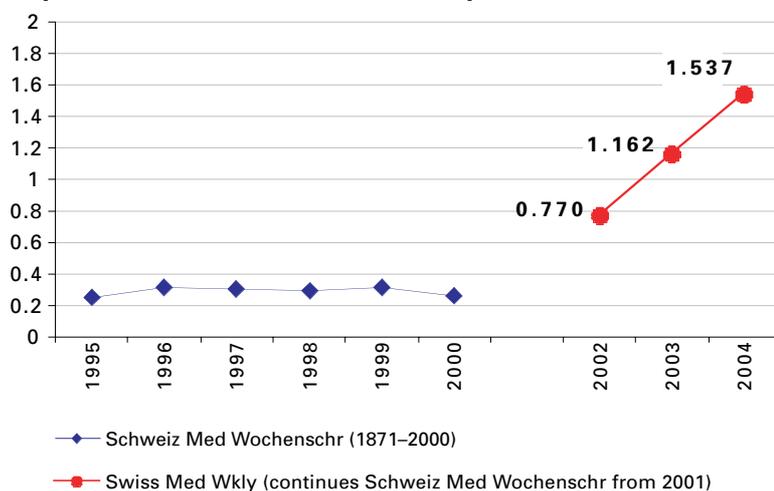
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