



Self-rated Health among Young People with Type 1 Diabetes in Relation to Risk Factors in a Longitudinal Study

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Care for type 1 diabetes mellitus should both alleviate the physical complications of the disease and improve overall quality of life. The Wisconsin Diabetes Registry, comprising a population-based cohort that is followed longitudinally from diagnosis of type 1 diabetes, provided the authors with a unique opportunity to examine quality of life in children, adolescents, and young adults with type 1 diabetes and its relation to both sociodemographic and clinical risk factors. The authors analyzed data from 1987–2002 with a mean of 10.2 years' duration of diabetes ($n = 569$). They used ordinal-scaled self-rated global health as a measure of quality of life. In this paper, they propose a random-effects model for drawing inferences on individuals regarding the relation of longitudinally measured quality of life to multiple risk factors. Results showed that male gender, higher parental socioeconomic level, younger age at diabetes diagnosis, shorter diabetes duration, no hospitalization in the preceding 6 months, lower glycosylated hemoglobin level, and questionnaire responses by a person other than the subject were independently associated with better reported health. The authors found that individuals varied in their reported health even after adjustment for all identified risk factors. This could imply either that there is variability in perception even with the same health status or that there are independent unmeasured risk factors for poor health in persons with type 1 diabetes.

adolescent; child; diabetes mellitus, type I; health; longitudinal studies; quality of life; risk factors

Type 1 (insulin-dependent) diabetes mellitus is usually first diagnosed in children or young adults. Approximately one in every 400–500 US children and adolescents has type 1 diabetes (1). People with type 1 diabetes often feel challenged by the demands of day-to-day management of the disease and the fear of developing serious complications; therefore, their quality of life, which includes a person's perception of health and satisfaction with life, is substantially affected. It has become accepted that the goal of medical care should be not only to alleviate the physical complications of a disease but also to improve the patient's overall quality of life (2). Studying quality of life among persons with type 1 diabetes and its relation to risk factors can help us understand and identify the best treatment regimen and target persons with a low quality of life for intervention.

People with type 1 diabetes have been shown to have a lower quality of life than the general population (3, 4). In the literature, quality of life has also been found to be better

among persons with better glycemic control (5–7), male gender (2, 8), younger age (5, 8), higher socioeconomic status (5, 9, 10), and fewer late complications (5, 9, 11). Findings have been mixed regarding the relations between quality of life in people with type 1 diabetes and duration of diabetes (either no association (5, 11) or a better quality of life with a shorter duration (2, 9)) and treatment regimen (either no association (11, 12) or a better quality of life with more intensive treatment (3, 8)). In these studies, three types of measures were implemented to conceptualize and quantify quality of life: generic quality of life, which measured various domains of functioning and well-being that were applicable to different diseases (2, 4, 5, 8, 9, 11); diabetes-specific quality of life, which focused on the specific problems posed by diabetes (6, 7, 11, 12); and overall quality of life, which provided a global assessment of quality of life and could be a score for multidimensional generic quality of life or a single-question measurement (10, 13).

Despite the rich research on quality of life in persons with type 1 diabetes, results have been limited or inconclusive, for the following three reasons. First, although type 1 diabetes is most often diagnosed in childhood, most studies have been conducted in adults (2, 4, 5, 8, 9, 11). Less has been done in studying quality of life among young people (6, 7, 12). Second, many studies have had rather small sample sizes (approximately 69–108 (5, 7, 9, 11, 12)) and therefore may not have had enough power to address some questions. Third, there have been few longitudinal studies (4, 14), which permit assessment of change in quality of life over time and the effects of risk factors within a given person.

The Wisconsin Diabetes Registry Study is a population-based cohort study that follows participants from the diagnosis of type 1 diabetes. We have longitudinally collected data on these persons' self-rated global health status and risk factors. The data provided us with a unique opportunity to examine one measure of quality of life among youths and young adults with type 1 diabetes. Therefore, we aimed to use self-rated global health to evaluate quality of life in a population-based cohort of children, adolescents, and young adults followed continuously from diabetes diagnosis and to examine its association with longitudinally measured clinical and sociodemographic factors.

MATERIALS AND METHODS

Population

Between May 1987 and April 1992, all patients aged less than 30 years with newly diagnosed type 1 diabetes in south-central Wisconsin (28 counties) were invited to participate in the study. Diabetes was defined by the classic symptoms of polyuria and polydipsia with initiation of exogenous insulin use. Subjects were identified by their physicians, by nurse educators, or by themselves or their families. Details on recruitment and case ascertainment have been published previously (15, 16). An estimated 97 percent of hospitalized children, 82 percent of hospitalized adolescents, and 23 percent of hospitalized adults were identified. Among the 733 persons identified at all ages, 569 provided self-rated health data for this analysis, giving us 8,567 measurements through April 2002. There was no difference in sex between participants and nonparticipants (48 percent of participants and 49 percent of nonparticipants were female). Participants were slightly younger than nonparticipants (the mean ages at diagnosis were 11.1 years and 13.7 years, respectively), and participants were predominantly White (94 percent of participants vs. 51 percent of nonparticipants).

Data collection

Details on data collection and specimen handling and testing are available elsewhere (15, 16). In brief, demographic information, including birth date, parental educational level, parental occupation, race, and sex, was collected by telephone interview 2–3 months after diagnosis. Although parental educational level and occupation can change over time, only the baseline values were recorded. Starting 3–4 months after diagnosis, subjects were asked to

submit a blood specimen at each routine visit to their local physician or clinic, or every 4 months if no visit was scheduled. The blood was delivered in plastic foam containers to the study's central laboratory, where it was analyzed for total glycosylated hemoglobin. Among 569 subjects in the present analysis, 79 percent returned at least one sample per year across the duration of their study participation.

We mailed questionnaires every 6 months to obtain self-reports on diabetes management, perception of health, and diabetes-related hospitalizations, as well as information on the patient's physician and health insurance. At least one questionnaire was returned each year by 95 percent of persons in the analysis.

Participants were examined for eye retinopathy and kidney microalbuminuria complications by means of standard protocols (15, 17) during the first year after diagnosis and at 4, 7, and 9 years' duration. Retinopathy status was determined using a severity scale developed previously (17, 18), ranging from no retinopathy in either eye to treated or proliferative retinopathy in both eyes. Subjects were classified as having retinopathy if they had at least one eye with retinopathy. Urinary albumin excretion rates were quantified from 24-hour urine specimens (obtained at the initial and 4-year examinations) or from timed overnight urine specimens (obtained at the 7- and 9-year examinations). Microalbuminuria was defined by a urinary albumin excretion rate ≥ 70 $\mu\text{g}/\text{minute}$ in 24-hour samples and ≥ 20 $\mu\text{g}/\text{minute}$ in timed overnight samples. In the present analysis, 80 percent of participants had three or more valid measures of retinopathy status, and 77 percent had three or more valid measures of microalbuminuria status.

Self-rated health status and risk factors

Information on participants' self-rated health was collected through a question on the mailed questionnaire: "Compared with other people your age, do you feel that right now your health is excellent, good, fair, or poor?"

We hypothesized the following risk factors to be potentially related to self-rated health. These factors can be divided into three categories. Sociodemographic factors included participant's age at questionnaire completion, sex, race, mother's total number of years of education, and parental socioeconomic level, defined using the scheme of Stevens and Cho (19), which assigned a score between 14 and 90 to rank occupations from the lowest to the highest. Diabetic factors included participant's age at diagnosis of diabetes, duration of type 1 diabetes, any hypoglycemic episodes in the previous 6 months, any hospitalization in the previous 6 months, number of insulin injections per day, insulin dose per day, glycosylated hemoglobin level, and presence of retinopathy or microalbuminuria. We also examined questionnaire-management factors, including information on who completed the questionnaire (the participant or a proxy respondent) and the effect of noncompliance, measured by the average number of questionnaires submitted per year. Among these risk factors, sex, race, mother's years of education, parental socioeconomic level, age at diabetes diagnosis, and the compliance measure were

time-independent variables, and others varied across time points.

From each questionnaire submission, we obtained data on the subjects' self-rated health and risk factors, except for glycosylated hemoglobin and complication measurements, which were assessed at different time points. The glycosylated hemoglobin level chosen to correspond to each time point of self-rated health was the average of all glycosylated hemoglobin measurements made between the current questionnaire submission and the previous questionnaire submission. For complication measurements, each self-rated health point was related to the closest complication status measured prior to the questionnaire submission.

Statistical methods

Means or percentages for identified risk factors in the four categories of self-rated health were used to describe the characteristics of four health perception groups. We performed significance testing to compare the four health groups using the generalized estimating equations approach with the exchangeable correlation structure (20), which took into account correlation among measurements from the same person. Generalized estimating equations analyses were performed using the GENMOD procedure in SAS (21).

To display the longitudinal pattern of self-rated health, we plotted the probability of reporting health better than or equal to "good" against duration of type 1 diabetes for different age-at-diabetes-diagnosis groups. We obtained the plot by smoothing the scatterplot of the indicator of reporting health that was better than or equal to good versus diabetes duration. This was done for each age-at-diagnosis group. We used a plot that converted the probability scale to the log odds scale to empirically check whether a more complex trend for the log odds of self-rated health and diabetes duration across age-at-diagnosis groups was needed in the regression model described below.

We examined the relation between self-rated health and multiple risk factors using a random-effects model for ordinal response data (22–25). This model can describe the dependence of longitudinally measured "ordinal" self-rated health responses (with alternatives: excellent, good, fair, and poor) on multiple risk factors. The random-effects model for ordinal response data uses the proportional odds model (26) to characterize the relation of ordinal-scaled self-rated health to risk factors. It assumes that the regression coefficients in the proportional odds model vary from person to person, thus reflecting the natural heterogeneity of self-rated health caused by unmeasured factors. Since self-rated health reflects people's own perceptions, and everyone's definition of, for example, excellent health is different even with the same true health, the heterogeneity assumption is suitable for our data. The model also assumes that the variability in regression coefficients can be represented by a probability distribution and, therefore, correlation of repeated self-ratings of health from the same person arises from their sharing a probability distribution (27).

Because participants in the Wisconsin Diabetes Registry Study had repeated measurements taken across time, we can estimate the change in self-rated health between two levels

of a risk factor within a given person, in addition to the change averaged across different persons. The *within*- and *between*-individual changes can be quite different; therefore, it is necessary to consider these two changes jointly (28). Here, we adopted a modeling technique that can distinguish between-individual changes from within-individual changes (28).

More specifically, suppose Y_{ij} is the level of health reported by participant i at questionnaire submission j and the possible values of Y_{ij} are 1, 2, 3, and 4 (1 = poor, 2 = fair, 3 = good, and 4 = excellent); then the random-effects model used is

$$\log \left[\frac{\Pr(Y_{ij} > c)}{\Pr(Y_{ij} \leq c)} \right] = (\alpha_c + a_i) + \gamma z_i + \beta_b \bar{x}_i + \beta_w (x_{ij} - \bar{x}_i), \quad (1)$$

where $c = 1, 2,$ or 3 represents different health levels; z_i represents all of the time-independent risk factors identified for participant i (the boldface type denotes multiple factors); x_{ij} represents time-dependent risk factors for participant i at questionnaire submission j ; \bar{x}_i denotes the average time-dependent risk factor value of all questionnaire submissions for participant i ; α_c , γ , β_b , and β_w are the fixed values (the "fixed" effects); and a_i is the intercept of participant i and is assumed to follow a normal distribution with mean zero and variance δ^2 (the "random" effect).

For time-independent variables, $\exp(\gamma)$ is the odds ratio for reporting better health in a comparison of, for example, females with males. For time-dependent variables, the model decomposes risk factors into components from the average value of all submissions and differences between each submission and the average value. $\exp(\beta_b)$ is interpreted as the odds ratio for reporting better health when comparing participants who, for example, were hospitalized in the previous 6 months versus those who were not. $\exp(\beta_w)$ is interpreted as the odds ratio for reporting better health for a participant who was hospitalized in the previous 6 months versus self-reporting by the same participant if he/she had not been hospitalized. $\exp(\beta_b)$ estimates the population average, and $\exp(\beta_w)$ estimates the change within the same person. Through the random effect a_i , equation 1 allows each participant to have his/her own probability of reporting better health. The variance δ^2 represents the degree of heterogeneity across participants in reporting of self-rated health that is not attributable to identified risk factors (27).

The random-effects model for ordinal response data in equation 1 can be fitted using PROC NLMIXED in SAS, version 7, or later versions. An example program is shown in the Appendix. Details on the program description can be found in the paper by Agresti et al. (24).

To investigate potential effects of noncompliance, we included the return rate for the questionnaires in equation 1 as a main effect and as interactions with other important risk factors. Risk factor coefficients were then readjusted to the mean compliance of all study participants. This approach can be viewed as a "pattern-mixture" model (29). The idea is to first estimate the relation between risk factors and self-rated health under given compliance patterns and then to obtain an average effect over the mixture of compliance patterns. A difference between the mixture effect and the

TABLE 1. Baseline levels of risk factors (mean values or percentages) by age at diagnosis of type 1 diabetes mellitus in the Wisconsin Diabetes Registry Study, 1987–2002

Baseline characteristic	Age (years) at diagnosis of type 1 diabetes						
	0–5	>5–8	>8–11	>11–14	>14–17	>17–20	>20
No. of subjects	95	103	113	108	64	26	60
Female gender (%)	47.37	44.12	53.57	49.53	46.88	50.00	43.33
White race (%)	93.68	95.10	93.75	92.52	90.63	100	98.33
Mother's education (years)	13.99 (2.26)*	13.62 (1.82)	13.67 (2.15)	13.13 (2.32)	13.37 (2.14)	13.73 (2.25)	13.05 (2.03)
Socioeconomic level of parents†	49.26 (24.47)	44.50 (20.75)	44.87 (22.14)	40.85 (21.01)	43.22 (23.75)	42.40 (21.71)	39.23 (23.41)
Duration of diabetes (years) at time of last questionnaire	10.70 (2.72)	10.83 (2.11)	10.53 (1.98)	9.35 (3.28)	9.83 (3.32)	9.24 (3.15)	9.90 (3.20)
Any hypoglycemia in the previous 6 months (%)	86.05	78.22	84.26	80.37	76.67	73.08	85.00
Hospitalization in the previous 6 months (%)	11.58	7.84	6.25	14.02	6.25	19.23	8.33
Insulin injection (%)							
Three or more times per day	36.84	10.78	20.54	25.23	17.19	11.54	23.33
Use of an insulin pump	0	0	0	0	0	0	0
Insulin dose per day (units/kg)	0.64 (0.18)	0.60 (0.19)	0.67 (0.30)	0.73 (0.28)	0.52 (0.29)	0.50 (0.26)	0.46 (0.19)
Glycosylated hemoglobin level (%)	9.93 (2.00)	9.56 (2.36)	9.15 (2.16)	9.26 (2.48)	8.84 (2.63)	9.26 (2.59)	8.47 (1.94)
Retinopathy (%)	0	0	0	0	0	7.14	3.13
Microalbuminuria (%)	0	0	0	2.90	5.56	0	3.23
Questionnaire answered by the subject (%)	0	2.94	6.25	28.04	42.19	69.23	85.00
No. of questionnaires submitted per person	16.41 (5.00)	16.76 (4.02)	15.58 (3.88)	13.19 (5.24)	13.78 (5.54)	13.58 (4.87)	14.95 (5.90)

* Numbers in parentheses, standard deviation.

† Socioeconomic level was based on the scheme of Stevens and Cho (19), which assigned a score between 14 and 90 to rank occupations from lowest to highest.

effect without the compliance adjustment indicates the need to adjust for noncompliance.

RESULTS

Table 1 shows baseline levels of risk factors in the study population, stratified by age at diagnosis of diabetes. The mean total glycosylated hemoglobin level of our population was 10.8 percent, which corresponds to average glycemic control according to American Diabetes Association guidelines (30). Participants were followed for a mean of 10.2 years.

Risk factor distributions by self-reported health status

As table 2 shows, 34 percent, 53 percent, 11 percent, and 2 percent of the questionnaire responses rated health as excellent, good, fair, and poor, respectively, indicating that the distribution was skewed toward better health. People who reported better health were younger, were more likely to be male, were more likely to be White, had a higher maternal educational level, had a higher socioeconomic level, were younger at diabetes diagnosis, had a shorter duration of diabetes, were less likely to have been hospitalized in the

previous 6 months, had a lower glycosylated hemoglobin level, and were less likely to have retinopathy. The “good” health group had the highest percentage of use of an intensive insulin regimen, and the “poor” health group had the lowest. Insulin dose per day differed among the four health groups, with the poor health group taking the lowest amount of insulin per day and the fair health group taking the highest amount per day. Questionnaires that were answered by the diabetic subject were less likely to identify health as excellent or good than questionnaires answered by others. A higher compliance rate for returning questionnaires was associated with reporting of better health. Distributions of hypoglycemic episodes and the presence of microalbuminuria were not significantly different across self-rated health status groups.

Longitudinal pattern of self-rated health

Figure 1 shows the longitudinal relation between the probability of reporting better health and duration of diabetes across age-at-diagnosis groups. Participants who had been diagnosed with diabetes before age 6 years (0–5 diagnosis group) and participants who had been diagnosed after age 20 years (>20 diagnosis group) had patterns different from

TABLE 2. Distribution of risk factors for poor health by self-reported health status among persons with type 1 diabetes in the Wisconsin Diabetes Registry Study, 1987–2002

Variable*	Self-rated health				<i>p</i> value†
	Excellent	Good	Fair	Poor	
No. of measurements	2,938	4,576	921	132	
Age (years) at questionnaire completion	13.57	17.04	19.65	21.95	<0.001
Female gender (%)	38.39	52.43	62.54	62.12	<0.001
White race (%)	97.72	96.04	90.01	93.18	0.012
Mother's education (years)	13.90	13.53	13.30	12.84	<0.001
Socioeconomic level of parents‡	49.48	44.33	38.02	34.59	<0.001
Age (years) at diagnosis of type 1 diabetes	8.72	11.39	13.16	14.97	<0.001
Duration of diabetes (years)	4.85	5.66	6.49	6.98	<0.001
Any hypoglycemia in the previous 6 months (%)	78.81	79.94	81.85	87.02	0.64
Hospitalization in the previous 6 months (%)	4.53	7.80	16.63	24.43	<0.001
Insulin injection (%)					<0.001
Three or more times per day	49.46	51.55	46.25	46.21	
Use of an insulin pump	1.77	3.43	4.45	3.79	
Insulin dose per day (units/kg)	0.85	0.88	0.91	0.80	<0.001
Glycosylated hemoglobin level (%)	10.51	11.17	12.24	13.81	<0.001
Retinopathy (%)	6.55	13.66	19.78	19.44	<0.001
Microalbuminuria (%)	1.89	2.51	3.01	2.78	0.45
Questionnaire answered by the subject (%)	27.16	46.46	62.65	69.65	<0.001
No. of questionnaires completed per year	1.55	1.52	1.45	1.39	<0.001

* All available longitudinal data were used for calculating the distribution.

† *p* values were based on the generalized estimating equations approach with the exchangeable correlation structure.

‡ Socioeconomic level was based on the scheme of Stevens and Cho (19), which assigned a score between 14 and 90 to rank occupations from lowest to highest.

those of others. In comparisons of participants from the same age-at-diagnosis group, the probability of reporting good health decreased as duration of diabetes increased, except for the 0–5 diagnosis group, in which the probability increased during the first 6 years of duration and decreased after that, and the >20 diagnosis group, in which the probability stayed fairly constant. For a specific duration of diabetes, participants who were diagnosed at earlier ages were more likely to report better health than those diagnosed at later ages, excluding the diagnosis groups 0–5 and >20.

Relation between self-rated health and multiple risk factors

By converting the probability scale of figure 1 to the log odds scale (not shown), we observed several features that might affect the model choice. A linear relation between log odds and duration was apparent within all age-at-diagnosis groups except for the 0–5 group. The fact that the difference between the log odds for two consecutive diagnosis groups at a given duration decreased gradually with age suggested that there was a nonlinear relation between the log odds and age at diagnosis. The crossover between diagnosis groups 0–

5 and >20 and other groups might indicate a possible interaction between age at diagnosis and duration. Similar plots between log odds and other risk factors were also created (not shown). None indicated a nonlinear relation. Because the effects of age at diagnosis, duration, and age at questionnaire completion cannot be estimated simultaneously, the model used only age at diagnosis and duration. Odds ratio estimates from the final random-effects model (equation 1) are given in table 3. The final model included linear terms for all identified risk factors and a quadratic term for age at diagnosis. The interaction between age at diagnosis and duration was not significant and was not included in the final model. The “unadjusted” odds ratio for a diabetic factor was obtained from a model that also included sociodemographic factors and an indicator variable for the person who answered the questionnaire (participant vs. other). The unadjusted odds ratios for sociodemographic factors and the questionnaire-answering indicator were from a model containing these variables only. The adjusted odds ratios were from a multivariate model that included all available risk factors.

We first examined within-individual changes for time-dependent risk factors to draw conclusions on how risk

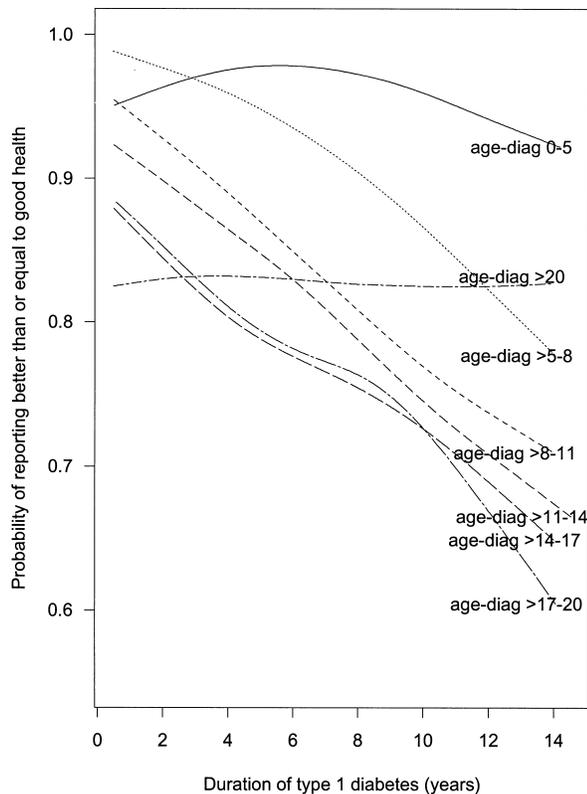


FIGURE 1. Relation of duration of type 1 diabetes mellitus to the probability of reporting health better than or equal to "good" for different age-at-diabetes-diagnosis ("age-diag") groups in the Wisconsin Diabetes Registry Study, 1987–2002. Age-at-diagnosis groups: 0–5 years, —; >5–8 years, ····; >8–11 years, - - - -; >11–14 years, - · - ·; >14–17 years, — — —; >17–20 years, — · — ·; >20 years, - - - - -.

factors affect a person's health perception over time. Race, insulin injection frequency, insulin dose, and retinopathy, which were significant in the unadjusted model, became nonsignificant in the adjusted model. Among sociodemographic factors, sex and socioeconomic level had the two most significant effects. Younger age at diagnosis of diabetes had a positive effect on reporting of better health. However, as the age at diagnosis increased, this effect flattened. With every 1-year increase in duration of diabetes, a participant was 0.86 times as likely to report better health than he or she was the previous year, even after adjustment for all other risk factors. The odds of reporting better health for a participant decreased with hospitalization. Glycemic control was the predominant effect among diabetes-management factors (insulin injection frequency, insulin dose, and glycosylated hemoglobin). The better the glycemic control (lower glycosylated hemoglobin level) for a participant, the more likely that good health was reported. Diabetic microalbuminuria and retinopathy were not associated with a participant's self-rated health after adjustment for other risk factors.

When comparing within- and between-individual effects for time-dependent risk factors, we found that the within-

individual effect had less variation (a narrower confidence interval) than the between-individual effect, and the significance of the effect could change. This indicates that the relation of longitudinally measured self-reported health to risk factors within the same person was more reliable and consistent than the relation based on the cross-sectional average among different people.

Parents or other family members often answered questionnaires in the early years for participants who were diagnosed with diabetes at a young age. Therefore, age at diagnosis was related to having questionnaires answered by others. Results from table 3 show that participants were less likely to report good health when they themselves answered the questionnaire than when the questionnaire was answered by others. After adjustment for age at diagnosis and other diabetic factors, this effect was still significant but became less apparent. Furthermore, the interaction between age at diagnosis and the indicator variable for who answered the questionnaire was not significant. The tendency for parents to report better health remained the same among children diagnosed at different ages.

The compliance index was added to each model for the unadjusted diabetic factor effect of table 3. Results showed little change in diabetic factor coefficients, comparing the mixture effects with the unadjusted effects in table 3 (not shown).

Variability in self-rated health

The estimate of variance δ^2 in the random-effects model (equation 1) with all identified risk factors was 3.51 (95 percent confidence interval: 2.84, 4.18), which indicated that participants varied in their reported health even after adjustment for all identified risk factors. This variability reflected the possibility that unmeasured factors and individual differences in health perception could lead to heterogeneity.

DISCUSSION

To our knowledge, this is the first population-based longitudinal study of an incident cohort showing that demographic, socioeconomic, and diabetes-related factors are related to self-rated health status among persons with type 1 diabetes. Because longitudinal data were available, we used a random-effects model (equation 1), which allowed separate between- and within-individual covariate effects, to study trends in self-rated health within the same person.

In our study, males reported better health than females, and people at higher socioeconomic levels generally reported better health than those at lower levels. This is consistent with the findings of other studies (2, 5, 8–10). We also found that questionnaires answered by the subjects themselves were less likely to show good health ratings than those answered by others. This is an important consideration for studies, such as ours, in which surrogate responses are used for children. Parents who respond on behalf of their children may have difficulty separating their own feelings from their child's and may be affected by feelings of guilt, or may respond favorably as a method of coping with their child's chronic illness. Since we included very young chil-

TABLE 3. Odds ratios from a random-effects model for the relation between better self-rated health and multiple risk factors in the Wisconsin Diabetes Registry Study, 1987–2002†

Risk factor‡	Unadjusted odds ratio§				Adjusted odds ratio¶			
	Between-individual		Within-individual		Between-individual		Within-individual	
	OR#	95% CI#	OR	95% CI	OR	95% CI	OR	95% CI
Female gender	0.47*	0.34, 0.64			0.42*	0.28, 0.62		
White race	3.46*	1.67, 7.18			3.20	1.17, 8.71		
Mother's years of education (1 year)	1.01	0.93, 1.10			0.96	0.86, 1.07		
Socioeconomic level of parents (1 unit)**	1.02*	1.01, 1.03			1.02*	1.01, 1.03		
Age (years) at diagnosis of type 1 diabetes (1 year)††								
0–5	0.82*	0.77, 0.88			0.76*	0.70, 0.84		
>5–8	0.86*	0.82, 0.90			0.80*	0.75, 0.86		
>8–11	0.88*	0.85, 0.91			0.83*	0.79, 0.88		
>11–14	0.91*	0.88, 0.94			0.86*	0.82, 0.90		
>14–17	0.93*	0.90, 0.96			0.89*	0.85, 0.94		
>17–20	0.96	0.92, 1.00			0.93*	0.87, 0.98		
>20	0.98	0.93, 1.04			0.96	0.89, 1.03		
Duration (years) of diabetes (1 year)	0.96	0.83, 1.11	0.88*	0.86, 0.89	1.00	0.80, 1.25	0.86*	0.82, 0.89
Any hypoglycemia in the previous 6 months	0.98	0.69, 1.40	0.87	0.74, 1.01	0.76	0.48, 1.19	0.76	0.59, 1.01
Hospitalization in the previous 6 months	0.20	0.01, 3.71	0.49*	0.41, 0.59	0.22	0.00, 53.50	0.50*	0.37, 0.67
Insulin injection (less than three times per day)								
Three or more times per day	0.72*	0.63, 0.82	0.72*	0.63, 0.82	1.18	0.92, 1.50	1.18	0.92, 1.50
Use of an insulin pump	0.45*	0.32, 0.62	0.45*	0.32, 0.62	1.37	0.83, 2.28	1.37	0.83, 2.28
Insulin dose per day (1 unit)	0.66	0.33, 1.31	0.86*	0.78, 0.95	0.98	0.40, 2.36	0.95	0.81, 1.11
Glycosylated hemoglobin level (1 percentage point)	0.75*	0.70, 0.81	0.89*	0.87, 0.91	0.75*	0.67, 0.84	0.90*	0.86, 0.94
Retinopathy	0.46	0.07, 2.89	0.49*	0.39, 0.61	1.03	0.17, 6.28	0.83	0.63, 1.11
Microalbuminuria	0.59	0.01, 43.06	0.82	0.52, 1.29	0.58	0.01, 58.42	1.26	0.75, 2.09
Questionnaire answered by the subject	0.38*	0.21, 0.69	0.37*	0.32, 0.42	0.86	0.36, 2.07	0.67*	0.54, 0.84

* $p < 0.05$.† Time-independent risk factors have only between-individual odds ratios, which were calculated on the basis of $\exp(\gamma)$. For time-dependent risk factors, between-individual odds ratios were calculated on the basis of $\exp(\beta_b)$ and within-individual odds ratios were calculated on the basis of $\exp(\beta_w)$.

‡ Parentheses identify the unit of increase or the reference group for which the odds ratio was calculated.

§ The unadjusted odds ratio for a diabetic factor was obtained from a model that also included sociodemographic factors and an indicator variable for the person who answered the questionnaire. The unadjusted odds ratios for sociodemographic factors and the indicator variable for the person who answered the questionnaire were obtained from a model containing these variables only.

¶ Adjusted odds ratios were obtained from a model that included all available risk factors.

OR, odds ratio; CI, confidence interval.

** Socioeconomic level was based on the scheme of Stevens and Cho (19), which assigned a score between 14 and 90 to rank occupations from lowest to highest.

†† A quadratic term for age at diagnosis was included in the model, and odds ratios shown are for every 1-year increase in the median age of the corresponding diagnosis group.

dren, we did not exclude parents' responses, but we adjusted the results of the final models for type of respondent.

Our findings demonstrate that people who are younger at diagnosis of diabetes rate their health more highly than do people who are older at diagnosis, even after adjustment for respondent, duration, and possible risk factors. This may be

due to "unmeasured" exposures and/or to better adaptation in coping with diabetes among persons with younger ages at diagnosis. We also find that self-rated health for people with type 1 diabetes decreases gradually as duration of diabetes increases, even when diabetes management and complications are taken into account. The duration effect may be

absent in the diagnosis group >20 years (figure 1). Several studies reported no significant association between quality of life and duration of diabetes (5, 11). In most of these studies, older diagnosis groups were mixed with younger diagnosis groups, which might partially explain this absence of significance, especially if there was a wide range in ages at diagnosis in the study population.

Another important finding is that better glycemic control was associated with better health perception, even after adjustment for additional risk factors. This is important to know for children and adolescents, because achieving near-normal glycemia can be especially challenging and stressful for this age group over time. We also noted a significant inverse relation between number of insulin injections and self-rated health. However, this might be explained by treatment changes made in response to poor perceived health, and the relation was attenuated after adjustment for diabetes duration, glycemic control, and hospitalization. Maintaining good glycemic control during the first decade of diabetes may outweigh the increased burden involved, even in children and adolescents, and long-term factors or hospitalization may have a greater importance in overall perception of health than daily-care aspects. Two other studies also reported a significant correlation between glycemic control and quality of life in young people (6, 7).

The presence of retinopathy was associated with reporting worse health, but this effect was marginal after adjustment for other risk factors. Microalbuminuria was not associated with health perception. Studies of adults with diabetes have consistently found that complications are associated with worsened quality of life (5, 9, 11). Our findings might be due to the low complication rate in these particular children and adolescents, or the presence of microalbuminuria and early measures of retinopathy might have no immediate impact on a person's perception of health. Unlike adults, most of our study population has not developed overt kidney disease or vision problems, so they may have little or no change in their health perceptions due to complications. An additional reason for little correspondence between complications and quality of life is the long intervals between assessments of complications relative to the questionnaire frequency. Children and their parents might have known about complications from their nonstudy care long before complications were measured in the study; thus, the estimated effects based on the study measurements may not be as significant as they would have been otherwise.

Self-rated health was used as a measure of quality of life in our study. This measurement reflects people's overall perceptions of health, is easy to obtain, and has been shown to be a powerful predictor of morbidity and mortality (31, 32). However, unlike other, more complex quality-of-life measurements (e.g., the generic Medical Outcomes Study 36-Item Short Form (SF-36) (3) and the diabetes-specific Diabetes Quality of Life questionnaire (11)), it does not allow examination of the impact of risk factors on different aspects of quality of life (e.g., physical, emotional, and social well-being). Nevertheless, our results provide useful information for selecting potential risk factors, understanding longitudinal patterns, and creating appropriate statistical methods for more detailed studies of quality of life among persons with type 1 diabetes.

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APPENDIX

SAS (PROC NL MIXED) Code for Fitting the Random-Effects Model for Ordinal Response Data

To keep the illustration simple, we have included only the time-independent risk factor sex and the time-dependent variable hospitalization.

```
data healthdat;

/* read the data set, where hospm is the mean value of all
hospitalization statuses for each participant */
set healthinput (keep = id health sex hospm hosp);

/* indicators of self-rated health */
if health = 1 then y1 = 1; else y1 = 0;
if health = 2 then y2 = 1; else y2 = 0;
if health = 3 then y3 = 1; else y3 = 0;
if health = 4 then y4 = 1; else y4 = 0;

/* within-hosp change */
hospwithin = hosp - hospm;
run;

proc nlmixed data = healthdat;
  bounds a2del a3del > 0;

/* initial values */
  parms a1 = 8.01 a2del = 2.28 a3del = 3.16 r = -0.59 bb =
    -1.26 bw = -0.75 delta = 1;

/* logit of cumulative probabilities */
  eta1 = a1 + ai + (r*sex) + (bb*hospm) + (bw*hospwithin);
  eta2 = (a1 - a2del) + ai + (r*sex) + (bb*hospm) +
    (bw*hospwithin);
  eta3 = (a1 - a2del - a3del) + ai + (r*sex) + (bb*hospm) +
    (bw*hospwithin);

/* probability of each health level */
  p1 = 1 - (exp(eta1)/(1 + exp(eta1)));
  p2 = 1 - (exp(eta2)/(1 + exp(eta2))) - p1;
  p3 = 1 - (exp(eta3)/(1 + exp(eta3))) - p1 - p2;
  p4 = 1 - p1 - p2 - p3;

/* likelihood of the data */
  jp = (p1**y1)*(p2**y2)*(p3**y3)*(p4**y4);
  ll = log(jp);
  model y1 ~ general(ll);
  random ai ~ normal(0, delta*delta) subject = id;
run;
```