

Quality of life and type 1 diabetes: a study assessing patients' perceptions and self-management needs

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Purpose: The main objective of this study was to assess quality of life (QoL) and treatment satisfaction in a group of patients with type 1 diabetes (T1D) and explore their needs regarding and their perception of QoL living with diabetes.

Materials and methods: Patients with type 1 diabetes attending the outpatient endocrinology clinics of a reference hospital were invited to participate in a cross-sectional study. Clinical and sociodemographic data were obtained (interview and clinical records), and diabetes-related QoL was assessed using a standardized questionnaire. In 67 participants, satisfaction with treatment was also assessed, and an open interview was performed, assessing the impact of diabetes, long-term worries, flexibility, restrictions, and self-perception of QoL. Descriptive statistical analysis, bivariate analysis, and multivariate analysis were performed in order to find factors associated with QoL. Interviews were analyzed and summarized questionwise.

Results: Mean patient age was 31.4±11.6 years, diabetes duration 14.2±9.3 years, and glycated hemoglobin (HbA_{1c}) 8.5%±1.9% (69±20.8 mmol/mol International Federation of Clinical Chemistry [IFCC]). The questionnaires showed good average QoL scores (94.6±22.9) and treatment satisfaction scores (25.7±6.7). QoL worsened with increasing HbA_{1c}, female sex, severity of complications, and lower education ($r^2=0.283$, $P<0.005$). In the open interview, 68.5% of the patients reported that diabetes had changed their lives, 83.5% identified complications as their most important long-term concern, and 59.7% said that they needed more training to manage the disease.

Conclusion: Poor glycemic control, lower education, complications, and female sex are associated with worse QoL. Semi-structured interviews identified aspects not included in the standardized questionnaires.

Keywords: type 1 diabetes, qualitative, quality of life, self-management, patients' perceptions

Introduction

Treatment of type 1 diabetes (T1D) consists of multiple insulin injections and a high degree of self-management, in order to prevent complications of the disease. The Diabetes Control and Complications Trial (DCCT) proved that intensive insulin treatment, where the patient plays an active role (multiple insulin injections and blood glucose measurements, carbohydrate quantification), allows patients to achieve better glycemic control and reduces the risk of complications.¹ Indeed, since the publication of its results, intensified insulin treatment has become the standard of care in T1D. However, achieving good glycemic control is not easy, and even during the DCCT, patients in the intervention group were at increased risk of severe hypoglycemia and weight gain.¹

The Canary Islands have the highest incidence of childhood T1D described in Spain, with 23.2 cases/100,000 persons/year in the 1990s² and 31.6/100,000 at the start

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of the present century.³ Furthermore, the high incidence of ketoacidosis⁴ calls for immediate preventive measures.

Patient behavior will, to a great extent, determine the outcome of diabetes,⁵ and current care has progressively become more patient-centered. People with T1D have to cope with many factors that affect everyday disease management. The study of quality of life (QoL) in these patients is somewhat different from other populations, since T1D requires a high degree of patient involvement and frequent decision making (frequent glucose monitoring, insulin injection and dose adjustment, carbohydrate estimation, planning of therapeutic adjustments to physical activity, etc). Indeed, an Australian guideline on the assessment of diabetes education programs recommended the inclusion of not only knowledge-based evaluations but also self-management, QoL, and psychological well-being.⁶

QoL in T1D has been assessed before^{7–11} mostly in association with the presence of chronic complications,^{12–14} glycemic control,^{15–18} and duration of the disease.¹⁹ A review of instruments used to measure QoL in diabetes²⁰ drew attention to the excessive simplification of the term QoL, which often included other aspects, such as treatment satisfaction and psychological and health-related well-being. Indeed, several diabetes-specific instruments have been developed:²¹ Appraisal of Diabetes Scale, Diabetes 39, Audit of Diabetes-Dependent Quality of Life (ADDQoL), Diabetes Quality of Life Measure (DQoL), eDiabetes Health Profile, Diabetes Quality of Life Clinical Trial Questionnaire, Barriers to Physical Activity in Diabetes, Diabetes Obstacles Questionnaire, Diabetes Treatment Satisfaction Questionnaire (DTSQ), Diabetes Treatment Satisfaction Questionnaire for Inpatients, Diabetes Symptom Checklist-Revised, Diabetes Computerized Adaptive Testing, Diabetes Impact Survey, Insulin Treatment Satisfaction Questionnaire, Diabetes Empowerment Scale, and Diabetes Specific Quality of Life Questionnaire and Satisfaction with Oral Anti-Diabetic Agent Scale. However, only two questionnaires with good psychometric properties, specifically evaluating QoL, have been validated in Spain: DQoL and ADDQoL.

The aim of this study was to assess QoL and treatment satisfaction in patients with T1D, as well as to explore their needs, before starting an educational intervention.

Materials and methods

Study design and study population

Patients were consecutively seen in the diabetes outpatient endocrinology clinic at a reference hospital and invited to participate as they arrived to their routine clinical appointments. This was done once a week (the day when a higher number of patients with T1D were expected) between March 2010 and March 2011. They all signed a written, informed consent

before entering the study, which had been previously presented to and approved by the CEIC Complejo Hospitalario Universitario Insular-Materno Infantil de Las Palmas Ethics Committee.

A total of 100 patients with T1D (>6-month duration) were individually seen by one investigator (DA-M), who was independent of care provision. All participants completed a diabetes-specific QoL questionnaire, and 67 also completed a treatment satisfaction questionnaire, as well as an open, semi-structured interview. Most of the participants did this while they waited for their scheduled appointment.

Methods

Clinical and sociodemographic information

Clinical and sociodemographic information was obtained by interviewing the patients and by reviewing their clinical records. Data were extracted (RV) and verified (RMS-H) by clinicians who were blind to the interview information. Chronic complications of diabetes were defined following American Diabetes Association criteria.²² In addition, they were classified into mild–moderate or severe, according to the following ad hoc criteria: blindness or significantly reduced sight, and predialysis or dialysis. Cardiovascular risk factors (hypertension, dyslipidemia, smoking, and obesity) were also identified.

Quality of life

QoL was assessed using the Spanish version of the Diabetes Quality of Life questionnaire (EsDQoL).²³ It was created for the DCCT, to assess the impact of intensive insulin treatment on lives of people with T1D, by the DCCT Research Group in 1988. It was validated²⁴ and used to evaluate QoL during DCCT and Epidemiology of Diabetes Interventions and Complications.^{1,14,25} It is one of the most frequently used tools to measure patients' perception about their QoL and has been translated into and validated in several languages.²⁰ It comprises 43 items in four dimensions: life satisfaction (15 items), diabetes impact (17 items), social/vocational concerns (seven items), and worries about diabetes (four items). Each item can be given 1–5 points on a Likert scale. A lower score reflects better QoL, but there are no validated cut-off points to define poor/good QoL.

Treatment satisfaction

Treatment satisfaction was evaluated using the validated, Spanish version of the DTSQ,²⁶ which comprises eight items that can be scored from 0 to 6. Global satisfaction is calculated by adding the scores of six of the items, and a higher score reflects more satisfaction. The other two items assess the perceived frequency of hypo- and hyperglycemia.

Table 1 Questions included in the open interview

Question 1	Do you think that diabetes has changed your life? If so, how?
Question 2	What worries you most about your diabetes in the long run?
Question 3	Which part of diabetes treatment is most difficult?
Question 4	Do you feel free when you eat? Do you eat what you like and when you like? If not, then why not? Do you avoid injecting more insulin than what is prescribed by your endocrinologist? Do you avoid eating snacks to avoid extra insulin?
Question 5	Do you feel happy with the way you manage your diabetes?
Question 6	Define what you consider quality of life in relation to diabetes. What is quality of life living with this disease?
Question 7	Do you think that you need more knowledge about the disease? In what area? Are you ready to be trained?
Question 8	Have you experienced or do you experience restrictions for having diabetes? Which? Why are they restrictions? Who has imposed them on you? Have you concealed your diabetes any time to make things easier?

Qualitative interviews

An exploratory interview was performed, to identify important aspects in the QoL of people with T1D. A semi-structured design was chosen, in order to guarantee discussion about areas previously identified as relevant. It consisted of eight questions assessing the impact of diabetes, long-term worries, flexibility (diet and dose adjustment), limitations, and self-perception of QoL (Table 1). To design the questions, expert opinion was considered. This was based on the clinical experience of the involved (AC, JN, AMW) and other endocrinologists, as well as that of the interviewer (DA-M), who had worked for 10 years at the local diabetes association, and spontaneous remarks made by the initial 33 patients.

Analysis

Quantitative analysis (clinical information and standardized questionnaires)

DA-M and AMW analyzed the data. Each participant was given a consecutive number as he/she was included in the study and then registered in the database (I1–I102; two excluded due to diagnosis of type 2 diabetes). Analyses were performed using the software package SPSS 16.0 for Windows (SPSS Inc, Chicago, IL, USA). Quantitative variables are described as mean \pm standard deviation (SD) or as median (range), according to their distribution (Kolmogorov–Smirnov), and qualitative variables, as percentages. Bivariate correlations were analyzed (Pearson's r), and comparisons were made between groups (Student's t -test or analysis of variance [ANOVA], for two or more group comparisons, respectively). In addition, age and diabetes duration were categorized in quartiles and compared using ANOVA and post hoc multiple comparisons (Bonferroni).

In order to find factors associated with QoL (EsDQoL), a step-by-step, multivariate regression analysis was performed. The variables significantly correlated with EsDQoL in the bivariate analysis (except DTSQ results) were included in the model as independent variables, and the model with the best fit (defined by the highest r^2) was identified. A two-tailed $P < 0.05$ was considered significant.

Qualitative analysis (interviews)

Qualitative research was based on the performance of semi-structured interviews, based on specifically designed questions. All interviews were literally transcribed by the interviewer during the conversation. Further reading of the transcripts aimed to identify and group the replies. Finally, results were analyzed, summarized questionwise, and described.

Table 2 Patients' characteristics

Sex, male (%) (N=100)	55
Age (years), mean (SE) (N=100)	31.4 (11.6)
Duration of T1D, mean (SE) (N=100)	14.2 (9.3)
Level of education (%) (N=100)	
Primary education	32
Secondary education	42
University education	25
Treatment (%) (N=100)	
Multiple insulin injections	95
Pump treatment	5
HbA _{1c} (most recent 1–2 weeks before the appointment), mean (SE) (N=100)	8.5 \pm 1.9% (69 \pm 20.8 mmol/mol)
HbA _{1c} (4–6 months earlier) (median [range]) (N=97)	8.0 (5.3–19)% (64 [34–184] mmol/mol)
At least one associated cardiovascular risk factor (%) (N=100)	33
Drug treatment for depression or anxiety (%) (N=100)	11
Complications (%) (N=100)	30
Retinopathy	30
Nonproliferative	16
Proliferative	13
Macular edema	1
Nephropathy	14
Microalbuminuria	6
Proteinuria	3
Renal failure – stages 1–4	4
Hemodialysis	1
Treatment of retinopathy (%) (N=100)	
Laser-treated	5
Vitrectomized or with vitreous hemorrhage	8
Severity of complications (%) (N=100)	
Mild–moderate	21
Severe	9

Abbreviations: SE, standard error; T1D, type 1 diabetes; HbA_{1c}, glycated hemoglobin.

Table 3 Results obtained in the standardized questionnaires

	Average	SD	Lowest	Highest	Scale
Quality of life total (EsDQoL)	94.6	22.9	50	167	43–215
Satisfaction	35.5	9.6	18	69	15–75
Impact	34.9	9.5	18	69	16–80
Social/vocational concerns	14.0	4.9	7	26	9–45
Worries about diabetes	10.0	3.5	4	20	4–20
Treatment satisfaction (DTSQ)	25.7	6.7	8	36	0–36

Notes: Higher EsDQoL scores reflect worse QoL, whereas higher DTSQ scores reflect more satisfaction.

Abbreviations: SD, standard deviation; EsDQoL, Spanish version of the Diabetes Quality of Life questionnaire; DTSQ, Diabetes Treatment Satisfaction Questionnaire.

Results

Patient characteristics (100 patients) and results of the questionnaires are shown in Tables 2 and 3, respectively.

When patients were stratified according to sex, women showed worse QoL (102.1 ± 18.2 points vs 88.5 ± 24.6 points, $P=0.003$), less satisfaction (38.6 ± 7.8 points vs 33.0 ± 10.3 points, $P=0.004$), more impact (37.8 ± 7.9 points vs 32.7 ± 10.2 points, $P=0.008$), and social concerns (15.1 ± 4.5 points vs 13.1 ± 5.1 points, $P=0.051$) associated with diabetes than their male counterparts. In addition, patients with longer education showed better QoL (100.6 ± 26.1 points for primary, 93.5 ± 19.8 for secondary, and 86.3 ± 18.4 for university studies, $P=0.005$), and those with at least one associated cardiovascular risk factor showed reduced QoL (102.5 ± 24.8 points vs 90.1 ± 20.6 points, $P=0.009$), as did those receiving psychoactive drugs (113.4 ± 27.8 points vs 92.1 ± 21.3 points, $P=0.003$) and those suffering from more severe, chronic complications (111.2 ± 38.8 points for severe complications, 96.7 ± 21.4 for mild–moderate complications, and 91.8 ± 19.9 for the absence of complications, $P=0.05$).

Correlations between total QoL and its subscales and other continuous variables are displayed in Table 4. QoL was worse with increasing glycosylated hemoglobin (HbA_{1c}) and age and improved with treatment satisfaction.

Age

Age was categorized in quartiles, and QoL scores were compared. Age categories and their mean (SD) EsDQoL scores were as follows: 14–20 years: 32.6 (8.4), 21–31 years: 34.3 (7.4), 32–39 years: 35.4 (2.0), and 40–58 years: 39.9 (9.4). A trend toward a difference was found in the satisfaction subscale ($P=0.052$), whereas no significant differences were found in the other subscales or in total QoL. In multiple post hoc comparisons (Bonferroni), a significant difference for satisfaction was found between Q1 and Q4 ($P=0.047$).

Diabetes duration

Diabetes duration was also categorized in quartiles (0–7 years, 8–13 years, 14–20 years, and 21–41 years). No differences in EsDQoL scores were found using ANOVA or post hoc multiple comparisons. Total QoL scores (SD) were as follows: 87 (17.6), 95.6 (24.5), 92.3 (28.5), and 103.6 (22.2) ($P=0.078$ for ANOVA and $P=0.067$ for Q1 vs Q4 in post hoc comparisons). No significant differences were found for any of the subscales (data not shown).

No differences were found between men and women regarding treatment satisfaction. Longer education tended to be associated with lower HbA_{1c} (9.0 ± 1.9 vs 8.6 ± 2.0 vs 7.7 ± 1.3 for primary, secondary, and university studies, respectively, $P=0.053$), and patients receiving psychoactive drugs tended to have worse control (9.5 ± 2.9 vs 8.4 ± 1.6 , $P=0.067$).

Multiple regression analysis showed that higher HbA_{1c} , female sex, and severity of complications explain 25.2% of the variance in QoL (Table 5). If level of education was also included in the model, this variance increased to 28.3%. Age, psychoactive drug treatment, and cardiovascular risk factors did not reach statistical significance in multivariate analysis.

Semi-structured interview (67 patients)

Question 1

Having diabetes had changed the lives of 68.5% of the participants. When replying to how it had changed, patients gave replies like the following.

I have a lot of restrictions [Patient code I36, 20 years of diabetes, male]

More worries and limitations [I33, 37 years of diabetes, female]

Having to inject, control food, etc [I38, 6 years of diabetes, female]

Having to program everything in my life, changing my habits [I44, 2 years of diabetes, female]

They are more observant of me [I70, 2 years of diabetes, female]

Question 2

A total of 83.5% of the participants named chronic complications as their main long-term concern. Some of their replies were the following.

Blindness, disability [I42, 23 years of diabetes, female]

That my organs are damaged [I56, 4 years of diabetes, male]

Complications, not being constant with treatment [I64, 10 years of diabetes, female]

Table 4 Bivariate correlations between EsDQoL and its subscale scores and other continuous variables

	1	2	3	4	5	6	7	8	9	10
1. Satisfaction subscale	–	0.65**	0.47**	0.47**	0.87**	–0.51**	0.30**	0.15	0.18	0.28**
2. Impact subscale		–	0.41**	0.62**	0.88**	–0.42**	0.30**	0.31**	0.04	0.19*
3. Social/vocational concerns subscale			–	0.59**	0.68**	–0.13	0.03	0.04	0.12	0.04
4. Worries of diabetes subscale				–	0.74**	–0.31**	0.23*	0.18	0.06	0.16
5. Quality of life (EsDQoL)					–	–0.46**	0.29**	0.23*	0.13	0.23*
6. Treatment satisfaction						–	–0.13	–0.17	–0.02	–0.08
7. HbA _{1c} (most recent)							–	0.53**	0.04	–0.06
8. HbA _{1c} (4–6 months earlier)								–	–0.07	–0.08
9. Duration of T1D									–	0.48**
10. Age										–

Notes: * $P < 0.05$. ** $P < 0.001$.

Abbreviations: EsDQoL, Spanish version of the Diabetes Quality of Life questionnaire; T1D, type I diabetes; HbA_{1c}, glycated hemoglobin.

That it affects my organs and that my children inherit it [I91, 8 years of diabetes, female]

It worries me to dependent as I am [I37, 41 years of diabetes, male]

Question 3

Regarding treatment, 37.3% identified monitoring and registering glycemia as the most difficult part, and 16.4% said they hated injecting insulin. Some of their statements included the following.

Being observant of [glucose] controls [I42, 23 years of diabetes, female]

Glycemia, having to check so many and writing them down [I44, 2 years of diabetes, female]

I hate injecting; I prefer not to eat, to avoid injections [I48, 20 years of diabetes, female]

I feel ashamed of injecting insulin in a public place [I49, 11 years of diabetes, male]

I hate pricking my finger [I62, 34 years of diabetes, male]

Not having time to dedicate to diabetes [I64, 10 years of diabetes, female]

Diet and, earlier, I was afraid of injecting [I70, 2 years of diabetes, female]

Having to carry a glucose meter, food and insulin with me [I81, 16 years of diabetes, female]

Having to diet, take insulin and do [glucose] controls [I85, 8 years of diabetes, male]

Dieting, not being able to eat everything, although I do it unseen [I91, 8 years of diabetes, female]

Question 4

35.8% felt limited by their diet, and 31.3% reported avoiding insulin doses above those recommended by their endocrinologist. Some replies included the following.

I am almost always on a strict diet [I35, 27 years of diabetes, female]

I feel guilty when I eat things I shouldn't [I41, 11 years of diabetes, female]

Table 5 Multiple regression analysis of factors influencing quality of life (EsDQoL) in patients with type I diabetes

Predictor	B	SE of B	β	t	P	F (df)	Adjusted R ²
Step 1							
HbA _{1c}	3.60	1.16	0.29	3.09	0.003	9.57 (1.98)	0.08
Step 2							
HbA _{1c}	3.78	1.10	0.31	3.40	0.001	11.07 (2.97)	0.16
Sex	14.29	4.20	0.31	3.39	0.001		
Step 3							
HbA _{1c}	3.48	1.07	0.28	3.24	0.002	10.75 (3.96)	0.22
Sex	15.52	4.07	0.33	3.80	0.000		
Severity of complications	8.92	3.07	0.25	2.90	0.005		
Step 4							
HbA _{1c}	2.90	1.09	0.24	2.64	0.010	9.35 (4.95)	0.25
Female sex	14.70	4.03	0.32	3.65	0.000		
Severity of complications	8.47	3.03	0.24	2.79	0.006		
Level of education	–5.40	2.67	–0.18	–2.02	0.046		

Abbreviations: EsDQoL, Spanish version of the Diabetes Quality of Life questionnaire; SE, standard error; df, degrees of freedom; HbA_{1c}, glycated hemoglobin.

Question 5

Most (64.1%) expressed that they felt happy and satisfied with their diabetes management. Some patients' replied as follows.

Yes, because the pump has helped me improve [I34, 17 years of diabetes, male]

I had not been to the hospital for 5 years [I98, 20 years of diabetes, male]

I am not satisfied; I should get more involved, but I don't know how [I96, 13 years of diabetes, female]

Question 6

Regarding the patients' personal definition of QoL, 26.8% defined it as not having complications, 14.9% as not having diabetes, and 23.8% as being well controlled or having an acceptable HbA_{1c}. Some of the replies were as follows.

Having more flexibility in my life and not having complications [I33, 37 years of diabetes, female]

Living like someone without diabetes [I36, 20 years of diabetes, male]

That diabetes does not interfere with my everyday life [I42, 23 years of diabetes, female]

Having a good HbA_{1c} [I53, 12 years of diabetes, male]

Having diabetes is not having quality of life [I54, 2 years of diabetes, male]

Having a less aggressive treatment [I58, 6 months of diabetes, male]

There is no quality of life with diabetes [I66, 14 years of diabetes, female]

Accepting and managing the disease [I73, 15 years of diabetes, male]

Not having complications [I86, 28 years of diabetes, male]

Being more relaxed, because I feel stressed [I101, 10 years of diabetes, male]

Question 7

More than half (59.7%) of the patients regarded that they needed more training on diet, carbohydrate counting, and insulin dose adjustments.

Yes, on eating and dose adjustment [I33, 37 years of diabetes, female]

Yes, I need to develop some habits [I50, 15 years of diabetes, female]

Yes, adjusting food and insulin [I54, 2 years of diabetes, male]

Working on my attitude is what I need [I91, 8 years of diabetes, female]

Question 8

41.7% said that they had had some limitations during their lives, especially with work.

Yes, I didn't risk having more children [I35, 27 years of diabetes, female]

Professionally [I36, 20 years of diabetes, male]

Accepting the disease has been very difficult. I have set my own limits [I42, 23 years of diabetes, female]

Yes, professional diving [I45, 5 years of diabetes, male]

Yes, with my driving license [I60, 6 years of diabetes, male]

I was not accepted at a school camp for being different [I74, 5 years of diabetes, female]

The first year at work I hid my diabetes [I49, 11 years of diabetes, male]

Nobody knows about it at work, I don't tell anyone [I55, 11 years of diabetes, male]

None of my friends knows about it; I hide it [I71, 12 years of diabetes, female]

Discussion

The results of the present study suggest that, in our patients with T1D, HbA_{1c}, severe chronic complications, female sex, and having a shorter education were associated with higher EsDQoL scores, that is, with worse QoL. The open interviews yielded additional, very relevant information and showed a higher degree of concern for glycemic control, eating, and chronic complications.

Our study aimed to identify patients' worries and needs before the implementation of an education program. The Diabetes, Attitudes, Wishes and Needs 2 study is one of the largest and most ambitious designed to date. It included not only patients but also family members and health care professionals from several countries. Attention was drawn to patient implication, self-management, and psychological support. In Spain, a need for patient and health care professional education was identified.²⁷ In the present study, QoL was assessed using the EsDQoL, one of the two validated tools in Spain and one of the most frequently used tools worldwide. This questionnaire has no validated cut-off points and is interpreted based on mean scores. It is sometimes difficult to compare studies using DQoL, since some authors use an inverse scoring system (higher scores reflecting better QoL). In the present study, we used the original scoring method and found results (total QoL score 94.6±22.9) that were similar to a previous study performed in Spain (92.5±16.15).²⁸ DTSQ scores were also similar to what has been reported.^{29,30}

Previous studies where DQoL was also used showed worse QoL in patients with chronic complications,^{7,12–14,16,31,32} especially with increasing number and severity.^{7,12,32} Some have also shown an association between glycemic control and QoL in patients with T1D,^{13,16,17,32–35} whereas others have not.^{28,36,37} Indeed, HbA_{1c} on its own was not a very strong predictor of QoL in the present study. In agreement with our results, previous work also shows that women have less satisfaction and more impact of diabetes on their lives,²³ as well as more worries about diabetes³⁸ and worse well-being,³⁹ and younger people show better QoL.²³ Finally, contrary to our findings, other studies using DQoL have shown an effect of duration of the disease on QoL.^{19,23} The semi-structured interviews in the present study revealed dietary constraints as a relevant concern. In agreement with this, other studies have identified them as one of the main factors determining QoL,^{40,41} and indeed, a flexible diet is associated with improved QoL.^{42,43}

The present study combines a quantitative and a qualitative approach, which was found to be complementary. The semi-structured interview revealed more concerns for glycemic control, food, insulin injections, and complications than what could be concluded from the EsDQoL. Although EsDQoL is a validated questionnaire with good internal consistence, the patients' role in the management of diabetes has changed, since it was developed for the DCCT. No cure has been found for the disease, but many aspects of diabetes management have evolved: glucose meters have improved, insulin treatment is more flexible, patients have easier access to information, and therapeutic education is more patient-centered. All of these factors should be taken into consideration when measuring QoL: living with T1D now is very different from what it was 20 years ago.

During the performance of the study, a discordance between what patients spontaneously said and their results according to the standardized questionnaires was detected. Therefore, the open, structured interview was only performed in 67 participants, after the first 33 had been assessed already. Although this represents only two-thirds of the total sample, previous studies including open interviews are smaller and assess between four and 30 participants. Despite the difficulty in quantifying and summarizing the results obtained from this kind of interview, previous, smaller studies identify similar concerns to those described in the present paper.^{44–48}

We recognized everyday needs and worries not detected through the standardized questionnaires.

One of the strengths of the study is sample size, which is relatively large (67 patients) for a study involving qualitative, semi-structured interviews. It provides a precedent for the creation of a new instrument to measure QoL in patients with T1D and to design a therapeutic education program tailored to patients' needs.⁴⁹

However, we do acknowledge some limitations of this study. The population need not be representative of all patients with T1D. The endocrinology department at our center treats patients aged 14 and older. Thus, young children and their parents are not represented. Furthermore, people with insufficient knowledge of written and spoken Spanish were not included, either. In addition, although most did, not all patients who were invited to participate accepted, and we did not register the percentage of acceptance. We cannot rule out these facts as potential sources of bias. Finally, the interview was not audio-recorded but literally transcribed. Although the transcriptions allow for independent review of the data, we are aware that certain nuances could have been missed.

Conclusion

Poor glycemic control, lower education, complications, and female sex are associated with worse QoL in our population. Open, semi-structured interviews identified aspects not included in the standardized questionnaires. The results of the present study show the need to investigate further in the QoL of patients with T1D. A new, updated questionnaire should be designed and validated, to include aspects of everyday life with diabetes, and not only negative consequences such as poor glycemic control and complications. In fact, a new instrument has been developed by our group and is now being validated. It includes aspects such as QoL perception, social and family aspects, leisure time, employment limitations, self-management, sexual life, physical activity, complications, physical and psychological well-being, sleep, and disease acceptance, among others. This instrument could potentially be used in the future to assess intervention programs in T1D.

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Author contributions

DA-M and AMW conceived and designed the study. RV, AC, FJN, and AMW participated in patient recruitment. DA-M performed the interviews. DA-M, RMS-H, and AMW analyzed the data. DA-M and AMW wrote the paper. All authors contributed toward data analysis, drafting and revising the paper and agree to be accountable for all aspects of the work.

Disclosure

The authors declare that they do not have any competing interests related to the contents of this study.

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