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RESEARCH:EDUCATIONAL AND PSYCHOLOGICAL ASPECTS

The JUBILE cohort: Quality of life after more than 40 years with type 1 diabetes

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Abstract

Aim: The incidence of type 1 diabetes is increasing, and more people are going to live many years with the disease. Quality of life might become the most challenging long-term complication. The JUBILE study describes the quality of life of people living with type 1 diabetes for more than 40 years.

Methods: Patients were recruited from 35 French regional or university hospitals: patients and physicians completed questionnaires, validated by the Delphi method. From 1200 questionnaires circulated, 808 patients and their physicians returned questionnaires.

Results: The duration of type 1 diabetes was 49 ± 6 years (mean±SD), age at diagnosis 15 ± 10 years, HbA1c 7.4 ± 0.9% [58 ± 10 mmol/mol] and 52% were men. Macrovascular disease was present in 32%, 46% had no or only mild non proliferative retinopathy. Insulin pumps were used by 25% and insulin pen/syringe users injected 3.9 ± 2.1 times per day. Blood glucose was self monitored at least five times per day by 67% of patients. Men had 1.8 ± 1.2 children, women 1.4 ± 1.0. More than half (55%) of this population was working, 38% had a university degree. Patients still had a busy life, going out (59%), eating out (82%), playing sports (38%) and travelling (66%). No differences appeared based on age, duration of diabetes, demography or social features.

Conclusions: Living a long and pleasant life is possible with type 1 diabetes. Diabetes does not prevent people from having children, working at highly qualified jobs, travelling abroad: a message of hope that is comforting for patients, their family, relatives and the medical teams.

KEYWORDS

lifestyle, long duration diabetes, quality of life, type 1 diabetes

1 | INTRODUCTION

Over the last century, concerns about people with type 1 diabetes have greatly changed in developed countries. Before the discovery of insulin in 1922,[1] they died rapidly from diabetes. Then the main issue was the prevention of acute metabolic complications. Improvements in diabetes care have progressively reduced the mortality from these complications, but the burden of chronic complications remains. There has been a significant increase in life expectancy, which in a US cohort has increased from 53 years at birth for people diagnosed with type 1 diabetes in 1950–1964 to 69 years for those diagnosed in 1965–1980,[2] but compliance with treatment is very important.[3]

Little is known about the quality of life of people living with diabetes for a very long time. This is a growing issue as type 1 diabetes is more and more prevalent in very young children,[4] and a low quality of life might become the most worrying chronic complication. Two excellent studies, the Golden Years Cohort and the Medalist Study, have studied clinical and biological characteristics of people with type 1 diabetes for over 50 years[5,6]; these studies mainly reviewed medical charts. The quality of life of people with long-standing type 1 diabetes has not been described in a large population. In a pilot study on 57 people with type 1 diabetes, recruited in two centres in Paris, we previously showed that they had a good quality of life.[7] The JUBILE study is an extension of that pilot study, to the national level in France.

The primary objective of the JUBILE study was to evaluate by questionnaire, the quality of life of people living with type 1 diabetes for 40 years or more. Secondary objectives were to compare those with a 40–50-year duration with those with 50+ year duration and to analyse the quality of life according to demographic characteristics, age at completing the questionnaire, age at diagnosis, sex, urban/rural residence and the presence or not, of diabetes complications.

Novelty statement

- Only two large studies, the Golden years Cohort and the Medalist Study, have investigated the characteristics of patients living with type 1 diabetes for more than 50 years, using mainly medical charts; they did not study quality of life.
- Forty+ years of type 1 diabetes does not prevent people from having a high quality of life – a long happy family life, having children, highly qualified jobs, travelling abroad
- This study provides a message of hope for the patients, their family and relatives and the medical teams involved in the care of these patients

2 | PARTICIPANTS AND METHODS

2.1 | Study design

Local and national institutional ethical review boards (Comité de protection des personnes, Comité consultatif sur le traitement de l'information en matière de recherche, Commission nationale de l'informatique et des libertés) approved the study. All participants gave informed consent and completed the questionnaire during a routine visit to their doctor, or they returned it by mail.

As quality of life questionnaires from other countries are not adapted to French people with type 1 diabetes of long duration, participant and medical questionnaires were developed in a three-round 1-year-long process, according to the Delphi method,[8] with high response rates for all rounds. It was conducted by a nation-wide panel of 250 individuals involved with diabetes: hospital and office-based diabetologists, people with diabetes, medical journalists and health economists.

The final participant questionnaire included 62 questions on lifestyle, socio-cultural and professional characteristics, sporting activities and travel. Questions to describe the psychological characteristics used the Revised NEO Personality Inventory (Neo-PI-R) test.[9] Physicians reported standard medical and biological data by answering a 24-item medical questionnaire. These questionnaires were completed in 20 and 5 minutes, respectively. (See supporting information).

2.2 | Patient selection

All people who had lived with type 1 diabetes for more than 40 years (diagnosed with type 1 diabetes in 1970 to 1972 or earlier) were eligible for inclusion. To contact them, 1200 questionnaires were distributed to medical members of the French-Speaking Diabetes Society (‘Société Francophone de Diabétologie’) between December 2010 and September 2012 or directly addressed to people with diabetes through the French Juvenile Diabetes Help Association (‘Aide aux Jeunes Diabétiques’). Repeated follow-up letters, e-mails, telephone calls, press articles, wall posters, and meeting sessions, were used in order to inform and recruit the largest possible number of eligible people. Prepaid envelopes were provided for the return of questionnaires. Participants were recruited from all 22 Regions of mainland France.

2.3 | Statistical analysis

To describe the population, continuous variables were expressed as mean±SD or as median (quartile 1;quartile 3), and

categorical variables as number and percentage, n (%). The percentages were calculated on the numbers responding.

The description of the population included: demographic data (age at inclusion and age at diabetes onset, sex, duration of diabetes), quality of life (position in family, autonomy and life style, social life, current work), assessment of current clinical profile (treatment and management of diabetes, current clinical and biological characteristics, complications). Complications were defined as: retinopathy; albuminuria; estimated glomerular filtration rate (eGFR, Modification of Diet in Renal Disease) <60 ml/min/1.73 m^2; history of angina, myocardial infarction, angioplasty with or without stents, coronary bypass; history of peripheral arteriopathy, angioplasty with or without stents, bypass of lower limb arteries; history of stroke; history of chronic foot ulcers; history of amputation.

Comparisons between subgroups used Student's t or Wilcoxon tests for quantitative parameters and Chi-square or Fisher tests for qualitative parameters.

All analyses used SAS version 9.3 (SAS Institute Inc., Cary, North Carolina) and differences between subgroups is reported as significant for *P*-values <.05.

3 | RESULTS

3.1 | Population

A total of 35 regional or university hospitals, including 98 physicians from all over the country, participated in the study (See supporting information). Among the 1,200 questionnaires sent to people with diabetes, 808 (67%) were returned by them. While not all questions were answered by all participants, all questionnaires were used (the number of responses to each question is shown in the Tables). The main demographic data are summarized in Table 1. Men accounted for 52% of the participants with no difference between the 50+ and 40–50 year diabetes duration groups. Age ranged from 41 to 90 years with a mean age of 64 ± 10 years (median 63 years, quartiles: 56;70). The age at diagnosis ranged from 1 to 53 years and diabetes duration was 49(44;54) years.

There were 312 (46%) participants with a diabetes duration of 50+ years, 371 (54%) with a 40–50 year duration.

3.2 | Diabetes treatment

Only 3.4% of participants did not consult with a diabetologist. Most (94%) injected insulin either alone (90%) or with the occasional help of their spouse (3%) or a nurse (1%); 25% used an insulin pump. Insulin pen/syringe users injected 4(3;4) (median(quartiles)) times per day. The frequency of self monitoring of blood glucose was 4 or more per day in 84% (45% tested more than six times per day and only 3.8% tested fewer than three times). Continuous glucose monitoring was not available at the time of the study. Glycosuria was checked by about 28%. The last recorded HbA1c was 58 ± 10 mmol/mol (7.4 ± 0.9%).

3.3 | Acute complications

Hypoglycaemia unawareness was permanent in 8.5% of participants and occasional in 35%, with more than half (56%) reporting being fully aware of hypoglycaemia. The number of self-reported hypoglycaemia was 5(3;10), [7.9 ± 8.8] events per month with 0(0;0), [0.3 ± 0.9] events per month of severe episodes requiring assistance. Since diagnosis of type 1 diabetes, the number of hypoglycaemic coma was 1(0;2), [2.3 ± 7.3] per year, and the number of diabetes ketoacidosis events 0(0;1), [1.3 ± 3.6].

3.4 | Chronic complications

Moderate or severe non-proliferative retinopathy was present in 25% of participants, proliferative retinopathy had been diagnosed in 30%. While 15% had vision loss (<6/20 for the best eye), 46% had either no retinopathy at all or only mild non-proliferative retinopathy, after more than 40 years of type 1 diabetes. Our data did not distinguish between eyes, and so refer to either eye.

eGFR was 78 ± 28 ml/min/1.73 m^2 with 2.9% having a creatinine level >200 μmol/L. The prevalence of albuminuria was 27% and 73% received a treatment for hypertension. A total of 27 people (3%) had a renal transplant or dialysis. Only 32% had a history of cardiac, cerebral or vascular peripheral disease complications.

3.5 | Family life and lifestyle

Only 5.8% of the participants were current smokers, 53% had never smoked (Table 2). The usual home location was urban for 59% and 73% lived as a couple. Men had 2(1;3) children while women 2(1;2) children with 2(1;3) pregnancies.

Sexual activity was satisfactory in 35%, but 34% of men reported difficulties or in need of treatment. Only 52% of women had used hormonal contraception.

Most people (82%) were fully autonomous in daily life, but 38% had a sedentary lifestyle.

TABLE 1 Main demographic, clinical and biological characteristics of people with type 1 diabetes for more than 40 years: the JUBILE cohort

	N	Mean ±SD or n (%)	Median (Q1; Q3)
Age at completing questionnaire (years)	710	64 ± 10	63 (56; 70)
Age at diagnosis of diabetes (years)	712	15 ± 10	13 (7; 20)
Men	712	372 (52%)	
Diabetes duration (years)	705	49 ± 6	49 (44; 54)
BMI (kg/m^2)*	760	25.1 ± 3.9	24.5 (22.3; 27.5)
Last HbA1c (%)*	776	7.4 ± 0.9	7.4 (6.8; 8.0)
Last HbA1c (mmol/mol)*	776	58 ± 10	57 (51; 64)
LDL cholesterol (mmol/L)*	746	2.6 ± 0.8	2.5 (2.0; 3.0)
HDL cholesterol (mmol/L)*	741	1.7 ± 0.5	1.6 (1.3; 2.0)
Triglycerides (mmol/L)*	751	0.9 ± 0.6	0.8 (0.6; 1.1)
Systolic blood pressure (mmHg)*	758	132 ± 16	130 (120; 140)
Diastolic blood pressure (mmHg)*	752	71 ± 9	70 (65; 80)
High blood pressure treatment*	791	576 (73%)	
Insulin regimen			
Method of insulin delivery	702		
Pen/syringe		484 (69%)	
Insulin pump		174 (25%)	
Both Pen and Insulin Pump		44 (6%)	
Number of daily insulin injection(s)	557	3.9 ± 2.1	4 (3;4)
Number of daily insulin injection(s) in Pen/syringe only	484	3.9 ± 0.9	4(4;4)
Mean daily insulin dose (UI)	693	38 ± 19	34 (26;45)
Mean daily insulin dose (UI) in Pen/syringe only	476	39 ± 21	35 (27;46)
Daily self-monitoring of blood glucose	707		
0		4 (0.6)	
1		4 (0.6)	
2		18 (2.6)	
3		85 (12)	
4		123 (17)	
>4		473 (67)	
Hypoglycemia unawarness	697		
Yes		59 (8.5%)	
No		394 (56%)	
Sometimes		244 (35%)	
Hypoglycaemia: number per month	653	7.9 ± 8.8	5 (3; 10)
Ketoacidosis: number since diagnosis of diabetes	520	1.3 ± 3.6	0 (0;1)
Retinopathy*	727		
No or mild non proliferative retinopathy		331 (46%)	
Moderate or severe non proliferative retinopathy		181 (25%)	
Proliferative retinopathy		215 (30%)	
Photocoagulation*	770	477 (62%)	
Low vision (≤6/20 for the better eye)*	755	111 (15%)	
Cataract surgery *	767	356 (46%)	
Estimated glomerular filtration rate (MDRD) (ml/min)*	516	78 ± 28	77 (58;96)

(Continues)

TABLE 1 (Continued)

	N	Mean ±SD or n (%)	Median (Q1; Q3)
Men	265	90 ± 28	92 (74;108)
Women	251	64 ± 22	65 (51;80)
Albuminuria*	777	213 (27%)	
Specialized nephrology follow-up*	788	97 (12%)	
Renal transplant or dialysis*	787	27 (3%)	
Macroangiopathy*	787	256 (32%)	
History of angina, myocardial infarction, angioplasty with or without stents, coronary bypass*	787	167 (22%)	
History of peripheral arteriopathy, angioplasty with or without stents, bypass of lower limbs arteries*	787	110 (14%)	
History of stroke*	787	64 (8.1%)	
History of foot ulcers*	787	61 (7.6%)	
History of amputation*	787	26 (3.3%)	
Cognitive disorders*	799	11 (1.4%)	
Follow-up	702		
Primary care physician only		24 (3.4%)	
Diabetologist +/- primary care physician		678 (97%)	

Data shown are N the number of responses, n (%), mean ±SD, median (Q1; Q3).

*Data provided by physician, all other data from the self-questionnaire.

3.6 | Education and professional life

The education level was: primary school (12%), junior high school (8.7%), high school (15%), technical school or apprenticeship (23%) and 38% went to university, with 3.7% having had no schooling (Table 3).

Participants who had retired (n = 315) did so at 60(60;60) years of age, but 55% of them were still working at the time of the survey.

Diabetes-related sick leave was reported by 40% of participants, but for 76% of them, it was less than once a year. About half (45%) reported a role of diabetes in their professional life, that was qualified as negative in 24% and positive in 21%.

3.7 | Social life (activities earlier and now)

Regarding social life, 61% felt it was at least as good as that of their peers (people without diabetes of the same age), with 59% still going out regularly (theatre, movies, parties, museums) (Table 4). Among those who did not go out, 31% declared this was because of difficulties. Most (82%) dined out on a regular basis, and 22% of those who did not, cited difficulties.

While 45% were members of a diabetes association, 64% had been members at a younger age.

3.8 | Travel

A large majority of participants (87%) had a driving licence. Two thirds of them (66%) still travelled, mostly in France (76%), but also in other European countries (43%), and outside of Europe (35%). Transport was by plane: 53%, personal car: 74%, train: 42%, bus: 17% and different means of transport were often combined for individual participants.

3.9 | Psychological features

No clear psychological trait could be characterized: neither a definite positive or negative attitude but rather a neutral attitude, with no difference according to the duration of diabetes: 50+ and 40–50 years.

3.10 | Secondary objectives

No differences were seen in lifestyle and quality of life according to: age at completing the questionnaire, age at diagnosis of type 1 diabetes, sex, residence: urban/rural and presence of diabetes complications.

A total of 163 (21%) participants were free of any complications (Table 5). Comparing those with and without

TABLE 2 Family life and lifestyle characteristics of people with type 1 diabetes for more than 40 years: the JUBILE cohort

Participants' family life and lifestyle characteristics	N	Mean ±SD or n (%)	Median (Q1; Q3)
Family situation	706		
Single		77 (11%)	
Couple		517 (73%)	
Separated		59 (8.4%)	
Widow / Widower		53 (7.5%)	
Residence	681		
Alone		144 (21%)	
With family		525 (77%)	
Institutional care		12 (1.8%)	
Offspring			
Number of pregnancies in women	322	1.9 ± 1.4	2 (1;3)
Number of children			
Men	327	1.8 ± 1.2	2 (1;3)
Women	364	1.4 ± 1.0	2 (1;2)
Number of grandchildren	558	2.4 ± 2.5	2 (0;4)
Number of great grandchildren	358	0.7 ± 3.2	0 (0;0)
Autonomy for daily tasks	707		
No difficulties		579 (82%)	
Some difficulties		93 (13%)	
Many difficulties		35 (4.9%)	
Self-reported vision difficulties	705	235 (34%)	
Daily physical activity	567		
None		215 (38%)	
More than 30-minute walk		347 (61%)	
Gardening / do-it-yourself		317 (56%)	
Other		180 (32%)	
Smoking	702		
Current smoker		41 (5.8%)	
Former smoker		290 (41%)	
Years of smoking	305	20 ± 12	20 (10;30)
Did you used to have a satisfactory sexual activity?	683	599 (88%)	
Do you currently have a satisfactory sexual activity?	667	235 (35%)	
Do you have sexual difficulties and/or do you take a treatment (men)?	323	109 (34%)	
Did you use contraception? (women)	328	171 (52%)	

Data are from paticipant questionnaires.

Data shown are N, the number of responses, n (%), mean ±SD, median (quartiles).

complications, their ages and their ages at diabetes diagnosis were similar but the duration of the disease was 2 years longer in the group with complications. More men had complications and in the group with complications, fewer ate out, and fewer had a satisfactory sexual life, whereas more used to have a satisfactory sexual life. No other statistically significant differences were observed.

4 | DISCUSSION

Living with type 1 diabetes has always been a challenge. It has been shown in young people (11 to 17 years) who already had long-standing type 1 diabetes from age 0 to 4 years, that the quality of life did not differ from the general population.[10] Another study was less optimistic: in 388 participants,

TABLE 3 Education and professional life of people with type 1 diabetes for more than 40 years: the JUBILE cohort. Data are from participant questionnaires

Participants' education and professional life characteristics	N	Mean ±SD or n (%)	Median (Q1; Q3)
Level of education	705		
No schooling		26 (3.7%)	
Primary school		83 (12%)	
Junior high school		61 (8.7%)	
High school		103 (15%)	
Technical school		102 (14%)	
Apprenticeship		63 (9%)	
University		267 (38%)	
Current professional activity	688	381 (55%)	
Age of retirement (years)	315	60 ± 3	60 (60; 60)
History of diabetes-related sick leave	694		
Yes		278 (40%)	
Yes, but less than once a year		210 (76%)	
Yes, more than once a year		58 (21%)	
Yes, but no frequency given		10 (3.6%)	
Diabetes-related occupational injury	678	31 (4.6%)	
Influence of diabetes on professional life	706		
None		387 (55%)	
Yes, negative		172 (24%)	
Yes, positive		147 (21%)	

Data shown are N, the number of responses, n (%), mean ±SD, median (Q1; Q3).

age 28 ± 3 years, diabetes duration 17 ± 3 years, the authors suggested a heavy impact of the disease on morale.[11] Little is known about the quality of life of people living with type 1 diabetes for more than 40 years. This is important as parents caring for very young children with type 1 diabetes need information and support,[12] as their level of stress can affect the glycaemic control of their child.[13]

One of the first issues raised by the parents of a child diagnosed with type 1 diabetes is whether he/she will have a 'normal life' and a normal life expectancy.[14] Mortality rates are higher than in people without diabetes, especially for women with.[15] These studies were done before technological improvements such as self monitoring of blood glucose. Life expectancy has greatly improved over the years. In Sweden from 1988 to 2014, mortality and the incidence of cardiovascular diseases declined substantially.[16] In 2015, for the 952 Medalists glycaemic control was a significant predictor of mortality, physical activity had a protective effect.[17]

Beside life expectancy, quality of life is a key issue: this involves personal, familial and professional life. We did not develop a mathematical score for quality of life, as has been done with the Audit of Diabetes Dependant Quality of Life (ADDQoL) questionnaire [18]; we constructed, using a rigorous process, questionnaires specifically adapted to the French population, to be able to describe characteristics and burdens of living with type 1 diabetes. Among our participants, 73% lived as a couple and only 8.4% were separated, 11% were single. Women had on average 1.4 children, men 1.8, a little below the birth rate in France.[19] The impact of type 1 diabetes on relationships with a partner was evaluated in people who had lived for about 20 years with type 1 diabetes[20]; the support of a partner was highly valued as in our cohort.

Most of our participants (82%) had full autonomy, with fewer than 5% having real difficulties, mostly those with 50+ years duration. It has been strongly suggested by the Diabetes Control and Complications Trial (DCCT), that a high rate of hypoglycaemia and even severe hypoglycaemia is not associated with a decline in cognitive function.[21] Impaired cognitive functioning has been associated with micro vascular complications, smoking and high blood pressure.[22]

In one of the last reports from the Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications Research Group (DCCT/EDIC), among the modifiable risk factors, hyperglycaemia was the strongest determinant of kidney disease,[23] while management of traditional non-glycaemic cardiovascular disease risk factors may have increasing benefits in an ageing population.[24] The mean HcA1c at baseline in the DCCT/EDIC trial was 69 mmol/mol (8.8%),[23] as opposed to 58 mmol/l (7.4%) in the JUBILE cohort, providing protection from the burden of complications with an adverse impact on quality of life. The very low prevalence of smoking in our population, the good control of blood pressure and the relatively low rate of chronic complications could also account for the preservation of autonomy. In a recent large French study of people with type 2 aged >70 years, those with a mean HbA_{1c} <67 mmol/mol(8.6%) had a significantly lower mortality.[25]

A striking feature of our population is the high frequency of self monitoring of blood glucose: 67% tested more than four times daily, resulting in good glycaemic control. In France, a national survey reported that 58% of people with type 1 diabetes tested three or more times daily.[26] In our cohort, this frequency was reached by 97%, more than in the DCCT study.

Concerning professional life, the mean age at retirement was 60 years for those who had retired, the legal age for retirement in France at the time of the survey.[27] In a US survey

TABLE 4 Social activities, earlier and now of people with type 1 diabetes for more than 40 years: the JUBILE cohort

Participants' social activities	N	Mean ±SD or n (%)	Median (Q1; Q3)
Quality of life compared to people without diabetes	668		
Reduced		260 (39%)	
Same or better		408 (61%)	
Did you used to go out to movies, theatre, concerts, museums, sport or cultural events?	701	596 (85%)	
Do you still go out?	702		
Yes		412 (59%)	
No		290 (41%)	
No by choice		105 (36%)	
No because of visual or mobility difficulties		90 (31%)	
No for other reasons		95 (33%)	
Did you used to eat out (restaurants, friends' house)?	696	657 (94%)	
Do you still eat out?	693		
Yes		571 (82%)	
No		122 (18%)	
No by choice		30 (25%)	
No because of visual or mobility difficulties		27 (22%)	
No for other reasons		65 (53%)	
Did you used to play a sport?	702	410 (58%)	
Do you still play a sport?	699		
Yes		268 (38%)	
Frequency (times per month)	242	13 ± 11	9 (4; 19)
Do you have a driving licence?	703	613 (87%)	
For your daily travels, do you?	536		
Drive your car		488 (91%)	
Use public transport		284 (53%)	
Walk		422 (79%)	
Bike		107 (20%)	
Did you used to travel?	696	568(82%)	
Do you still travel?	693	459 (66%)	
Frequency (times per year)	444	3.8 ± 6.0	2 (1; 4)
Destination:	532		
France		406 (76%)	
Rest of Europe		227 (43%)	
Outside of Europe		185 (35%)	
Means of transport:	538		
Car		400 (74%)	
Train		226 (42%)	
Bus		94 (17%)	
Plane		285 (53%)	
Did you used to participate in a club, political or union meetings?	705	371 53%)	
Do you still participate?	702	274 (39%)	
Were you a member of a diabetes association?	701	449 (64%)	
Do you still participate	702	314 (45%)	

Data are from participant questionnaires.

Data shown are N, the number of responses, n (%), mean ±SD, median (Q1; Q3).

TABLE 5 Comparison of people with at least one complication compared to those with no complications[a], among people with type 1 diabetes for more than 40 years: the JUBILE cohort

	At least one complication		No complications		
Participants' characteristics	**N**	**Mean ± SD;;or n (%)**	**N**	**Mean ± SD;;or n (%)**	***P***
Age at completing questionnaire (years)	618	64 ± 10	163	63 ± 11	.14
Men	618	367 (59%)	163	81 (50%)	.02
Age at diagnosis of diabetes (years)	618	14 ± 10	163	15 ± 15	.54
Diabetes duration (years)	618	50 ± 7	163	48 ± 6	<.01
BMI (kg/m^2)	618	25.2 ± 3.9	163	24.6 ± 3.7	.10
Last HbA1c (%)	618	7.4 ± 0.9	163	7.5 ± 0.9	.53
Last HbA1c (mmol/mol)		58 ± 10		59 ± 10	
LDL cholesterol (mmol/L)	618	2.5 ± 0.8	163	2.7 ± 0.9	.10
HDL cholesterol (mmol/L)	618	1.7 ± 0.6	163	1.8 ± 0.6	.15
Systolic blood pressure (mmHg)	618	132 ± 16	163	130 ± 14	.07
Diastolic blood pressure (mmHg)	618	71 ± 9	163	70 ± 8	.21
Family situation	514		141		.29
Single		62 (12%)		13 (9.2%)	
Couple		388 (72%)		112 (79%)	
Separated		46 (8.5%)		9 (6.4%)	
Widow		45 (8.3%)		7 (5.0%)	
Residence	520		139		.28
Alone		117 (22%)		23 (16%)	
With family		392 (75%)		115 (83%)	
Institutional care		11 (2.1%)		1 (0.7%)	
Offspring					
Number of pregnancies	271	1.9 ± 1.3	81	1.8 ± 1.3	.85
Autonomy for daily tasks	541		142		.85
No difficulties		431 (80%)		128 (90%)	
Some difficulties		78 (14%)		12 (8%)	
Many difficulties		32 (5.9%)		2 (1.4%)	
Level of education	539		142		.80
No schooling		24 (4.5%)		2 (1.4%)	
Primary school		65 (12%)		16 (11%)	
Junior high school		38 (7.1%)		20 (14%)	
High school		82 (15%)		18 (13%)	
Technical school		78 (14%)		21 (15%)	
Apprenticeship		53 (9.8%)		9 (6.3%)	
University		199 (37%)		56 (39%)	
Current professional activity	527	284 (54%)	139	85 (61%)	.13
Age of retirement (years)	544	60 ± 5	142	60 ± 3	.84
Did you used to go out to movies, theatre, concerts, museums, sport or cultural events?	535	450 (84%)	141	124 (88%)	.26
Did you used to eat out (restaurants, friends' house)?	532	497 (93%)	139	138 (99%)	.02
Did you used to play a sport?	537	315 (59%)	141	80 (57%)	.68

(Continues)

TABLE 5 (Continued)

Participants' characteristics	At least one complication N	At least one complication Mean ± SD;;or n (%)	No complications N	No complications Mean ± SD;;or n (%)	*P*
Do you have a driving licence?	537	470 (88%)	142	120 (84%)	.34
For your daily travels, do you?	534		140		
Drive your car		365 (59%)		97 (60%)	
Use public transport		211 (34%)		62 (38%)	
Walk		322 (52%)		91 (56%)	
Bike		84 (14%)		21 (13%)	
Did you used to travel?	534	439 (82%)	137	107 (78%)	.27
Means of transport	534		137		
Car		301 (49%)		85 (52%)	
Train		169 (27%)		50 (31%)	
Bus		71 (12%)		23 (14%)	
Plane		210 (34%)		68 (42%)	
Did you used to have a satisfactory sexual activity?	523	465 (89%)	137	112 (82%)	.02
Do you currently have a satisfactory sexual activity?	512	160 (31%)	132	64 (48%)	<.01
Did you use contraception? (women)	239	124 (52%)	80	42 (52%)	.92

Data are from participant questionnaires.

Data shown are N, the number of responses, n (%), mean ± SD.

[a]To have at least one complication among the following: retinopathy; albuminuria; creatinine clearance: Modification of Diet in Renal Disease (MDRD) <60 ml/min; history of angina, of myocardial infarction, angioplasty with or without stents, coronary bypass; history of peripheral arteriopathy, angioplasty with or without stents, bypass of lower limb arteries; history of stroke; history of chronic foot ulcers; history of amputation.

on 723 individuals diagnosed with type 1 diabetes before 17 years of age between 1950 and 1964,[28] it was already noted that absenteeism from work was comparable to their non-diabetic siblings. In the JUBILE cohort, about 6 out of 10 individuals never took sick leave because of diabetes, and only one quarter took more than one sick leave per year. Almost one quarter even declared a positive role of type 1 diabetes in their professional life.

It is also probable that our participants, with 40 or more years of type 1 diabetes, could have been protected against complications through a genetic trait, as some polymorphisms have been reported to be protective.[29] The absence of complications in people with long-standing poorly controlled type 1diabetes, sometimes up to 62 years,[30] is in favour of the existence of such genetic factors, although they have not been clearly identified.

The study has some limitations. We have studied only the population of survivors and it is probable that some individuals with long-standing type 1 diabetes were missed by the JUBILE study. The strategy of recruitment ensured that the number of eligible people identified was high with 67% of responders (808/1200), who filled-out questionnaires with great care. Even if the study population is likely to be biased in term of education, therapy, glycaemic control, it was possible to characterize a large sample of the French type 1 diabetes population. A comparison with a control group that did not reach 40 years of living with type 1 diabetes was not possible by the design of the study. It has been shown recently in the Medalist cohort that some people with long-standing type 1 diabetes had significant residual insulin secretion, with 28% having monogenic diabetes variants.[31] Genetic research was not an aim of our study. If some participants did not have type 1 diabetes, but a monogenetic or other form of insulin-treated diabetes, it will not impact significantly on our results, as the duration of the disease would be similar.

In our cohort of participants with long-standing type 1 diabetes, had no or limited complications, took care of their health with very frequent self monitoring of blood glucose, had good glycaemic control with multiple injections or pump therapy, and they had a high level of education. However, they have also probably been protected by genetic factors that remain to be identified.

5 | CONCLUSIONS

Living with type 1 diabetes supposes sustained daily efforts (frequent self monitoring of blood glucose, multiple

injections, planning of meals and of activities) and is a huge burden, together with the risk of hypoglycaemia. It can be hard to manage especially in young children. The usual sad message often perceived by people newly diagnosed with type 1 diabetes and by their relatives is: glucose control is poor even with new technologies, acute and chronic complications are persistent, life expectancy is limited. This was not an explanatory study and whatever its limitations, the results of the JUBILE study brings a message of hope: living a long, pleasant, fully rewarding life is possible even with type 1 diabetes. Diabetes does not prevent people from having children and a happy family life, working in highly qualified jobs with limited diabetes-related sick leave, as well as travelling abroad. This message of hope is very comforting for people with type 1 diabetes, their family and relatives and the medical teams involved in their care.

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CONFLICTS OF INTEREST

No competing interests for any of the authors.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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