

Original article

# Long-term impact of childhood-onset type 1 diabetes on social life, quality of life and sexuality

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## Abstract

**Aim.** – This study describes the socio-professional outcomes, health-related quality of life (HRQOL) and sexuality of adults with childhood-onset type 1 diabetes (T1D).

**Methods.** – The study participants ( $n=388$ ), recruited from a nationwide registry (age:  $28.5 \pm 3.1$  years; T1D duration:  $17.0 \pm 2.7$  years), completed a questionnaire (198 items); the results were compared with the French general population using standardized incidence ratios (SIRs) and Z scores matched for age, gender and period with/without education levels and patterns of family life. Linear regression models also investigated correlates of SF-36 Physical (PCS) and Mental Composite Scores (MCS).

**Results.** – Compared with the French general population, education levels of people with T1D were similar, with 68.6% having at least a high-school diploma or higher (SIR: 1.06, 95% CI: 0.93; 1.20), as were also their patterns of family life. Unemployment was higher in T1D women (15.3%, SIR: 1.50, 1.00; 2.05), but not in T1D men (8.6%, SIR: 0.96, 0.51; 1.57). Social discrimination was more common (SIR: 5.64, 4.64; 6.62), and frequency of daily alcohol consumption was higher (SIR: men, 3.34, 2.38; 4.54; women, 6.53, 4.57; 12.99). PCS and MCS were decreased moderately (mean  $\pm$  SD:  $52.0 \pm 7.5$ ; mean Z score:  $-0.2$ , 95% CI:  $-0.3$ ;  $-0.1$ ) and substantially (mean  $\pm$  SD:  $42.1 \pm 12.4$ ; mean Z score:  $-0.7$ ,  $-0.8$ ;  $-0.6$ ), respectively. Fatigue and abandoning sports were predictive of a lower HRQOL. Both men and women were more frequently dissatisfied with their sex life. Prevalence of sexual problems was higher in women (SIR for: dysorgasmia, 1.91, 1.21–2.88; decreased/loss of desire: 2.11, 1.35–3.08), but similar in men. Participants with T1D-related complications had preserved social outcomes, but altered HRQOL.

**Conclusion.** – Young adults with T1D have satisfactory social participation. However, their higher alcohol consumption, lower MCS and frequent dissatisfaction with sexuality suggest a heavy impact of the disease on morale, especially in women. Improving the everyday well-being of these young adults represents a key challenge for diabetes healthcare.

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**Keywords:** Pediatric type 1 diabetes; Long-term outcomes; Education; Social status; Quality of life; Sexuality

## 1. Introduction

Type 1 diabetes (T1D) is one of the most common chronic diseases in Western countries [1]. For several decades, incidence rates have increased worldwide (from 9.5 to >60 cases/100,000/year) [1], especially in young children [2,3]. Despite recent improvements in T1D care [1], life expectancy remains shorter in people with T1D than in the general population (GP) [4].

**Abbreviations:** GP, General population; HRQOL, Health-related quality of life; INSEE, French National Institute of Statistics and Economic Studies; MFI-20, 20-item Multidimensional Fatigue Inventory; SF-36, 36-item Short-Form Health Survey; SIR, Standardized incidence ratio; T1D, Type 1 diabetes.

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Health and social vulnerabilities interact with a reciprocal causal relationship. In adults with T1D, it has been shown that social deprivations, especially in relation to employment status and education levels, are independent risk factors of mortality [4,5]. However, little is known of the social consequences of T1D during adulthood. A review of 20 studies conducted before 2002 on the social impact of childhood-onset T1D reported heterogeneous outcomes for employment status and education level [6]. Further surveys also evaluated the social consequences of T1D in adults, but were nonetheless often based on rather outdated data [7–9]. As the T1D burden may have been alleviated by advances during the recent decade [1], adult social outcomes need to be reevaluated under current conditions.

The concept of well-being in chronic conditions is complex and multifaceted [10], and requires the broadest possible view of the real-life conditions of patients. Previous studies have been published on health-related quality of life (HRQOL) [11–14] and sexuality [15–17] in adults with T1D. However, a global approach including both socio-professional and well-being data may give a broader picture of adults with T1D in terms of their subjective and functional outcomes and, as a consequence, permit a deeper understanding of the issues they face.

The aim of the present national survey of adults with childhood-onset T1D was to describe their educational, professional and social outcomes, and their HRQOL and level of satisfaction in relation to their sexuality, and to compare these data with those observed in the French GP to evaluate the long-term impact of the disease. Our main objective was to improve the long-term outcomes for T1D children and adolescents by better defining the areas requiring additional management.

## 2. Methods

### 2.1. Population

Since 1988, the French Registry of Incidence of Diabetes has inventoried all children with T1D in four French regions (Aquitaine, Lorraine, and Haute- and Basse-Normandie) recognized as representative of the overall French population. For the present survey, 905 adults were identified, including 721 who met the eligibility criteria (age  $\geq 18$  years at the time of survey; age at T1D diagnosis  $\leq 14$  years; updated follow-up  $\leq 12$  months before study initiation; valid postal address). All received a paper questionnaire, and participants who fully filled in the questionnaire also signed an informed consent form. The Inserm Institutional Review Board approved the protocol (IRB 0000388).

### 2.2. Procedures

The questionnaire contained 198 items on social and professional life, medical characteristics, HRQOL, sexuality, and transition from pediatric and adult healthcare. (These transition data are described in a separate report.) A multidisciplinary working group (comprising pediatricians, epidemiologists and biostatisticians, including the present authors) devised the questionnaire based on that used by the Radiation Epidemiology

Group [18] and the French Working Group on the Long-Term Outcome of Transplanted Children [19]. Investigators checked each questionnaire and, whenever incoherent or incomplete answers appeared, they systematically telephoned the participant to clarify or complete the answers.

HRQOL was measured using the validated French version of the 36-item Short-Form Health Survey (SF-36) [20], a multidimensional questionnaire comprising eight scales (physical function, physical role, bodily pain, general health, vitality, social function, emotional role and mental health) from 0 to 100, with higher scores indicating better functioning or well-being. These were then computed into a physical component scale (PCS) and a mental component scale (MCS). Fatigability was measured by the validated French version of the 20-item Multidimensional Fatigue Inventory (MFI-20) [21], a self-reporting instrument consisting of five scales (general fatigue, physical fatigue, reduced activity, reduced motivation and mental fatigue) from 4 to 20, with higher scores indicating greater fatigue status. In the absence of a composite score, the score for the ‘general fatigue’ dimension was used to define fatigue in the linear regression models, as recommended [21].

### 2.3. Statistical analyses

Qualitative variables are expressed as frequencies (percentages), and quantitative variables as means  $\pm$  standard deviation (SD). Comparisons with the GP were established using Student's *t* test, Chi<sup>2</sup> test, and standardized incidence ratio (SIR; adjusted for period, age, gender and/or education level, family life, parental education level) or Z scores (adjusted for period, age and gender), depending on the distribution of the reference data. Regarding the GP, all reference data for social life and HRQOL were provided by the French National Institute of Statistics and Economic Studies (INSEE) [22], except for specific data on risk-taking behaviors not collected by INSEE and thus obtained from another national source, the National Institute for Health Prevention and Education (INPES) [23]. Data concerning sexuality were compared with those of the well-recognized nationwide CSF (Context of Sexuality survey in France) [24]. Linear regression models were performed to identify predictors of PCS and MCS. Selection of variables was carried out by a stepwise procedure (significance levels for: entering an effect into the model, 0.2; staying in the model, 0.05). Analyses were conducted using SAS version 9.3 software (SAS Institute Inc., Cary, NC, USA). All tests were bilateral (significance level: 0.05).

## 3. Results

### 3.1. Population

Of the 721 eligible adults, 388 (54%; mean age:  $28.5 \pm 3.1$  years, mean duration of T1D:  $17.0 \pm 2.7$  years) completed the questionnaire between January 2008 and December 2009 (Table 1). Of the non-participants, 13 had incomplete responses, 68 declined to participate and 252 did not respond.

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