

## Secondary Publication



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### European Survey on Adults with Type 1 Diabetes and their Caregivers : Insights into Personal Experience and Needs for Improving Diabetes Care

Date of secondary publication: 07.10.2025

Version of Record (Published Version), Article

Persistent identifier: urn:nbn:de:bvb:473-irb-110667x

#### Primary publication

Penfornis, Alfred; Down, Su; Seignez, Antoine; u. a. (2025): European Survey on Adults with Type 1 Diabetes and their Caregivers: Insights into Personal Experience and Needs for Improving Diabetes Care, in: Diabetes therapy: research, treatment and education of diabetes and related disorders, New York, NY [u.a.]: Springer Healthcare Communications, Jg. 16, Nr. 4, S. 471–484, doi: 10.1007/s13300-024-01685-5

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# European Survey on Adults with Type 1 Diabetes and their Caregivers: Insights into Personal Experience and Needs for Improving Diabetes Care

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Received: July 16, 2024 / Accepted: December 10, 2024 / Published online: January 30, 2025  
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## ABSTRACT

**Introduction:** Type 1 diabetes (T1D) requires constant self-management and substantially impacts daily life. We surveyed the experiences/burdens of people with T1D (PWD) and their caregivers.

**Methods:** An online survey of PWD/caregivers (aged  $\geq 18$  years) living in five European countries was conducted from July to August 2021. The survey included questions on the impact of T1D on physical and mental abilities, the

frequency of hypoglycemic and hyperglycemic episodes and the impact of T1D on the daily lives of PWD.

**Results:** Respondents included 458 PWD and 54 caregivers. The main impacts of T1D included fatigue (50% of PWD rated a high/very high impact), a hindrance to daily activities (43%), feeling different than others (42%), and anxiety (40%). The perceived impact of complication risk was significantly lower for PWD paying more attention to controlling their disease ( $p < 0.001$ ). Most caregivers (80%) reported feeling more anxious than the PWD about their T1D complications. Hypoglycemia/hyperglycemia was a significant predictor of perceived distress owing to T1D. Most PWD (68%) would have liked more psychological support. Over half of respondents (PWD: 53%, caregivers: 56%) felt they had insufficient knowledge about T1D. Acceptance, positivity, and self-organization are the main strategies recommended by PWD/caregivers for living with T1D.

**Conclusions:** T1D remains a significant burden for PWD/caregivers, and more educational and psychological support for T1D management is required.

**Keywords:** Burden; Complications; Diabetes distress; Hyperglycemia; Hypoglycemia; Type 1 diabetes

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**Supplementary Information** The online version contains supplementary material available at <https://doi.org/10.1007/s13300-024-01685-5>.

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## Key Summary Points

### *Why carry out this study?*

Diabetes affects the social life and emotional well-being of people with diabetes and its psychological burden on caregivers.

This survey was conducted in Europe to understand the perceptions and needs for improving support for people with type 1 diabetes (T1D) and their caregivers, along with the use of technology for T1D management, to be reported separately.

### *What was learned from the study?*

Fatigue, a hindrance to daily activities, feeling different than others, and anxiety have shown an impact on the well-being of people with T1D. Over half of the people with T1D and caregivers in the survey felt they had insufficient knowledge, and most people with T1D would like more psychological support, whereas most of the caregivers felt more anxious about complications than those they cared for.

Type 1 diabetes remains a significant burden for both people with diabetes and their caregivers, and discussing the available options for greater educational and psychological support with their healthcare professionals.

## INTRODUCTION

Diabetes is an important public health issue that affects 60 million people in Europe [1]. Type 1 diabetes (T1D) accounts for 10% of all diabetes cases, with its prevalence increasing worldwide [2]. T1D is a complex condition to treat [3], which puts a significant burden/demand on people with T1D (PWD) to self-manage every day and has a substantial impact on quality of life [4], with complex medication regimens requiring specific skills for the daily implementation of therapy, as well as lifestyle changes. Sub-optimally controlled diabetes puts PWD at greater risk of longer-term

microvascular and macrovascular complications [5]. Acute complications such as hypoglycemia and hyperglycemia are a major burden for PWD and have a negative impact on the quality of life and self-care behaviors [6, 7]. Worries and fears about future complications of T1D are pronounced in many PWD and found to be the greatest cause of diabetes-related distress in many studies [8].

Living with T1D requires acceptance of the disease and coping with the demands, limitations and challenges associated with diabetes [9]. PWD may also need to manage common comorbidities such as obesity and hypertension, which place an additional burden on their lives. This may affect their ability to manage their diabetes self-care due to additional barriers to lifestyle changes and regimen adherence [10, 11]. Living with and managing T1D can also place a psychological burden on PWD, and T1D was often associated with a higher prevalence of a variety of mental disorders, especially depression, anxiety, and eating disorders [9, 12, 13]. Diabetes management can also have a financial impact on PWD [11], which may cause stress and impact treatment adherence. T1D can lead to significant demands, stresses, and possibly barriers to working life [14]. PWD also face stigma, which impacts their work life, social life, and emotional well-being. This stigma can further hinder effective self-management and treatment adherence, creating an additional barrier to their overall well-being [11, 15]. T1D can also be a psychological burden on caregivers, to a degree that can be even more pronounced than PWD in some aspects, such as hypoglycemia [16–19].

Very limited data exist on the experiences and perspectives of adults with T1D and their caregivers on how they experience their diabetes, their reactions to the diagnosis and how they assess their treatment. Also, there is a great need to consider the persons' perspectives in the management of diabetes and the evaluation of therapeutic measures. The experiences and perspectives of adults with T1D and their caregivers in Western Europe (France, Germany, Italy, Spain, and the UK) were analyzed. This report focuses on understanding PWD and caregiver

perceptions of T1D, to identify needs for improving support for PWD and their caregivers.

## METHODS

### Survey Design

This ad hoc survey was conducted on the Carenity online platform in the T1D community (PWD and caregivers) in France, Germany, Italy, Spain, and the UK. This survey also generated data on use and perceptions of technology for T1D management and these outcomes have been reported separately; the survey design and some parts of the methodology are the same [20]. The questionnaire was developed by Carenity with a group of experts from the UK, France, and Germany with different specialty backgrounds (clinician, psychologist, and nurse educator). Two PWD from the UK and France (a 25-year-old French female and a 56-year-old British male) shared their experiences and views to refine the questionnaire. Data were collected during July and August 2021. All the survey questions were translated into the respective national languages and instructions were provided to the survey participants. All the translated questions were corrected by the authors of this publication.

The survey contained a variety of questions on the experiences and perceptions of living with T1D, including questions on the frequency of hypoglycemic (symptoms and/or blood glucose  $\leq 70$  mg/dl) and hyperglycemic (symptoms and/or blood glucose  $\geq 250$  mg/dl) episodes in the last 2 weeks, and severe hypoglycemia (defined as requiring third party assistance) or severe hyperglycemia (with/without ketosis, requiring third party assistance) in the last year. The survey also included a question where the participants were asked to choose from a selection of pictures that best reflected the impact of T1D on their daily lives. The pictures included were selected by the experts based on their potential interpretations. This question also included a free text field where respondents could explain their choice of image.

### Participants

Invitations to complete the survey were sent to Carenity users registered as a PWD or as a caregiver of a PWD (invitations and reminders sent by email). A message about the survey with a link was also posted on the Carenity Facebook page and on the Facebook pages of other T1D patient groups. Invitations were also sent to PWD registered in Carenity partners' panel.

The eligibility criteria included: adult (male or female aged  $\geq 18$  years at the time of inclusion into the survey); living in France, Germany, Italy, Spain, or the UK; diagnosed with T1D or living with an adult diagnosed with T1D. The caregivers were not necessarily caregivers of PWD who were registered with Carenity or completed the survey. Caregivers answered some questions about the PWD's experience of T1D and some questions directly about their experiences as a caregiver living with someone affected by T1D.

### Ethics Considerations

All the participants provided their informed consent. This is not a clinical study or clinical survey and was conducted in accordance with the organization's intended regulations for qualitative market research studies. This study was exempt from the Institutional Review Board oversight in accordance with exemption guidelines listed in the 2022 EPHMRA (European Pharmaceutical Market Research Association) Code of Conduct for the market research conducted in France, Germany, Italy, Spain, and the UK [21, 22].

### Statistical Analysis

The sample size was based on feasibility and Carenity's experience of patient and PWD studies; the expected sample size was 100 respondents in each country (France, Germany, Italy, Spain, and the UK; soft quotas), 90% PWD and 10% people living with PWD (caregivers). The total expected sample size for

the survey was 450 PWD and 50 caregivers. Incomplete questionnaires were not included in the analysis (i.e., no missing data in the dataset). Data quality checks were performed on all completed questionnaires. Respondents who spent too little time completing the questionnaire (an average of fewer than 5 s per question, which equates approximately to fewer than 3 min for the questionnaire) or provided inconsistent responses across related questions were excluded from the analysis.

As a first step, a detailed descriptive analysis was performed for each question (univariate analysis). For close-ended questions with qualitative variables, number of respondents ( $n$ ) and percentages (%) were calculated; for close-ended questions with quantitative variables, mean, 95% confidence interval (CI), median, first and third quartiles (p25 and p75), standard deviation, and grouping in classes ( $n$ , %) were determined. Analysis of open-ended questions included grouping by theme, number of respondents and occurrences by themes, and verbatim extracts.

Bivariate descriptive analysis was performed depending on the sample sizes ( $n \geq 30$  for each category). In order to study the impact that variables have on one another and to determine links or dependencies between variables, different hypothesis tests were performed depending on the variable type. For two qualitative variables, chi-square independence tests were performed (if the conditions were not met, the Kruskal–Wallis test was performed). For a quantitative and a qualitative variable, Student's  $t$  test to compare two groups (if the conditions were not met, the Wilcoxon–Mann–Whitney test was performed) or the ANOVA test to compare more than two groups was used (if the conditions were not met, the Kruskal–Wallis test could be performed). The link between two quantitative variables was evaluated by the Pearson's correlation. The Cochran–Armitage test was used to test whether two qualitative variables are independent, when at least one is an ordinal qualitative variable. Statistical tests were performed once all application conditions were met.

## Objectives

The objective of this survey analysis was to generate real-world insights to assess the experiences and perceptions of both PWD and caregivers, assess the impacts of T1D, barriers to diabetes management, and identify needs for improvement in management and support.

## RESULTS

### Responder Profile

Overall, 774 participants consented to taking part in the survey and 637 questionnaires were completed. The total number of evaluable respondents included in the analysis was 458 PWD and 54 caregivers. Respondents were evenly distributed between the five European countries (France, Germany, Italy, Spain, and the UK; Table 1). The PWD included 54% women, with a mean age of 47.8 years, mean age at diagnosis was 24.4 years, and a mean time elapsed since diabetes diagnosis of 23.3 years (approximately 48% of the participants were diagnosed with T1D at the age of below 20 years); 77% of PWD had at least one other illness that significantly impacted their daily life (Table 1). The caregivers included 57% women, with mean age 43.2 years; mean time since diagnosis was 21.2 years and mean age at diagnosis was 26.6 years for caregivers answering for PWD. The caregivers identified their relationship with the PWD as being a couple (42%) or close family (PWD% was parent/uncle/aunt; 31%). There was some variation in socio-demographic profiles of PWD across countries (Supplementary Fig. 1); PWD were older in France (mean age 57) and younger in Spain and Italy (mean age 42). The level of education of respondents was varied and ranged from GCSE to PhD; 24% of PWD and 13% of caregivers were educated to the GCSE level, 32% of PWD and 30% of caregivers had completed A-Levels, and 44% of PWD and 57% of caregivers were educated to a bachelor's degree level or higher.

**Table 1** Responder profile

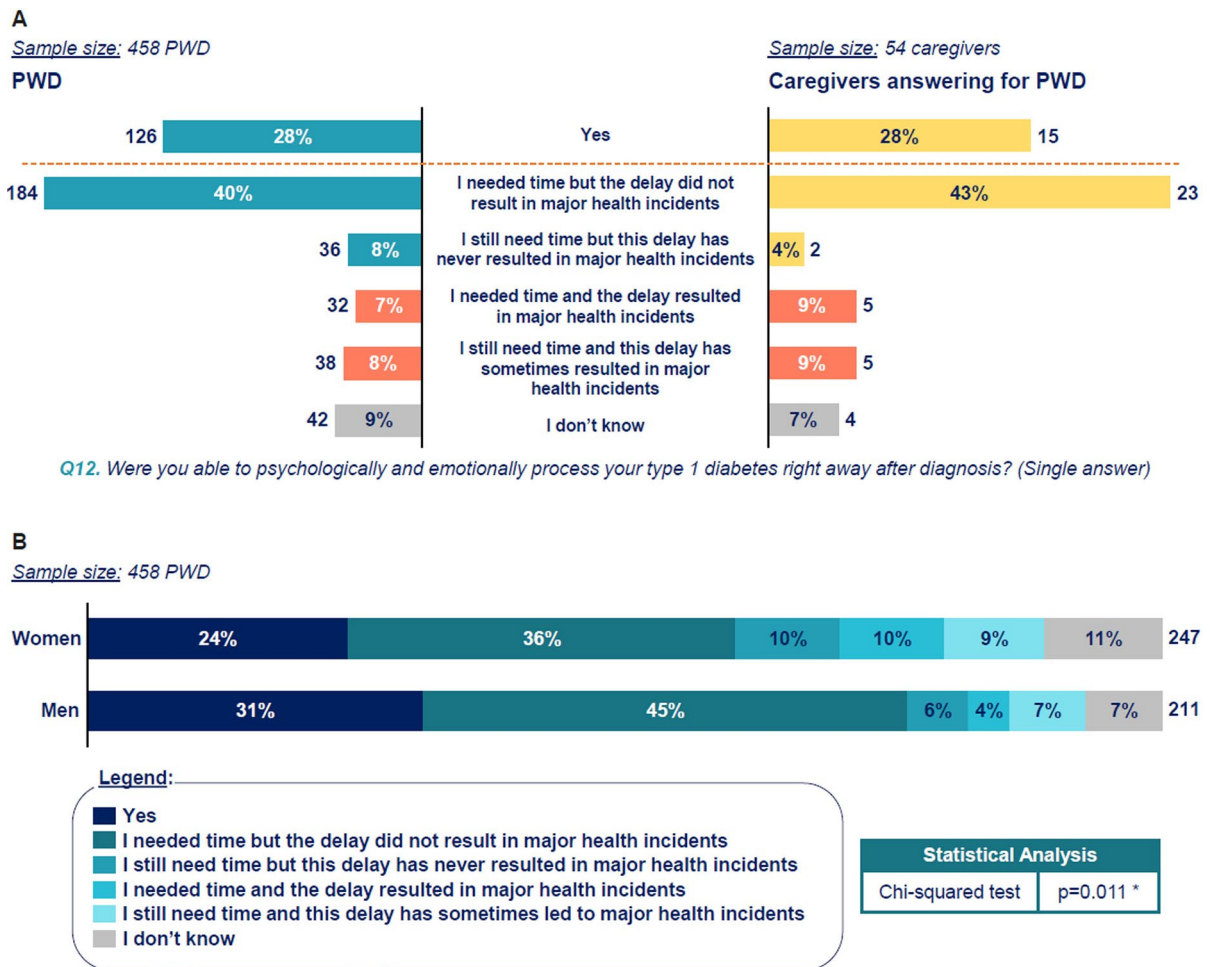
	PWD	Caregivers
<i>N</i>	458	54
Country, %		
France	22	13
Germany	16	24
Italy	20	20
Spain	19	21
UK	23	22
Female, %	54	57
Age (years), mean	47.8	43.2
≤ 40 years, %	34	48
41–60 years, %	43	30
> 60 years, %	23	22
Age of PWD at T1D diagnosis (years), mean	24.4	26.6
Time elapsed since T1D diagnosis (years), mean	23.3	21.2
Number of hypoglycemic episodes in the last 2 weeks, median	2	2
0 episodes, %	19	31
≥ 5 episodes, %	30	31
Number of severe hypoglycemic episodes in the last year, median	0	0
0 episodes, %	58	55
≥ 4 episodes, %	15	13
Number of hyperglycemic episodes in the last 2 weeks, median	2	2
0 episodes, %	28	34
≥ 5 episodes, %	30	26
Number of severe hyperglycemic episodes in the last year, median	0	0
0 episodes, %	67	66
≥ 4 episodes, %	13	9
Number of other illnesses with a significant impact on daily life, mean	2.0	1.7
1 illness, %	25	28
≥ 2 illnesses, %	51	48
Hypertension, %	29	28
Depression, %	26	13

PWD, people with type 1 diabetes; T1D, type 1 diabetes, UK, United Kingdom

Approximately two-thirds (64%) of PWD used an insulin pen, 26% used an insulin pump and 7% used a smart insulin pen (3% did not know). Answers were similar from caregivers answering for PWD (63%, 20%, 9%, and 8%, respectively). Approximately 43% of PWD used a classic glucose meter to monitor blood glucose, and 63% used a continuous or flash glucose monitoring device (10% of PWD used two devices to monitor their blood glucose). The PWD had experienced a median of two hypoglycemic and a median of two hyperglycemic episodes in the last 2 weeks; 30% had experienced five or more episodes. A higher proportion of caregivers than that of PWD reported

no episodes in the last 2 weeks (hypoglycemia: 31% caregivers vs. 19% PWD and hyperglycemia: 34% vs. 28%, Table 1). The majority of the PWD had not experienced any severe hypoglycemic (58%) or severe hyperglycemic (67%) episodes in the last year. More than 10% of PWD had experienced four or more episodes of severe hypoglycemia (requiring assistance from another person) or severe hyperglycemia in the last year; the results from caregivers answering for PWD were similar. No correlation was observed between the number of episodes and the time elapsed since diagnosis.

Besides T1D, the top two other illnesses that had a significant impact on the daily life of



**Fig. 1** Initial psychological burden of T1D diagnosis **A** ability to psychologically and emotionally process diagnosis and **B** differences by gender. *PWD* people with type 1 diabetes, *T1D* type 1 diabetes

PWD were hypertension (29% of PWD) and depression (26%) (Table 1). There were no significant differences in the number of comorbidities between men and women. However, a larger proportion of women reported being impacted by depression than men (29% vs. 22%) and a larger proportion of men reported sexual issues than women (19% vs. 6%).

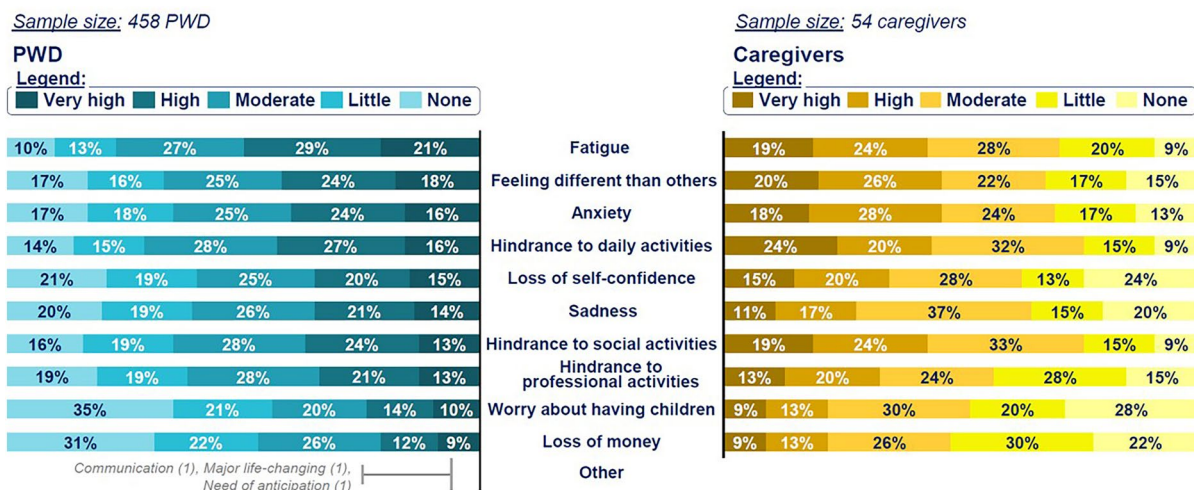
### Initial Psychological Burden of T1D Diagnosis

The majority of PWD (63%) had needed or still needed time to psychologically and emotionally process their diagnosis; 15% reported that struggling to process their diagnosis resulted in major health incidents (Fig. 1A). The answers given by the caregivers were similar. The ability to psychologically and emotionally process their T1D differed significantly between women and men ( $p=0.011$ ); 24% of women reported that they were able to process their disease immediately after their diagnosis versus 31% of men (Fig. 1B). More women than men (19% vs. 11%, respectively) reported major health incidents.

### Impact of T1D on Daily Life and Mental State

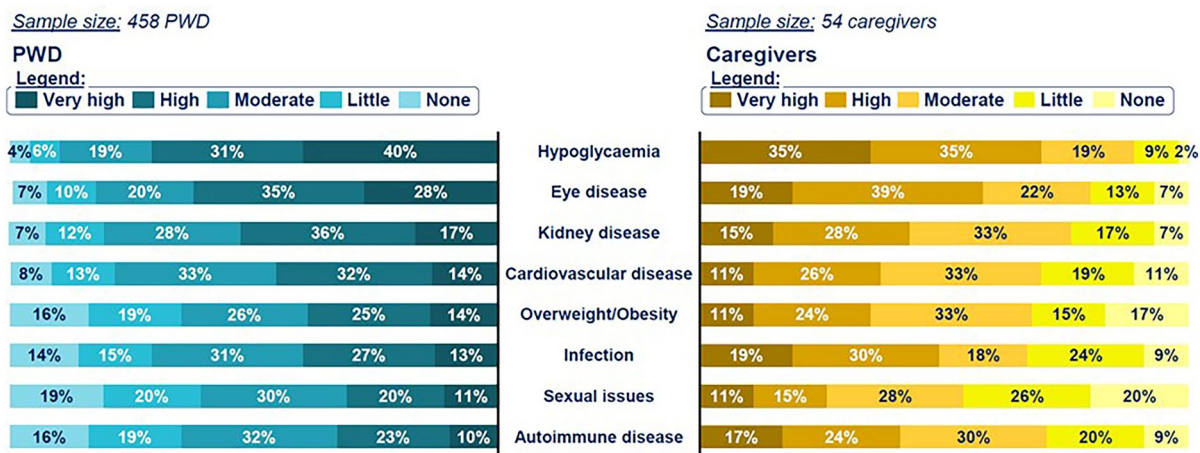
The PWD reported a range of burdens associated with T1D. The main impacts included fatigue (reported as high/very high impact by half of the PWD), a hindrance to daily activities (43% reported high/very high impact), feeling different than others (42%) and anxiety (40%) (Fig. 2). The reported impact of T1D in terms of a hindrance to daily activities (e.g., meals, sleep, etc.) and a hindrance to social activities and leisure (e.g., travel, sports, family gatherings, etc.) were not associated with age group. Two-thirds (65%) of PWD reported worry about having children as an impact of T1D and a quarter (24%) reported it as a high or very high impact. The impact of T1D on worry about having children was rated significantly differently between men and women; 15% of women reported very high impact, versus 4% of men ( $p=0.0024$ ).

Almost all of the respondents (99%) reported that T1D was not a financial issue; however, 46% had to pay or contribute to the costs of their T1D care. The proportion of people who had to contribute to the costs differed significantly between countries ( $p<0.0001$ ); 88% of Spanish respondents had to contribute, compared with over half of the Italian (53%) and German (55%)



Q14. In your opinion, what are the impacts of type 1 diabetes? (1 answer per line)

Fig. 2 Impact of T1D on daily life and mental state. PWD people with type 1 diabetes, T1D type 1 diabetes



Q14. In your opinion, what are the impacts of type 1 diabetes? (1 answer per line)

Fig. 3 Impact of T1D: risk of complications. PWD people with type 1 diabetes, T1D type 1 diabetes

respondents, and less than a quarter in the UK (23%) and one-fifth (20%) in France (Supplementary Fig. 2).

**Impact of T1D: Perceived Risk of Complications**

Most of the caregivers (80%) reported that they sometimes, often, or always felt more anxious than the PWD about their T1D complications. Both PWD and caregivers believed hypoglycemia (71% of PWD and 70% of caregivers rated a high or very high impact), eye disease (63% of PWD and 58% of caregivers) and kidney disease (53% of PWD and 43% of caregivers) were the three main complication risks for T1D (Fig. 3). Almost a third (31%) of PWD and 26% of caregivers rated the impact of T1D on the risk of sexual issues as high or very high. The male PWD rated the risk of sexual issues significantly higher than the female PWD did ( $p=0.0004$ ); only 13% of male PWD thought that T1D had no impact on the risk of sexual issues. The caregivers were also particularly aware of the risk of infections (49% reported high or very high impact).

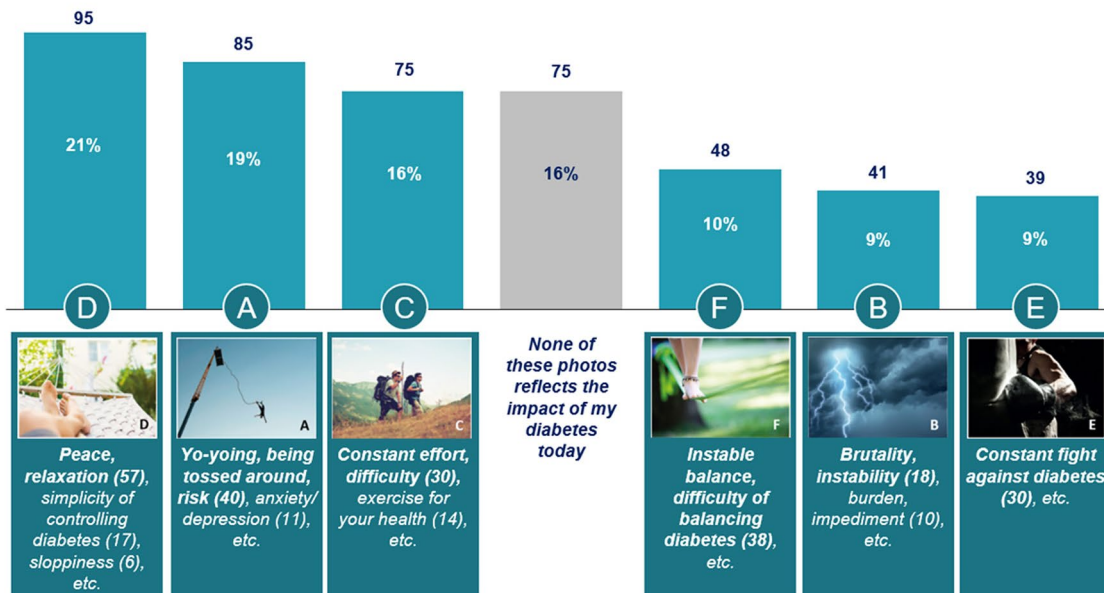
**Measures for Controlling T1D and Its Impact**

The PWD paid attention to all the items listed for means of controlling the disease and its impacts (Supplementary Fig. 3A); the most attention was paid to blood glucose control (8.1/10, 0=pay little attention; 10=very close attention), whereas the least attention was paid to regular physical activity (6.1/10). The caregivers reported helping PWD with healthy eating (6.8/10) and, to a lesser extent, carbohydrate intake for hypoglycemia correction (5.6/10) (Supplementary Fig. 3B). The perceived impact of the risk of T1D complications was significantly associated with PWD paying more attention to controlling their disease ( $p<0.001$ ).

**Perception of the Disease**

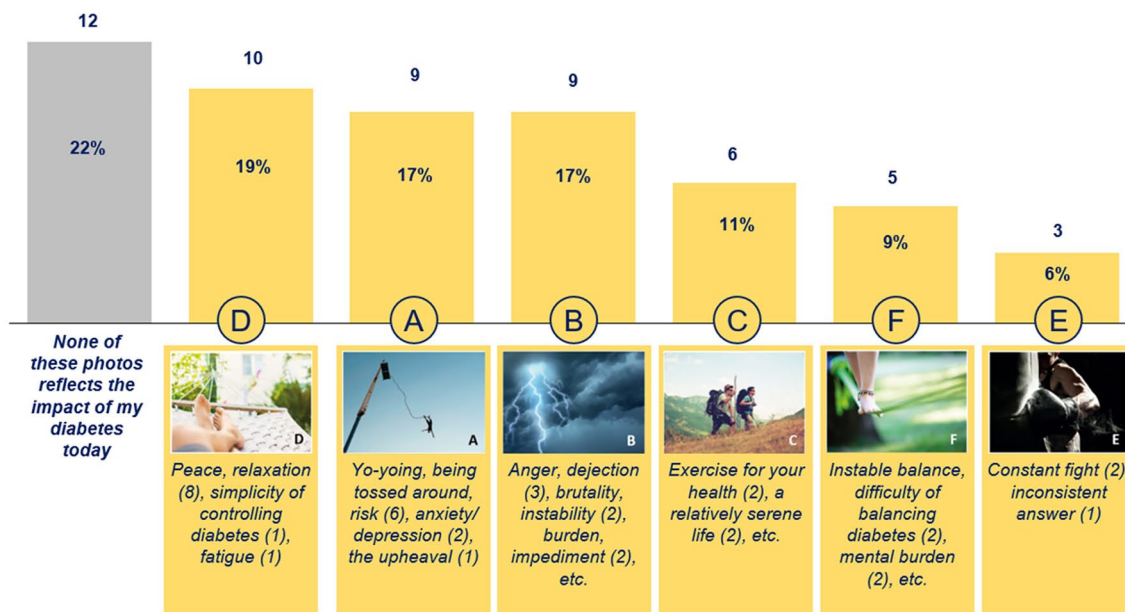
The perceptions of PWD on the current impact of diabetes on their lives were varied. The participants chose from six photographs that best reflect the actual impact that T1D has on their own lives and provided free-text descriptions (Fig. 4). A picture depicting peace, relaxation, and simplicity was the most selected by PWD (photo D; 21%). Pictures that reflected a negative perception (risk, instability, and constant effort; photos A, F, B, and E), were selected by 47% of PWD. Caregivers' perceptions were similar to those of the PWD; half

**A** Q11. Which photo best reflects the impact of your type 1 diabetes on you today? (Single answer + open field)



Sample size: 458 PWD

**B** Q11. Which photo best reflects the impact of the patient's type 1 diabetes on him/her today? (Single answer + open field)



Sample size: 54 caregivers

**Fig. 4** Perception of the disease A people with T1D, B caregivers. *PWD* people with type 1 diabetes, *T1D* type 1 diabetes

(49%) selected pictures A, F, B, and E. The perception of the impact of diabetes (choice of picture) differed significantly with the frequency of hypoglycemic and hyperglycemic episodes experienced in the last 2 weeks (Supplementary Fig. 4). The PWD who chose picture D (reflecting primarily peace, relaxation) had experienced significantly fewer hyperglycemic episodes in the last 2 weeks ( $p=0.032$ ); the PWD who chose pictures A, B, and E had experienced more severe hypoglycemic and severe hyperglycemic episodes in the last year ( $p<0.001$ ).

### Mental Abilities for Managing T1D

Acceptance of the disease is the most important mental ability for management of T1D, ranked first by 41% of PWD and 37% of caregivers (Supplementary Fig. 5). This was followed by the need for a positive attitude and self-organization. Two-thirds (68%) of PWD would have liked more psychological support, primarily from healthcare professionals (HCPs); 28% would like to consult a psychologist.

### T1D Knowledge, Diabetes Education Programs and Advocacy Groups for PWD

Approximately half of the respondents (53% of PWD and 56% of caregivers) would like to know more about T1D. HCPs were the main source of information for the PWD and caregivers (59% and 44%, respectively). The other main sources of information were specialized health websites (27% and 26%, respectively) and other people with T1D, both online (23% and 17%, respectively) and in real life (21% and 41%, respectively).

Many PWD (43%) reported that they had never participated in a diabetes education program. Participation differed significantly by country ( $p=0.0004$ ), with 60% of PWD in Italy reporting that they had never participated in an education program, 53% in the UK, 41% in Spain, 32% in France, and 25% in Germany. Compared with the caregivers, the PWD participated more (57% vs. 39%). Among the PWD and caregivers who had already participated in education programs, less than 30% were still

regularly attending, and there was no significant difference between countries in the percentage of PWD who still regularly attended. The PWD who still regularly took part in education programs experienced fewer hypoglycemic episodes (mean 3.8 vs. 6.0 in the last 2 weeks) and hyperglycemic episodes (3.7 vs. 4.8, respectively); these differences were not statistically significant ( $p=0.07$  for hypoglycemia and  $p=0.31$  for hyperglycemia).

Only 15% of PWD are members of a patient advocacy group. Among the participants who were not members, a majority of PWD (64%) and caregivers (73%) indicated that they would like to be but did not have enough time/energy. Older PWD were less likely to want to be a member of a patient advocacy group ( $p=0.0002$ ), and responses also differed significantly by country ( $p<0.0001$ ). The country with the highest proportion of PWD belonging to a patient advocacy group was France (22%). Over half (54%) of respondents in Germany indicated that they did not want to join a patient advocacy group.

## DISCUSSION

This survey provides insights into both PWD and caregiver experiences and perspectives on T1D. The male respondents were less likely to have difficulty psychologically processing their diagnosis than the female respondents, consistent with the results of the international Diabetes Attitudes, Wishes and Needs (DAWN) study [23]. T1D has a great impact on various aspects of daily life and mental state. Respondents reported that T1D can be a hindrance to daily activities and a cause of fatigue and anxiety. Depression was reported by more than a quarter of participants. While the results of the global SAGE study suggest that diabetes has a low impact on quality of life [24], the results of this survey indicate that T1D can be a substantial burden for both PWD and their caregivers. A survey on quality of life in adults with diabetes in Poland found that T1D negatively impacts various aspects of life and over 80% of respondents with T1D felt that their quality of life would improve if they did not have diabetes [25].

Hypoglycemia and hyperglycemia remain a significant burden for PWD, and the frequency of episodes did not change according to disease duration. It can be difficult to balance the risk between hypoglycemia and hyperglycemia [26, 27]. In this survey, hypoglycemia, eye disease and kidney disease (potential complications of hyperglycemia) were the risk factors that the PWD and caregivers worried about the most. Most of the caregivers felt that they were more worried than the PWD about the risk of complications associated with T1D. The frequency of hypoglycemic and hyperglycemic episodes appeared to negatively impact the perception of the disease. On the other hand, the perceived risk of T1D complications was significantly associated with PWD paying more attention to controlling their disease.

The respondents in this survey appear to be determined to make efforts to overcome the impacts of T1D on their daily lives and pay attention to various factors to control their disease. This survey also provided important insights into the factors considered important for coping with T1D, particularly acceptance of the disease, a positive attitude, and self-organization. However, almost a third of PWD and caregivers reported that they would like more support from psychologists. Perceptions of the disease and its impacts varied. Many PWD were at peace with the disease at the time of the survey; however, many had a negative perception and some reported that living with T1D involved constant effort and instability.

Many PWD and caregivers would like to have more knowledge about T1D, suggesting that they require more diabetes education. HCPs were the main source of information for people with T1D and caregivers, and both groups would like to receive more support from HCPs. Diabetes self-management education is the key to enable people with diabetes to achieve effective glycemic control [28, 29]. The PWD who regularly participated in education programs experienced fewer hypoglycemic and hyperglycemic episodes than those who did not. Only a small proportion of PWD are members of a patient advocacy group and most of those who were not reported that they did not have the time or energy.

A strength of this survey is that the questionnaire was designed and refined with the input of two PWD who shared their experience, identified the most relevant questions, and helped to refine the questions. The questionnaire was developed by the experts who are clinicians, psychologists or nurse educators with T1D specialty, from the UK, France, and Germany. Social desirability bias could be avoided as the participants completed the survey online. Also, the survey was conducted with a relatively large sample size for adults with T1D. As well as PWD, this survey assessed the impact of T1D on caregivers, who are less commonly surveyed. Responses were mostly consistent between the PWD and caregivers of PWD throughout the survey. Diversity in the cultural and health-care systems among the survey respondents is another strength as the respondents were from 5 different Western European countries and differences were identified between those countries. Moreover, globally, respondents had a large age range (34% ≤ 40 years old, 43% 41–60 years old, 23% > 60 years old), and were socioeconomically diverse with varied educational backgrounds, ranging from GCSE to PhD level. A limitation of this survey is that it was conducted online and therefore required a level of computer literacy to complete. Additionally, participants would have been aware of diabetes management as they were already registered on the Carenity social network or on different Facebook groups related to T1D, which would likely have introduced engagement bias. The questionnaire did not use previously validated questionnaires, making the comparisons with other survey outcomes not possible. However, the importance of the items to ask questions on and the type of questions were discussed with the two individuals with T1D, one from UK and one from France and the comments and suggestions were taken into account to build the questionnaire. The survey does not include a questionnaire related to diabetes distress, impact of device usage on quality of life and user satisfaction as this was not the scope of it. However, this survey also assessed participants' perceptions of the use of advanced technology for insulin delivery and diabetes management and found that approximately 60% of participants reported that the

use of the devices or digital tools were useful for diabetes management and made their lives easier [20]. There is also the potential for erroneous reporting from respondents due to recall bias. Another limitation of the survey results is the small sample size that was attributed to the caregivers, as few of them are registered with the Carenity platform. Finally, the survey was conducted during the later waves of the COVID-19 pandemic, which may have impacted PWD and caregiver perceptions of T1D.

## CONCLUSIONS

Overall, this survey analysis shows that T1D remains a significant burden for people with the disease and their caregivers due to the significant impact on daily life and the risks of hypoglycemia and long-term complications. More psychological support and education are required to reduce the burden of T1D on daily life.

## ACKNOWLEDGEMENTS

The authors thank the PWD and experts who contributed to the development of the survey and the survey participants. The authors also thank Pierre Evenou, PhD (Sanofi) for coordinating the development, facilitating author discussions, and critical review of the manuscript.

**Medical Writing/Editorial Assistance.** Editorial and writing support was provided by Lois Grant, PhD, of Fishawack Communications Ltd, part of Fishawack Health, funded by Sanofi, and Deepak Reddy Gade, PhD (Sanofi).

**Author Contributions.** Conceptualization: all authors (Alfred Penfornis, Su Down, Antoine Seignez, Alizé Vives, Mireille Bonnemaire, and Bernhard Kulzer). Data curation: Antoine Seignez and Alizé Vives. Formal analysis: all authors. Funding acquisition: Sanofi. Investigation: Antoine Seignez and Alizé Vives. Methodology development and design: all authors contributed to the design of this work. Project

administration (of research activity): Carenity. Resources (for study, excluding finance): all authors. Software: R software. Supervision (of research activity): Antoine Seignez. Validation/verification of research output: Antoine Seignez. Visualization (of data presentation): Antoine Seignez and Alizé Vives. Writing, review and editing: all authors.

**Funding.** This work was funded by Sanofi. The journal's Rapid Service Fee was funded by Sanofi.

**Data Availability.** Qualified researchers may request access to participant-level data and related documents. Participant-level data will be anonymized, and survey documents will be redacted to protect the privacy of survey participants. Further details on Sanofi's data sharing criteria, eligible studies, and process for requesting access can be found at <https://www.vivli.org/>. The authors confirm that all personal identifiers have been removed or disguised so the person(s) described are not identifiable and cannot be identified through the details of the story.

## Declarations

**Conflict of Interest.** Alfred Penfornis—Advisory panel member for AstraZeneca, MSD, and Novo Nordisk, and speaker for Abbott, Amgen, Bayer MSD, Sanofi, Novo Nordisk, Eli Lilly, and Medtronic; Su Down—Funding from the following companies for providing educational sessions and documents, and advisory boards: Abbott, AstraZeneca, Boehringer Ingelheim, Eli Lilly, GlaxoSmithKline, MSD, Mylan, Napp, Novo Nordisk, Roche, Sanofi, and Viatrix; Antoine Seignez and Alizé Vives—Employees of Carenity, providing consultancy to Sanofi; Mireille Bonnemaire—Employee of Sanofi, holds stocks/shares in Sanofi; Bernhard Kulzer—Speaker's honoraria and/or advisory boards and/or research grants from Abbott, Ascensia, Bayer, Becton Dickinson, Berlin Chemie, Dexcom, Insulet, Novo Nordisk, Roche, and Sanofi.

**Ethical Approval.** All the participants provided their informed consent. This is not a clinical study or clinical survey and was conducted in accordance with the organization's intended regulations for qualitative market research studies. This study was exempt from the Institutional Review Board oversight in accordance with exemption guidelines listed in the 2022 EPH-MRA (European Pharmaceutical Market Research Association) Code of Conduct for the market research conducted in France, Germany, Italy, Spain, and the UK.

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