How do patients with type 2 diabetes perceive their disease? Insights from the French DIABASIS survey

H. Mosnier-Pudar, G. Hochberg, E. Eschwege, M.-L. Virally, S. Halimi, P.J. Guillausseau, O. Peixoto, C. Touboul, C. Dubois, S. Dejager

Abstract

Aim. – The main purpose of this survey was to describe type 2 diabetes (T2DM) from the patient’s standpoint in a representative French panel in 2008.

Methods. – Fourteen thousand two hundred and one individuals from the general population aged 45 or older completed a self-questionnaire exploring knowledge about diabetes; 1092 replies were from patients with T2DM.

Results. – The prevalence of T2DM in this population was 7.7%, with demographics as follows: 60% men; mean age: 66 years; mean age at diagnosis: 55 years; mean BMI: 29 kg/m². Eighty-five percent of T2DM patients reported that they wanted more information about at least one aspect of the disease at diagnosis; they reported feeling anxious (30%), frightened (13%), angry (4%) or that the disease was unfair (12%). Half of the patients had modified their dietary habits but 71% found it difficult to engage in regular physical activity. Most patients (90%) were treated with drugs: 81% with oral antidiabetic drugs (OAD) (44% in monotherapy) while 19% received insulin (alone or in combination with OAD). Twenty-three percent complained of weight gain since start of current therapy (average gain of 7.3 kg). Insulin initiation represented a turning point for patients who became more aware of the disease severity, more willing to follow advice and to take greater control over their disease management. The mean time from diagnosis to insulin initiation was 13.8 years. Half of the patients perceived their disease as severe especially women, patients who initially reacted with anxiety, insulin-treated patients and those actively involved in their disease management. Some gender differences emerged: women took the disease more seriously, were more engaged in self-management, and reported a higher impact on daily life.

Conclusions. – DIABASIS provides important information for diabetes care by highlighting patients’ views of the disease, such as distress at diagnosis, lack of adequate information to cope with this distress and the important supportive role played by the family. A deeper understanding of patients’ perception of the disease would help optimize customized care.

Keywords: Type 2 diabetes; Self-questionnaires; Patient perceptions; Self-management; Family support

Résumé

Quelle perception de leur maladie ont les patients français atteints de diabète de type 2 ? Approche par l’étude DIABASIS.

Objectif. – L’objectif principal de cette étude était de décrire le diabète de type 2 (DT2) du point de vue des patients à partir d’un échantillon représentatif de la population française en 2008.

Méthodes. – Quatorze mille deux cent un autoquestionnaires explorant la connaissance de la maladie dans la population générale âgée de 45 ans et plus ont été analysés, 1092 réponses provenaient de patients DT2.
Résultats. – La prévalence du DT2 dans cette population était de 7,7 %, avec les caractéristiques démographiques suivantes : 60 % d’hommes ; âge moyen : 66 ans ; âge au diagnostic : 55 ans ; IMC : 28,9 kg/m². Quatre-vingt-cinq pour cent des patients auraient souhaité avoir plus d’informations sur la maladie au moment du diagnostic ; ils rapportaient des sentiments d’inquiétude (30 %), de peur (13 %), de colère (4 %) et d’injustice (12 %). La moitié des patients avait modifié leurs habitudes alimentaires, mais 71 % n’avaient toujours pas d’activité physique régulière. Quatre-vingt-dix pour cent des patients recevaient un traitement médicamenteux : 81 % un antidiabétique oral (ADO) (44 % en monothérapie) et 19 % de l’insuline (seule ou en association à un ADO). Vingt-trois pour cent déclaraient une prise de poids (en moyenne de +7,3 kg). La mise à l’insuline (qui intervenait en moyenne 13,8 ans après le diagnostic) marquait une étape importante dans la maladie, avec une prise de conscience de sa gravité et une plus grande implication dans sa prise en charge. La moitié des patients percevait la maladie comme grave, plus fréquemment les femmes, mais aussi les patients anxieux à l’annonce, ayant un diabète de plus de dix ans, traités par insuline et ceux le plus investis dans la gestion de leur maladie. Des différences intersexes sont apprises : les femmes ayant davantage conscience de la gravité de la maladie, étant plus investies dans la gestion de celle-ci, avec un retentissement plus important sur leur vie quotidienne.

Conclusions. – DIABASIS, en partant du vécu des patients, apporte des informations clés pour la prise en charge du DT2, telle que l’importance de l’annonce du diagnostic, avec le stress engendré et la forte demande d’informations complémentaires, et le soutien fondamental représenté par la famille dans la prise en charge quotidienne de la maladie. Une meilleure compréhension du point de vue des patients devrait permettre une prise en charge plus individualisée.

Mots clés : Diabète de type 2 ; Autoquestionnaire ; Qualité de vie ; Perception patient ; Entourage familial

1. Introduction

Type 2 diabetes mellitus (T2DM) is a major public health issue in France, which – like many other countries in the world – has an increasing number of patients with T2DM and has to face the increasing burden of diabetes-related complications.

Over the past ten years, several campaigns in France have focused on the public health dimension of the disease, including the ambitious public health program conducted by the National Health Insurance Fund which ran information campaigns to the general public and promoted guidelines (Caisse nationale d’assurance maladie des travailleurs salariés [CNAMTS] Printing Office, 1999). In parallel, a number of epidemiological studies have provided interesting data on the prevalence of the disease and the quality of care, as well as the prevalence and current management of associated cardiovascular risk factors and of diabetes complications. The most important ones to date are: Échantillon national témoin représentatif des personnes diabétiques (ENTRED), Échantillon permanent des assurés sociaux (EPAS)–CNAMTS, ECODIA and INSTANT [1–7].

These coordinated actions have led to an improvement in the quality of care [8,9]. However, some characteristics of the disease are changing, along with a continuing increase in prevalence [3] closely linked to the rapidly rising prevalence of obesity (OBEPi) [10].

While we have a better understanding of the epidemiology of the disease and its current routine management in France, some aspects of the disease remain under-investigated. Very few studies have focused on the patient’s perception of the disease and the impact of T2DM in all aspects of their daily life. The DIABASIS survey, conducted in 2008 with “Association de langue française pour l’étude du diabète et des maladies métaboliques” (ALFEDIAM) and “Diabète éducation de langue française” (DELF), set out to assess the disease from the patient’s standpoint.

The study was conducted through self-questionnaires mailed to a representative French panel of individuals aged ≥45 years, and provides new insight on two accounts: knowledge in the general population and patients’ perception, their views on disease management and their expectations regarding medication and side effects.

2. Research design and methods

2.1. Study design

This national survey was conducted between December 2007 and January 2008 (covering a total of five weeks) among a representative sample of the French population aged ≥45 years.

Questionnaires were mailed by a polling institute, TNS Healthcare-Sofres, to a panel of 20,000 individuals. This voluntary panel enables the selection of different sizes of representative samples of the French population by quotas (114 clusters), based on the distributions of the closest national reference (“Institut national de la statistique et des études économiques [INSEE]”) for age-class, sex, occupational class, region, and size of city of residence. The representativity of this permanent panel is regularly checked by INSEE statisticians because this panel is frequently used to complete epidemiological studies and produce governmental economic data. The reliability of the data provided was further checked by comparing answers from a set of common questions obtained in the ENTRED study.

In addition to the collected data on age, sex, socioprofessional and marital status, income level, and size of city of residence, there were a total of 37 questions related to the disease, of which 28 were targeted to patients with diabetes and nine to the overall population (see original questionnaire on line).

Compliance was assessed through five validated questions [11] and an additional one, to account for exceptional cases (“windows” while on vacation, weekends, family gatherings and birthdays parties etc). Good compliance was thus defined by no negative answer to any of the six questions.

Collected data were checked for consistency and completeness and then computerized with double entry.
2.2. Study assessments

The main areas of investigation focused on patients’ opinions and attitudes towards various aspects of the disease, the reactions following diagnosis, the impact of the disease on daily activities and quality of life, the relationship with healthcare providers, the therapeutic management of the disease and compliance with drugs and lifestyle, the drug-related adverse effects and finally the role of the family and the patient’s inner circle.

2.3. Response rates

Of the 18,988 questionnaires sent, 77% were returned and 14,201 (75%) were exploited: 1258 were from patients with diabetes and 12,943 from individuals without diabetes.

Only patients with T2DM, whether under drug therapy or not, were kept for analysis (N= 1092). A diagnosis of type 1 diabetes was considered likely for patients who had been diagnosed before age 45 and treated with insulin only less than two years after diagnosis.

2.4. Data analysis–statistics

Quantitative variables were described by the mean and standard deviation (S.D.). Categorical variables were described by the numbers and relative proportions in the relevant categories. Where appropriate, differences between groups were compared by the Student’s t-test (if the size of the groups to be compared was >30) for quantitative data or by the Z-test for categorical data. Statistical results were considered significant at $P \leq 0.05$.

3. Results

3.1. Knowledge of the T2DM disease in the general population and among the diabetic population

Eighty-six percent of our general population knew that more than one type of diabetes existed. One third of these individuals had no idea about the possible risk factors for diabetes; among the answers provided by the remaining two third, a “bad” lifestyle was the first to be cited (57%) – represented mostly by diet (44%) and much less by lack of exercise (9%) – while excessive weight and obesity were only cited by 15% of individuals. A genetic predisposition to the disease was widely recognized (cited spontaneously by 37% in open question, while 85% replied “yes” to a closed question). HbA1c was largely unknown by the general population: only 17% had heard about it and 13% knew what it was used for. Disease knowledge tended to be better among women, in individuals over 65 years of age and in higher socioprofessional categories.

As expected, among the diabetic population, the overall knowledge of the disease was better and increased with duration of disease. Ninety-seven percent of patients were aware of the different types of the disease and 84% knew about HbA1c but only 58% knew what it was used for. Disease knowledge improved with treatment intensification and experience: it was greater in drug-treated patients than in patients on diet and lifestyle management only and greater in insulin-treated patients than in patients treated with oral antidiabetic drugs (OAD).

3.2. Prevalence of T2DM and demography of the diabetic population

The overall prevalence of diabetes in this population aged 45 and over was 7.9%. Type 1 diabetes was only present in 0.2% (no further analysis).

T2DM prevalence (7.7% in our population) was higher in men (10%) than in women (6%). It continuously increased with age up to 75 years: from 4% in men and 3% in women in the age range 45 to 54 years up to 18% in men and 9% in women aged 75 and older. It also increased with BMI (from <4% in individuals with BMI $\leq 25 \text{ kg/m}^2$ to 8% in the overweight population and 19% in the obese population). There was an increasing west–east gradient with a slightly higher prevalence (9%) in the north-eastern part of France. Prevalence also varied slightly with marital status, being lower in people living in a couple (7%) than single (9%). The main characteristics of the T2DM population were as follows: 60% men; mean age: 66 years old; mean age at diagnosis: 55 years; mean BMI: 29 kg/m2 (with 39% of the patients overweight and 37% obese); mean duration of disease: 11 years.

Seventy-six percent had no current professional activity (12% unemployed and 64% retired) (Table 1).

3.3. Disease management and patient–physician relationship

The disease was essentially diagnosed (80%) and then managed (93%) by primary care physicians (PCP). In 74% of cases, diagnosis was made following routine biological testing. The disease was managed by a diabetologist in only 29% of cases overall. However, with intensification of therapy the specialist became more often involved and his role grew to be largely predominant after insulin initiation: 71% of T2DM patients on insulin were regularly seen by a diabetologist versus only 21% of those treated with OAD and 10% of those on diet alone. Only 41% of all patients had consulted an ophthalmologist in the 12 previous months but this varied widely according to the stage of the disease: 20% of those on diet alone, 38% of those treated with OAD and 66% of those treated with insulin.

The disease was relatively well controlled through routine PCP visits: six visits on average during the previous year. The frequency of visits increased with intensification of therapy to reach up to 9.9 per year for insulin-treated patients. Over the 12 previous months, more than three quarter of the T2DM patients had their HbA1c assessed at least once, with a mean of 2.8 measurements per year, and one third of patients had four measurements. Glucose control was acceptable in a majority of cases, with 45% of patients having an HbA1c $<7$%; the mean HbA1c was 7%. To limit reporting bias, subjects were asked wherever possible to send a copy of last available biological results: out of the 77% (875 individuals) with at least one HbA1c measurement who were asked to provide information regarding blood glucose control, 252 patients actually sent a copy of the
Table 1
Characteristics of the type 2 diabetes mellitus (T2DM) population and comparison with ENTRED.

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Screened on general population over 45 Self-questionnaire to all patients diagnosed with T2DM</td>
<td>Only diabetic patients treated with drugs and reimbursed by the French National Health Insurance System (no age restriction)</td>
</tr>
<tr>
<td>Number of questionnaires analyzed</td>
<td>14,201</td>
<td>7676</td>
</tr>
<tr>
<td>Number of T2DM patients questionnaires</td>
<td>1092</td>
<td>NA, only diabetic patients included</td>
</tr>
<tr>
<td>Prevalence T2DM (%)</td>
<td>7.7</td>
<td>NA</td>
</tr>
<tr>
<td>Demographic data</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex-ratio (M/F) (%)</td>
<td>60</td>
<td>52</td>
</tr>
<tr>
<td>Mean age (years)</td>
<td>66</td>
<td>65 (median 67)$^a$</td>
</tr>
<tr>
<td>Mean Age at diagnosis (years)</td>
<td>55</td>
<td>NA (median 58)$^a$</td>
</tr>
<tr>
<td>Mean BMI (kg/m²)</td>
<td>28.9</td>
<td>NA</td>
</tr>
<tr>
<td>% of overweight patients (BMI &gt; 25 kg/m²) (%)</td>
<td>77</td>
<td>NA 80%$^a$</td>
</tr>
<tr>
<td>Disease management</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under diet &amp; lifestyle management (%)</td>
<td>10</td>
<td>NA</td>
</tr>
<tr>
<td>Drug treatment (%)</td>
<td>90</td>
<td>100</td>
</tr>
<tr>
<td>Among drug-treated patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>OAD only (%)</td>
<td>81</td>
<td>77</td>
</tr>
<tr>
<td>Monotherapy (%)</td>
<td>44</td>
<td>42</td>
</tr>
<tr>
<td>Bitherapy (%)</td>
<td>27</td>
<td>27</td>
</tr>
<tr>
<td>Tritherapy or more (%)</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>OAD + insulin (%)</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Insulin only (%)</td>
<td>9</td>
<td>13</td>
</tr>
<tr>
<td>Metformin (%)</td>
<td>60</td>
<td>59</td>
</tr>
<tr>
<td>SU (%)</td>
<td>53</td>
<td>48</td>
</tr>
<tr>
<td>Frequency of BG control</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 HbA1c/year or more (%)</td>
<td>37</td>
<td>39</td>
</tr>
<tr>
<td>At least twice /year (%)</td>
<td>59</td>
<td>66</td>
</tr>
<tr>
<td>At least once a year (%)</td>
<td>77</td>
<td>87</td>
</tr>
<tr>
<td>Mean HbA1c value (%)</td>
<td>7.0</td>
<td>7.2%$^a$</td>
</tr>
<tr>
<td>Physicians seen for T2DM over the last year</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General practitioner (%)</td>
<td>93</td>
<td>90</td>
</tr>
<tr>
<td>Diabetologist (%)</td>
<td>29</td>
<td>11</td>
</tr>
<tr>
<td>Cardiologist (%)</td>
<td>35</td>
<td>33</td>
</tr>
<tr>
<td>Ophthalmologist (%)</td>
<td>41</td>
<td>45</td>
</tr>
<tr>
<td>Side effects (AE) overall</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypoglycaemia (%)</td>
<td>24</td>
<td>NA</td>
</tr>
<tr>
<td>Gastrointestinal disorders (%)</td>
<td>34</td>
<td>NA</td>
</tr>
<tr>
<td>Weight gain (%)</td>
<td>23</td>
<td>NA</td>
</tr>
</tbody>
</table>

OAD: oral antidiabetic drugs; AE: adverse events; SU: sulfonylureas/sulfamides hypoglycémiants.$^a$ data available at: www.invs.sante.fr/entred (03/16/09).

last HbA1c dosage and 424 provided the value but did not send the copy. Results of the self-reported values were consistent with those of the paper copy, suggesting the validity of results.

Patients were mostly treated with OAD: 10% of patients were under diet and lifestyle management only and 90% on drug therapy; among the latter, 81% were treated with OAD alone, 10% with both OAD and insulin, and 9% with insulin alone. The mean time from diagnosis to insulin initiation was 13.8 years. Among OAD, metformin and sulfonylureas were the most frequently prescribed drugs (60 and 53% respectively), while Thiazolidinediones (TZDs) represented 11%. Forty-four percent of patients were treated with monotherapy, 27% were on bitherapy and 10% received three OAD or more. The mean number of antidiabetic drugs taken daily was four tablets and this increased when glucose control deteriorated (only 24% of patients with HbA1c ≥ 8% were still on monotherapy versus 55% of those with HbA1c < 7%).

3.3.1. Treatment satisfaction rate and tolerability
Most patients did not complain about their treatment, with a high overall satisfaction rate (between 8 and 10/10 in 64%, with an average rating at 8.1/10). However, when prompted, adverse events (AE) were reported by 61% and especially in patients receiving multiple OAD: 54% on monotherapy, 69% in bitherapy and 80% if three drugs or more, or insulin. The AE profile was highly variable with the type of drugs and consisted mostly of abdominal pain and diarrhea with metformin (38%) and of hypoglycaemia with SU (33%). Twenty-three percent of diabetic patients declared that they had gained weight since the start of the current therapy (with an average weight gain of 7.3 kg). This was more frequent for patients with a longer disease
history and for those taking multiple medications, increasing from one fifth of patients in monotherapy to one third of those taking three OAD or more.

3.3.2. Compliance
Compliance was evaluated as described in methods. Twenty percent of patients declared that they forget to take their medication under special circumstances (“windows” while on vacation, weekends, etc), and the final rate of good compliance was 70%.

Patients with poor compliance had a particular profile (versus compliant patients): they reported more AE (72% versus 57%); they took more daily tablets for diabetes (4.6/day versus 3.7/day) but were less satisfied with treatment (satisfaction rated at 7.5/10 versus 8.3/10) and reported more frequent weight gain (28% versus 21%). They had less acceptable glycaemic control (42% with an HbA1c above 7% versus 35% of the compliant patients), expressed more impact of the disease on their daily habits, and were more often in need of additional information at time of diagnosis. They were younger: 52% of patients <65 years in the poorly compliant group versus 43% in the compliant group.

The patient–provider relationship was qualified as “unilateral” (i.e. more passive: “the physician decides and the patient simply complies and follows the advice”) by 67% of the patients overall. However, in a number of situations, patients became partners in their health care process and engaged in a more “bilateral” patient–provider relationship (i.e. decisions taken together): when managed by a diabetologist (44% versus 26% if PCP), when on insulin (40% versus 24%), when younger (32% versus 23% below and above 65 years of age), and for active higher socioprofessional categories (45% versus 24% of retired patients) (Table 2). Patients engaged in an active partnership with their physician were more inclined to effectively change their lifestyle behavior: 59% improved their diet (versus 47% in the “unilateral” relationship), 36% modified their shopping habits (versus 27%) and 35% engaged in regular exercise (versus 28%).

3.4. Disease perception

3.4.1. Reaction at diagnosis
Patient reactions when first told of the diagnosis were highly variable but a need for more discussion with the health care provider emerged: 85% complained of not having enough detailed explanations about at least one aspect of the disease: the main items were medications (49%), potential consequences of diabetes on health (43%) and disease origin (40%), as well as lifestyle modifications (33% overall, with 26% lacking information about diet and 14% about exercise). At diagnosis, distress was frequent with 30% of patients expressing anxiety, 13% fear, 4% anger, or 12% that the disease was unfair. Twenty percent were indifferent and 9% expressed disbelief. Anxiety was more frequent in women (37% versus 26%) and in younger patients (below 65 years old) (32% versus 25%).

3.4.2. Disease impact on daily life and self-perceived role in disease management
Seventy-four percent of T2DM patients considered their overall health to be rather good. However, the disease was perceived as serious by half of the patients, especially those who initially reacted with anxiety at the onset, those with a shorter disease duration (<10 years), those treated with insulin, and patients more involved in their disease management.

For lifestyle management items, dietary habits were those most often modified (½ of the patients: stopped snacking, reduced the overall quantity of food ingested and especially sweet and fatty food), while increasing regular physical activity remained extremely difficult and was only achieved by 29% of patients. The impact on daily life (social, professional, familial, sexual, etc...) tended to be greater in patients with longer disease duration, poorer glycaemic control, in women and in patients treated with insulin. Starting with insulin appeared to be a turning point: patients became aware of the disease severity and were either more willing to follow advice (especially when it came to diet and physical activity with greater implementation of lifestyle changes) or started taking greater control over the disease (playing an active role in disease management more frequently).

3.5. Importance of the family/inner circle
Forty-eight percent of the patients stated that their family was supportive and helpful. This support was recognized mostly to help modify dietary habits and to encourage exercise.

Table 2
Type of patient–provider relationship.

<table>
<thead>
<tr>
<th>Type of patient/provider relationship (%)</th>
<th>“The physician decides and the patient follows his advice”</th>
<th>“Both the physician and patient decide together”</th>
<th>“The physician gives advices and the patient decides himself”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>67</td>
<td>27</td>
<td>6</td>
</tr>
<tr>
<td>According to physicians</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If GP</td>
<td>68</td>
<td>26</td>
<td>6</td>
</tr>
<tr>
<td>If diabetologist</td>
<td>51</td>
<td>44</td>
<td>5</td>
</tr>
<tr>
<td>According to treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet only</td>
<td>43</td>
<td>29</td>
<td>20</td>
</tr>
<tr>
<td>OAD</td>
<td>72</td>
<td>24</td>
<td>4</td>
</tr>
<tr>
<td>Insulin (± OAD)</td>
<td>53</td>
<td>40</td>
<td>5</td>
</tr>
<tr>
<td>According to disease duration</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;4 years</td>
<td>65</td>
<td>29</td>
<td>6</td>
</tr>
<tr>
<td>5–9 years</td>
<td>67</td>
<td>28</td>
<td>5</td>
</tr>
<tr>
<td>≥10 years</td>
<td>67</td>
<td>28</td>
<td>5</td>
</tr>
</tbody>
</table>
However, only 13% of T2DM patients considered that the family had changed their behavior towards them. In addition, 90% of patients declared eating the same as the rest of the household. Support was also recognized in other areas: approximately one third said that their family helped them to “live with the disease”, to improve compliance with medication and in the overall disease management.

3.5.1. Gender differences in disease perception and self-management

Women tended to have better knowledge of the disease in the general population. Several gender differences in the way to deal with the disease also emerged in the T2DM population. Women were more likely than men to perceive the disease as serious (57% versus 48% in men), had seen a specialist more frequently than men (both ophthalmologists – 46% versus 38% – and diabetologists – 33% versus 26% –) and were more likely to become partners in their health care process with a “bilateral” patient–provider relationship (in 30% of cases versus 25% in men). Women were more dismayed about the disease (30% versus 19% of men); were more often obsessed with diet (15% versus 10% in men) but also complained more frequently of weight gain, and found it more difficult to increase physical activity (37% versus 23% in men). At diagnosis, women also felt more anxious (37% versus 26% in men), less indifferent (16% versus 23% in men) and less in disbelief (7% versus 11% in men). The impact on every aspect of daily life was rated higher in women than in men, with the exception of sexual life, which was less affected. On the other hand, men seemed to consistently receive more daily support from their family (not only with diet and lifestyle but also with medication compliance, PCP visits, in getting information about the disease, etc).

4. Discussion

The purpose of this study was two-fold: to investigate disease knowledge in the general population and, more importantly, to describe self-perception of type 2 diabetes in a representative panel of the French population. The present survey is the first in France to examine the disease as seen from the patients’ standpoint and to obtain their views on T2DM management. It provides insight into the behavioral dimension of the disease: a deeper understanding of patient disease perception is key to improve education strategies and to enable customized care in routine practice. Indeed, multiple factors including knowledge as well as effective and well-tolerated therapies, have been shown to affect the behaviors of patients and influence their ability to make optimal use of available treatments [12–15].

The main study to date thoroughly investigating these issues was the Diabetes Attitudes, Wishes and Needs (DAWN) study, a large cross-sectional international survey (initiated in 2001 by Novo Nordisk in collaboration with the International Diabetes Federation) carried out in 13 countries. Data were self-reports obtained through structured interviews. The DAWN study helped identify a broad set of “attitudes, wishes and needs” among both people with diabetes and care providers to lay a foundation for efforts to improve diabetes care internationally. It clearly confirmed what had been known intuitively for years: that diabetes causes multiple psychosocial problems that are barriers to achieving adequate glycaemic control and that interfere with self-management behaviors [12]. Another survey investigating the beliefs and perceptions of T2DM patients, the Réunion diabetes (REDIA) epidemiological study [16] which was conducted in the Reunion Island where the disease is highly prevalent, identified a few findings similar to ours: unawareness of excess weight and physical inactivity as potential triggers for the disease, high recognition of heredity factors and unawareness of the disease severity until onset of complications.

Key learnings from DIABASIS

Results (demography and disease management, treatment with monotherapy or multiple drugs, use of OAD and insulin, referrals to specialists, etc.) as summarized in Table 1, were highly consistent with ENTRED 2007 data [8], confirming the reliability of the DIABASIS methodology and results, even though the two studies had slightly different scopes (DIABASIS including patients under lifestyle management, while ENTRED focused on patients aged >18 and reimbursed of drug therapy). The majority of the patients (81%) were treated with OAD (44% in monotherapy) and 19% received insulin, with a mean time from diagnosis to insulin initiation of 13.8 years. Demography and data on glycaemic control are also similar to those of the recent ECODIA 2, which reported a mean HbA1c in 2005 of 7.2% [9].

Disease knowledge clearly increased with duration of T2DM and treatment intensification, illustrating that living with T2DM requires that patients develop a range of competencies over time, allowing some patients to take greater control over their disease. However, the importance of physical activity in disease management was still largely under-recognized, highlighting the challenge of focusing on the key benefit of lifestyle changes for diabetes education programs.

The role of the primary care physician is central in diagnosis and disease management. The disease is managed with frequent routine visits and is relatively well controlled. Metabolic control is acceptable in 45% of patients. Even if most declared being generally satisfied with their treatment, side effects were actually frequent (61%) and markedly increased with intensification of therapy. Physicians should ask patients specifically about side effects experienced in an effort to adapt drug therapy and improve compliance whenever possible. Weight gain was reported by one quarter of patients but with a substantial gain of 7.3 kg on average. With disease progression, especially once insulin is started, patients saw their PCP more frequently and the specialists played an increasingly important role, in line with good practice.

At the time of diagnosis, most patients report a high level of distress and the need for more information to help cope with this distress is striking (85% complained of lack of sufficient information on one aspect or another of the disease). This highlights a key shortcoming in our diabetes care system: educational activities are under-recognized and the mean time spent at a routine visit is too short for in-depth counseling. The demand
for information at disease onset also remains insufficiently rec-
ognized: emphasis should be put on patients’ worries as these
concerns will likely interfere with long-term self-management
efforts. Even if T2DM is often diagnosed following routine
biological testing, the time of diagnosis should always be con-
sidered as a decisive moment for the future management of the
disease. Many participants reported feelings of anxiety, depres-
sion and helplessness, fear, dismay or anger, very much in line
with the DAWN study, which showed that diabetes-related dis-
tress, was common, especially at time of diagnosis [17]. These
findings suggest that a specialist’s input earlier in the disease
could be beneficial not only to take into account the need for
information at the time of diagnosis, but also to provide educa-
tional support after listening to and understanding the patient’s
feelings. Indeed, many years after diagnosis (mean time from
diagnosis was almost 12 years in this survey), an initial neg-
avative reaction can still be linked to problems a patient might
have living with diabetes, including a higher perceived disease
burden. It should however not be forgotten that therapeutic edu-
cation, while starting at the time of diagnosis, is a long-term and
continuous process throughout the disease course.

The type of patient–physician relationship is critical and
has a considerable impact on patients’ diabetes-related rou-
tines: effective lifestyle changes were more frequent as patients
 gained more autonomy and were more active in decision mak-
ing. Primary care providers should be encouraged to further
promote the benefits of diabetes self-management. The interna-
tional DAWN survey clearly showed the key role of an effective
patient–provider collaboration, which was positively associated
with all diabetes outcomes in the study [18].

Family support is important. Family members are frequently
involved and recognized as supportive: they act as counselors
encouraging diet and exercise behaviors, facilitating compli-
ance with medication, and altogether helping patients to “live
with the disease”. Interestingly, families seem to adapt to the
disease without changing their way of life: they did not really
behave differently towards patients. It is noteworthy that patients
declared eating the same as the household, highlighting the
importance and benefit of including family in lifestyle education
(as a healthy T2DM diet is good for everyone in the household
and not specific to the disease).

DIABASIS evidenced clear gender differences in the percep-
tion and self-management of disease. Women took the disease
more seriously, reported a higher impact on daily life and were
more engaged in self-management, while men tended to rely
more on family support. Physicians would do well to take these
differences in attitudes into account when they are counsel-
ing, educating and treating patients. A recent Canadian study
[19] suggested that men and women with T2DM have dif-
f erent psychosocial and clinical characteristics that can affect
their behavior toward self-care for diabetes, and consequently
their health outcomes (women valued support from their health
care team and saw self-management as beneficial while men
had lower expectations of the benefits of self-management).
The DAWN study [18] also found gender differences: men
reported less diabetes-related distress and greater well-being
than women. Interestingly, the study by Peel et al [20] to explore
patients’ attitudes to self-monitoring of blood glucose, further
highlighted relevant gender differences: women tended to see
readings as a proxy measure of ‘good’ and ‘bad’ behavior, blam-
ing themselves when readings were high. Men, on the other hand,
were more inclined to attribute high readings to external causes
such as their medication. Moreover, the ways in which partici-
pants made either internal (such as their food consumption) or
external (such as lack of medication) attributions for their blood
glucose readings affected their attitudes to self-monitoring: iron-
ically, participants who attributed their results to external causes
were more likely to continue self-monitoring than those (typi-
cally women) who blamed their own behavior for high readings
[20].

Some methodological limitations of the DIABASIS study
have to be acknowledged. The survey was not based on samples
randomly selected from the whole population but on the
permanent panel of a poll institute (which is frequently used
to complete epidemiological studies). This has to be weighed
against its main advantage of feasibility: the low cost and sim-
plicity of the quota method facilitate the study of large samples
with regular updates. A second limitation arises from the fact
that all the collected information is based on self-declaration.
However this led to valid data, as confirmed by the similari-
ties with both the ENTRED 2007 and ECODIA2 results [8,9].
Furthermore, a third of the self-reported HbA1c values could
be checked against a paper-copy and were found to be highly
consistent indicating the validity of the self-reports.

All in all, these findings point towards the interest of fine-
tuning the primary care provider’s approach to the individual
patient taking into account their disease perception. However,
because interpretations of the associations observed in this study
are largely speculative, the findings need to be further confirmed
and can only be considered as hypotheses for future research.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found,

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diabetes: relationship between disease management and quality of care.


