Fear of hypoglycaemia in patients with type 1 diabetes: Do patients and diabetologists feel the same way?

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Abstract

Aim. – This study described and compared the perception of hypoglycaemia in both patients with type 1 diabetes and diabetologists.

Methods. – This was an observational cross-sectional study undertaken in France in 2011. Data for what hypoglycaemia represents and practices related to it were collected using a questionnaire completed by patients with type 1 diabetes (all > 12 years of age) and their diabetologists. Agreement between patients and physicians was evaluated by the intraclass correlation coefficient (ICC) and Gwet’s coefficient (GC).

Results. – A total of 485 patients were enrolled by 118 diabetologists. Half the patients thought that hypoglycaemia was always symptomatic. According to both patients and diabetologists, hypoglycaemia impaired quality of life, caused anxiety and was disturbing, especially at night. Clinical symptoms of hypoglycaemia (sweating, shakiness, anxiety) were linked to patient’s age and diabetes duration. Regarding hypoglycaemia frequency, agreement was good for severe hypoglycaemia (GC: 0.61 and 0.72 for diurnal and nocturnal hypoglycaemia, respectively) and poor for mild hypoglycaemia (ICC: 0.44 and 0.40, respectively). Diabetologists correctly evaluated the impact of hypoglycaemia on quality of life, but overestimated the hypoglycaemia-induced burden and anxiety. Counteractive behaviours were frequent: 23% of patients decreased their insulin dose, 20% increased their sugar intake and 12% ate extra snacks. Diabetologists were generally aware of these measures, but not of how often patients used them.

Conclusion. – Diabetologists and patients do not share enough information about hypoglycaemia. Fear of hypoglycaemia and counteractive behaviours should be looked for by diabetologists. Systematic advice and specially adapted education should also be provided to increase patients’ awareness of hypoglycaemia.

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Keywords: Hypoglycaemia; Type 1 diabetes; Patient; Diabetologist; Fear of hypoglycaemia

Résumé

Les diabétiques de type 1 face au risque d’hypoglycémie : les patients et leurs médecins partagent-ils la même information ?.

Objectifs. – Décrire et comparer les représentations des hypoglycémies de diabétiques de type 1 et de leurs diabétologues.

Méthodes. – Une étude observationnelle transversale a été menée en France en 2011. Les données qui concernaient les représentations et les pratiques relatives aux hypoglycémies ont été collectées au moyen d’un questionnaire rempli par des diabétiques de type 1 (âgés de plus de 12 ans) et leurs diabétologues. La concordance entre les médecins et les patients a été évaluée par le coefficient de corrélation intraclasse (CCI) et par le coefficient de Gwet (CG).

Résultats. – Quatre cent quatre-vingt cinq patients recrutés par 118 médecins diabétologues ont été interrogés. La moitié des patients pensaient que les hypoglycémies étaient toujours symptomatiques. Les patients et leurs médecins s’accordaient pour considérer que les hypoglycémies étaient gênantes, surtout si elles survenaient au cours de la nuit ; elles altéraient la qualité de vie et étaient anxiogènes. Le profil symptomatique des hypoglycémies évoluait avec l’âge du patient et la durée du diabète (moins de tremblements ou de sudation excessive, davantage d’anxiété). En ce qui concernait la fréquence des hypoglycémies, la concordance entre patients et médecins était bonne pour les hypoglycémies sévères (CG : 0,61 et 0,72 respectivement pour les épisodes diurnes et nocturnes) mais faible pour les hypoglycémies modérées (CCI : 0,44 et 0,40, respectivement).

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Les médecins évaluaient correctement l’impact des hypoglycémies sur la qualité de vie des patients et surestimaient l’anxiété générée et la gêne occasionnée. Les conduites d’évitement (diminution de la dose d’insuline [23 %], ressacage excessif [20 %], collation de précaution [12 %]) étaient fréquentes d’autant plus que le patient était angoissé. Si les médecins n’ignoraient pas totalement l’existence de ces mesures, ils ignoraient à quelle fréquence leurs patients les adoptaient.

**Conclusion.** – Patients et médecins n’échangent pas suffisamment au sujet des hypoglycémies. Les médecins devraient évaluer davantage la crainte générée par les hypoglycémies des patients et les conduites d’évitement. Il semble nécessaire de proposer davantage d’activités d’éducation thérapeutique aux patients pour les rendre attentifs aux signes d’hypoglycémie.

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**Mots clés :** Hypoglycémie ; Diabète de type 1 ; Patient ; Médecin ; Crainte des hypoglycémies

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1. Introduction

Keeping blood glucose at near-normal levels delays the onset and progression of diabetic complications in patients with type 1 and type 2 diabetes, improves the quality of life and is cost-effective [1]. Hypoglycaemia is the most common adverse event associated with insulin treatment in type 1 and 2 diabetes patients [2]. However, the Diabetes Control and Complications Trial (DCCT) showed that strict glycaemic control resulted in a three-fold increase in the number of hypoglycaemic events in patients with type 1 diabetes [3], making hypoglycaemia a serious issue when aiming for tight blood glucose control. Hypoglycaemic episodes are unpleasant experiences with sometimes serious and even life-threatening consequences. Symptoms vary with age and usually decrease with diabetes duration [4]. Thus, it is extremely important for patients to recognize the early signs of hypoglycaemia. Indeed, hypoglycaemia unawareness is associated with a three- to 10-fold greater risk of severe hypoglycaemia (SH) [5].

Many patients with either type 1 or type 2 diabetes have a fear of hypoglycaemia (FoH) [6,7]. Patients and their relatives (parents [8], spouses [9] and children) share the same concerns about hypoglycaemia, especially nocturnal hypoglycaemia (NH) [10] and SH with loss of consciousness [11]. FoH is more important in patients with a history of SH [12–14], especially when episodes are frequent and the patient has previously experienced hypoglycaemic coma or been hospitalized [15]. Hypoglycaemia unawareness has also been found to be associated with FoH [13,16], and personality traits such as anxiety [14,17] contribute to the development and severity of FoH [2]. To avoid hypoglycaemia, patients may resort to counteractive measures such as decreasing their insulin dose [2,7], eating extra snacks [2], avoiding physical exercise [18,19] or raising their blood glucose targets [7,20]. Some researchers have found a positive relationship between FoH and HbA1c, suggesting that patients with high FoH levels may be less compliant or perhaps initiate wrong coping behaviours [2,4,20,21].

Patient education targeting improved prediction and avoidance of hypoglycaemia has been advocated [22,23], and education is now considered the cornerstone of diabetes management. Education improves patients’ self-management by increasing their knowledge of diabetes and its treatment as well as boosting their confidence in their own self-care abilities. As far as diabetologists are concerned, the education process requires knowledge of the patient’s beliefs, expectations and behaviours. This suggests that healthcare providers and their patients need to share information.

The ‘Perception and Reality’ survey was the first study designed to describe and compare the feelings of patients with type 1 diabetes and their diabetologists, as regards hypoglycaemia. In addition, as symptoms are known to vary with patients’ age, the patients’ answers and the concordance between patient–physician answers were analyzed according to age.

2. Methods

2.1. Patient selection

This observational multicentre, prospective, cross-sectional survey was undertaken in France between February and September 2011. The procedures used in the study were in accordance with the recommendations found in the Helsinki Declaration. Physicians were drawn from an extensive list of diabetologists practising in France in hospitals and in private practice, and the selected physicians were invited to participate in the study. They were asked about the criteria defining SH and whether they thought hypoglycaemic symptoms could occur for values >70 mg/dL. Diabetologists were also asked to enrol five consecutive patients meeting the inclusion criteria. Patients were eligible if they were >12 years of age, diagnosed with type 1 diabetes for at least 2 years and treated with a basal/bolus regimen (multiple daily injections or insulin pump). The diagnosis of type 1 diabetes was confirmed in a declarative way by each diabetologist. Patients using beta-blockers or who were unable to read and understand the questionnaire were not enrolled. All patients (or one parent if the patient was aged <18 years) gave their oral informed consent to participate.

2.2. Data collection

The patients’ and diabetologists’ questionnaires were collected separately so that physicians were totally unaware of their patients’ responses during the visit. Patients’ questionnaires were collected just before the visit so that patients and diabetologists could not have discussed hypoglycaemia before the visit. All questionnaires were anonymous, although a common identification number for each patient’s questionnaire and his diabetologist’s questionnaire allowed their questionnaires to be matched up for the concordance studies. These patients’ and diabetologists’ questionnaires are available online (Supplementary...
data, questionnaires S1 and S2 are in French, and S3 and S4 are in English). Data collected from patients included education level, knowledge of their own HbA1c target, their most recent HbA1c value, symptoms suggestive of hypoglycaemia, definition of SH, frequency of SH during the previous 3 months and frequency of mild hypoglycaemia over the previous week, blood glucose monitoring habits when experiencing hypoglycaemic symptoms and their blood glucose threshold for symptoms. Patients and physicians were asked to assess to what extent hypoglycaemia was disturbing, and how it impaired their quality of life and caused anxiety; using a 100-mm visual analogue scale (VAS) with 0 = ‘not at all’ and 100 = ‘very important’. Using a five-level Likert scale, patients also assessed their degree of agreement with 0 = ‘not at all’ and 100 = ‘very important’. Using a five-level Likert scale, patients also assessed their degree of agreement with 0 = ‘not at all’ and 100 = ‘very important’. Using a five-level Likert scale, patients also assessed their degree of agreement with 0 = ‘not at all’ and 100 = ‘very important’. Using a five-level Likert scale, patients also assessed their degree of agreement with 0 = ‘not at all’ and 100 = ‘very important’. Using a five-level Likert scale, patients also assessed their degree of agreement with 0 = ‘not at all’ and 100 = ‘very important’. Using a five-level Likert scale, patients also assessed their degree of agreement with 0 = ‘not at all’ and 100 = ‘very important’. Using a five-level Likert scale, patients also assessed their degree of agreement with 0 = ‘not at all’ and 100 = ‘very important’. Using a five-level Likert scale, patients also assessed their degree of agreement with 0 = ‘not at all’ and 100 = ‘very important’.

Concordance between patients’ and diabetologists’ answers was assessed by the intraclass correlation coefficient (ICC) [24]. This, however, is highly sensitive to high interrater agreement. Gwet’s coefficient (GC) [25] was preferred when conditions for using the ICC were not optimal. Agreement coefficients were based on the common principle of subtracting the probability that agreement was obtained by chance from the observed agreement. Estimation of the chance agreement probability is highly sensitive to either a high or low prevalence of the studied trait. This means that the agreement coefficient may be strikingly and counter intuitively low when the trait prevalence is either very high or very low. An ICC or GC equal to 1.00 represents the best agreement. Descriptive statistics were presented as means ± SD for continuous variables and as n (%) for categorical variables. Comparisons according to patients’ age were performed by analysis of variance (ANOVA) for continuous variables and Chi² or Fisher’s exact test for categorical variables.

2.3. Statistical analysis

Concordance between patients’ and diabetologists’ answers was assessed by the intraclass correlation coefficient (ICC) [24]. This, however, is highly sensitive to high interrater agreement. Gwet’s coefficient (GC) [25] was preferred when conditions for using the ICC were not optimal. Agreement coefficients were based on the common principle of subtracting the probability that agreement was obtained by chance from the observed agreement. Estimation of the chance agreement probability is highly sensitive to either a high or low prevalence of the studied trait. This means that the agreement coefficient may be strikingly and counter intuitively low when the trait prevalence is either very high or very low. An ICC or GC equal to 1.00 represents the best agreement. Descriptive statistics were presented as means ± SD for continuous variables and as n (%) for categorical variables. Comparisons according to patients’ age were performed by analysis of variance (ANOVA) for continuous variables and Chi² or Fisher’s exact test for categorical variables.

3. Results

Paired data (diabetologists and their patients) were obtained for 497 patients. Six patients failed to meet the inclusion criteria and six further patients were of unknown age, so these 12 patients were excluded from the analysis. The final analysis therefore included 485 patients. The patients were recruited by 118 French diabetologists, the majority (n = 79, 66.9%) of whom were working in hospitals either part-time or full-time.

The patients’ demographic and clinical characteristics are shown in Table 1. Mean age was 40.3 ± 17.7 years and 51.4% were female. Results were expressed according to age group (12–18, > 18–30, > 30–50, > 50–70 and > 70 years). Overall, 25 to 45.6% of the adult patients were highly educated and this proportion decreased with age. Mean duration of diabetes was 17.3 ± 12.1 years and increased with age. Target HbA1c values varied with age, with tighter target values for middle-aged patients. Diabetologists reported that HbA1c target values were achieved by only 28.3% of the patients. For 40.3% of the patients with HbA1c over target levels, the diabetologists believed that FoH was fully or partly responsible, with a greater influence of FoH in patients aged > 50 years (≤ 50 years old: 36%, > 50 years old: 53%; P < 0.01). A total of 215 patients (44.3%) reported a history of hypoglycaemic coma. HbA1c targets determined by the diabetologists were positively correlated with daytime SH (P = 0.001), nocturnal SH (P = 0.002) and nocturnal non-severe hypoglycaemic episode (P = 0.009) frequencies. Frequency of daytime non-severe hypoglycaemia had no effect on HbA1c targets set by the diabetologists (P = 0.27).

Regarding the clinical symptoms of hypoglycaemia, patients aged > 70 years less frequently reported shakiness, sweating and mental confusion than younger patients (P < 0.0001, P < 0.0001 and P < 0.01, respectively). On the other hand, patients aged > 70 years more often reported anxiety (P < 0.01). The mean threshold blood glucose level for hypoglycaemic symptoms was 61 ± 13 mg/dL, with a significant linear trend towards lower values with increasing age (P < 0.0001).

The proportion of patients reporting hypoglycaemic symptoms with glycaemia > 70 mg/dL increased with the patient’s age and decreased with duration of diabetes (from 21.4% in patients with diabetes duration < 5 years to 5.1% for those with diabetes duration > 20 years; P = 0.001).

When asked about the criteria used to define SH, 95.7% of the diabetologists and 82.4% of the patients reported the need for assistance (no significant difference between patients and diabetologists). Also, 94% of the diabetologists, but only 39.6% of the patients, thought that some hypoglycaemic episodes could be asymptomatic, suggesting that patients were often unaware of asymptomatic episodes. This may explain why only 67.8% of the patients (vs. 93.1% of the diabetologists) thought that hypoglycaemia could occur at night. Furthermore, 67% of the patients, but 96.6% of the diabetologists, thought that symptoms of hypoglycaemia could occur even if blood glucose levels were > 70 mg/dL. Almost one-third of the patients reported SH during diurnal and nocturnal periods (Supplementary data, Table S1).

Diabetologists and patients agreed on the frequency of SH within the previous 3 months. For diabetologists, 26.8% of the patients had experienced at least one severe diurnal hypoglycaemic episode within the previous 3 months whereas 31.1% of patients reported such an event (GC: 0.61, 95% CI: 0.56–0.67). Similar agreement was found for severe NH (23.5% vs. 28.7%, respectively; GC: 0.72, 95% CI: 0.68–0.77). Agreement was weaker for non-severe hypoglycaemic episodes within the last week (ICC: 0.44, 95% CI: 0.36–0.51) for daytime events; ICC: 0.40, 95% CI: 0.31–0.48 for NH). Overall, 80.0% and 54.8% of
the patients reported at least one episode of non-severe diurnal and night-time hypoglycaemia, respectively, during the previous week (Supplementary data, Table S1). When experiencing diurnal symptoms, 70.2% of the patients “often” or “always” monitored their blood glucose levels, whereas 60.5% did so for symptoms occurring at night. Agreement with the diabetologists’ opinion for monitoring blood glucose levels in the presence of symptoms of hypoglycaemia was moderate for diurnal and nocturnal symptoms, respectively. Diabetologists underestimated the burden of diurnal hypoglycaemia ($P < 0.01$), but generated higher levels of anxiety in older patients ($P < 0.001$ and $P < 0.0001$ for diurnal and nocturnal symptoms, respectively; Table 2). No relationship was found between duration of diabetes and discomfort, impact on quality of life or anxiety, and agreement between patients and their diabetologists was low or moderate: ICC was 0.41 and 0.29 for diurnal and nocturnal discomfort, respectively. Diabetologists underestimated the burden of diurnal hypoglycaemia ($P < 0.01$); the ICC was 0.43 for impact on quality of life. Anxiety was overestimated by diabetologists ($P < 0.01$ for hypoglycaemia occurring during the day and at night) and agreement was moderate (ICC was 0.42 and 0.46, respectively; Table 2). Finally, there was no relationship between anxiety caused by hypoglycaemia and HbA$_{1c}$ ($P = 0.94$).

Patients aged <60 years (the legal age of retirement in France at the time of the study) worried about having an accident at work (62.2%). In general, patients feared the possibility of negative consequences on diabetes control (60.0%), which had a significant linear positive relationship with age ($P < 0.01$). They also worried about embarrassing their relatives (58.7%) and sometimes thought that hypoglycaemia could make a negative impression (42.3%). Agreement between patients and diabetologists was low (ICC: 0.27–0.35) on these issues. Social consequences of FoH were frequent: 26.9% of the patients’ possible use of counteractive measures was partially known by the diabetologists, who nevertheless tended to overestimate their frequency: 23.0% of the patients frequently reduced their insulin dose or ate extra snacks ($P < 0.05$ and $P < 0.0001$, respectively). Similar results were found in patients who had experienced hypoglycaemic coma ($P < 0.05$).

Table 1
Patients’ clinical characteristics, target HbA$_{1c}$ levels and threshold of hypoglycaemia perception according to patients’ age.

<table>
<thead>
<tr>
<th>Age 12–18 years (n = 69)</th>
<th>Age &gt; 18–30 years (n = 81)</th>
<th>Age &gt; 30–50 years (n = 191)</th>
<th>Age &gt; 50–70 years (n = 115)</th>
<th>Age &gt; 70 years (n = 29)</th>
<th>Overall (n = 485)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Females (%)</td>
<td>29 (42.7)</td>
<td>52 (64.2)</td>
<td>91 (48.2)</td>
<td>63 (55.3)</td>
<td>12 (41.4)</td>
</tr>
<tr>
<td>Diabetes duration (years)</td>
<td>5.5 ± 3.2</td>
<td>10.6 ± 4.9</td>
<td>18.1 ± 9.9</td>
<td>24.0 ± 12.7</td>
<td>29.9 ± 17.9</td>
</tr>
<tr>
<td>HbA$_{1c}$ (%)</td>
<td>8.3 ± 1.4</td>
<td>8.2 ± 1.4</td>
<td>7.9 ± 1.2</td>
<td>7.6 ± 1.0</td>
<td>7.3 ± 0.8</td>
</tr>
<tr>
<td>Target HbA$_{1c}$</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 6.5%</td>
<td>1 (1.5)</td>
<td>15 (18.5)</td>
<td>25 (13.1)</td>
<td>9 (7.8)</td>
<td>0</td>
</tr>
<tr>
<td>&lt; 7%</td>
<td>15 (21.7)</td>
<td>42 (51.9)</td>
<td>121 (63.4)</td>
<td>62 (53.9)</td>
<td>11 (37.9)</td>
</tr>
<tr>
<td>&lt; 7.5%</td>
<td>38 (55.1)</td>
<td>16 (19.8)</td>
<td>40 (20.9)</td>
<td>27 (23.5)</td>
<td>14 (48.3)</td>
</tr>
<tr>
<td>&gt; 7.5%</td>
<td>15 (21.7)</td>
<td>6 (7.4)</td>
<td>4 (2.1)</td>
<td>14 (12.2)</td>
<td>4 (13.8)</td>
</tr>
<tr>
<td>Unknown</td>
<td>0</td>
<td>2 (2.5)</td>
<td>1 (0.5)</td>
<td>3 (2.6)</td>
<td>0</td>
</tr>
<tr>
<td>Target HbA$_{1c}$ value reached(^{\text{a}})</td>
<td>19 (27.9)</td>
<td>18 (24.3)</td>
<td>43 (23.0)</td>
<td>37 (33.6)</td>
<td>15 (53.6)</td>
</tr>
<tr>
<td>Target HbA$_{1c}$ value not reached because of FoH(^{\text{b}})</td>
<td>8 (16.7)</td>
<td>25 (45.5)</td>
<td>55 (39.0)</td>
<td>37 (52.9)</td>
<td>6 (54.5)</td>
</tr>
<tr>
<td>Threshold of diurnal hypoglycaemia perception(^{\text{c}})</td>
<td>0.67 ± 0.12</td>
<td>0.62 ± 0.12</td>
<td>0.61 ± 0.13</td>
<td>0.58 ± 0.12</td>
<td>0.56 ± 0.09</td>
</tr>
<tr>
<td>(min–max, g/L)</td>
<td>(0.30–0.95)</td>
<td>(0.30–0.90)</td>
<td>(0.20–1.0)</td>
<td>(0.30–0.90)</td>
<td>(0.40–0.80)</td>
</tr>
<tr>
<td>Threshold of nocturnal hypoglycaemia perception(^{\text{c}})</td>
<td>0.60 ± 0.15</td>
<td>0.58 ± 0.14</td>
<td>0.55 ± 0.12</td>
<td>0.50 ± 0.11</td>
<td>0.51 ± 0.08</td>
</tr>
<tr>
<td>(min–max, g/L)</td>
<td>(0.30–0.92)</td>
<td>(0.35–1.20)</td>
<td>(0.25–1.0)</td>
<td>(0.30–0.77)</td>
<td>(0.35–0.62)</td>
</tr>
</tbody>
</table>

Results are expressed as means ± SD or n (%); percentages are calculated from documented data; FoH: fear of hypoglycaemia.

\(^{\text{a}}\) Values missing for 18 patients.

\(^{\text{b}}\) Fully or partly responsible for not achieving HbA$_{1c}$ target value.

\(^{\text{c}}\) Patient’s perception.

\(^{\text{*}}\) $P < 0.0001$ (Anova).

\(^{\text{**}}\) $P = 0.0001$ (Anova).
Impact of hypoglycaemia according to patients’ and diabetologists’ assessments.

Results are expressed as means ± SD; impact on quality of life, discomfort and anxiety due to hypoglycaemia were assessed on a 100-mm visual analogue scale; * P < 0.01 between patients’ perception and physicians’ perception.

There was a significant impact of patients’ age on quality of life (P < 0.01) and on anxiety related to diurnal and nocturnal symptoms (P < 0.001 and P < 0.0001, respectively).

4. Discussion

looseness1 This observational survey has evaluated for the first time the concordance between patients’ and their diabetologists’ responses concerning hypoglycaemia, what it represents and its psychosocial impact. This study also evaluated the frequency of the various counteractive measures adopted by patients without recent discussions with their diabetologists. Doctors and patients did not share the same definition of hypoglycaemia, which can potentially lead to underestimation of hypoglycaemia frequency by patients, especially at night. Moreover, hypoglycaemia appears to be particularly worrying in the oldest patients. Physicians appeared to underestimate the inconvenience caused by hypoglycaemia (especially daytime episodes), yet overestimated the anxiety generated by hypoglycaemia. FoH and the possible counteractive behaviours should probably be looked for more often by diabetologists.

4.1. Frequency of hypoglycaemia

In all, 44% of the patients had a history of hypoglycaemic coma, and nearly one-third of the patients reported at least one severe daytime hypoglycaemic episode or one severe nocturnal episode within the previous 3 months. However, these frequencies may have been artificially increased, as no definition of hypoglycaemia was given to the patients before they answered their questionnaires. However, these hypoglycaemia frequencies were similar to those reported by others [30,31].

4.2. Fear of hypoglycaemia

According to diabetologists, FoH was reported to be at least partly responsible for patients being above their target HbA1c values, especially middle-aged and older patients. However, no relationship was found between the anxiety caused by hypoglycaemia and HbA1c values (P = 0.94). Some authors have reported a negative relationship between FoH and HbA1c, thus suggesting poorer compliance [2,4,20,21], whereas others have failed to find such a relationship [32–34].

4.3. Elderly patients

Patients aged > 70 years were more anxious about hypoglycaemia than were younger subjects. This might be explained by several considerations. First, older patients less frequently reported shakiness, sweating and mental confusion than did others (P < 0.001) when experiencing hypoglycaemia. Yet, other less-specific symptoms of hypoglycaemia, such as anxiety, were more often reported by patients in this older age group. This might be because the recognition of early symptoms of hypoglycaemia is more difficult for elderly patients, a point that has been reported elsewhere [35,36]. Interestingly, older patients also reported a lower glycaemic threshold for hypoglycaemia symptoms compared with younger patients and a similar trend was found with duration of diabetes, suggesting that hypoglycaemia unawareness occurred more frequently in elderly patients and in those with longer durations of diabetes. This ‘syndrome’ has been reported to affect around 25% of patients with type 1 diabetes [37]. The effect of age detected in the present study could not be explained by gender ratio. Anderbro et al. [13] found that FoH was more frequent in the female population, whereas the gender ratio for FoH was not influenced by age in our present population.

4.4. Poor agreement between patients and diabetologists

The most important and original finding of the present study was the poor concordance in answers between diabetologists and their patients regarding the definition, frequency and consequences of hypoglycaemia, and the patients’ counteractive
measures. When considering hypoglycaemia, patients referred more often to symptoms, whereas diabetologists referred preferentially to blood glucose levels. While 94.0% of the diabetologists knew about hypoglycaemia unawareness, only 39.6% of the patients were aware of the possibility of asymptomatic hypoglycaemia. This finding certainly explains why one-third of the patients believed that hypoglycaemia could not occur at night. Diabetologists and patients agreed on the frequency of SH within the previous 3 months, although agreement was weaker for non-severe hypoglycaemia. Nevertheless, accurate assessment of the frequency of mild episodes is still important as it has been shown that repeated mild hypoglycaemia has a negative impact on counter regulatory responses to hypoglycaemia and can progressively lead to hypoglycaemia unawareness and, therefore, to a three- to 10-fold greater risk of SH [5,16,21,38]. Diabetologists and patients both agreed on the psychosocial consequences of hypoglycaemia, although the patients’ anxiety was overestimated by diabetologists. While diabetologists were aware that some patients may take counteractive measures, they did not know precisely who did it or how frequently. It is noteworthy that 23.0% of patients regularly reduced their insulin dose, 20.1% regularly ate more sugar than required when experiencing hypoglycaemic symptoms, and 12.1% and 7.8% regularly ate extra snacks during the day and at bedtime, respectively. Regarding these behaviours, agreement between patients and diabetologists was low. Interestingly, anxious patients or those who had experienced hypoglycaemic coma were more likely to adopt such measures.

The agreement between patients and diabetologists was also low regarding the importance of glucose monitoring during hypoglycaemic events and needs to be improved because the feedback offered by self-monitored glucose monitoring data (including data related to hypoglycaemic episodes) could lead to improvement in overall glycaemic control and a reduction in moderate/severe hypoglycaemia [39].

This suggests that FoH should be addressed in educational programmes [2]. Specific educational interventions could become even more effective if they were designed for vulnerable patients, including those with a history of frequent hypoglycaemia, anxious patients, those with hypoglycaemia unawareness, those living alone and those with poor coping behaviours [2]. While providing training on early recognition and avoidance of SH, they could also encourage appropriate diabetes management behaviours [2,22,23]. Blood Glucose Awareness Training [22] is a specific training programme for diabetic patients designed to improve awareness of low blood glucose symptoms. The programme was shown to reduce both the frequency and fear of hypoglycaemia as well as the sense of loss of control or uncertainty associated with hypoglycaemia. This leads to improvement in terms of worry over hypoglycaemia [22] and quality of life. Nevertheless, education cannot be limited to just training for early recognition of hypoglycaemia symptoms as other aspects remain of tremendous importance. Indeed, teaching patients about insulin pharmacokinetics might even remove barriers to physical activity [19]. Patients should also be taught to more closely monitor their blood glucose levels particularly when experiencing mild non-specific symptoms, which could be early signs of hypoglycaemia [2].

4.5. Limitations

The present study has some limitations. Patients’ opinions may differ from what they really feel or do. This has already been reported [40] in patients with type 1 diabetes. Our present patients were asked to report any SH within the previous 3 months according to their own definition of it. This clearly can lead to inaccuracies even if most patients with type 1 diabetes had good recall of SH over a 1-year period [5]. It was also reported that patients with a high frequency of SH underreported the number of such episodes [5]. In addition, reports of mild hypoglycaemia did not extend beyond a week, as was previously recommended [30]. However, potentially the most important study bias was that patients were not randomly selected, thereby limiting how representative our present population was. Furthermore, as the proportion of patients aged > 70 years was small, this could have distorted interpretation of the data for this subpopulation. However, as expected, older people reported more anxiety over life conditions and expectations, and hypoglycaemia is likely to reinforce this feeling. Overall, our patients’ characteristics were similar to those reported in many previous studies. Moreover, our survey has probably helped diabetologists to pay more attention to hypoglycaemia. Above all, despite these potential concerns, our study has shown that the opinions of patients and diabetologists are rather different.

5. Conclusion

Diabetologists and patients do not share accurate information on the definition, frequency and consequences of hypoglycaemia, or on the potential counteractive measures resorted to by patients. The issue of hypoglycaemia remains a crucial aspect in the management of type 1 diabetes. Achieving good glucose control while limiting glucose fluctuations is challenging and requires optimal self-management by patients. In addition to the trust and honesty that characterize the relationship between patients and their doctors, both must also agree on how to recognize and prevent not only hyperglycaemia, but also hypoglycaemia. The collaborative care involving diabetologists and their patients also requires educational programmes focused on the importance of mild and severe hypoglycaemia.

Given the idiosyncratic nature of the symptoms patients may have, all patients should be asked about their own specific symptoms and information needs to be given to increase their awareness of hypoglycaemia. Elderly patients need special attention in this area. Also, the patient’s FoH needs to be evaluated to allow for the appropriate care and help. Finally, diabetologists should clearly question each patient on the possible counteractive behaviours they might resort to when facing the risk of hypoglycaemia. Correcting false beliefs, training patients on the early recognition of symptoms and discussing the subject of hypoglycaemia to avoid excessive counteractive behaviours would certainly contribute to better control of diabetes.
Disclosure of interest

All members of the GEODE group have served as members of medical advisory boards for LifeScan, a Johnson & Johnson company. Financial support for this study was also provided by LifeScan.

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All members of the GEODE group contributed to the design of the study, researched and interpreted the data, edited the manuscript and contributed to the discussion.

The authors are wholly responsible for the study design, analysis and scientific evaluation.

PB and EB researched and interpreted the data, wrote and edited the manuscript. EC and NC researched and interpreted the data, and reviewed and edited the manuscript. PB is the guarantor of this work and, as such, had full access to all data in the study and takes the responsibility for the integrity of the data and the accuracy of the data analysis.

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Appendix A. Supplementary data

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References