A total of 25,000 children under the age of 18 are currently living with type 1 diabetes mellitus in Germany, making this disease the most common childhood metabolic disorder in this country. Current estimates place the prevalence of type 1 diabetes in children and adolescents at 1:600, or 0.17% in Germany, with an annual increase in incidence of 3% to 5%. National (1, 2) and international evidence-based guidelines (3, 4, 5, 6) recommend that these patients be offered an ongoing integrated package of long-term care, including close coordination of inpatient and outpatient care, by a multidisciplinary pediatric diabetes team. This approach should aim not only for good glycemic control and the avoidance of severe hypoglycemia and ketoacidosis. It must also strive for physical, cognitive, emotional, and social development that is as close to normal as possible over the long term. Doing so requires, in addition to individually tailored insulin therapy, ongoing and age-appropriate diabetes education for young patients and their parents, as well as psychosocial support and social services to help patients and their families cope with living with this chronic disease.

In 1993, the first nationwide survey examining the state of diabetes care for children and adolescents with type 1 diabetes was conducted on behalf of the German Working Group on Pediatric Diabetology (Arbeitsgemeinschaft Pädiatrische Diabetologie; AGPD) (7). The results of the survey revealed a clear discrepancy between expectations and reality (8), leading the German Diabetes Association (Deutsche Diabetes-Gesellschaft, DDG) to introduce a variety of measures to improve the quality of care. These included

- Training and certification as diabetologists for pediatricians (DDG)
- Training and certification for diabetes nurse educators (DDG)
- Diabetes care specialization and certification for psychologists (DDG).

Additional measures included

- Developing, evaluating, and implementing pediatric diabetes education programs for children, adolescents, and parents (9)
Creating regional pediatric quality circles

Introducing a computerized diabetes information system (Diabetes Patienten Verlaufsdokumentation; DPV) for quality management in diabetology (10).

To assess the impact of these measures, the AGPD conducted a second national survey on the diabetes care situation as of 1998 in children's hospitals and pediatric units throughout Germany (11). The results of the survey showed a clear increase in the number of pediatric units that satisfied the quality standards set forth in national guidelines, as well as improvements in the density of care. However, the results also revealed regional variations and shortcomings, especially with regard to outpatient education and supportive services for children and adolescents with diabetes. The participating hospitals attributed the small number of outpatient services at the time to insufficient funding, in particular for non-medical staff (11).

A third national survey was scheduled to be conducted 5 years later with the aim of examining how supportive services and quality of care had progressed in the interim. This third survey was particularly relevant in light of the Type 1 Diabetes/Pediatrics Disease Management Program (DMP) (12), which was published in 2003 and stipulated that a certified pediatrician or pediatric health care unit always manage diabetes care in children and adolescents under the age of 16, and optionally manage diabetes care in young people under the age of 21. This raised the question of whether it would be possible to achieve and maintain this high standard of care throughout all of Germany (1).

Methods

In late 1998 and 2003, standardized questionnaires were sent on behalf of the AGPD to all children's hospitals and to all pediatric units in general hospitals listed in the annual German Hospital Index (13). Questionnaires were also sent to all private practices in Germany specializing in pediatric diabetes care; their addresses were obtained from the various Regional Associations of Statutory Health Insurance Physicians. In total, questionnaires were sent to 367 and 372 pediatric units for the years 1998 and 2003, respectively.

The standardized questionnaires were identical in both surveys and collected data on inpatient and outpatient care, including information about

- The number of diabetes team members
- The qualifications of the individual team members in the field of diabetology
- The proportion of patients treated on an inpatient basis during that particular year, including the indication for and length of inpatient stays
- The number of long-term outpatients, including the average frequency of visits per patient per year
- Outpatient and inpatient diabetes education
- 24-hour telephone access to advice from the diabetes team
- Quality management measures
- Reimbursement for outpatient care and diabetes education.

Respondents were asked to base their answers whenever possible on the data collected prospectively with the DPV system mentioned above (10). Data were collated centrally, checked for plausibility, and, if necessary, corrected after consultation with the respondents. Data processing and statistical analysis were performed using SPSS 13.1. The results are reported either as absolute frequencies or as percentages.

Results

The response rates were 79% (286 units) and 80% (298 units) for the years 1998 and 2003, respectively. A one-time telephone follow-up of non-responders revealed that lack of time and personnel was the main reason for not replying to the survey. There were no differences between responding and non-responding healthcare facilities in terms of their size, structure, or regional distribution across the German federal states.

In both surveys, 26% of respondents indicated that they had referred children with diabetes, following acute treatment, to specialized pediatric diabetes units for expert follow-up care. The remaining institutions (1998: n = 210 and 2003: n = 221) reported a total of 1 618 (in 1998) and 2 274 (in 2003) inpatient admissions of children or youth under the age of 18 with new onset diabetes. Initial treatment required an average of 16 inpatient days in 1993, 14 days in 1998, and 13 days in 2003.
A total of 6,107 and 8,836 children and adolescents with diabetes were admitted as inpatients in 1998 and 2003, respectively. The most frequent indication was individual optimization of glycemic control combined with diabetes education (28% versus 26%), followed by structured group education (19% versus 25%) and treatment of new onset diabetes combined with diabetes education (26% versus 25%). Acute complications made up only 5% and 4% (severe hypoglycemia) and 9% and 10% (ketoacidosis) of inpatient admissions. When providing these data, 76% of participating healthcare facilities with more than 10 cases of treatment per year based their responses on the data collected prospectively with the DPV information system (10).

**Qualifications of diabetes care teams**

In 1998, only 52 pediatric healthcare units had a diabetes care team that met the standards set forth in the guidelines, i.e. consisting of a DDG-certified pediatric diabetologist and a DDG-certified diabetes educator and offering a 24-hour telephone access to advice from the diabetes team and structured diabetes education. By 2003, however, this figure had increased to 94. The number of inpatient units with a DDG-certified pediatric diabetologist increased from 73 to 110 during that same period. Similarly, the number of institutions with a DDG-certified diabetes educator rose from 90 in 1998 to 125 in 2003.

In contrast to this decidedly positive trend, the number of patients with access to other certified professionals such as dieticians, psychologists, and social workers decreased between the two study periods, in particular in outpatient care. *Diagram 1* provides a summary of the different health-care professionals who participated on an inpatient basis in the initial treatment of children and youth with new onset diabetes, as well as in the education provided to parents. *Diagram 2* provides a summary of the different health-care professionals who participated in the long-term care of children and adolescents with diabetes in the outpatient setting.

**Long-term outpatient care**

In the healthcare units that participated in the surveys, a total of 10,990 and 14,198 children and adolescents under the age of 18 with diabetes were in long-term outpatient care in 1998 and 2003, respectively. Like the number of children with new onset diabetes, these figures also show that there has been a remarkable increase in the number of patients with type 1 diabetes in pediatric care despite the declining birth rate in Germany.

Comparing the size of outpatient clinics in 1998 to that in 2003 reveals a process of increasing centralization. Whereas 71% of children and adolescents were followed up in units with 60 or more outpatients in 1998, this figure had increased to 81% by 2003. In turn,
the percentage of patients followed up in outpatient clinics with fewer than 30 patients per year decreased from 9.8% in 1998 to 4.9% in 2003. In 1998, each patient made an average of 5.7 outpatient visits per year compared to 5.5 visits per year in 2003.

Reimbursement for outpatient care
In 1998, outpatient treatment and care were financed by means of special authorizations of hospital physicians or healthcare facilities in 93% of outpatient clinics. In 2003, 84% of diabetes units were reimbursed for outpatient care in this manner. This form of reimbursement limited the extent to which services provided by non-physician team members could be billed, leading to deficiencies in this area of care for the affected institutions. Only 7% (1998) and 16% (2003) of these healthcare facilities were able to obtain funding for outpatient services – such as the regular follow-up education called for in the guidelines – through regional contracts as diabetes specialty practices.

Diabetes education
In 1998 only a very small number of children and parents were offered structured diabetes education in the outpatient setting (nationwide: n = 142). However, just 5 years later, a total of 2794 families were taking part in guideline-based education programs. The number of inpatient education programs for children and youth also rose between 1998 and 2003, showing that age-appropriate diabetes education is increasingly becoming the standard of care in pediatric treatment. Indeed, diabetes follow-up education, combined with the optimization of glycemic control, made up 47% (1998) and 51% (2003) of indications for hospital admission among children and adolescents with diabetes.

Regional distribution of care
A comparison of the different federal states in Germany (table) reveals that families – especially those in regions with low population density and a small proportion of persons under 18 years of age – have to travel long distances between their places of residence and a certified pediatric diabetes unit. The trend towards large, supra-regional centers becomes clear if we consider the disproportionately large number of patients in the federal states of Berlin, Hamburg, and Bremen. Faced with 5 to 6 outpatient visits per year and a number of additional appointments for diabetes education, many families must pay for the higher quality of centralized care with the additional burdens of long journeys and extra costs.
Discussion

Two nationwide surveys conducted on behalf of the German Working Group on Pediatric Diabetology (AGPD) for the years 1998 and 2003 were able to show continuous improvements in the qualifications of diabetes care teams and in the education of children and adolescents with type 1 diabetes in Germany compared to the first survey in 1993 (8). These improvements can be attributed primarily to the continuing medical qualification programs offered by the German Diabetes Association (DDG).

The number of healthcare units that satisfied the quality standards set forth in German and international evidence-based guidelines for the management of children and adolescents with type 1 diabetes (1, 2) almost doubled over the 5 year period between the 2 surveys. These improvements in care benefit a relatively high percentage of the estimated 25 000 diabetes patients under the age of 18 in Germany (14).

The few comparable representative international surveys in England (15) and Denmark (16) pointed to large discrepancies between the high-quality, nationwide pediatric diabetes care called for in national guidelines and the reality of medical care in these countries. In comparison, the findings of the present surveys indicate that the quality of medical care received by children and adolescents with type 1 diabetes in Germany is relatively high. This can also be seen when the quality of glycemetic control in children and adolescents with diabetes is compared internationally. Indeed, mean HbA1c levels and the number of acute complications in large, representative samples of pediatric patients in Germany are lower than those seen within comparable populations in other countries and can be regarded as relatively good overall. For example, the mean HbA1c levels in a population of 840 children and adolescents between the ages of 11 and 18 in Germany were 7.8% ± 1.5% (17) versus 8.7% ± 1.7% in an international sample of 2 101 patients in the same age range (18). It is

<table>
<thead>
<tr>
<th>Federal state</th>
<th>Number of pediatric outpatients with diabetes</th>
<th>Outpatient pediatric clinics or specialty practices</th>
<th>Outpatient clinics or specialty practices with diabetes care teams (i.e. certified diabetologist and diabetes educator)</th>
<th>Inhabitants &lt;18 years of age per recorded patient with diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baden-Württemberg</td>
<td>1 982</td>
<td>23</td>
<td>9</td>
<td>1 060</td>
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<tr>
<td>Bavaria</td>
<td>1 830</td>
<td>24</td>
<td>11</td>
<td>1 304</td>
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<tr>
<td>Berlin</td>
<td>812</td>
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<td>2</td>
<td>678</td>
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<td>Brandenburg</td>
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<td>0</td>
<td>6 565</td>
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<tr>
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<td>3</td>
<td>2</td>
<td>348</td>
</tr>
<tr>
<td>Hamburg</td>
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<td>4</td>
<td>4</td>
<td>455</td>
</tr>
<tr>
<td>Hessen</td>
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<td>7</td>
<td>1 577</td>
</tr>
<tr>
<td>Mecklenburg-West Pomerania</td>
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<td>1 162</td>
</tr>
<tr>
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<td>873</td>
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<td>Saarland</td>
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<td>1</td>
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</tr>
<tr>
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<td>3</td>
<td>1 330</td>
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<tr>
<td>Saxony-Anhalt</td>
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<td>1 056</td>
</tr>
<tr>
<td>Schleswig-Holstein</td>
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<td>3</td>
<td>1 496</td>
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<tr>
<td>Thuringia</td>
<td>404</td>
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<td>4</td>
<td>980</td>
</tr>
<tr>
<td>Total</td>
<td>14 198</td>
<td>175</td>
<td>94</td>
<td>1 083</td>
</tr>
</tbody>
</table>

* DDG, German Diabetes Association

**TABLE**

Number of outpatients with diabetes in 2003 in relation to the number of inhabitants under the age of 18 in each of Germany's 16 federal states. Outpatient healthcare units and teams consisting of a pediatric diabetologist and a diabetes educator (both DDG certified)*
important to consider, however, that glycemic control varied considerably among the centers within individual countries.

The response rate for both questionnaires was roughly 80%, and the participating healthcare units were comparable in terms of size and structure. Although a second data source for testing the external validity of this survey was not available, it should be noted that 76% of the facilities with at least 10 patients per year based their responses on data that had been collected prospectively with the nationwide DPV information system, which was designed for quality management in diabetology (10). Comparing the data from both surveys revealed remarkable increases over a 5-year period in the absolute number of cases of new onset diabetes, inpatient admissions, and patients receiving outpatient pediatric care. These findings correspond to those of recent studies that point to an increase in the incidence of childhood diabetes (1, 14). It is to be expected that the number of children and adolescents in Germany who are dependent on long-term diabetes care administered by skilled professionals will continue to grow.

Between 1998 and 2003, the number of pediatric units with fewer than 60 outpatients decreased steadily in favor of a centralization of long-term care. A similar trend could be observed in the inpatient treatment of children and adolescents with new onset type 1 diabetes. For many parents, this process of centralization entails longer journeys, meaning increased costs and lost time. In socioeconomically disadvantaged groups, in particular, this development carries with it the risk of suboptimal diabetes care in children, leading over the long-term to social disparities (19). Compensation is not generally provided to families affected in this manner.

**Conclusion**

The current, far-reaching changes in the way the German healthcare system is financed will have a variety of impacts in the coming years on the quality of care provided to children and adolescents with type 1 diabetes. Under Germany’s new inpatient prospective payment system based on diagnosis-related groups, opportunities for funding multidisciplinary diabetes care teams will be limited. A decrease in the number of specialized non-physician team members is to be expected, especially in mid-sized regional centers (20). Continued decreases in the length of hospital stays for pediatric patients with new onset diabetes will make it more difficult for parents and children to prepare themselves adequately for coping with the everyday challenges of this life-long chronic condition, especially in families with additional psychosocial risk factors.

With regard to the outpatient sector, it is to be feared that funding under the so-called EBM 2000plus doctors’ fee scale in Germany will not be sufficient to cover the expense of professional and age-appropriate care delivered by a multidisciplinary team (21). The extent to which the Type 1 Diabetes/Pediatrics Disease Management Program will be able to finance, and thus maintain, the current high quality of care in children and adolescents with type 1 diabetes in Germany remains to be seen. Despite clearly positive achievements over the past several decades, the first effects of these changes are already making themselves felt in the decreasing number of non-physician professionals in outpatient care, such as dieticians, psychologists, and social workers. Although they are recommended in the guidelines, individuals from these occupational groups – unlike diabetologists and diabetes educators – are not required for a facility to be recognized as a pediatric diabetes care center. Considering the increasing number of chronically ill children with additional psychosocial risk factors, such as having divorced parents or coming from educationally disadvantaged or migrant families, this development is cause for concern. This is confirmed by a recent survey of 408 persons between 16 and 25 years of age in the DAWN Youth Study, in which participating patients criticized, in particular, a lack of psychological support (22).

As in other areas of pediatrics, such as oncology and neonatology, the trend towards centralization in the management of certain pediatric diseases also appears to have proved its worth in diabetology. Parents of children with diabetes are evidently willing to travel long distances if doing so means receiving high-quality, guideline-based treatment. Ensuring that these reference centers have sufficient structural and financial resources could help counter the current decline in psychosocial support services. Because of this, a new survey of fundamental data in pediatric diabetes care is highly advisable, especially in light of the changes currently underway in the German system of healthcare financing.
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Conflict of Interest Statement
PD Dr. Lange and Ms. Hildebrandt declare that no conflict of interest exists according to the guidelines of the International Committee of Medical Journal Editors.

Prof. Danne is chairman of the German Working Group on Pediatric Diabetology (Arbeitsgemeinschaft Pädiatrische Diabetologie e.V.).

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