



Long-term Occupational Consequences for Families of Children With Type 1 Diabetes: The Mothers Take the Burden

Diabetes Care 2021;44:2656–2663 | <https://doi.org/10.2337/dc21-0740>

Andrea Dehn-Hindenberg,¹
Heike Saßmann,¹ Verena Berndt,²
Torben Biester,³ Bettina Heidtmann,⁴
Norbert Jorch,⁵ Su-Jong Kim-Dorner,¹
Katja Konrad,⁶ Eggert Lilienthal,⁷
Nicole Nellen-Hellmuth,⁸ Andreas Neu,⁹
Ralph Ziegler,¹⁰ and Karin Lange¹

OBJECTIVE

To investigate the occupational and financial consequences for parents following the onset of type 1 diabetes in their child.

RESEARCH DESIGN AND METHODS

A questionnaire assessing occupational and financial situations before and in the first year after the onset of diabetes was distributed to all families with a child ≤ 14 years of age at diagnosis with a diabetes duration of at least 12 months in nine German pediatric diabetes centers.

RESULTS

Data of 1,144 children (mean age at diagnosis 6.7 [3.6] years; 46.5% female) and their families were obtained. Mothers' occupational status reflected in paid working hours was significantly reduced in the first year after their child's diabetes diagnosis ($P < 0.001$). Overall, 15.1% of mothers stopped working, and 11.5% reduced working hours. Mothers of preschool children were particularly affected. Fathers' working status hardly changed ($P = 0.75$). Nearly half of the families (46.4%) reported moderate to severe financial losses. Compared with an earlier similar study in 2003, significant negative occupational consequences for mothers and financial burden on families remained unchanged in 2018 ($P = 0.59$ and 0.31, respectively).

CONCLUSIONS

Mothers of young children with newly diagnosed diabetes experienced negative consequences in their occupational situation. This inequality for mothers can have long-term negative consequences for their mental health and future economic situation. There is an urgent need for action to reduce the burden on families and to provide professional, social, and regulatory support, especially for mothers of young children with diabetes.

Diabetes is a chronic condition that requires constant monitoring to minimize acute and long-term negative effects. When a young child is diagnosed with diabetes, self-management of the disease is impossible. Therefore, the successful management of diabetes implies additional tasks and burdens for parents. Despite improved treatment options and the introduction of new technologies, diabetes therapy for young children is time consuming and challenging for parents (1,2).

¹Medical Psychology, Hannover Medical School, Hannover, Germany

²Social-Pediatric Centre Lichtenberg, Sana Hospital Group Berlin-Brandenburg, Berlin, Germany

³Diabetes Centre for Children and Adolescents, Children's Hospital Auf der Bult, Hannover, Germany

⁴Catholic Children's Hospital Wilhelmstift, Hamburg, Germany

⁵University Clinic for Pediatrics, Evangelisches Klinikum Bethel, Bielefeld University, Bielefeld, Germany

⁶Pediatrics, Elisabeth-Hospital Essen, Essen, Germany

⁷University Clinic, University Children's Hospital, Ruhr-University Bochum, Bochum, Germany

⁸Clinic for Pediatrics, Leopoldina-Hospital Schweinfurt, Schweinfurt, Germany

⁹Pediatric Endocrinology and Diabetes, Eberhard Karls University Tuebingen, Tuebingen, Germany

¹⁰Diabetes Clinic for Children and Adolescents Muenster, Muenster, Germany

Corresponding author: Karin Lange, lange.karin@mh-hannover.de

Received 5 April 2021 and accepted 26 September 2021

This article contains supplementary material online at <https://doi.org/10.2337/figshare.16689370>.

A.D.-H. and H.S. contributed equally to this work.

This article is featured in a podcast available at <https://www.diabetesjournals.org/content/diabetes-core-update-podcasts>.

© 2021 by the American Diabetes Association. Readers may use this article as long as the work is properly cited, the use is educational and not for profit, and the work is not altered. More information is available at <https://www.diabetesjournals.org/content/license>.

They are often tasked with delivering diabetes therapy every day while providing age-appropriate parenting, supporting the rest of the family, and balancing family life and their occupational demands (3,4). Family psychosocial factors have been shown to affect diabetes outcomes in children (5–7). Therefore, diabetes therapy should include the whole family and incorporate their needs and challenges in their professional and everyday lives (8–10) to achieve the most successful therapy outcome for the child with diabetes.

Despite the growing trend toward gender equality within families and shared parenting responsibilities, family health care is still predominantly considered a female task (11,12). Accordingly, providing care for a chronically ill child with diabetes can increase daily burdens for mothers (13–15). Because of the special demands of continuous self-administered therapy, parents of young children with complex chronic conditions, primarily mothers, reduce their professional engagement (15,16). These mothers reported higher parental distress, anxiety, and depressive symptoms than mothers of children without a chronic condition (15–17).

In 2003, occupational and financial consequences of diabetes onset in a child were assessed in a representative sample of parents from four German pediatric diabetes centers (15). Fourteen percent of mothers stopped working, with mothers of children younger than 6 years of age being particularly affected. Forty-four percent of the parents reported a moderate to severe financial burden resulting from their child's diagnosis. Other studies have also reported financial and occupational constraints in parents of young children with diabetes (18,19) and other severe diseases (16).

During the last decade, diabetes technology has improved tremendously (20,21), resulting in the reduction of acute complications (22,23). Currently available and widely used technologies such as insulin pumps (continuous subcutaneous insulin infusion [CSII]), continuous glucose monitoring (CGM), and sensor-augmented insulin therapy have a positive impact on children's metabolic control (24) and parental emotional well-being by reducing fear of hypoglycemia and depressive symptoms

(25,26). However, if the parents experience fewer occupational and financial burdens under current diabetes therapies remains unclear. Therefore, the aim of this study was to investigate the impact of diabetes onset in a child on the occupational and financial situations of the parents in the first year after diagnosis. Our goal is to highlight the burden of type 1 diabetes on families and provide necessary information to diabetes therapy/technology developers and policymakers to improve the quality of life of the families living with a child diagnosed with diabetes.

RESEARCH DESIGN AND METHODS

In 2018, a cross-sectional multicenter study was conducted at nine pediatric diabetes centers in Germany. The study procedures were approved by the Ethical Committee on Human Studies at Hannover Medical School (number 3689–2017; Hannover, Germany) in accordance with the Declaration of Helsinki.

Participants

The study participants were mothers, fathers, or other primary caregivers of children and adolescents diagnosed with type 1 diabetes visiting one of the nine pediatric diabetes centers for a routine quarterly checkup. Inclusion criteria were: child's age at diagnosis ≤ 14 years, diabetes duration of at least 12 months, and caregiver's ability to understand the German language sufficiently to complete the questionnaire.

Procedure

The eligible families were informed about the study procedure, its aims, anonymous data collection, and the analyses to be performed. The completed questionnaires were either collected in a closed box in each diabetes center or sent in anonymously using a prepaid envelope, addressed to the study center.

Questionnaire

A questionnaire constructed as part of a survey in 2003 (15) was used in the current study. The translated questions are presented in the Supplementary Material. The questionnaire captures changes in the occupational and financial situations of parents resulting from their child's

diagnosis of diabetes, including both parents' occupational status (based on hours of paid work per week before and during the first year after diabetes onset), constraints in professional development activities, and the financial loss as a result of the diagnosis. In addition, current clinical and sociodemographic characteristics were assessed. The questionnaire was completed by one parent for the entire family.

Data and Statistical Analyses

Data were double entered at the central administration center. Descriptive statistics are presented as means and SDs or absolute numbers and percentages. Local HbA_{1c} values were mathematically standardized to the Diabetes Control and Complications Trial reference range (4.05–6.05%) to adjust for different laboratory methods by using the multiple of the mean transformation method (27). Parents' occupations were classified into 4 groups according to the International Labor Organization (28) for paid hours of work per week: full time (≥ 37 h per week), part time (< 37), marginal (up to 12), and no professional occupation.

Group differences were analyzed by using the χ^2 test for categorical variables. The Wilcoxon signed rank test was used to compare the occupational differences before and the first year after the diagnosis, and the Mann-Whitney *U* test was used between the two independent groups for ordinal dependent variables. A logistic regression test was performed between parents' occupational changes (same vs. reduced work) following the diabetes onset as the dependent variable and child's age at onset, living arrangement (child living with both parents), parents' migration status, and professional qualification (university degree) as independent variables. Another logistic regression was performed between the subjective financial loss (no or minimal loss vs. moderate, substantial, or severe loss) as the dependent variable with the same abovementioned predictors.

Findings from this study were compared with data from a previous study conducted in 2003 (15) on the compatibility of modern pediatric diabetes therapies with the working and living situations of today's families.

Significance was set at a two-tailed level of $P < 0.05$. Missing variables were handled by using the pairwise deletion method to maximize all data available. All analyses were conducted using the statistical software package IBM SPSS version 25.0 (SPSS, Inc., Chicago, IL); Excel (Microsoft Office Professional Plus 2016) was used to create figures.

RESULTS

Study Population

Of 1,470 eligible families in the nine centers, 1,192 (81% response rate) agreed to participate and completed the questionnaire. A total of 48 questionnaires had to be excluded because of a high number of missing data. Thus, the final sample consisted of 1,144 families.

Participant characteristics are summarized in Table 1. A majority of respondents were mothers (82%), completing the questionnaire for the family. The children were diagnosed at a mean age of 6.7 (3.6) years, and the mean diabetes duration was 5.9 (3.8) years, with 85.9% and 99.0% diagnosed with diabetes in the past 10 and 15 years prior to the survey, respectively. Of them, 442 (40.5%) were diagnosed before the age of 6 years, 446 (40.9%) between 6 and 10 years, and 203 (18.6%) between 11 and 14 years. At the time of the survey, 62.5% of preschoolers, 62.5% of 6- to 10-year-olds, 45.0% of 11- to 14-year-olds, and 41.4% of >14-year-olds achieved the 2019 treatment target of $HbA_{1c} < 7.5\%$ (58 mmol/mol) according to the German guidelines (29).

The mean level of HbA_{1c} and the distribution of therapeutic principles as CSII and CGM in this sample were similar to the published data from Diabetes Patient Progress Documentation (Diabetes Patienten Verlaufsdocumentation) registry (29–31). The proportion of single parents in our sample was similar to that in the German population (19%) (32), and the number of families with a migration background was lower in this study compared with all families living in Germany but comparable to Diabetes Patienten Verlaufsdocumentation data (31,33).

Parents' Occupational Status Before and in the First Year After the Onset of Diabetes

Before diabetes diagnosis in their child, 22.8% of mothers were employed full

time, and in the year after diabetes diagnosis, 14.0% worked full time (Fig. 1A). Part-time employment was the same at 38.3% before and after diagnosis. The overall number of unemployed mothers increased from 25.8% prior to diagnosis to 33.7% in the first year following the diagnosis: on parental leave (7.7 and 7.5%), retired (0.3 and 0.4%), looking for work (1.1 and 1.8%), unspecified (2.0 and 2.1%), and being a homemaker (14.8 and 21.8%), respectively. Among previously working mothers, 15.1% stopped working, and 11.5% reduced working hours. The Wilcoxon signed rank test revealed that mothers' occupational status changed, reflecting reduced paid work hours in the year after their child's diabetes diagnosis ($z = -9.60$; $P < 0.001$). This significant change in employment status was found for all mothers, but mothers of preschool children were particularly frequently affected (Fig. 1B).

In contrast to the mothers, the working status of fathers hardly changed

($z = -0.31$; $P = 0.75$) (Fig. 1A). Overall, 91% of fathers worked full time before and in the year after the child's diabetes onset. This was the case regardless of the age of the child at diabetes onset. Approximately 5% of fathers were unemployed before and in the year after the diagnosis: on parental leave (before 0.2 and after 0.2%), retired (0.8 and 0.7%), looking for work (1.4 and 1.4%), unspecified (1.7 and 1.6%) and being a homemaker (0.9 and 0.9%), respectively.

Among the mothers initially working full time ($n = 257$), 21.4% changed their working status to part time, and 15.6% gave up their job in the year after diagnosis (Fig. 2A). This trend was more noticeable among mothers with a preschool child with diabetes (Fig. 2B). Furthermore, 10.9% of mothers working part time before diagnosis ($n = 431$) also stopped working completely. Among fathers who worked full time previously ($n = 986$), 1.2% switched to part time, and 0.6% stopped working after the diagnosis.

Table 1—Participant characteristics

	<i>n</i>	Mean (SD) or <i>n</i> (%)*
Youth characteristics		
Current age, years, mean (SD)	1,144	12.7 (3.9)
Sex	1,144	
Female		513 (44.8)
Male		591 (51.7)
Missing		40 (3.5)
Age at type 1 diabetes diagnosis, years, mean (SD)	1,091	6.7 (3.6)
Child's living arrangement	1,144	
With both parents		901 (78.8)
With a single mother		205 (17.9)
With a single father		17 (1.5)
With other primary caregivers or missing		21 (1.8)
One or more siblings	1,144	859 (75.1)
Current clinical characteristics		
Current HbA_{1c} , %/mmol/mol, mean (SD)		
All	1,003	7.67 (1.1)/60.3 (12.4)
<6 years	40	7.28 (0.7)/56.0 (7.7)
6–10 years	225	7.33 (0.9)/57.1 (9.8)
11–14 years	338	7.71 (1.2)/61.0 (13.1)
>14 years	365	7.87 (1.2)/63.0 (13.1)
Current use of CSII	1,135	740 (65.2)
Current use of CGM	695	202 (29.1)
Parent characteristics, mothers/fathers		
Completed the questionnaire	1,144	939 (82)/202 (17.7)
Born in Germany	1,113/1,008	935 (84.0)/835 (82.8)
Professional qualification	1,121/1,078	
University degree (associate degree and above)		348 (31.1)/429 (39.8)
Apprenticeship or traineeship		656 (58.5)/530 (49.2)
Other or no qualification		117 (10.4)/119 (11.0)
Age at child's diagnosis, years, mean (SD)	1,104/985	38.0 (6.4)/40.7 (7.1)

Percentages were calculated excluding missing values unless otherwise noted. *Values are *n* (%) except where mean (SD) is specified in the left column.

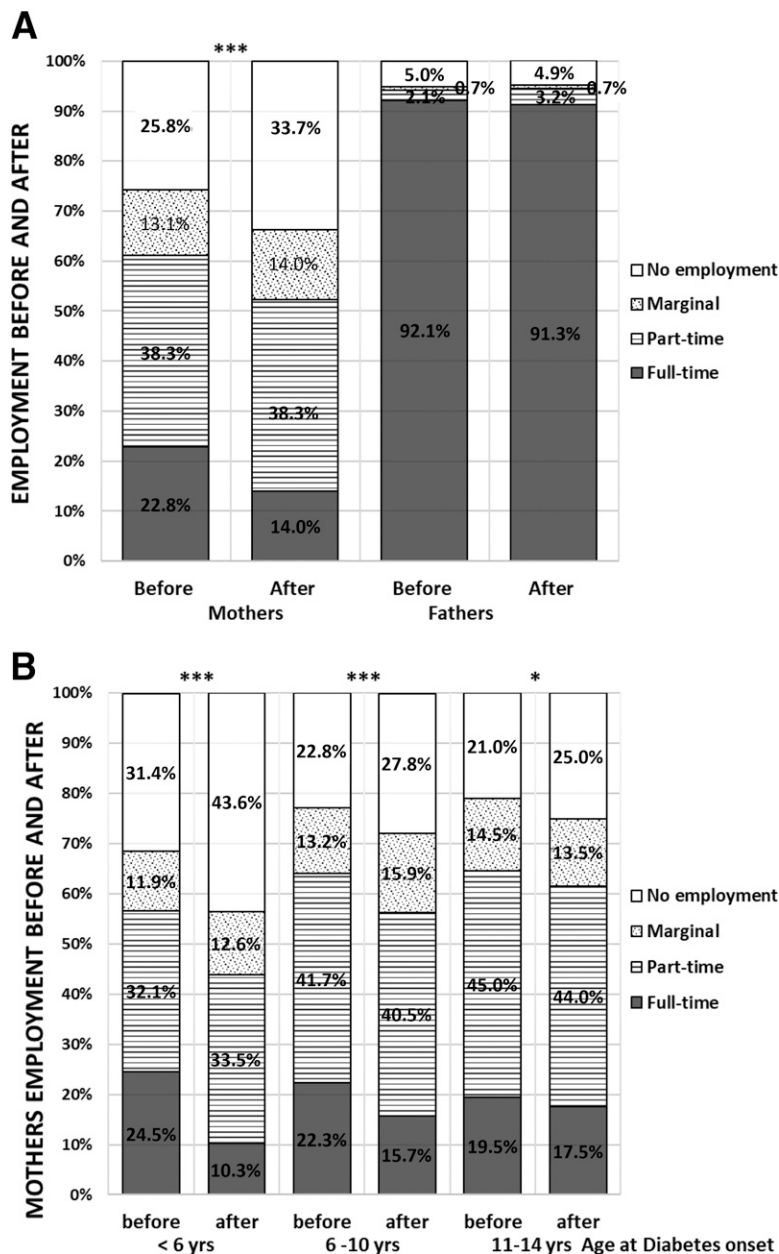


Figure 1—A: Employment status of mothers and fathers before and in the first year after the diagnosis of type 1 diabetes in their child. B: Employment status of mothers before and in the first year after the diagnosis in their child separated by the child’s age at diagnosis. The “no employment” category comprises parental leave, retirement, seeking work, homemaker, or unspecified. Sample sizes were as follows: all mothers $n = 1,124$; all fathers $n = 1,070$; and mothers by the child’s age at diagnosis <6 years $n = 436$, 6–10 years $n = 439$, and 11–14 years $n = 200$. Before and after difference significant at $*P < 0.05$ and $***P < 0.001$ according to the Wilcoxon signed rank test.

Before diabetes onset, the working status of the parents mirrored the data on parental employment in Germany published by the Federal Statistical Office (34), with ~90% of fathers working full time and between 20 and 30% of mothers working full time and 40 and 60% part time, depending on the age of the youngest child.

The variables associated with mothers’ changing work status (same vs. less work) were examined using logistic regression, with child’s age at onset, child’s living arrangement, parents’ professional qualification, and migration status as predictors. The only significant predictor of mothers’ work change was the child’s age at diabetes onset. One-

year increase in the child’s age at diagnosis lowered the odds of reducing work among mothers by 13% ($B = -0.14 [0.03]$; $\beta = 0.87 [95\% \text{ CI } 0.83-0.91]$; $P < 0.001$).

The working status change (same vs. less work) among mothers in all nine participating pediatric diabetes centers was examined. The mothers’ working status change was not statistically different between centers ($\chi^2 [8] = 8.46$; $P = 0.39$). However, because the Berlin center is located in former East Germany (the German Democratic Republic), the data from the Berlin center ($n = 118$) were compared with those from the Hamburg center ($n = 198$), the second-largest city in Germany by population and located in former West Germany (the Federal Republic of Germany). Mothers at the Berlin center had significantly more full-time jobs before and in the first year after the diagnosis (54.2 and 39.8%, respectively) compared with the mothers from the Hamburg center (28.3 and 18.2%) (before $z = -4.71$; $P < 0.001$ and in the first year after $z = -4.72$; $P < 0.001$). These two groups of mothers did not differ in their professional qualification (university degree: Berlin 32.8 and Hamburg 32.8%). However, the proportion of mothers lowering paid working hours for these two groups was not significantly different (Berlin center mothers 21.2 vs. Hamburg center mothers 19.7%) ($\chi^2 [1] = 0.15$; $P = 0.70$). The fathers from both centers did not show a work status change in the year after the diagnosis; 105 fathers (96.3%) from the Berlin center and 176 (97.2%) from Hamburg retained the same work status after the diagnosis ($\chi^2 [1] = 1.14$; $P = 0.29$).

Parents’ Report of Constraints in Their Professional Development

Constraints in the other areas of professional development such as career planning and training or studies were assessed. Changes in career planning were reported by 15.1% of mothers, and 8.7% reported less participation in qualification courses. On the other hand, half of the mothers (50.7%) reported no negative impact on their occupational activities as a result of their child’s diabetes. A vast majority of

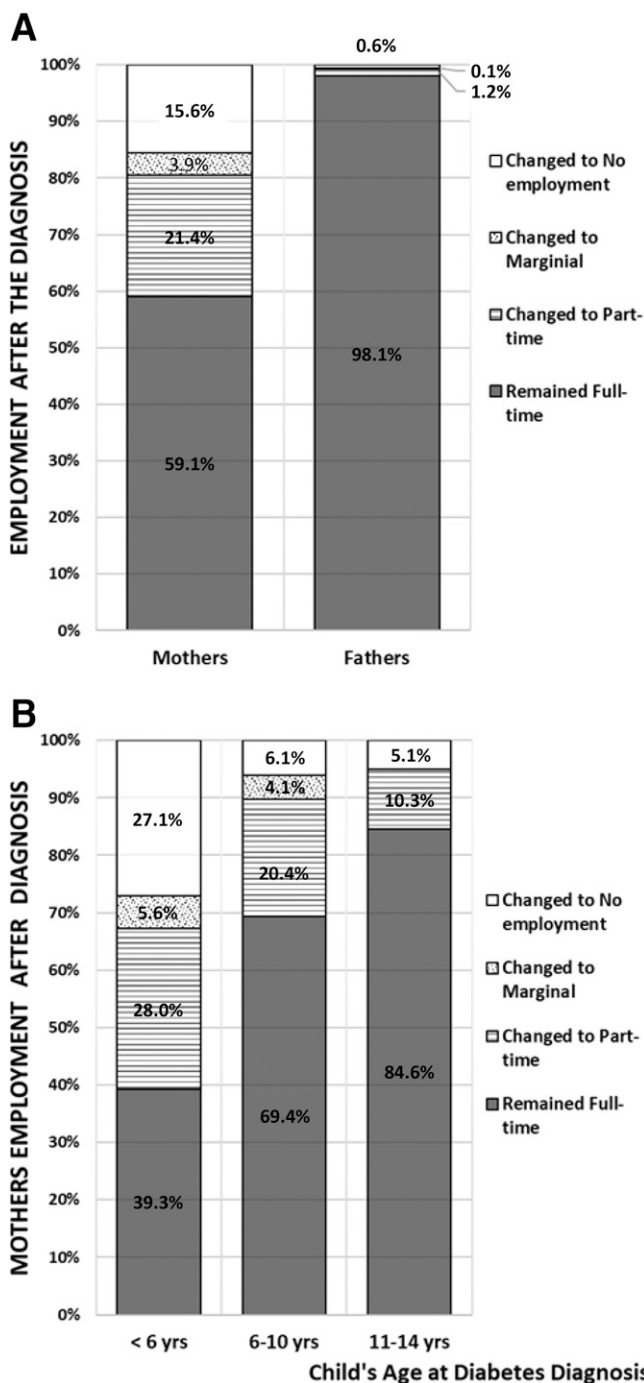


Figure 2—A: Employment status change in previously full-time working mothers and fathers in the first year after the diagnosis of type 1 diabetes in their child. B: Employment status change in previously full-time working mothers in the first year after the diagnosis of type 1 diabetes in their child separated by the child's age at diagnosis. The “no employment” category comprises parental leave, retirement, seeking work, homemaker, or unspecified. Sample sizes were as follows: all full-time working mothers $n = 257$; all full-time working fathers $n = 986$; and full-time working mothers by the child's age at diagnosis <6 years $n = 107$, 6–10 years $n = 98$, and 11–14 years $n = 39$.

fathers (95.9%) reported no changes in occupational activity.

Financial Burden Resulting From Diabetes Onset in a Child

Nearly half of the families reported a moderate to severe financial burden

(46.4%) after the onset of type 1 diabetes. The younger the child, the more severe the families' financial loss; 56.8% of the parents reported moderate to severe financial loss with a child diagnosed at age <6 years, 44.5% between 6 and 10 years, and 33.0% >10 years.

A logistic regression was performed to predict financial loss (no to minimal vs. moderate to severe loss) with child's age at onset, child's living arrangement, and parents' professional qualification and migration status as predictors. The results indicated that child's age at diabetes onset (older) ($B = -0.104$ [0.019]; $\beta = 0.90$ [95% CI 0.87–0.94]; $P < 0.001$), child living with both parents ($B = -0.49$ [0.19]; $\beta = 0.61$ [95% CI 0.42–0.89]; $P = 0.01$), and father's qualification (university degree) ($B = -0.36$ [0.15]; $\beta = 0.70$ [95% CI 0.52–0.94]; $P = 0.018$) all reduced the odds of reporting subjective financial burden. The father's status as an immigrant increased the odds of financial burden ($B = 0.57$ [0.26]; $\beta = 1.77$ [95% CI 1.08–2.92]; $P = 0.025$).

Comparison of Parents' Occupational Status and Financial Burden After a Child's Diabetes Diagnosis in 2003 and 2018

The first German multicenter study on this topic was performed in 2003 with 580 families from four diabetes centers (15). The children's mean age at diabetes onset was 6.9 (3.9) years in 2003 and is comparable to the current study, with a mean age of 6.7 (3.6) years. Among the sample in 2003, 10.5% were single-parent families compared with 19.6% in the current study (χ^2 [1] = 22.16; $P < 0.001$). In 2003, more mothers were not employed at their child's diabetes onset (39.5% compared with 25.8% in 2018) (χ^2 [1] = 52.67; $P < 0.001$). Among the mothers, 14% stopped working after the diagnosis in 2003, and 15.1% stopped in 2018 (χ^2 [1] = 0.30; $P = 0.59$). Similar to the current study, in 2003, few fathers with a newly diagnosed child reported changes in their work situation; 1.9% of fathers stopped working in 2003, while 0.7% stopped working in 2018 (χ^2 [1] = 4.57; $P < 0.05$). The proportion of families reporting moderate to severe financial burden because of diabetes onset in their child was comparable, with 43.8% in 2003 and 46.4% in 2018 (χ^2 [1] = 1.04; $P = 0.308$).

CONCLUSIONS

The current study examined families' occupational changes and financial burden in the first year following the

diabetes diagnosis in a child, with a focus on a large sample of 1,144 families from diabetes centers across Germany. Our findings demonstrated that mothers, rather than fathers, compromised their occupational success to provide care for the child with diabetes. Reduction in paid working hours was found among mothers regardless of the center location or the size of the medical center's catchment area. The only explanation for this working status change was the child's age at diagnosis. Moreover, the high response rate of parents to participate in the study (81%) further indicates that the compatibility of diabetes therapy and professional work is of great interest and relevant to parents. However, as evidenced in the uneven distribution of parents accompanying their children to the clinic and completing the questionnaire, diabetes care remains primarily the task of mothers.

Even today, the diagnosis of a chronic disease such as type 1 diabetes is almost exclusively associated with occupational stress and restrictions for mothers. This affects approximately half of all mothers, especially those with preschool-age children. Fathers, on the other hand, report negative occupational consequences only in exceptional cases. This is evident not only in diabetes, but also in other serious childhood diseases (16,35). In Germany, large gender-related inequalities still exist (36,37), and the politically desired joint management of child-rearing of mothers and fathers is difficult to master, even for families with healthy children (34,36). When a chronically ill child has to be treated and monitored continuously, the mother usually takes on these tasks at the expense of her own employment. Overall, the employment level of mothers after the diagnosis of any chronic disease in their child is below the national average (37), and this was also evident in the current study.

The reasons for this gender-specific work status change are unclear. The parents' decisions may be financially, emotionally, or socially motivated. Considering the gender pay gap, mothers reducing their working hours may result in less financial impairment for the entire family. Furthermore, mothers may have a strong emotional need to

be around their ill child or consider it socially more acceptable to work part time or as a homemaker than fathers, based on a traditional family model. This gender gap has been further highlighted recently with the COVID pandemic, where mothers accommodated changes in their work life when immediate support of children and household was needed (12). Alternatively, the parents' decision to reduce working hours may be in part due to insufficient support in nurseries, day care centers, and schools because of the high demands placed upon educators and teachers in monitoring a child using current diabetes therapies and technologies (38). Clearly, additional studies examining the reasons behind these decisions are warranted so that appropriate aid can be allocated based on their needs.

The very different behaviors along a gender-specific intrafamily division of labor also have an impact on the occupational positions of women and men throughout their lives (36). Despite recent family policy measures aimed at a more egalitarian division of labor, a vast majority of care-related career interruptions and reductions are seen among mothers. This has short- and long-term effects on gender equality in occupational as well as family life. The disadvantages resulting from this inequality are also reflected in the fact that women's average lifetime earnings and pension entitlements are only approximately half those of men. Even in the event of a divorce, the financial situation of mothers deteriorates, as would their pension provision as a result of the interruption of work. These financial losses are relevant not only for the individual, but also for society, because highly qualified women are missing in the labor market. Another consequence of the gender-specific imbalance in a child's diabetes care is that fathers are often excluded and feel incompetent to care for their own child, which can result in unfavorable family dynamics. A lack of support from their spouses can place excessive demands on mothers, which can threaten mothers' well-being by increasing diabetes-related distress, depression, and anxiety (8,39).

Since the first study in 2003, there have been significant changes not only

in diabetes therapy but also in the legal regulations in Germany (e.g., the extra-familial care of children and the gender-equitable implementation of parental leave). Nevertheless, the negative consequences of a diabetes diagnosis in a child with regard to maternal occupation remain unchanged. Since 2003, the overall proportion of working mothers has increased (36,37), and correspondingly, more mothers have experienced impairments to their activities. Statutory assistance in Germany has only been for short-term care of a sick child, not for long-term responsible treatment over years. Furthermore, the support that families with chronically ill children receive varies. The possibility of flexible working hours or a home office depends on the employer, and the support for a child's daily therapy is determined by each kindergarten and school (38). Diabetes education programs are available for teachers and carers; however, without a nationwide legal regulation around the responsibility and insurance of schools and kindergartens, these programs have not been successful in providing relief to these families.

New technologies, such as CGM and CSII, have significantly contributed to more stable metabolic control in patients and to parents' well-being by reducing fear of severe hypoglycemia in their child (21,22,40). These technologies, however, require consistent monitoring and competent handling, which demands constant supervision. If educators in day care centers and teachers in schools are willing to administer these therapies, they need extensive training (38). In recent years, the automated insulin delivery system has become more widely available; however, whether the use of automated technology can reduce the occupational burden among parents remains unclear. Further research on the use of automated insulin delivery technologies and the impact on parental employment is clearly warranted.

The current investigation has several weaknesses. The major weakness of this study was a potential recall bias, because we relied on self-reporting of participants, and the answers could not be verified. Similarly, the financial burden was based on self-reported burden rather than the exact amount that the family spent on diabetes-related care.

Another limitation is that nonresponders (19%) could have caused a selection bias that limits the generalizability of the study results, and a majority of respondents being mothers might have resulted in a bias. Furthermore, the short questionnaire did not ask for specific reasons for reducing or interrupting employment, the lengths of changed work status, or the distribution of parenting tasks. Such information could aid in providing more tailored assistance to these families, and additional investigations on these topics are needed. Lastly, the influence of diabetes technologies on mothers' occupational situation could not be investigated. In Germany, almost all children with diabetes younger than 6 years of age receive a CSII and an increasing number of children receive a CGM system at the time of diagnosis, and thus, the technology choice and use are confounded by the child's age at diagnosis. Therefore, an investigation regarding the choice and the influence of different diabetes technologies on mothers' occupational situation could not be executed.

In summary, mothers of young children diagnosed with type 1 diabetes experience significant employment and financial losses that can deteriorate their economic situation and mental health. A more equal division of diabetes care within the family and consistent support from work, childcare, and schools mandated by legal regulations can provide relief for parents in the family and professional spheres. Actions to reduce the burden and to provide professional, social, and regulatory support for mothers of young children with diabetes are urgently needed.

Acknowledgments. The authors are grateful to all investigators of the nine participating German pediatric diabetes centers: Social-Pediatric Centre Lichtenberg, Sana Hospital Group Berlin-Brandenburg, Berlin; Diabetes Centre for Children and Adolescents, Children's Hospital Auf der Bult, Hannover; Catholic Children's Hospital Wilhelmstift, Hamburg; University Clinic for Pediatrics, Evangelisches Klinikum Bethel, Bielefeld University, Bielefeld; Pediatrics, Elisabeth-Hospital Essen, Essen; University Clinic, University Children's Hospital, Ruhr-University Bochum, Bochum; Clinic for Pediatrics, Leopoldina-Hospital Schweinfurt, Schweinfurt; Pediatric Endocrinology and Diabetes, Eberhard Karls University Tuebingen, Tuebingen; and Diabetes Clinic for

Children and Adolescents Muenster, Muenster, Germany.

Funding. The study was supported by an unrestricted grant from diabetesDE-Deutsche Diabetes Hilfe (German Charitable Diabetes Foundation).

Duality of Interest. No conflicts of interest relevant to this article were reported.

Author Contributions. A.D.H., H.S., and K.L. organized and conducted the study, performed the statistical analysis, interpreted the results, proposed the structure of the paper, and formulated the paper. V.B., T.B., B.H., N.J., K.K., E.L., N.N.-H., A.N., and R.Z. collected data in their centers, critically appraised the paper, and made final suggestions. S.-J.K.-D. made substantial contributions to the data analysis and draft revision. All authors reviewed and revised the manuscript and agreed to the submission of the final manuscript. H.S. and K.L. are the guarantors of this work and, as such, had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Prior Presentation. Parts of this study were presented at the 45th Annual Conference of the International Society for Pediatric and Adolescent Diabetes, Boston, MA, 30 October–2 November 2019, and at the 54th Annual Congress of the German Diabetes Association, Berlin, Germany, 29 May–1 June 2019.

References

- American Diabetes Association. 13. Children and Adolescents: *Standards of Medical Care in Diabetes-2021*. Diabetes Care 2021;44(Suppl. 1):S180–S199
- Sundberg F, Barnard K, Cato A, et al. ISPAD guidelines. Managing diabetes in preschool children. *Pediatr Diabetes* 2017;18:499–517
- Commissariat PV, Harrington KR, Whitehouse AL, et al. "I'm essentially his pancreas": parent perceptions of diabetes burden and opportunities to reduce burden in the care of children <8 years old with type 1 diabetes. *Pediatr Diabetes* 2020;21:377–383
- Iversen AS, Graue M, Haugstvedt A, Råheim M. Being mothers and fathers of a child with type 1 diabetes aged 1 to 7 years: a phenomenological study of parents' experiences. *Int J Qual Stud Health Well-being* 2018;13:1487758
- de Beaufort CE, Lange K, Swift PG, et al.; Hvidoere Study Group. Metabolic outcomes in young children with type 1 diabetes differ between treatment centers: the Hvidoere Study in Young Children 2009. *Pediatr Diabetes* 2013;14:422–428
- Kordonouri O, Lange K, Biester T, et al. Determinants of glycaemic outcome in the current practice of care for young people up to 21 years old with type 1 diabetes under real-life conditions. *Diabet Med* 2020;37:797–804
- Cameron FJ, de Beaufort C, Aanstoot HJ, et al.; Hvidoere International Study Group. Lessons from the Hvidoere International Study Group on childhood diabetes: be dogmatic about outcome and flexible in approach. *Pediatr Diabetes* 2013;14:473–480
- Delamater AM, de Wit M, McDarby V, et al. ISPAD clinical practice consensus guidelines 2018: psychological care of children and

adolescents with type 1 diabetes. *Pediatr Diabetes* 2018;19(Suppl. 27):237–249

- Papadakis JL, Anderson LM, Garza K, et al. Psychosocial aspects of diabetes technology use: the child and family perspective. *Endocrinol Metab Clin North Am* 2020;49:127–141
- Haugstvedt A, Wentzel-Larsen T, Rokne B, Graue M. Psychosocial family factors and glycemic control among children aged 1–15 years with type 1 diabetes: a population-based survey. *BMC Pediatr* 2011;11:118
- Thiessen B. Geschlechteraspekte in der familialen Versorgung. In *Handbuch Geschlecht und Gesundheit*. Kolip P, Hurrelmann K, Eds. Göttingen, Germany, Hogrefe Verlag, 2016, pp. 349–359
- Collins C, Landivar LC, Ruppanner L, Scarborough WJ. COVID-19 and the gender gap in work hours. *Gen Work Organ*. 2 July 2020 [Epub ahead of print]. DOI: 10.1111/gwao.12506
- Haugstvedt A, Wentzel-Larsen T, Rokne B, Graue M. Perceived family burden and emotional distress: similarities and differences between mothers and fathers of children with type 1 diabetes in a population-based study. *Pediatr Diabetes* 2011;12:107–114
- Sullivan-Bolyai S, Deatrick J, Gruppuso P, Tamborlane W, Grey M. Constant vigilance: mothers' work parenting young children with type 1 diabetes. *J Pediatr Nurs* 2003;18:21–29. DOI: 10.1053/jpdn.2003.4
- Lange K, Danne T, Kordonouri O, et al. Diabetesmanifestation im Kindesalter: Alltagsbelastungen und berufliche Entwicklung der Eltern. *Dtsch Med Wochenschr* 2004;129:1130–1134 [in German]
- Hatzmann J, Peek N, Heymans H, Maurice-Stam H, Grootenhuys M. Consequences of caring for a child with a chronic disease: Employment and leisure time of parents. *J Child Health Care* 2014;18:346–357
- Van Gampelaere C, Luyckx K, van der Straaten S, et al.; Ghent University. Families with pediatric type 1 diabetes: a comparison with the general population on child well-being, parental distress, and parenting behavior. *Pediatr Diabetes* 2020;21:395–408
- Herbert LJ, Wall K, Monaghan M, Streisand R. Parent employment and school/daycare decisions among parents of young children with type 1 diabetes. *Child Health Care* 2017;46:170–180. DOI: 10.1080/02739615.2015.1124776
- Kimbell B, Lawton J, Boughton C, Hovorka R, Rankin D. Parents' experiences of caring for a young child with type 1 diabetes: a systematic review and synthesis of qualitative evidence. *BMC Pediatr* 2021;21:160. DOI: 10.1186/s12887-021-02569-4
- Gerhardsson P, Schwandt A, Witsch M, et al. The SWEET project 10-year benchmarking in 19 countries worldwide is associated with improved HbA1c and increased use of diabetes technology in youth with type 1 diabetes. *Diabetes Technol Ther* 2021;23:491–499
- Prahalad P, Tanenbaum M, Hood K, Maahs DM. Diabetes technology: improving care, improving patient-reported outcomes and preventing complications in young people with type 1 diabetes. *Diabet Med* 2018;35:419–429
- Tauschmann M, Hermann JM, Freiberg C, et al.; DPV Initiative. Reduction in diabetic ketoacidosis and severe hypoglycemia in

- pediatric type 1 diabetes during the first year of continuous glucose monitoring: a multicenter analysis of 3,553 subjects from the DPV registry. *Diabetes Care* 2020;43:e40–e42
23. Karges B, Schwandt A, Heidtmann B, et al. Association of insulin pump therapy vs insulin injection therapy with severe hypoglycemia, ketoacidosis, and glycemic control among children, adolescents, and young adults with type 1 diabetes. *JAMA* 2017;318:1358–1366
24. Biester T, Nir J, Remus K, et al. DREAM5: an open-label, randomized, cross-over study to evaluate the safety and efficacy of day and night closed-loop control by comparing the MD-Logic automated insulin delivery system to sensor augmented pump therapy in patients with type 1 diabetes at home. *Diabetes Obes Metab* 2019;21:822–828
25. Bisio A, Brown SA, McFadden R, et al. Sleep and diabetes-specific psycho-behavioral outcomes of a new automated insulin delivery system in young children with type 1 diabetes and their parents. *Pediatr Diabetes* 2021;22:495–502. DOI: 10.1111/pedi.13164
26. Burckhardt MA, Abraham MB, Mountain J, et al. Improvement in psychosocial outcomes in children with type 1 diabetes and their parents following subsidy for continuous glucose monitoring. *Diabetes Technol Ther* 2019;21:575–580
27. Nathan DM, Genuth S, Lachin J, et al.; Diabetes Control and Complications Trial Research Group. The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *N Engl J Med* 1993;329:977–986
28. International Labour Office. Ensuring decent working time for the future. Presented at the 107th Session of the International Labour Conference, 28 May–8 June 2018, at the Palais des Nations, Geneva, Switzerland
29. Neu A, Bürger-Büsing J, Danne T et al. Diagnosis, therapy and follow-up of diabetes mellitus in children and adolescents. *Exp Clin Endocrinol Diabetes* 2019;127(Suppl. 01):S39–S72
30. DeSalvo DJ, Miller KM, Hermann JM, et al.; T1D Exchange and DPV Registries. Continuous glucose monitoring and glycemic control among youth with type 1 diabetes: International comparison from the T1D Exchange and DPV Initiative. *Pediatr Diabetes* 2018;19:1271–1275
31. van den Boom L, Karges B, Auzanneau M, et al. Temporal trends and contemporary use of insulin pump therapy and glucose monitoring among children, adolescents, and adults with type 1 diabetes between 1995 and 2017. *Diabetes Care* 2019;42:2050–2056
32. Statistisches Bundesamt, Ed. Alleinerziehende—Ergebnisse des Mikrozensus, 2018 [Single parents—results of the microcensus, 2018]. Accessed 1 March 2021. Available from https://www.destatis.de/DE/Themen/Gesellschaft-Umwelt/Bevoelkerung/Haushalte-Familien/_inhalt.html#sprg233374
33. Bundesministerium für Familie, Senioren, Frauen und Jugend, Ed. Gelebte Vielfalt: Familien mit Migrationshintergrund in Deutschland, 2020 [Living diversity: families with a migrant background in Germany, 2020]. Accessed 1 March 2021. Available from <https://www.bmfsfj.de/bmfsfj/service/publikationen/gelebte-vielfalt-familien-mit-migrationshintergrund-in-deutschland-116882>
34. Hochgürtel T. Realisierte Erwerbstätigkeit zur Messung des Vereinbarkeitsarrangement von Familie und Beruf [Realised employment to assess the reconciliation arrangement of family and work]. Statistisches Bundesamt 2018. Accessed 3 March 2021. Available from https://www.destatis.de/DE/Methoden/WISTA-Wirtschaft-und-Statistik/2018/01/realisierte-erwerbstaetigkeit-012018.pdf?__blob=publicationFile
35. Limburg H, Shaw AK, McBride ML. Impact of childhood cancer on parental employment and sources of income: a Canadian pilot study. *Pediatr Blood Cancer* 2008;51:93–98
36. Brehm U. Innerfamiliäre Arbeitsteilung und die Gleichstellung der Geschlechter [Intra-family division of labour and gender equality]. Statistisches Bundesamt Datenreport 2021. Accessed 3 March 2021. Available from <https://www.destatis.de/datenreport>
37. Keller M, Kahle I. Realisierte Erwerbstätigkeit von Müttern und Vätern zur Vereinbarkeit von Familie und Beruf [Realised employment of mothers and fathers on the reconciliation of family and work]. Statistisches Bundesamt 2018. Accessed 3 March 2021. Available from https://www.destatis.de/DE/Methoden/WISTA-Wirtschaft-und-Statistik/2018/03/realisierte-erwerbstaetigkeit-032018.pdf?__blob=publicationFile
38. Gutzweiler RF, Neese M, In-Albon T. Teachers' perspectives on children with type 1 diabetes in German kindergartens and schools. *Diabetes Spectr* 2020;33:201–209
39. Nieuwesteeg A, Hartman E, Emons W, et al. Paediatric parenting stress in fathers and mothers of young children with type 1 diabetes: a longitudinal study. *Diabet Med* 2017;34:821–827
40. Pate T, Klemenčić S, Battelino T, Bratina N. Fear of hypoglycemia, anxiety, and subjective well-being in parents of children and adolescents with type 1 diabetes. *J Health Psychol* 2019;24:209–218