

REGULAR ARTICLE

Parental burnout in relation to sociodemographic, psychosocial and personality factors as well as disease duration and glycaemic control in children with Type 1 diabetes mellitus

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ABSTRACT

Aim: To examine associations between burnout and sociodemographic, psychosocial, personality and medical factors in parents of children with Type 1 Diabetes Mellitus (T1DM).

Methods: A total of 252 parents of children with T1DM participated in a population-based study. We used self-report questionnaires to assess symptoms of burnout and background factors.

Results: Psychosocial background factors were significantly associated with burnout in parents, whereas there were no associations between sociodemographic or medical factors and burnout. For both genders, parental burnout was associated with low social support, lack of leisure time, financial concerns and a perception that the child's disease affects everyday life. Low self-esteem and high need for control were risk factors for maternal burnout.

Conclusion: In the screening of risk factors for long-term stress in parents of children with T1DM, we should recognize parents' attitudes as well as situational psychosocial issues. In clinics, we need to pay attention to the day-to-day life circumstances in the support of these parents. Certain factors were associated with the risk for burnout only for mothers, which warrant further investigation of gender aspects. Continued research about the causal relationship between the parental responsibility, psychosocial factors and burnout is warranted.

INTRODUCTION

We have recently shown that burnout symptoms are over-represented in parents of children with a chronic disease compared with control parents (1). Burnout is a reaction to enduring stress that includes physical, emotional and mental exhaustion. It is caused by long-term stress in situations that are emotionally demanding (2,3) or when a person is threatened and obstructed in the performance of a role that is central to the person's identity (4). Moreover, burnout is a condition that may pose a serious health risk (5).

When a child is diagnosed with Type 1 Diabetes Mellitus (T1DM), the parents are informed that they themselves will have to take care of the treatment to a great extent. The treatment includes self-care with measurements of plasma glucose, adjustment of insulin injections, physical exercise and wholesome food intake. Some parents also have to deal with coeliac disease, and they may worry about hypoglycaemic episodes (6) and long-term complications (7). This extended parental responsibility can lead to stress for many years (8) also when the child grows up and the parents must gradually hand over the responsibility to the child (9).

Parental crisis reactions are seen at the time of diagnosis (10). However, there is limited knowledge of how parents' situation is influenced over time (11,12). Specifically, we need to know more about which factors influence this risk of long-term stress and burnout. Work-related research has observed risk factors and protective factors in the burnout process. Social support (13–15) and time for recovery (16) have a protective effect, while environmental factors and personality traits influence the burnout process in both

Key notes

- In clinical practice parents of children with Type 1 diabetes should be screened for the occurrence of burnout.
- Attention should be paid to some psychosocial factors associated with the development of burnout, especially in mothers.
- Affected parents must be offered professional support when needed.

directions (13,17). Other predictors for burnout are gender and socio-demographic factors (18). In addition, certain factors have an impact on parents' mental health when a child is ill: sleep disorders (19), support by the network (20), the impact of the disease on daily life (8) and the child's HbA1c value (21).

Considering the complex explanation model for burnout and the specific context of parenting a chronically ill child, the general aim of this study was to examine associations between burnout in fathers and mothers of children with T1DM and a number of factors known to be associated with burnout in other contexts. These factors related to *sociodemographic* (parent's and child's sex, education, employment and whether a parent is in a couple relation), *psychosocial* (perception of work strain, concerns about family finances, support from network, sleep deprivation, satisfaction with the couple relationship, time for recovery and the impact of the disease on daily life), *personality* (performance-based self-esteem, degree of control), and *medical aspects* (glycaemic control and duration of the T1DM disease).

METHODS

This paper reports results from a study on parents of children with T1DM recruited from the Department of Paediatrics, Örebro University Hospital, Örebro, Sweden. A first part about prevalence of burnout among parents of chronically ill children has been published (1).

Participants

A total of 354 parents (180 mothers and 174 fathers) of 187 children with T1DM were eligible and invited to participate in the study. The mean age of the children at the onset of T1DM was 7.5 (0.9–15.5) years, and the mean duration of their disease was 5.4 (0.5–16.5) years. One hundred and

seventy-four children were being treated with insulin injections, and 13 children were using an insulin pump. All the children performed several daily self-measurements of plasma glucose levels. Nine per cent of the children with T1DM also had coeliac disease.

The final study group comprised 142 mothers and 109 fathers of 148 patients. The response rate was 79.4% for mothers and 62.6% for fathers. Demographic information about the parents participating is presented in Table 1. The children of the participating and the nonparticipating parents did not differ regarding gender, age at T1DM onset or duration of the disease.

Procedure

The Regional Ethics Committee of Uppsala approved the study. Data on burnout and demographic, psychosocial, and personality factors were collected through self-report questionnaires, sent by mail to the participants' homes. The sampling and data collection procedure are described in further detail elsewhere (1).

Assessments

Burnout

To assess burnout, we used the Shirom–Melamed Burnout Questionnaire, SMBQ (5). This self-report instrument contains 22 items that measure different facets of the burnout syndrome. The response format is a Likert scale graded 1–7. Mean scores constitute the individual results, with a higher score reflecting more burnout symptoms. An estimation of *clinical burnout* was obtained based on the cut-off level set by Grossi et al. (22). A score of 3.75 or higher is assumed to indicate evident symptoms of burnout (22). The SMBQ has demonstrated satisfactory validity (22), and internal consistency in the present sample was excellent (Cronbach's Alpha 0.96).

Demographic factors

- Level of education was specified as compulsory school, high school or university.
- Level of employment was reported as working full time, part time or not working.
- Marital status was reported as either one parent or being married/cohabiting/being in a couple relationship (even without living together).
- The number of children in the family.
- The child's sex.
- The child's age in the analyses categorized into three groups: under 7, 7–12 or over 12 years.

Psychosocial factors

- Work stress was assessed with a single question 'Would you describe your work as stressful?'
- Financial stress was assessed with a single question 'Are you often worried about your finances?'

Table 1 Demographic data on parents to children with T1DM presented in mean (range) or percentage (n)

	Mothers (n = 142)	Fathers (n = 109)
Family factors		
Parent's age, mean (range)	42 (25–56)	44 (30–56)
Number of children in the family, mean (range)	2.5 (1–6)	2.5 (1–6)
Couple relationship, % (n)	87.3 (124)	85.3 (93)
Lone parent, % (n)	12.7 (18)	14.7 (16)
School education		
Compulsory school, % (n)	6.3 (9)	11.0 (12)
High school, % (n)	62.0 (88)	66.1 (72)
University, % (n)	31.7 (45)	22.0 (24)
Parental origin		
Swedish-born, % (n)	92.3 (131)	91.7 (100)
Immigrants to Sweden, % (n)	7.7 (11)	8.3 (9)
Employment		
Working full time, % (n)	47.2 (67)	90.8 (99)
Working part time, % (n)	43.7 (62)	3.7 (4)

- Partner support/strain in the couple relationship was assessed with a single item 'You are satisfied with your couple relationship'.
- The three aspects of general social support (emotional support, practical support and advice) were assessed with three single items: 'You get *emotional support* from relatives and friends', 'You get *practical support* from relatives and friends', and 'You get *advice* from relatives and friends'.
- Partner/family support regarding children in the family was assessed with a single item 'You share the responsibility for your children with another adult'.
- The parent's ability to ask for social support was assessed with a single question 'Could you ask relatives and friends for support to the extent that meets your/the family's need?'
- Perception of disease-related stressors was assessed with a single question 'To what degree are you affected by problems related to your child's disease in your everyday life?'

All the above items had a 4-graded response format ranging from negative to affirmative.

- Subjective view of the child's disease was assessed with a single question 'How seriously ill would you say that your child is?' This item had a 4-graded response format ranging from 'not at all' to 'very ill'.
- Opportunities to recover were assessed with two questions: 'To what extent do you have any leisure time of your own?' and 'To what extent do you and your partner have any leisure time together?' answered on a 9-grade Likert scale from '0 h/month' to '15 h or more per month'.
- Disease-related obstacles for recovery were assessed with a single question 'Is your sleep disrupted because your child's disease demands your care?' with an answer of yes or no.

Personality factors

- The Performance-Based Self-Esteem scale (PBSE) (23) consists of four statements: 'I think that I sometimes try to prove my worth by being competent'; 'My self-esteem is far too dependent on my daily achievements'; 'At times, I have to be better than others to be good enough myself'; 'Occasionally I feel obsessed to accomplish something of value'. The response format is a 5-grade Likert scale, 'Fully disagree' to 'Fully agree'. Mean scores constitute the individual results, with a score of 3.5 or more reflecting 'high PBSE' according to Hallsten et al. (23), Cronbach's alpha in the present sample was 0.85, indicating good internal consistency.
- The need for control was assessed with a single question 'To what extent do you need a high degree of control in your everyday life?' and a visual-analogue scale from 1 ('To a minimum extent') to 10 ('To a maximum extent').

Medical factors

- To assess the child's treatment outcome, we used the value of glycaemic control. Glycaemia control was assessed as the mean of the cumulative HbA1c measurements from capillary blood obtained at clinical consultations every third month for the last 2–5 years (DCA 2000, Bayer, Munich, Germany). The mono-S standard was used with a reference interval of 3.5–5.3%, and this method gives about 1% unit lower values than the DCCT standard (24). The mean cumulative HbA1c value was categorized into three groups: <6, 6–8 and >8%.
- According to the duration of the child's disease, parents were assigned to either of three groups: 'short' (<24 months), 'medium' (24–60 months) and 'long duration' (>60 months).

Statistical analyses and data management

Respondents who had left more than 25% of the items of a subscale in the SMBQ unanswered were excluded from the analysis of that subscale. For parents with 25% or fewer items unanswered, missing values were replaced with the individual mean score of the scale in question, a strategy following the lines of common practice. A disadvantage of this strategy is that we may lose extremely low or extremely high values, analogous to regression towards the mean. The gain, on the other hand, is that we are not forced to exclude respondents with occasional missing values. In total 23, such imputations were made for a total of 18 respondents.

To analyse any associations between clinical burnout and demographic, psychosocial, personality and medical variables, we used chi-square test (the 4-graded responses were dichotomized by merging the responses 1–2 and 3–4, respectively), Kruskal–Wallis test (for variables with three categories) and Mann–Whitney's *U*-test (for continuous variables). The analyses were carried out using Statistical Package for the Social Sciences (SPSS version 15.01; IBM, Chicago, IL, USA).

RESULTS

Prior to the analyses, we examined whether any background factors differ with regard to gender for the entire study group. For the following 4 of 21 variables, we found a significant difference between mothers and fathers. Mothers felt less than fathers that they had a shared responsibility for the child; mothers reported that they had less practical support from their network, and they also had less personal leisure time and greater need for control compared to fathers. The main results were analysed separately for mothers and fathers; 37.5% of the parents (44.4% mothers and 28.4% fathers) scored for clinical burnout (SMBQ ≥ 3.75).

Burnout and demographic factors

There were no associations between demographic factors including the child's sex and age, parent's education, marital status and clinical burnout in parents. It was not possible to

Table 2 Associations between psychosocial and personality background variables and clinical burnout among 142 mothers and 109 fathers of children with T1DM

	SMBQ <3.75 % (n) Mothers	SMBQ ≥3.75 % (n) Mothers	p-value	SMBQ <3.75 % (n) Fathers	SMBQ ≥3.75 % (n) Fathers	p-value
Psychosocial variables						
Work is not stressful	67.1 (49)	32.9 (24)	0.04	75.0 (45)	25.0 (15)	0.35
Work is stressful	49.1 (28)	50.9 (29)		66.7 (30)	33.3 (15)	
Finances are not a concern	62.4 (63)	37.6 (38)	0.01	77.6 (66)	22.4 (19)	0.00
Finances are a concern ^a	39.0 (16)	61.0 (25)		47.8 (11)	52.2 (12)	
Satisfaction in couple relationship	63.1 (70)	36.9 (41)	0.00	74.7 (65)	25.3 (22)	0.09
Nonsatisfaction in couple relationship	8.3 (1)	91.7 (11)		42.9 (3)	57.1 (4)	
Perception that the illness is serious	54.0 (61)	46.0 (52)	0.52	70.7 (58)	29.3 (24)	0.47
Perception that the illness is not serious ^b	60.7 (17)	39.3 (11)		78.3 (18)	21.7 (5)	
Illness not affecting everyday life	84.6 (22)	15.4 (4)	0.00	90.0 (27)	10.0 (3)	0.01
Illness affecting everyday life ^c	64.1 (50)	51.3 (59)		64.1 (50)	35.9 (28)	
No sleep disruption because of illness	75.4 (52)	24.6 (17)	0.00	78.7 (48)	21.3 (13)	0.06
Sleep disruption because of illness ^d	37.1 (26)	62.9 (44)		71.7 (76)	37.8 (17)	
Shared responsibility	57.5 (65)	42.5 (48)	0.29	72.5 (74)	27.5 (28)	0.82
Nonshared responsibility ^e	46.2 (12)	53.8 (14)		27.5 (28)	33.3 (1)	
Practical support	65.7 (44)	34.3 (23)	0.02	78.8 (52)	21.2 (14)	0.04
No practical support ^f	45.9 (34)	54.1 (40)		60.6 (26)	39.5 (17)	
Advice from network	60.5 (26)	39.5 (17)	0.42	71.4 (20)	28.6 (8)	0.96
No advice from network ^g	53.1 (52)	46.9 (46)		70.9 (56)	29.1 (23)	
Emotional support	61.7 (50)	38.3 (31)	0.07	75.0 (54)	25.0 (18)	0.23
No emotional support ^h	46.7 (28)	53.3 (32)		63.9 (23)	36.1 (13)	
Ability to ask for social support	62.7 (50)	37.5 (30)	0.04	78.6 (55)	1.4 (15)	0.03
No ability to ask for social support ⁱ	45.0 (27)	55.0 (33)		59.0 (23)	41.0 (16)	
Personality variables						
PBSE < 3.5	66.7 (72)	33.3 (36)	0.00	72.6 (61)	27.4 (23)	0.57
PBSE ≥ 3.5 ^j	21.2 (7)	78.8 (26)		66.7 (16)	33.3 (8)	

Pearson Chi-square test.

Exclusions of questionnaires because of missing data: ^aOne father; ^bOne mother, four fathers; ^cOne mother, one father; ^dThree mothers, three fathers; ^eThree mothers, four fathers; ^fOne mother; ^gOne mother, two fathers; ^hOne mother, one father; ⁱOne mothers; ^jOne mother, one father.

analyse the employment variable because the group of unemployed parents was too small.

Burnout and medical factors

No association was found between duration of the disease, or the child's HbA1c value (neither categorized into three groups: <6, 6–8, >8%, nor with a linear regression analysis of the continuous variable) and clinical burnout in parents.

Burnout and psychosocial and personality factors

Table 2 shows the associations between psychosocial, personality factors and burnout comparing proportions of fathers and mothers with a score ≥3.75 to fathers and mothers with a SMBQ score <3.75. There were significant associations for both mothers and fathers; however, the result differs with regard to gender. Mothers' results were significant in eight of twelve variables, while fathers' were

Table 3 Associations between psychosocial and personality background variables and burnout among parents of children with T1DM

	Mothers SMBQ <3.75 Mean (SD)	Mothers SMBQ ≥3.75 Mean (SD)	p-value	Fathers SMBQ <3.75 Mean (SD)	Fathers SMBQ ≥3.75 Mean (SD)	p-value
Personality variables						
Need for high degree of control (1–10) ^a	6.8 (1.9)	7.9 (1.7)	0.00	6.4 (2.0)	7.1 (2.1)	0.14
Psychosocial variables						
Own leisure time (h/month) ^b	5.6 (2.6)	4.6 (2.7)	0.03	6.6 (2.7)	5.2 (2.7)	0.01
Own couple leisure time (h/month)	4.3 (2.7)	3.5 (2.6)	0.03	5.1 (3.0)	3.4 (2.3)	0.02

Mann–Whitney *U*-test.

Exclusions of questionnaires because of missing data: ^aThree mothers, four fathers; ^bFour mothers.

significant in four variables. The associations between PBSE and burnout were only significant for mothers.

Table 3 shows mean values of psychosocial and personality factors of mothers and fathers with high or low SMBQ values. The associations between high needs of control and burnout were only significant for mothers.

DISCUSSION

The results indicate an association between certain psychosocial and personality factors and burnout in parents to children with T1DM. These associations seemed to be more prominent for mothers than for fathers. Moreover, the sociodemographic and medical factors analysed here were not associated with burnout.

The burden of parenting a child with T1DM affects day-to-day life and involves stressors that may even lead to burnout (1). In the present study, we analysed three aspects of stressors directly related to the disease. First, we used the children's HbA1c values, previously pointed out as a potential stressor for the parents (21). Second, parents were asked to report to what degree they considered their children to be seriously ill. Third, parents reported whether their everyday life was affected by problems related to their children's disease. Of these three factors, only the latter turned out to be related to burnout. This corresponds to previous findings that the subjective perception of a child's disease often predicts adverse outcome in parents, while objective measures of disease severity seldom does (11). Consequently, it is important to pay attention to parents' subjective reports of their life situation. However, parents may be reluctant to talk about their own situation during the medical consultation, not wanting the child to hear how they experience negative consequences of the disease. Jackson et al. (25) noted that mothers often experience guilt, blaming themselves for the children's problems. These factors can lead to a situation where the parent's needs are not noticed.

Sleep disruption is a well-known parameter related to burnout, both as a risk factor and as a symptom (22,26). Accordingly, sleep disruption related to the child's disease was associated with burnout in our study. Medical advice to parents includes taking blood samples at night only when necessary, for example during gastrointestinal infections or when evening glucose values are unusually low. Yet, fear of hypoglycaemia may lead to a need to check the blood glucose level during the night (6,8).

In addition to highlighting the risk factors for burnout, we need to examine the protective factors, represented in our study by the network support and the opportunity to have personal leisure time. Investigations of network support in the work area (13,14) as well as in childcare (20) report that support has a protective effect against stress. In the present study, parents with a limited practical support from their network and a low ability to ask their network for help more often scored for clinical burnout compared with parents for whom support was available. The complexity of obtaining practical help can be illustrated in our clinical experience that some parents report that people in their

social network express uncertainty and fear of taking care of the child's treatment. Considering the importance of the social support, one step may be to offer people in their social network information and education about the disease.

Recovery is an important factor in stress management, and one prerequisite for recovery is leisure time (16). Parents of children with a chronic disease often report that the care for the sick child takes a lot of time (20). Moreover, part of the parenting role is to put the child's needs first, and for many parents, it can be difficult to switch focus to their own needs. Our finding that clinical burnout was more prevalent among parents who reported less leisure time highlights the importance of encouraging parents to engage in personal leisure activities.

Work-related stress (15) and worries about personal finances (27) are two well-known predictors of burnout. As expected, these factors were associated with burnout in the present study. As the sample was too small for a multivariate analysis, future studies of parents of children with T1DM are needed to further investigate the associations between disease-related and nondisease-related stressors. For the present, we may conclude that parents of chronically ill children are exposed to concurrent stressors in different areas.

The findings of the present study indicate that performance-based self-esteem (PBSE), previously shown to be associated with work-related burnout (23), also seems to be associated with burnout in parents of chronically ill children. The model of PBSE is built on the concept of self-esteem, which strongly predicts life satisfaction and coping with stressful events (23). Drawing on the work of Gustafsson et al. (28), we may suppose that complex interactions between personality traits and the living conditions are involved in the burnout process. In addition, an emotionally demanding environment (3) and threat against one's role and performance (25) are predictors of burnout. The new parenting role can be experienced in this way for parents of a chronically ill child.

We also found that another personality trait, the need for a high degree of control, was associated with burnout. This trait has not been studied separately but there are similarities with the personality trait described as neurotic perfectionism (29). Moreover, caring for chronically ill children places great demands on the parental role and may further trigger control behaviour. However, even with intense efforts, it is not always possible to control plasma glucose levels, with the effect that parents with a need for a high degree of control may be particularly vulnerable to frustration and stress.

Several of the psychosocial and personality factors studied were associated with burnout in mothers, but only a few in fathers. A tentative explanation to this gender difference may be that mothers commit themselves to the care for an ill child more than fathers and therefore are more vulnerable to psychosocial and personality risk factors. The main responsibility for the home and family often falls on the woman (30). In our study, mothers reported a

feeling of shared responsibility for the child less than fathers did. However, this question was not associated with burnout in mothers or fathers, which may indicate that mothers' perception of main responsibility has no crucial meaning for the risk of developing burnout. Nevertheless, these factors should be further investigated in future research, using a more elaborate design. As regards the assessed personality traits, the findings may indicate a link between parenting and burnout, where gender differences in the form of mothers' greater involvement becomes a risk factor for chronic stress. Nonetheless, there may be other factors and personality traits that are of importance for burnout in fathers of children with T1DM than the ones we have studied.

One limitation of the study is the lower response rate among fathers, reflecting a tendency generally seen in studies of parents. Another limitation is the small sample, preventing us from doing multivariate analysis. Furthermore, comparing the results with parents to healthy children could be an aim for future studies. Despite the limitations, the strength of the study is the population-based design, with a good response rate from mothers and participation of both mothers and fathers.

CONCLUSION

In summary, we have demonstrated that being a parent of a child with T1DM and perceiving occupational or financial strain in daily life and/or obstacles to recovery is a risk factor for developing of clinical burnout. Gender seems to influence several aspects of a parents' life related to the risk of developing clinical burnout. Attention should be paid to the psychosocial situation and day-to-day life circumstances of these parents, and adequate support should be offered when needed. Longitudinal studies are needed to clarify the causal relationship between the parental responsibility, background factors and burnout of parents to children with T1DM or other chronic diseases.

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