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Increased prevalence of burnout symptoms in parents of chronically ill children

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Abstract

Aim: To examine the prevalence of burnout symptoms in the context of parenting a chronically ill child.

Methods: A total of 252 parents of children with Type 1 Diabetes Mellitus and 38 parents of children with Inflammatory Bowel Diseases participated in a population-based study. A control group consisted of 124 randomly selected parents of healthy children. We used self-report questionnaires to assess symptoms of burnout.

Results: The main finding was that significantly more parents of children with chronic diseases (36%) scored for clinical burnout, compared with parents of healthy children (20%). Burnout symptoms were most prominent among mothers of children with diabetes, although fathers of children with diabetes and mothers and fathers of children with inflammatory bowel diseases also reported higher levels of various burnout symptoms.

Conclusion: Burnout may be a useful model for understanding long-term parental responses and should be acknowledged among the different types of psychological consequences of the multi-faceted experience of parenting a child with chronic illness. Gender seems to influence the risk of burnout symptoms. Continued research about other background factors, and how the parents' situation changes over time are warranted. In the clinic, we need to draw attention to the group of parents who may suffer from burnout.

INTRODUCTION

The psychosocial support of the family is a very important part of the treatment when a child has fallen ill in a chronic disease. Many parents react strongly when they get information about the diagnosis of their child (1–3). Parents' reactions during the first period after the disclosure of the diagnosis have been systematically surveyed and a number of studies ask for research about parents' physical health and psychological reactions in the longer term. The knowledge of how parents' situation is influenced over time is limited. A few studies investigating this subject have reported different results, namely that parental stress associated with child illness decreases over time (4,5) or that the psychological reactions persist (6). Symptoms of burnout are more common for mothers of children with a mental handicap compared with mothers of healthy children (1). Likewise, a Swedish study has shown an increased burnout rate in parents of children surviving brain tumours compared with reference mothers of healthy children (7).

When a child is diagnosed with Type 1 Diabetes Mellitus (T1DM), the parents get information about the seriousness of this chronic disease and that the treatment will be taken care of by the parents to a great extent. This extended parental responsibility can lead to parental stress (2,8–10) and when a child diagnosed at young age is growing up, the parents must gradually hand over their knowledge and responsibility to the child (11,12).

The diagnosis of an inflammatory bowel disease (IBD) is often a more drawn out process. The disease has a variable intensity. During episodes of relapse, the children often perceive that the illness limits their everyday life, sometimes leading to isolation and long absence from school (15,16). The parents have to handle the child's illness with sensitivity as the symptoms can make the child feel ashamed, especially during their teens (13–15).

In the clinic, we meet parents of children with chronic diseases who say that their own behaviour has changed. It seems that many of these parents live with a protracted burden and has symptoms of listlessness and fatigue, a condition commonly referred to as burnout. For a long time, work-related research has established that a protracted load can lead to both physical and psychological fatigue (16,17). Pines & Aronsson (18) note that burnout occurs in situations that are emotionally strenuous. Hallsten (19) conclude that burnout occurs when a person, during a long period of stress, is threatened and obstructed in the performance of a role that is central for the person's identity. All together, there are several stress factors in the parent's daily life that over time can lead to burnout symptoms.

The general aim of this study was to examine the prevalence of burnout symptoms and whether the concept of burnout was applicable in the context of parenting a child who has become ill in a chronic disease. This study describes the occurrence of burnout symptoms among mothers and fathers of children diagnosed with T1DM and IBD, including a comparison with mothers and fathers of children with no chronic disease.

METHODS

Participants

A total of 418 parents were eligible and invited to participate in the study. Of these, 354 were parents to 187 children with T1DM (180 mothers and 174 fathers). Two mothers and nine fathers of these children with T1DM were not possible to reach. Five children with T1DM were siblings. The study also invited 64 parents of 32 children with IBD (32 mothers and 32 fathers).

The parents of children with T1DM and IBD were recruited from the Department of Pediatrics, Örebro University Hospital. This department takes care of all children with T1DM and IBD in the county of Örebro that has a total population of 350 000 inhabitants. All the patients had an ongoing contact with the department during the study period. The child should have been diagnosed at least 6 months before the time of data collection and should be at least 1 year but not older than 18 years of age. The parents should be able to read the Swedish language and to complete the questionnaire. Two parents were excluded on the basis of the language difficulties. On the basis of these inclusion criteria, we invited the participation of both fathers and mothers of all children with T1DM and IBD on April 2007.

Reference parents

We also invited 216 randomly selected control parents of healthy children (108 fathers and 108 mothers). The random sample of addresses was obtained from the National Register of Personal Addresses (SPAR, statliga personadressregistret). These reference data were collected from parents in the general community in the county of Örebro. In this study, the reference group was set to include only parents of children with no serious and chronic diseases. Therefore, questionnaires from parents with chronically ill children were excluded from the reference group and were replaced by other randomly selected parents to reach the estimated number of 216 invited reference parents.

According to a power calculation using SMBQ as the main variable with a mean value and standard deviation taken from parents of children with brain tumours (7), we calculated that 216 control parents were required in the control group to detect a statistically significant difference to the 418 eligible parents with chronically ill children using a significance level of 5% and 80% power with an estimated loss of 20% in the study group and 40% in the control group. In parents of children with T1DM, the response rate was 79.4% for mothers and 62.6% for fathers. In parents of children with IBD, the response rate was 65.6% for mothers and 54.8% for fathers. In the control group, the response rate was 64.0% for the mothers and 47.2% for the fathers.

Demographic comparison

Demographic information about the participants is presented in Table 1. There was a significant difference in age between the parents of the study and control group. There was, however, only a 3-year difference on average. The percentage of immigrants was higher in the control group. We therefore analysed the material without the immigrants; these results did not differ from the original analysis. To exclude the effect of having a child with an additional chronic disease besides T1DM or IBD, we also analysed the material without these parents. These results did not differ from the original analysis either.

Medical treatment and outcome in children with T1DM or IBD

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. A total of 174 children were treated with insulin injections, and 13 children were using an insulin pump (Medtronic, Minneapolis, CA, USA). All the children performed several daily self-measurements of plasma glucose levels. Nine percent of the children with T1DM also had Celiac disease. In the group of IBD patients, 11 children had Crohn's disease and 14 had ulcerative colitis. The mean age of the onset of IBD was 9.9 (3.1–14.9) years and the mean duration of their disease was 4.6 (0.9–13.6) years. The diagnosis was verified by enteral biopsy and treatment was given with corticosteroids and/or other anti-inflammatory drugs combined with enteral or parenteral nutrition during

Table 1 Demographic data on parents of children with a chronic disease and reference parents

	T1DM parents n = 251	IBD parents n = 38	Reference parents n = 124
Parent			
Mothers (%)	56.6	55.3	58.9
Fathers (%)	43.4	44.7	41.1
Parent's age, years, mean (range)	43 (25–56)	45 (36–58)	41 (21–61)
Living situation			
Living together (%)	86.5	86.8	87.8
Single parents (%)	13.5	13.2	12.2
Number of children in the family, mean (range)	2.2 (1–8)	2.8 (1–5)	2.5 (1–6)
Education			
Elementary school (%)	8.0	10.5	6.5
College/high school (%)	64.4	57.9	58.5
University (%)	27.6	31.6	35.0
Ethnicity			
Swedish-born (%)	92.1	97.3	85.4
Immigrants to Sweden (%)	7.9	2.7	14.6
Occupation/employment			
Working full-time (%)	66.1	68.4	71.8
Working part-time (%)	26.3	18.4	20.2
Other (%)	7.6	13.2	8.0

periods with more intensive disease activity. Enteral resection had been carried out in two patients.

Procedure

The Regional Ethics Committee of Uppsala approved the study. The study group and the reference group were invited with the same study procedure. Data were collected through self-report questionnaires, sent by mail to the participants' homes. All mothers and fathers received the questionnaire personally. In a family with both parents living together, two envelopes were sent. The letter also contained written information about the study, the questionnaires, a pre-paid reply envelope and a slip that parents could return if they chose not to participate in the study. Reminders were sent to the parents who had not returned a completed questionnaire or a non-participation slip 2 weeks after the distribution. The procedure was repeated after another 2 and 4 weeks. Finally, we telephoned the parents who had not answered. This procedure was applied in both the study group and the reference group.

Assessments

SMBQ

The Shirom-Melamed Burnout Questionnaire (SMBQ) (16) was used to assess burnout. The SMBQ highly correlated with the emotional exhaustion subscale of the Maslach Burnout Inventory and with the Pines Burnout Measure in a Swedish sample (20), indicating satisfactory validity. This self-report instrument contains 22 items that measure different facets of the burnout syndrome, as expressed by four subscales: *emotional exhaustion* and *physical fatigue* (8 items; below referred to as *exhaustion/fatigue*), *listlessness* (4 items), *tension* (4 items) and *cognitive difficulties* (6 items). The response format is a Likert scale graded 1 to 7. Mean scores constitute the individual results, with a higher score reflecting more burnout symptoms. In this study, scores for each subscale as well as an overall burnout index (SMBQ-total) were calculated for each participant.

Karolinska exhaustion scale

To extend the assessment of burnout, as the SMBQ mainly assesses psychological symptoms, the items that address physical and behavioural symptoms of burnout were selected from a questionnaire previously used in clinical diagnostics; the Karolinska Exhaustion Scale (authors Aleksander Perski and Giorgio Grossi, Karolinska Institutet, Stockholm, Sweden). Twenty-four items were selected and categorized by factor analysis into four subscales (Karolinska University Hospital, Stockholm): *memory* (2 items), *physical symptoms* (12 items related to somatic complaints; for example, headache, gastrointestinal–cardiovascular–breathing balance or skin symptoms), *sleep disturbance/fatigue* (6 items) and *emotions* (4 items).

The response format is a Likert scale divided into 5 grades, 'never' to 'always'. Mean scores constitute the individual results, with a higher score reflecting more burnout symptoms. Scores for each subscale were calculated for each participant.

Satisfactory to good internal consistency of the instruments was indicated in this study. The Chronbach's alpha value for SMBQ-total in the study group was 0.96 and in the reference group 0.94. For the subscales of SMBQ and the Karolinska Exhaustion Scale, Chronbach's alpha values varied between 0.71 and 0.94.

Data management

Respondents who had left more than 25% of the items of a subscale 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.

The self-reported burnout was analysed in two ways:

(1) An estimation of a clinical burnout was obtained by categorizing the parental SMBQ-total scores. This procedure was based on the cut-off levels set by Grossi et al. (20): respondents with a score of 3.75 or more indicated considerable burnout. In this study, a score of ≥3.75 was therefore referred to as a measure of clinic burnout, which can be assumed to indicate evident symptoms of burnout.

(2) Quantity of burnout symptoms in the form of the individual SMBQ-total and subscale scores as well as the Karolinska Exhaustion Scale subscale scores represented a level of different burnout symptoms in each parent.

Statistical analyses

By using a Chi-square test or Fisher's Exact test, the prevalence of clinical burnout in study and reference group was compared. The scores of burnout symptoms in the study group and reference group were compared by the Mann–Whitney *U*-Test.

RESULTS

The occurrence of clinical burnout

In the total study group, 104 (36.0%) parents of children with chronic disease scored for clinical burnout (SMBQ ≥3.75) compared with 25 (20.2%) of the reference parents ($p = 0.001$). Moreover, 70 mothers (42.9%) and 34 fathers (27.0%) of the study group scored for clinical burnout. The corresponding frequencies in the reference group were 15 (20.5%) for mothers and 10 (19.6%) for fathers. The difference in prevalence was statistically significant in mothers ($p = 0.001$), but not in fathers ($p = 0.304$).

When the rates of clinical burnout in parents of children with T1DM and IBD respectively, were compared with the control group, the difference in clinical burnout was significant only for mothers of children with T1DM compared with control mothers (Table 2).

Level of burnout symptoms

Mean values and standard deviations (SD) for the SMBQ total together with the subscales of SMBQ and the Karolinska Exhaustion Scale are presented for mothers (Table 3) and fathers (Table 4). The levels of all burnout symptoms were significantly higher for mothers of children with T1DM compared with reference mothers. For mothers of

Table 2 Prevalence of SMBQ-scores ≥3.75 in mothers and fathers of children with a chronic disease in comparison to reference mothers and fathers respectively

	T1DM parents % (n)		IBD parents % (n)		Reference parents % (n)	
	Mothers (n = 142)	Fathers (n = 109)	Mothers (n = 21)	Fathers (n = 17)	Mothers (n = 73)	Fathers (n = 51)
Burnout (SMBQ ≥3.75)	44.4 (63)	28.4 (31)	33.3 (7)	17.6 (3)	20.5 (15)	19.6 (10)

T1DM mothers vs reference mothers p = 0.001.

Table 3 Scores of burnout symptoms in mothers of children with a chronic disease in comparison to reference mothers

Main variables subscales	T1DM mothers			IBD mothers			Reference mothers	
	Mean	SD	p	Mean	SD	p	Mean	SD
Burnout (SMBQ-total)	3.64	1.37	0.001	3.65	1.26	0.054	2.99	1.51
Exhaustion/fatigue	3.59	1.54	0.002	3.57	1.20	0.023	2.91	1.24
Listlessness	3.97	1.38	0.001	4.32	1.36	0.004	3.30	1.27
Tension	3.78	1.49	0.004	3.65	1.63	0.210	3.15	1.24
Cognitive difficulties	3.37	1.61	0.012	3.33	1.48	0.135	2.76	1.31
KS burnout subscales								
Memory	2.69	0.91	0.005	2.87	0.88	0.021	2.32	0.96
Physiologically	2.10	0.72	0.000	2.08	0.68	0.024	1.76	0.70
Sleep/fatigue	2.60	0.78	0.000	2.65	0.89	0.008	2.10	0.70
Emotions	2.83	0.84	0.003	2.82	0.86	0.076	2.42	0.96

children with IBD, we found significant differences in five of the eight subscales compared with the reference mothers. Fathers of children with T1DM had significantly higher scores in four of the eight subscales, and for fathers of children with IBD, we found higher scores only in two of the eight subscales compared with reference fathers. For study parents, SMBQ-total scores ranged from 1.23 to 7.00 and for reference parents the scores ranged from 1.00 to 5.77.

DISCUSSION

The results from our study indicate that parents of chronically ill children have significantly more burnout symptoms than parents of healthy children. This difference was particularly pronounced for mothers of children with T1DM of who almost half reported burnout symptoms, compared with one-fifth of the mothers of healthy children.

Most previous studies of parents of chronically ill children have assessed parents' mental health in time periods soon after the diagnosis. The few previous reports of long-term parental reactions show different results (4–6). One explanation of the disparate findings may be that the researchers to some extent have addressed different types of reactions. Indeed, the previous studies have typically used general terms such as *mental illness* or *distress* for various psychological reactions.

In this study, the purpose was to examine burnout, which is a psychological reaction that does not belong to the reactions of a crisis period. Rather, burnout is the unfavourable consequence of long-term strain, and this psychological reaction is assumed to increase the risk for the development of a permanent physical exhaustion syndrome (21,22). Our definition of the concept emanates from a model defining burnout as a combination of emotional fatigue, physical

Table 4 Scores of burnout symptoms in fathers of children with a chronic disease in comparison to reference fathers

Main variables subscales	T1DM fathers			IBD fathers			Reference fathers	
	Mean	SD	p	Mean	SD	p	Mean	SD
Burnout (SMBQ-total)	3.23	1.14	0.154	2.82	1.12	0.750	2.91	0.89
Exhaustion/fatigue	3.22	1.30	0.251	2.79	1.27	0.750	2.92	1.09
Listlessness	3.58	1.19	0.615	4.06	1.65	0.115	3.45	1.19
Tension	3.56	1.39	0.048	2.76	1.47	0.313	3.12	1.28
Cognitive difficulties	2.74	1.32	0.161	2.08	1.09	0.265	2.40	1.15
KS burnout subscales								
Memory	2.49	0.86	0.221	2.75	0.86	0.040	2.29	0.80
Physiologically	1.71	0.59	0.006	1.81	0.67	0.047	1.44	0.39
Sleep/fatigue	2.33	0.72	0.008	2.14	0.77	0.555	2.00	0.61
Emotions	2.41	0.84	0.002	2.26	0.78	0.166	1.97	0.72

weakness and cognitive symptoms (16,17). Considering the seriousness of the physical exhaustion syndrome, it is of major importance to identify parents with burnout symptoms as early as possible (21). In addition, psychological reactions may affect the parent's ability to manage the child's treatment, and therefore influence the child's health and development (23,24).

The findings of this study may imply that parenting a chronically ill child can contribute to the development of burnout. Undoubtedly, certain features of both T1DM and IBD may be stressful for parents (25,26). However, the two diseases have different characteristics. T1DM is a disease where the patient can have some control over their blood glucose levels and thus prevent future long-term complications. In IBD, on the other hand, relapses can occur without any apparent cause, despite treatment including a daily intake of tablets. In our study, parents of children with T1DM reported higher levels of most burnout symptoms compared with the control group, which could not be established for parents of children with IBD. This may reflect differences in the parenting demands between the two diseases. However, parents of children with IBD also reported higher levels of certain burnout symptoms compared with the control group. Accordingly, we may suggest that not only specific disease conditions are of importance for the development of burnout but also common stress factors associated with the chronic disease situation. Both these diseases last over time, influence everyday life and may lead to serious complications (27,28). For example, it seems that the child's physical limitations have an important impact on mothers of children with T1DM and other diseases as expressed by high stress scores (24,25,27).

Burnout symptoms were more prevalent among mothers of children with T1DM than among mothers of healthy children, while the corresponding difference among fathers was less apparent. The same trend was found for parents' of children with IBD, a result also found by others (29). Furthermore, other studies have shown that being a mother of a chronically ill child is associated with higher frequency of parenting stress (3) and differences in child rearing (30). This can reflect that mothers often take the greatest responsibility regarding the child's illness, which could be one explanation for the gender differences in burnout symptoms (31). The fact that parenting often is regarded as the mothers' domain may also have contributed to the lower response rate among fathers, thus reflecting a tendency generally seen in studies of parents. However, we do not know whether the comparatively larger proportion of non-responding fathers actually hide individuals experiencing burnout symptoms. Indeed, whether fathers' withdrawal from participation in studies of parenting is a consequence of indifference, alienation or perhaps coping with distress remains to be explored. Nonetheless, our findings indicate that being a father of a child with T1DM or IBD was also a risk factor for certain aspects of burnout symptoms. Consequently, it is just as important to consider the fathers in the psychosocial support of parents.

One limitation of the study is the small number of parents of IBD patients. In fact, parents of children with IBD had results that could reach significance if a larger group had been examined. Another limitation is that the response rate reached the estimated number only for mothers of children with T1DM and for mothers in the control group. However, no differences were found regarding the distribution of children's age and gender among responders and non-responders, indicating no selection bias. Moreover, in the reminding telephone calls, some of the study parents informed that they refrained from participation because being reminded of the child's illness that would cause distress. Consequently, it is possible that the difference regarding burnout symptoms may be underestimated. Another weakness is that the Karolinska Exhaustion Scale, which is a clinical diagnostic tool, has not yet been validated for research. The strength of the study is the population-based design with a good response rate in the diabetic group and participation of both mothers and fathers.

CONCLUSION

In summary, we demonstrated that parents of chronically ill children report higher level of burnout symptoms than parents to healthy children. Our findings indicate that burnout should be acknowledged among the different types of psychological consequences of the multi-faceted experience of parenting a child with chronic illness. Adequate support should be developed for these specific groups of parents. Gender seems to influence the risk of developing burnout. Nevertheless, other factors can also have an important role, and continued research about different background variables in relation to burnout is therefore urgent. To study the causal relationships between responsibilities and stress of parents of children with chronic diseases, we need longitudinal studies.

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