



# **Burnout in parents of chronically ill children**

av

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## **Akademisk avhandling**

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## Abstract

Caisa Lindström (2016): Burnout in parents of chronically ill children  
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Parents of children with a chronic disease are usually highly involved in their child's treatment and may be affected by the heavy demands and constant stress. This can increase the risk of developing burnout, which is an individual reaction to long-term stress consisting of symptoms associated with emotional exhaustion, as well as physical and cognitive fatigue. The overall aim was to estimate the prevalence of burnout in parents of children with Type 1 Diabetes Mellitus (T1DM) and inflammatory bowel disease (IBD) (paper I), identify the risk factors associated with parenting a child with T1DM (paper II), explore how mothers suffering from burnout describe their mothering of a child with diabetes, with special focus on their need for control and Performance-based self-esteem (PBSE) (paper IV), and to evaluate the effect of a group intervention aimed at reducing stress-related symptoms (paper III). A total of 251 parents of children with T1DM, 38 parents of children with IBD and 124 parents of healthy children participated in a population-based study (I, II). The validated Shirom-Melamed Burnout Questionnaire (SMBQ) was used to assess burnout. 16 parents (SMBQ  $\geq 3.75$ ) participated in a group intervention and were evaluated for changes in SMBQ and PBSE (III). A total of 21 mothers of children with T1DM who scored for clinical burnout (SMBQ) participated in a qualitative study. Semi-structured interviews were conducted and Inductive content analysis was used (IV). In the study group 36.0% parents of children with a chronic disease scored for clinical burnout (SMBQ  $\geq 3.75$ ) compared to 20.2% of the reference parents ( $p=0.001$ ) with a preponderance of mothers compared to fathers, 42% vs. 20.5% ( $p=0.001$ ), respectively (I). Less support from the social network, sleep disturbances and lack of personal leisure time and recovery seem to be important risk factors for clinical burnout in parents of children with T1DM, especially mothers (II). Mothers' experiences of mothering a child with T1DM were interpreted as one theme; *Mission impossible*, illustrating the extremely difficult circumstances under which they bring up the child with diabetes to adulthood (IV). Parents' subjective evaluation of the intervention group was mainly positive and SMBQ ( $p=0.01$ ) and PBSE scale ( $p=0.04$ ) measurements were significantly reduced 6 months after completion of the intervention (III). It is important to pay attention to how parents and especially mothers experience their daily life in order to support those who are at risk of developing burnout.

**Keywords:** Burnout, long-term stress, parents, children, chronic illness, T1DM, IBD, intervention group.

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