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"Mission Impossible"; the Mothering of a Child With Type 1 Diabetes – From the Perspective of Mothers Experiencing Burnout

Caisa Lindström [a,*], Jan Åman [b], Annika Lindahl Norberg [c], Maria Forssberg [d], Agneta Anderzén-Carlsson [e]

[a] Department of Pediatrics, Faculty of Medicine and Health, Örebro University, SE 701 85 Örebro, Sweden
[b] School of Health and Medical Sciences, Örebro University, SE 701 82 Örebro, Sweden
[c] Unit of Occupational Medicine, Institute of Environmental Medicine, and Childhood Cancer Research Unit, Department of Women's and Children's Health, Karolinska Institutet, SE 171 77 Stockholm, Sweden
[d] Department of Pediatrics, Central Hospital, 651 85 Karlstad, Sweden
[e] University Health Care Research Center, Faculty of Medicine and Health, Örebro University, SE 701 82 Örebro, Sweden

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ABSTRACT

Purpose: To explore how mothers experiencing burnout describe their mothering of a child with type 1 diabetes mellitus (T1DM), with a focus on their experienced need for control and self-esteem.
Methods: This study used a qualitative, descriptive design and aimed to reveal the experience of mothering a child with diabetes when experiencing burnout. Twenty-one mothers of children with T1DM who were experiencing burnout participated in this study. Data were collected via semi-structured interviews, and content analysis was performed.
Results: The main results (latent content of the data) were interpreted in one theme, *Mission impossible*, an inner feeling derived from an extremely challenging experience of mothering, encompassing involuntary responsibility and constant evaluation. Two sub-themes emerged: *Forced to provide extraordinary mothering* and *Constant evaluation of the mothering*.
Conclusions: In addition to monitoring the health of the child with T1DM, it is important for clinicians to pay attention to how mothers experience their daily life in order to support those who are at risk of developing burnout, as well as those who are experiencing burnout. The wellbeing of the mother could influence the wellbeing of the child, as well as the entire family. Further research on perceived parental responsibility, gender differences, psychosocial factors, and burnout is needed.
Practice Implications: Knowledge and understanding of how mothers suffering from burnout experience mothering a child with diabetes could help nurses, social workers, psychologists and counselors conducting pediatric diabetes care become more attentive to the mother's situation and have procedures for counseling interventions.

Introduction

In daily life, a child diagnosed with diabetes is dependent on her/his parents to receive successful treatment. The parents are responsible for supporting the child and performing the treatment, including measurement of plasma glucose levels, adjustment of the insulin dose, promotion of physical exercise and provision of wholesome food, which together constitute a huge and important undertaking aimed at achieving good metabolic control in the child (Lowes, Gregory, & Lyne, 2005; Powers et al., 2002; Wennick & Hallström, 2007; Wennick, Lundqvist, & Hallström, 2009). The goal of diabetes treatment is to achieve near-normal plasma glucose levels without hyper- or hypoglycemia (Liberman, Buckingham, & Phillip, 2012). While tightly controlling HbA1c levels using more sophisticated techniques is beneficial to children (Nimri et al., 2006) by diminishing morbidity and mortality (Nordwall, Arnqvist, Bojestig, & Ludvigsson, 2009) there may be unintended consequences for the parents, for example, in the form of psychological distress (Whittemore, Jaser, Chao, Jang, & Grey, 2012).

Diabetes is a common chronic disease in pediatric care. In Sweden, 744 children under the age of 18 were diagnosed with diabetes in 2012. The annual incidence of diabetes was 39/100000 based on the 2012 annual report from the National Quality Registry for Pediatric Diabetes in Sweden (SWEDIABKIDS). The annual incidence of type 1 diabetes mellitus (T1DM) varies considerably among the countries/regions in the world. After Finland and Sardinia, Sweden has the highest incidence in the world (De Beaufort, 2006; Karvonen et al., 2000).

* Corresponding author at: Department of Pediatrics, Örebro University Hospital, S-701 85 Örebro, Sweden.
E-mail addresses: caisa.lindstrom@regionorebrolan.se (C. Lindström), jan.aman@regionorebrolan.se (J. Åman), annika.lindahl.norberg@ki.se (A.L. Norberg), maria.forssberg@liv.se (M. Forssberg), agneta.anderzen-karlsson@regionorebrolan.se (A. Anderzén-Carlsson).

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Streisand, Swift, Wickmark, Chen, and Holmes (2005) showed that a significant portion of the variance in stress frequency and difficulties perceived by parents of children with T1DM are associated with the psychological and behavioral functioning of the parents, including lower self-efficacy, greater responsibility for diabetes management and greater fear of hypoglycemia. A recent systematic review revealed that nearly one-fifth of parents report psychological distress within the first four years after diagnosis. It was found that parental distress had negative effects on diabetes management and was associated with poorer psychological health for the child and with more problematic child behaviors (Whittemore et al., 2012). In a Swedish study parents of children with diabetes reported that psychological reactions persist over time (Boman, Viksten, Kogner, & Samuelsson, 2004).

In addition to psychological distress, burnout symptoms have been shown to be more prevalent in parents of children with T1DM than in parents of healthy children and mothers have reported experiencing burnout more frequently than fathers (Lindström, Åman, & Norberg, 2010). Burnout has been shown to correlate with parents' reported quality of everyday life. In the same study performance-based self-esteem (PBSE) and need for a high degree of control (as measured by self-rated questionnaires) was associated with burnout, particularly in mothers of children with diabetes T1DM (Lindström, Åman, & Norberg, 2011). Although previous studies have reported on several psychological consequences in daily life especially in mothers of children with T1DM (Haugstvedt, Wentzel-Larsen, Rokne, & Graue, 2011; Kobos & Imiela, 2015; Streisand et al., 2008, 2005) no qualitative study has focused on the experiences of parental burnout. A deeper understanding of this phenomenon would be valuable from a family health perspective, focusing on the wellbeing of the entire family.

The purpose of this study was to explore how mothers experiencing burnout describe mothering a child with diabetes, with special focus on their need for control and self-esteem.

Theoretical Underpinnings in Brief

The concept of burnout has been defined as a unique state of chronic depletion of an individual's coping resources. Burnout is characterized as a combination of emotional exhaustion as well as physical and cognitive fatigue (Melamed et al., 1999). It has also been suggested that distinct personality types are associated with different coping abilities, which may be one reason for the large variation in stress responses among individuals (Brunborg, 2008; Gustafsson, Persson, Eriksson, Norberg, & Strandberg, 2009; Rzeszutek & Schier, 2014).

PBSE is built on the concept of self-esteem. The magnitude of PBSE strongly predicts life satisfaction and the ability to cope with stressful events. PBSE is influenced by both factors related to an individual's previous history and situational features of the environment or the person. In theory, one aspect of the identity of a strongly goal-oriented individual includes a feeling of "I am what I achieve". Pressures in roles, domains, and tasks that are important to the individual are considered as triggering PBSE (Hallsten, 2005).

There are several explanatory models that facilitate understanding and interpretation of control and need for control (Bandura, 1997; Karasek, 1979; Lazarus & Folkman, 1984). A perceived imbalance between demands and control could lead to stress. Demands can be experienced as a negative factor, and one's own coping ability and available resources impact the level of perceived stress (Karasek, 1979). One common perspective is that perceived control is related to emotions; for example, a strong correlation between low perceived control and emotional exhaustion has been reported (Alexander & Klein, 2001).

Design and Methods

This study used a qualitative, descriptive design to provide an understanding of the experience of mothering a child with diabetes when experiencing burnout. This approach is regarded as appropriate for the purpose of gaining knowledge about a person's experience with a phenomenon or understanding an emic (insider) perspective (Richards & Morse, 2013). Data were collected via individual semi-structured interviews (Kvale, 2007) and analyzed by performing qualitative content analysis. Both the manifest and latent contents have been analyzed. The latent analysis implies an interpretation of the underlying meaning of the text (Graneheim & Lundman, 2004). Content analysis is applicable when searching for meaning, intentions and consequences under conditions in which the context must be taken into consideration (Downe-Wamboldt, 1992).

Participants

Mothers of children with T1DM were recruited from a department of pediatrics in a hospital in central Sweden. The inclusion criteria were being a mother of a child between 1 and 17 years old with diabetes and scoring positive for clinical burnout on the Shirom-Melamed Burnout Questionnaire (SMBQ) (Grossi, Perski, Evengård, Blomkvist, & Orth-Gomér, 2003; Melamed et al., 1999). The Child was diagnosed at least 6 months prior to the study.

A purposeful sampling method was employed to achieve variation in demographic characteristics such as maternal age, number of children in the family, child age and sex, duration since diabetes diagnosis, metabolic control (HbA1c level), cohabiting/non-cohabiting parents, and urban or rural area of residence. In addition, demographic data related to the mother's PBSE (Hallsten, 2005) and need for control was obtained (Lindström et al., 2011).

As outlined in Fig. 1, 150 mothers of children with diabetes matching the aforementioned inclusion criteria were initially approached to participate via a written invitation with information about the study from the department of pediatrics that the child visited. Twenty-one mothers were finally enrolled in the study.

Demographic information about the mothers who participated is presented in Table 1.

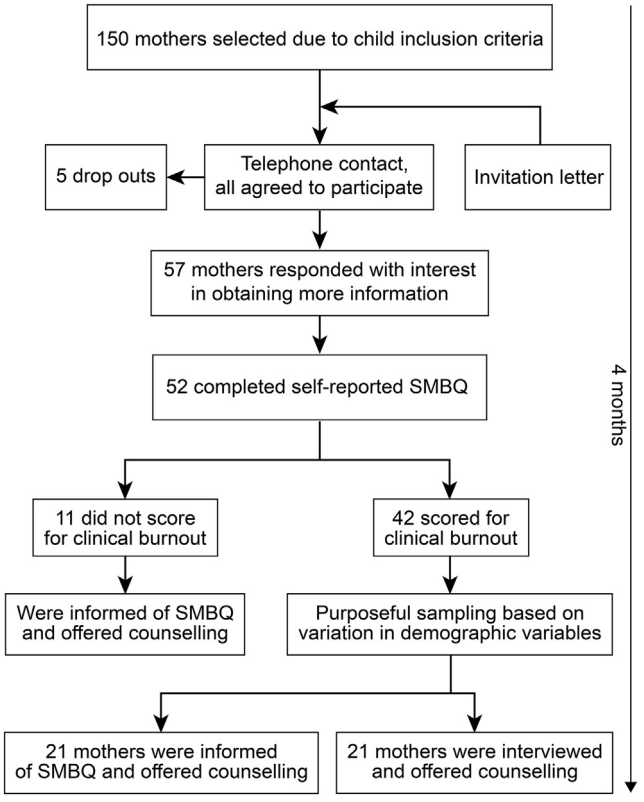

Fig. 1. Flowchart illustrating participant inclusion in the study.