Applied Nursing Research 28 (2015) 142–149

Contents lists available at ScienceDirect

Applied Nursing Research

journal homepage: www.elsevier.com/locate/apnr

Factors affecting the level of burden of caregivers of children with type 1 diabetes

Ewa Kobos, MSc, PhD [*], Jacek Imiela, MD, PhD

Social Nursing Institute, Health Education Faculty, Warsaw Medical University, ul. Ciołka 27, 01-445, Warszawa, Poland

ARTICLE INFO

Article history:
Received 12 May 2014
Revised 11 September 2014
Accepted 19 September 2014

Keywords:
Type 1 diabetes
Caregiver burden
Children

ABSTRACT

Aim: To analyze the correlations between factors associated with the family and child and the level of burden involved in care.
Background: The management of diabetes places substantial demands on families and direct caregivers.
Methods: 112 direct caregivers of children with type 1 diabetes from 4 clinics in Poland evaluated their level of burden using the Caregiver's Burden Scale. The additional data were collected through interviews.
Results: The highest level of burden was associated with general strain and disappointment. The level of burden correlated with the child's age and the professional status and level of education of the parents, and also with the number of glycemic tests at nighttime, the frequency of hyperglycemic episodes, and the number of hospitalizations.
Conclusions: Measuring the impact of factors influencing the level of burden in care makes it possible to develop effective programs supporting parents in providing care for children with type 1 diabetes.

Poland, despite the average incidence rate among European countries, is characterized by a high rate of growth in the incidence of type 1 diabetes in children (Jarosz-Chobot et al., 2011). It is estimated that this level exceeds 9% per year (Patterson et al., 2009). Cases of new onset as well as difficult-to-treat acute complications of diabetes require hospitalization in a specialized unit of pediatric diabetology, and subsequently the child remains under the care of the diabetes clinic. The frequency of visits to the clinic is not limited, they are recommended every 6–8 weeks, at least four times a year (Recommendations of the Polish Diabetes Association, 2014).

Previous studies emphasize that the perception of burden is a complex issue. It may be defined, among other things, as the strain experienced by people responsible for supporting patients suffering from medical or psychological conditions (Encyclopaedia of Public Health, 2008). Type 1 diabetes in children involves sudden and acute complications that lead to development of practical and emotional problems for patients and their families. Parents may experience 3 types of stress factors associated with the disease: low-level stress in the form of everyday difficulties; medium-level stress, where diabetes is an element permanently present in the family profile and must be considered in most life situations; and traumatizing stress, which appears, among other times, during situations that endanger the life of the child (acute complications of diabetes) or at the time of diagnosis of acute complications (Cyranka, 2012). Many parents have concerns associated with chronic complications, low glycemic levels, and their child's stays away from home (Mellin, Neumark-Sztainer, & Patterson, 2004). It has been demonstrated that the perception of burden resulting from caregiving to patients with diabetes is significantly correlated with the level of anxiety/depression in parents of children with diabetes (Malerbi, Negrato, & Gomes, 2012). The correlation between expenses of medical care and the level of financial burden for the family in relation to the child's condition, place of residence, and insurance status was researched by Lindley and Mark (2010). Parents of children with diabetes may experience feelings of guilt about not providing appropriate care, which may lead to conflicts occurring more frequently in these families than in those with healthy children (Coffey, 2006).

Treatment for patients with diabetes requires everyday self-testing of glycemic indices, nutrition, physical activity, and administration of insulin (Fichna, Skowrońska, & Stankiewicz, 2005). Parents may experience the feeling of constant burden with responsibility for providing care (Mellin et al., 2004). Treatment provided at home may also lead to misunderstandings between children and parents, which may prove very time-consuming. The results of studies indicate the following difficulties associated with providing care for children with diabetes: adhering to dietary restrictions, children becoming more independent, the need for conducting procedures, and learning difficulties (Gawłowicz & Krzyżaniak, 2009). Research shows that families of chronically ill children may experience problems in adjusting to the disease, possibly straining relations with the child and leading to increased conflicts in the family, and difficulty in solving problems (McClellan & Cohen, 2007). Long-term provision of care may intensify burnout syndrome in parents (Nitka-Siemińska, Myśliwiec, Landowski, Balcerska, & Wolnik, 2008). Low levels of social activity, financial difficulties, and the notion that the child's disease has an impact on everyday life are associated with burnout syndrome (Lindström, Aman, & Norberg, 2011).

---

[*] Corresponding author at: ul. Ciołka 27, 01–445 Warszawa, Poland. Tel.:/fax: +48 22 877 35 97.
E-mail address: kobewa@interia.pl (E. Kobos).

http://dx.doi.org/10.1016/j.apnr.2014.09.008
0897-1897/

The purpose of this study was to evaluate the perceived level of burden among caregivers of children with diabetes via analysis of correlations between factors associated with parents and children and the level of burden of care. This study plays an important role in planning holistic care for families of children with diabetes, both in a hospital environment and in a family's residence.

1. Methods

1.1. Procedure

The study was conducted in 2010 at four randomly selected diabetes clinics in Poland (Fig. 1). Interviews were conducted in the polyclinics during follow-up visits of caregivers and children. The caregivers completed the Caregiver's Burden Scale (CB Scale) forms at home and sent them back via post. Fifty caregivers were selected at each clinic. The groups of patients consisted of children with clinically diagnosed type 1 diabetes, diagnosed at least 6 months before the beginning of the study, aged 3–16 years, from complete families (not reconstructed), with siblings, without any chronic illnesses. The study involved a total of 200 caregivers who met the following criteria: declared themselves a direct caregiver for the child, lived with the child, devoted the largest amount of time and attention to the child in comparison to other family members, and submitted written consent to participate in the study. The return rate of CB Scale forms reached 56% (n = 112) (Fig. 1).

1.2. Measurement

1.2.1. Interview

A survey was used to collect data for analysis of the child's and parent's suffering from the disease. The survey consisted of 11 questions regarding the sick child, covering: age, type of education and special purpose center which the child attends, duration of the disease, methods of insulin therapy, frequency of glycemic indices blood tests, metabolic control of diabetes, number of hospitalizations, type of monitoring of blood glucose levels, and the occurrence of acute and chronic complications of diabetes. The survey included five questions regarding the family and caregivers of the child, covering: place of residence, financial situation, family structure, number of generations of the family, and age, education, health condition, and professional situation of the parents.

1.2.2. Caregiver's Burden Scale

With the author's written consent, the Caregiver's Burden Scale (CB Scale) was used to evaluate level of burden. The scale is used to measure the subjective perception of the level of burden. The scale consists of 22 questions and 5 subscales: general strain, social isolation, environment, emotional involvement, and disappointment. Each question was rated on a scale of 1 to 4 (not at all, seldom, sometimes, or often). The total score was calculated as a mean score of items constituting scales 1–4 and the 5 subscales. The higher the total score for a caregiver, the higher the level of burden. The following levels of burden have been assumed:

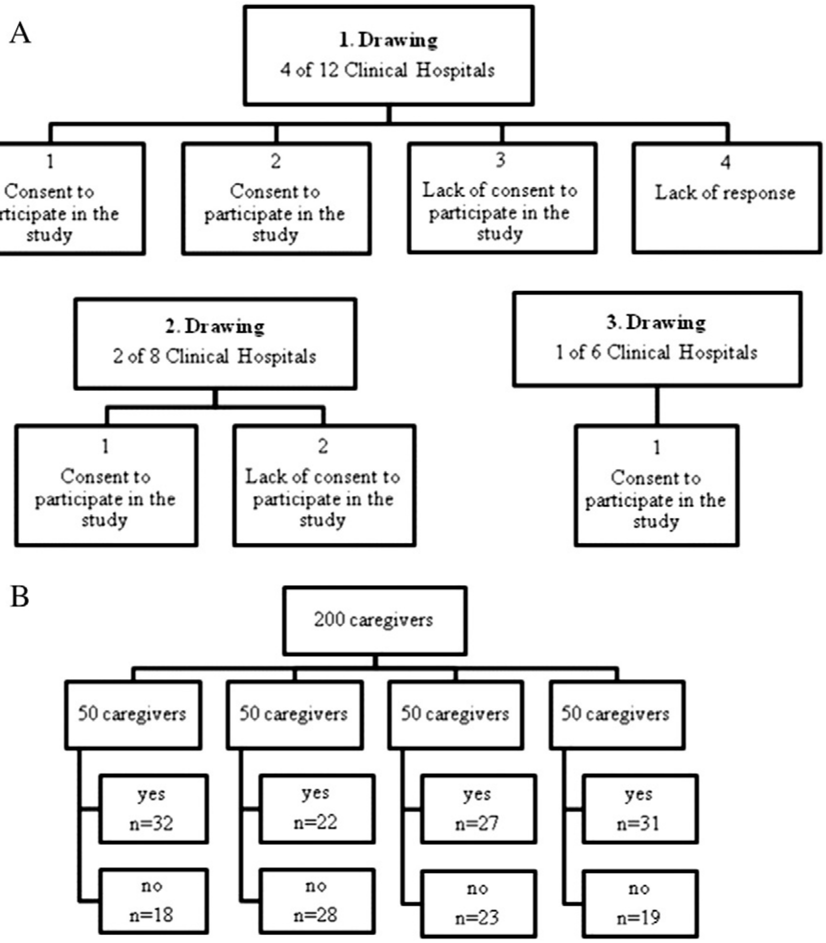

Fig. 1. Selection of clinics (A) and caregivers (B) to study.