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## Original research article

## Coping strategies of family with a chronically ill child

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#### ABSTRACT

Any childhood disease is stress for parents or other carers. The goal of this survey was to assess what coping strategies are used in families with a chronically ill child to cope with the resulting stress situations. The examined cohort consisted of parents of children suffering from a selected chronic disease (diabetes mellitus, bronchial asthma, juvenile rheumatoid arthritis, atopic eczema, celiac disease, epilepsy, and thyroid gland disease), and attending specialized paediatric out-patient's departments in Ostrava hospitals. The total number of respondents was 162 parents (122 mothers and 40 fathers). Chronically ill children in the parents' cohort included 80 boys and 82 girls. Data were collected by means of the quantitative cross-sectional survey method. The main research method was an F-COPES questionnaire (Family Crisis Oriented Personal Evaluation Scales). Stress in the family related to the disease of a child, was felt by 95 (59%) respondents of the cohort. The perception of stress by parents differed significantly (p < 0.01) according to the kind of chronic disease (mostly the parents of children suffering from celiac disease, juvenile rheumatoid arthritis and diabetes mellitus). It followed from the answers of respondents that they most frequently applied internal coping strategies to cope with problems - the redefinition of a stressful event as a more manageable one and the acceptance of stress by moderating reactivity, avoidance or passivity. In the use of coping strategies, no significant difference was found depending on the sex of parents, their age, the duration of the disease, the sex of the chronically ill child or the number of siblings. Unlike families with a single parent, complete families used their closer social surroundings significantly more (p = 0.046) for help in coping with stress, and thus they were distinguished by a more adaptive behaviour mechanism, similar to parents with a higher level of education.

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#### Introduction

The existence of a chronic disease is always connected with stress both for the ill persons themselves, and for their closest relatives. In the case of an ill child, the stress, concerns or

problems increase considerably, and are felt especially by the parents and the child's closest family. Chronic diseases proceed less sharply than acute ones but their symptoms are present more or less permanently. Many diseases have alternating periods when the ill person feels quite well and symptoms are hardly apparent, and periods when the

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condition sharply worsens. A child's chronic disease threatens their emotional and social development; and handicaps them: in education, due to frequent absence from school; in the selection of occupation due to various health limitations; and in friendships and peer relationships, due to the frequent disability or absence from play activities [1, p. 278]. In general, ill children are often exhausted, less resistant to stress, are more frequently absent from school and are limited in some activities, etc.

As Satirová states [2, p. 208], life with a healthy child, although joyful, also brings about stress and various worries. When a child falls ill, the stress, worries or problems increase considerably [3, p. 51]. A disease or its worsening, causes frustration to the members of the family, affects them in a negative way, limits their lifestyle and prospects. The family must often revaluate its previous lifestyle, change plans and goals and correct its previous view of the future [4, p. 117–8]. Families with an ill child are subject to many dangers which can influence their internal cohesion more easily [5, p. 279]. Messing up the family system by such stress can result in family dissolution, but on the other hand, it can strengthen internal family relationships when the family accepts the illness as a part of life, as their common task [6, p. 104].

In the case of child disease, parents particularly face a difficult task in coping with precarious situations. How they cope with specific problems and stress associated with the disease of the child also significantly affects the child, because parents are an example for the child who adopts their attitudes, opinions and feelings. The manner in which parents respond to stress, how they work with it and to what extent they manage it, co-determines how the situation will also be stressful for the child [6, p. 101]. It is very important for all family members and particularly for the child, that the parents and all the persons involved, cope with the current situation, and as far as possible live a normal satisfying life [7, p. 37]. Coping with stress depends on the respective processes which run in a stress situation. All strategies used in coping with precarious situations have the identical goal of helping the person to maintain an acceptable level of mental equanimity. Methods of coping (coping strategies) can differ and can have different effects [6, p. 85]. Coping is an active knowledgeable manner of coping with stress. It is used in cases of above-limit or sub-limit stress with regard to the circumstances of an individual when greater effort must be made to cope with it [8, p. 79]. Strategies for coping with such stress include the use of the nearest social support network, the search for spiritual support, the redefinition of a stress event, and the search for sources of help in society (e.g. civic associations, self-aid organizations, social and health services).

Researches dealing with stress and coping with it in the family are not as extensive as studies focusing on stress and coping with it by an individual [9, p. 77]. If a nurse is to help in coping with stress to families with a chronically ill child, common ways of family coping with stress must be identified and families which are most threatened by maladaptation must be identified.

Statistical data on the occurrence of chronic diseases in children are alarming. Epidemiological studies from abroad show that one in ten children up to the age of 15 suffers from a chronic disease [10, p. 1]. Colorosová [11, p. 61] includes

asthma, allergy, arthritis, diabetes, epilepsy and a tumour disease in the six major current chronic diseases of the present. According to the Institute of Health Information and Statistics of the Czech Republic [12, p. 35–9] the most frequent chronic diseases suffered by children from 0 to 18 (or 0–19 in the Czech Republic) are diabetes mellitus, epilepsy, atopic eczema and bronchial asthma. All the aforementioned diseases are connected with frequent contact with physicians, the long-term use of drugs and permanent restricting of the child's natural activities and needs.

The goal of the survey was to assess how families with a chronically ill child cope with stress situations. Furthermore, the goal was to determine whether the selected variables (the character of the disease and the characteristics of parents and children) influence coping with stress in the family with a chronically ill child.

#### Materials and methods

The surveyed cohort consisted of parents of children with one of the selected chronic diseases from a list: diabetes mellitus, bronchial asthma, juvenile rheumatoid arthritis, atopic eczema, celiac disease, epilepsy, and thyroid gland disease attending specialized children out-patient units of Ostrava hospitals, i.e. the Faculty Hospital Ostrava, the Municipal Hospital Ostrava and the Vítkovice Hospital in Ostrava. The total number of respondents was 162 parents, of which the majority (75%) were mothers of the ill children. The definition of a chronic disease in childhood is not uniform in the literature, but the present study understands it as a disease which must meet the following criteria: its occurrence at the age of 0-18; its diagnosis is based on medical scientific knowledge with the use of a valid method or tool; the disease is incurable or highly resistant to treatment, and it persists for more than three months, there is a presumed high probability of persistence for more than three months, acute symptoms have occurred three times and more times during the previous year: and they are likely to recur. The criteria were set by a team of specialists from the Netherlands [13, p. 1444] on the basis of a consensual approach.

The data collection method was the quantitative crosssection survey. The main research tool was the F-COPES (Family Crisis Oriented Personal Evaluation Scale) questionnaire which was one of the diagnostic methods published in "Family assessment: Resiliency, coping and adaption – inventories for research and practice" together with an extensive manual of test methods focusing on the operation of the family system under stress. The questionnaire itself was elaborated in 1981 by McCubbin et al. [14, p. 294-7] and the use of this assessment tool for research purposes was approved by the author of the tool. The Cronbach's alpha coefficient for individual sub-scales ranges from 0.64 to 0.84, and the authors of the questionnaire state the Cronbach's alpha ( $\alpha$ ) of 0.86 for the whole tool. Its goal is to identify strategies of problem solutions and behavioural strategies used by the family in difficult situations. The questionnaire was translated from the English original by two independent translators, the versions were compared and the final Czech version was translated to English and consequently to Czech. The final form of the questionnaire was compared

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