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CHRONIC DISEASES IN CHILDREN AS A CHALLENGE FOR PARENTING

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ABSTRACT

To be a parent or a caregiver in a modern society is a very difficult task, including multiple demands and expectations. Parenting imposes a special role in the life of any couple, especially for the mother, roles which must be learned through personal education, enriched by transgenerational experience.

Chronic disease is recognized as a large stressor that affects the current situation of a child and a child's family. In this difficult situation, the family must go through a process of learning how to cope with it. In the family, where a child has a long-term health problem, there are certain behaviours that hinder the normal functioning of family relationships.

According to the experience of many researchers, including my own, there is an indication that a child's illness often leads to the divorce of the parents. The fathers of sick children are often the initiators of such decisions.

The purpose of this article was to find if there are differences in parenting between mothers and fathers of chronically ill children.

The methodology is comprised of a review of published articles in PubMed over the last two decades related to parenting when there is chronic illness in children. More than 500 articles related to the topic were found. Obtained results were discussed.

Keywords: parenting, chronic diseases, children

INTRODUCTION

To be a parent or a caregiver in a modern fast-moving and competitive society is very difficult task which includes multiple demands and expectations. More precisely, parenting imposes a special role in the life of any couple, especially for the mother, a role which must be learned through personal education enriched by transgenerational experience. Shortly, a woman who has a specific role in her own professional career, is concurrently a lover and spouse. At the moment of the child's birth, she becomes "mother", a role which is quite different from others.

My personal experience with some family members inspired me to write this article. These were families who were facing a situation with a sick child, a child whose physical and psychological pain, sometimes social isolation and loneliness or emotional discomfort, was a great challenge to the families. The difference in attitude between mothers and fathers was so obvious that my purpose was to find and to analyse the results obtained from published articles related to this topic.

Chronic disease is recognized as a large stressor that affects the current situation of a child and a child's family. In order for a given illness to be classified as a chronic disease, it must meet the following criteria: it must have a biological,

psychological or cognitive base, and last at least one year. In addition, it must be the direct cause of the following consequences: limitation of daily functioning, including being active and fulfilling social roles in relation to the cognitive, physical, emotional or social development sphere; the need for medical, psychological and educational care, which is completely different from that addressed to healthy children.

In such a difficult situation, a family must go through a process of learning how to cope, this is referred to as adaptation. It is worth underlining that this process is not just a passive adjustment to the existing requirements by changing behaviour but must be a creative reaction to the difficulties and threats that can be encountered. There is a need to obtain some kind of resilience.

In a family whose child has a long-lasting health problem, there are certain behaviours that hinder the normal functioning of family relationships. Although mothers bear the main burden of care for sick children, there are also families where fathers alone look after the children. However, the experience of many researchers indicates that a child's illness often leads to the divorce of the parents, and the fathers of sick children are often the initiators of such decisions. In my experience, this was the situation in families who confronted the challenge of a child with cystic fibrosis as well as with autism. The perception of a difficult situation is fundamental to family management since parents believe the child's abilities are closely related to their understanding of the child's medical condition, as well as the requirements and restrictions associated with it.

The methodology of this research comprises a review of published articles in PubMed related to the parenting in the situation of chronic illness in children over the last two decades. Used key words were: parenting, chronic diseases, children. More than 500 articles related to the topic were found.

OF WHAT IS PARENTING COMPROMISED?

Following Merriam-Webster's dictionary, parenting means the raising or taking care of a child in the manner of parent. As I mentioned before, this is a special role in the life of an adult person. For many adults, the parental role is well planned and coordinated with other roles in life and developed with the individual's economic situation in mind. For others, parenting is related to a startling surprise and provokes some mixed emotions and romantic illusions about having child. Parenting, however, consists of a number of interpersonal skills and emotional demands, demands which are not learned through some defined formal education for this task. Most parents learn parenting practices from their own parents (i.e., transgenerational transmission). However, husbands and wives may bring different viewpoints of parenting practices to the marriage.

It must be pointed out that parenting is neither a manner for saving the marriage, nor the expectation of one's own children to take care of the parents in old age. Neither is it the expectation of the parent that the child will think, behave, and feel like the parent does, nor is it to be some learned copy of the parents. Additionally, parenting is not a simple instinct which does not require training and education. As Rose Kennedy, mother of many successful children said: "Child rearing is looked not only as a work of love and duty, but as a profession that was fully as interesting and challenging as any honourable profession in the world and one that demand the best that I could bring to it".

Becoming a parent is a period of life that is associated with brain changes, especially based on enhanced neural plasticity. New research in neuroscience confirmed that the brain adapts to the new life circumstances of caring for a newborn. Generally, a reduction of cortical volume, particularly in visual and default-mode networks which is found, adapting for better interaction with the baby. In this context, motherhood has been associated with changes in many brain areas that have been characterized as part of the "parental caregiving network". This is relevant for identifying what an infant wants and needs and then taking the appropriate action. But then there is the question as to if there are any changes emerging in the brain of father too? A new study published in the scientific journal Cerebral Cortex focused on exactly this question [1]. In this study magnetic resonance imaging (MRI) was used to investigate brain changes in first-time fathers. This study showed that fatherhood was associated with a roughly 1 percent reduction of the cortex of the brain. The scientists then analysed which specific networks in the brain changed in fatherhood. The visual network and the so-called default-mode network showed volume reductions in first-time fathers, changes which could be relevant for so-called mentalizing (e.g., reflecting and interpreting

the behaviour of the newborn baby). The visual network is relevant for recognizing the baby and his needs. In conclusion, the plasticity of the brain helps to reach the demand related to parenting role.

In psychology, some different styles of parenting are described:

Authoritarian parenting has a restrictive, punitive style in which the parents insist the child follow their directions and respect work and effort. Therefore, children of authoritarian parents are often anxious about social comparison, fail to initiate activities and have poor communication styles. New research has shown that strict parenting can alter the way the body reads the DNA of children. These changes can effectively become "hard-wired" to the DNA of those children who perceive their parents as harsh, thus increasing their biological risk for depression in adolescence and later life [2].

Authoritative parenting is a style in which the parent encourages children to be independent, but still place limits and controls on their actions. Children of those parent are socially competent, self-reliant and socially responsible.

Neglecting parenting is a style in which the parents are very uninvolved in the child's life; it is associated with children's social incompetence, especially a lack of self-control. These children do not handle independence well.

Indulgent parenting is a style in which parents are highly involved with their children but place few demands or control on them. They let their children do what they want, and the result is that the children never learn to control their own behaviour.

However, the National Academy of Sciences delineates four major responsibilities for all parents: maintaining children's health and safety, promoting their emotional well-being, instilling social skills, and preparing children intellectually. According to the parenting style, the attitude and behaviour of parents (both father and mother) will be different in the situation where a chronic disease of child is emerging.

CHRONIC DISEASE AND FAMILY FUNCTIONING

There are many different types of chronic diseases. Some are present at birth, while others may develop at a later stage of the child's development. While some children with chronic diseases may grow out of them later in life, most will not be able to lead normal lives in the absence of special care.

It is estimated that about 30% of children worldwide are affected by chronic conditions including asthma, cystic fibrosis, congenital heart disease, diabetes mellitus, attention-deficit/hyperactivity disorder, and depression. Examples of chronic physical disabilities include meningomyelocele, hearing impairments or visual impairments, cerebral palsy, and loss of limb function. These children can be divided into three groups: 66% with mild conditions that result in little or no difficulties or activity limitation; 29% with conditions of moderate severity that result in some difficulties or limitation of activity, but not both; and 5% with severe conditions that cause frequent difficulties and limitation of activity. The 5% with severe conditions account for 19% of physician contacts and 33% of hospital days related to chronic illness [Newacheck PW, and all, 1992]. The newest report of USA-National Health Interview Survey for 2019-2020 showed that percent of children aged 5-11 years who are in fair or poor health is 2.1% [CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), 2020].

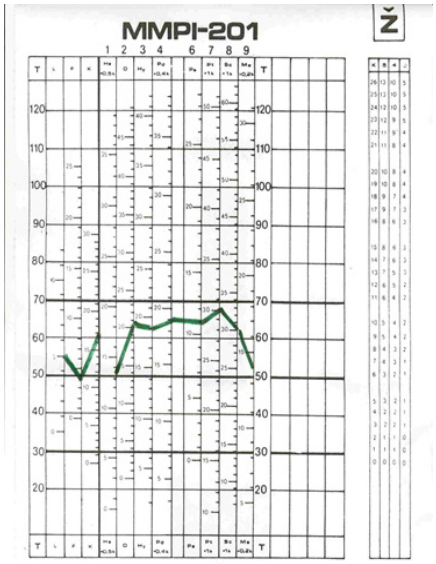
The impact of childhood chronic illness on other family members, including parents, has been a growing interest for two reasons. First, it is now recognised that parents who have significant emotional distress of their own and poor family functioning can either directly or indirectly affect a child's development outcomes by engaging in problematic responses to a child's pain behaviours [Logan 2005; Palermo 2007, 2009]. Second, it is now recognised that adaptive strategies used by parents can have a positive effect on child adjustment to chronic illness [Logan 2005].

Once the diagnosis of disorder is made, parents may react with shock, denial, anger, sadness or depression, guilt, and anxiety. In a study by Guz E. et al. in 2020 [9], the following reaction stages in parents are thus: shock, waiting, mourning, defence, proper behaviour, defensive behaviour (neurotic reaction), adaptation, intellectual and emotional adaptation. These reactions may occur at any time in the child's development, and each parent may be at a different stage of acceptance, making communication between them difficult. It is normal for parents to feel scared and guilty when their child is diagnosed with a chronic med-

ical illness, such as Type 1 diabetes, cystic fibrosis or asthma. It is also common for parents to feel angry. No one chooses to have a child with a medical condition. In most cases, these types of diagnoses are a shock to all, the parents and the child itself. Still, several studies of parents of children with chronic illness report considerably higher levels of anxiety and depression after the diagnosis.

The Fig. 1 and 2 are taken from my own experience and show MMPI profiles for parents of children with juvenile rheumatoid arthritis, a severe form of chronic disease involving joints. This chronic disease is related to chronic pain in the joints and different levels of immobility for the child. Thus, the parents must cope with this problem. Generally, the scores obtained are in the normal (i.e., non-pathological) range. However, fathers showed a L-Hy-Pt profile, where Pt scores are higher than the Hy score, corresponding to accentuated psychopathic traits. For mothers, the obtained profile is under the T-scores, but the Pt score is also the highest. Both parents showed a peak on the D score, meaning small levels of depression, while the Pt score is related to psychasthenia/psychopathic traits [10, 11, 12].

Figure 3 shows MMPI profiles for mothers and diabetic girls. Apart from the high L-score, the profile for mothers is in the normal range. For diabetic girls, the peaks on Pd-Pa-Sc are present, which corresponds to emotional instability as well as possible psychopathic traits.



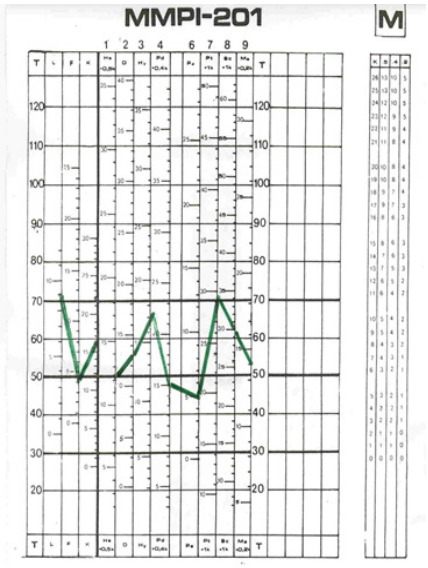
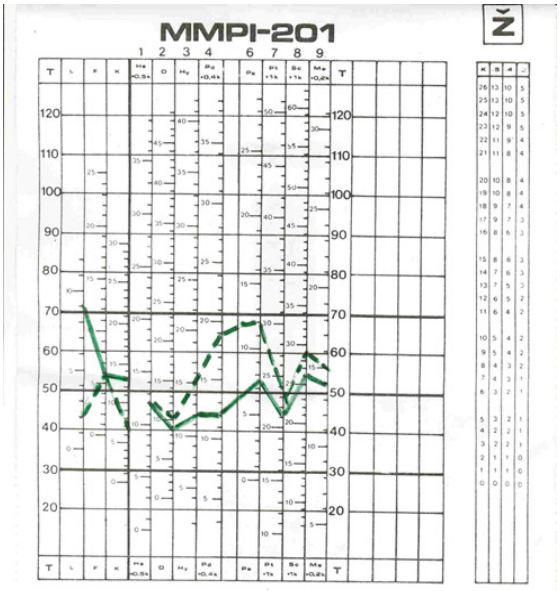


Figure 1 and 2. *MMPI profiles for parents of children with JRA*



Mothers
Girls

Figure 3. *MMPI profiles for parents of children with JRA*

Similarly, the study of Cohn LN. et al. (2020) showed that parents of chronically ill children had greater anxiety ($P < .001$) and depression scores ($P < .001$) than parents of healthy children. Thirty-five percent of parents of affected children met cut-offs for clinical depression, compared with the 19% in the control group. Fifty-seven percent of such parents met cut-offs for anxiety, compared with 38% in the control group.

Acute Stress Disorder (ASD) and subclinical symptoms of acute stress (SAS) may be a useful framework for understanding the psychological reactions of mothers and fathers of children, newly diagnosed with a paediatric malignancy [Patiño-Fernández AM, et al. 2008]. Figure 4 shows psychological reactions of parents due to the diagnosis of a malignant disease in children. Similar scores for arousal and acute stress disorders are obtained for both parents.

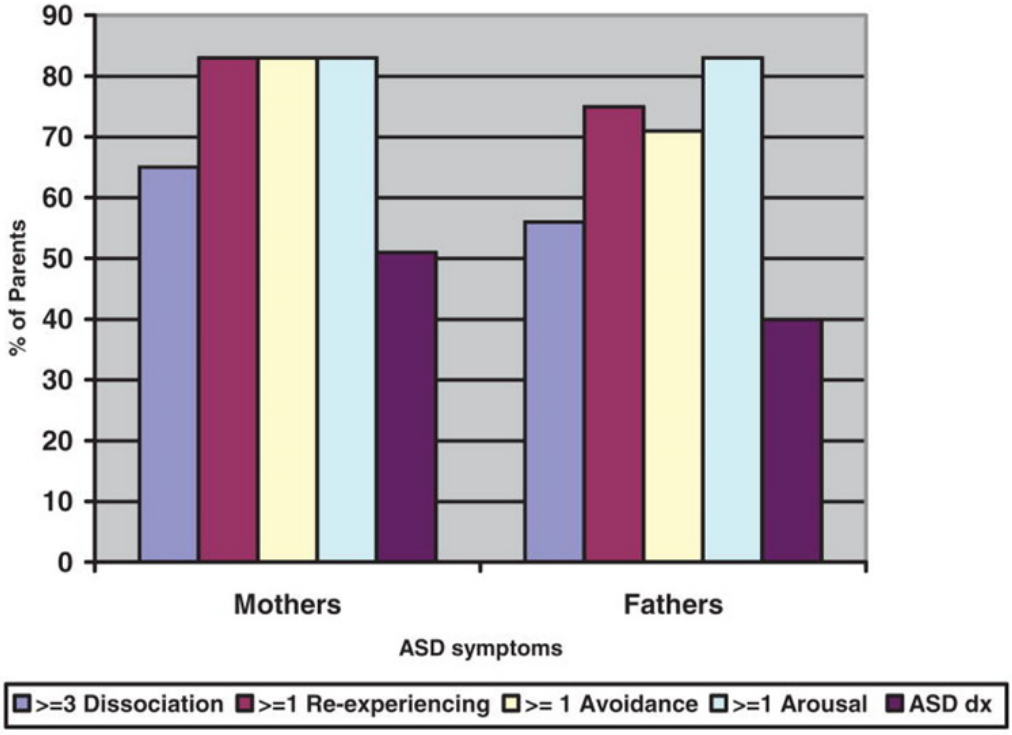


Figure 4. *Psychological reactions of parents due to chronic illness in children*
[Borrowed for Patiño-Fernández AM, et al. 2008]

Fifty-one percent of mothers and 40% of fathers met the DSM-IV diagnostic criteria for ASD. The majority of the sample reported experiencing at least one SAS. General anxiety, but not family functioning, was a strong predictor of SAS in both mothers and fathers.

Along with anxiety and depression, some parents whose children have chronic illness manifest burnout syndrome. Burnout is a state of emotional, mental, and often physical exhaustion brought on by prolonged or repeated stress. It is most often caused by problems at work, but it can also appear in other areas of life, such as parenting, caretaking etc. Findings show 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 [Lindström C, 2010].

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 (mothers being more likely to experience it). Clinical work needs to draw

attention to the group of parents who may suffer from burnout and organise psychological help.

Generally, parents of chronically ill children experience poorer mental health (as evinced by more anxiety and depression), but mothers of children with congenital anomalies may have a greater risk of cardiovascular disease and mortality than parents of unaffected children [Cohn LN, et al., 2020]. The scarcity of published studies focussing on physical health outcomes and mortality may be explained by feasibility issues. Studies need large sample sizes and prolonged observation periods to detect events that may be uncommon, such as premature mortality. However, the observed results pertaining to mental health may be associated with chronic stress, which itself has been found to be associated with poorer physical health outcomes, including cardiovascular, gastrointestinal, immune, and neurologic health issues [Guz E, et al.. 2020].

During the diagnosis of chronically ill children, parents should also be educated regarding the aforementioned health issues. Therapy and psychological help, as well as directing parents to relevant support groups, organizations or associations, is very valuable for coping with such a difficult life situation. First, relationships and interactions between family members are significant. The problems encountered by one family member can negatively affect not only that person, but also the whole family system, namely, other family members.

The child's current state of, the economic situation of the family, course of the disease and prognosis, as well as the received social support or relations prevailing in the family during the treatment of the child's disease all affect how the family will adapt to such a highly aggravating situation and whether they will be able to cope.

The reorganization of family life due to the child's disease mainly depends on the seriousness of the disease is and whether the parents raise the child alone, whether the child can attend classes in kindergarten or integration school, or whether the parents can receive support from other people. A disease that threatens the child's life or an incurable disease affect and change the image and function of the whole family and each of its members separately. Such families often feel guilty, and this guilt is not dependent on the fact that, objectively, the child's situation is not their fault.

According to the perspective in the life, some discrepancies between child and parent reports are found, reflecting their different perspectives and not merely inaccuracy or bias. In general, parents consider their children to have more difficulties related to the needs of rehabilitation than the children themselves do. In contrast, children with physical and performance problems reported more difficulties than their parents concerning their own emotional functioning and pain. Clinicians should prioritize obtaining children's views on subjective aspects, such as emotional issues as well as on pain. Thus, the perspectives of the child and his/her parents should be sought whenever possible, since both constitute important information concerning the child´s health and well-being [Hemmingsson H, 2017].

The expectations individuals hold about the future can influence the decisions they make toward achieving their goals in three areas (postsecondary education, employment, and living situation). Existing research suggests that parents of autistic adolescents hold expectations about the future that are related in particular to the postsecondary education outcomes they achieve. Proportions of agreement and disagreement did not significantly differ, demonstrating moderate agreement. Notably, fewer than half (37.0-47.8%) of adolescents and their parents partly or strongly agreed about their visions for the future in each of the three areas. Only 17.4% of dyads partly or strongly agreed across all three areas, and 23.9% did not agree in any area. When adolescents' and parents' views differed, adolescents were significantly more likely to have a higher expectation across all three areas ($p < 0.01$). [Kirby AV. 2022]

Psychological interventions are defined as any psychotherapeutic treatment specifically designed to change the parent's cognition or behaviour, or both, with the intention of improving the child's outcomes. Psychological interventions are varied in their approaches and there is still debate which treatment is the most effective for improving mental health and behaviour in parents and children with chronic illnesses. Such interventions include cognitive behavioural therapy (CBT), which has been found to be effective in modifying parent behaviour who have children with a painful condition (e.g. Palermo 2009a; Williams 2012). Problem-solving therapy (PST) has also been used to reduce distress in

parents of children with various chronic illnesses [D'Zurilla 1971; Sahler 2002, 2005]. Other treatments have emerged from a family-systems approach that focuses explicitly on the family as a unit of intervention [Ellis 2005; Wysocki 2004, 2006, 2009], such as multisystemic therapy (MST) or family therapy (FT).

A Cochrane review on psychological interventions for parents of children with chronic illness that included 47 randomized control trials, reported that there is little evidence available supporting the efficacy of psychological therapies for parents of children with a number of common chronic illnesses. However, the study reported that some psychological therapies, such as problem-solving therapy, were efficacious in improving parental mental health and behaviour [Eccleston C. et al., 2012].

Although some articles indicated that there may be a slight benefit may associated with telephone support interventions in some outcomes (e.g., anxiety and preparedness to care at the end of intervention). For most outcomes, including the primary outcomes, telephone-only interventions may have little or no effect on caregiver outcomes compared to usual care [Corry M, et al., 2019].

However, parental attitudes exert a great influence on a child's emotional development and the formation of complete a child's personality. It is known that a child's individual characteristics, as well as environmental impact, are also important, but the impact of the parent is so significant that it cannot be underestimated.

Children who reject parents are characterized by high affection, low emotional life control, emotional instability, aggressiveness, argumentative and rebellious attitudes towards the environment, while children who have democratic attitudes, have a sense of security, and have a mild and cheerful disposition [Pilecka W. et al., 2011].

IN SUMMARY

The modern family is unlike the one in which we ourselves grew up, not to mention our parents and grandparents. The distribution of roles has become more flexible. Women are equally immersed in work with men, but this is not the only reason why their husbands have become more actively involved in the care of children.

It seems that it is time to reconsider the functions of mother and father, especially their role in the mental development of the child. In the model of the patriarchal family, the founder of psychoanalysis, Sigmund Freud, had every reason to clearly distinguish between maternal and paternal functions. Today, in the modern family, the mother is identified with the union, she is "responsible" for the child's mental balance, while the father, on the other hand, embodies the law. Thanks to him, the child is separated from the mother and learns the rules of life in society. How can a father take his rightful place in the house without turning into either a tyrant or a fraud?

The majority of findings analysed in this article indicate that better outcomes are associated with more father involvement in illness and non-illness related activities, and higher father–child relationship quality. Contradictory findings may be due to the quality of the involvement being assessed, or the possibility that fathers become more involved with illness tasks in response to their child's poorer health outcomes. However, future research should include the development and use of psychometrically sound measures of father involvement and employ more diverse samples with rigorous methodology.

I expect that this review confirmed that both parents are equally important and needed for a child's development, especially in the situation of chronic disease. As such, both must cope with the problem and very work together on any decision, especially when leaving the family. However, some studies and my own experience as a paediatrician have confirmed that the father has an easier decision to leave the "battle" with a child's chronic disease. Is it a question of morality, weakness, or simply the need for easier life? Find your own answer!

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Резиме

ХРОНИЧНИТЕ БОЛЕСТИ КАЈ ДЕЦАТА КАКО ПРЕДИЗВИК ЗА РОДИТЕЛСТВОТО

Нада Поп-Јорданова

Македонска академија на науките и уметностите

Да се биде родител или старател во ова модерно време претставува тешка задача, која вклучува разни барања и очекувања.

Хроничната болест е голем стресор, кој ја загрозува тековната состојба на детето и неговата фамилија. Во ваква тешка ситуација, семејството мора да помине низ процес на учење за тоа како да се справи со неа. Во семејства во кои детето има долгорочни здравствени проблеми, се јавуваат однесувања што го попречуваат нормалното функционирање на семејните меѓуодноси.

Искуството на многу истражувачи, вклучително и моето, покажува дека болеста кај децата многу често доведува до развод на родителите, при што, најчесто, татковците се иницијатори за ваквите одлуки.

Целта на оваа статија е да се најде разликата во родителството меѓу мајките и татковците кај хронично болните деца.

Методологијата подразбира преглед на објавени статии во ПубМед во последните две децении поврзани со родителството во ситуации на хронична болест кај децата. Најдени се повеќе од 500 статии поврзани со оваа тема. Добиените резултати се дискутирани.

Клучни зборови:родителство, хронична болест, деца