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Management of behavioral problems in pediatric chronic illness: A psychosocial perspective

Aishvarya Upadhyay[1], Priyanka Singh[2]

Introduction

World Health Organization defines health as a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity. According to Eiser,[1] chronic illness is generally a long term, non- curable, ongoing health condition resulting in limitations in daily living and may require special assistance or adaptation in normal functioning. It is a major stressor for the child and families and is associated with outcomes ranging from reduced functioning to resilience.

Childhood chronic illness confronts the child and family in a new reality which includes physical aspects like hospital, doctor, medicine, surgery and the psychological one like trauma, lost, grief and in some instances death.[2] Besides suffering from physical illness, they have an increased risk for developing emotional and behavioral problems. Studies have shown that major physical illness usually has an impact on the psychological wellbeing of an individual.[3,4] An illness of early onset, with necessity of frequent diagnostic and therapeutic interventions can adversely affect the emotional balance and behavioral adjustment of children and adolescents. Hence, in addition to physical aspect, it is also necessary to focus on the psychological health of the child in order to ensure compliances and thus treat the child comprehensively.[5] Bilfield *et al* have found that psychosocial problem would be identified at higher rate in children with chronic illness than in healthy children.[6] More commonly observed problems are conduct disorder, aggressive behavior, attention problems and anxiety. [6,7]

Certain chronic illness may put the children at increased risk for psychological problems. Factors such as disease management activities, lifestyle of child and parents, and family dynamics, alone or collectively, may influence and exaggerate long-term health outcomes. The child is affected personally by the pathology of the disease, side effects or treatment, and by the required lifestyle and health management adaptations.

Relevance of the present study

The prolonged need to take medication, frequent contact with medical professionals, interruption in schooling and everyday activities, and parents' anxious concern about the course of the illness may be mechanisms through which children's behavioral problems increases.

Various psychological treatments are available for some of the common psychiatric disorders in children and young people. But, there is a lack for the guidelines regarding evidence-based interventions for mental health disorders in children. It appears that children with physical and mental health conditions are viewed as complex; the care of their physical health may be prioritized, inadvertently leading to neglect of their mental health needs. If clinicians who work with children in mental health and pediatric services are aware of the effectiveness of mental health treatment in this population, and the best ways for families to access them, then services can be organized to meet the need.

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1. Assistant Professor, Department of Psychology, DAV PG college, Banaras Hindu University, Varanasi, Mo: 7052995308; **Email:** dr.aishvaryaupadhyay@gmail.com
2. Associate Professor, Department of Sociology , Jananayak Chandrashekhar University, Ballia, Mo: +91 99356 83814; **Email:** priyankasocio.bhu@gmail.com

Corresponding Author: Dr. Aishvarya Upadhyay, Assistant Professor, Department of Psychology, DAV PG college, Banaras Hindu University, Varanasi, Mo: 7052995308; **Email:** dr.aishvaryaupadhyay@gmail.com

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Review of literature

Most of the studies have extensively assessed the clinical presentation, treatment, and outcome of chronic illness during childhood. The therapeutic benefits of medications are accompanied by significant side effects ranging from physical side effects such as growth retardation, obesity, hirsutism, cataract, etc., to neuro-psychological side effects. The significant behavioral abnormalities have been reported to be induced even by a single 12-week course of high-dose prednisolone and the more marked changes seen in patients on repetitive or long-term maintenance steroid treatment. Therefore, attention to potential behavioral problems and affected cognitive functions should be given early in the course of steroid therapy and parents should be counseled accordingly. Mehta *et al*[8] evaluated 70 children with nephrotic syndrome using Child Behavior Checklist (CBCL), Achenbach,[9] and observed that they were more depressed, had somatic complaints, aggressive and hyperactive behaviour. Hall *et al*[10] recruited 12 children with a new diagnosis of nephrotic syndrome and found statistically significant increase in the total behavior problem scores, as measured by the CBCL. Ruth *et al* [11] reported that the parents of children suffering from nephrotic syndrome rated four of total seven sub-scales of quality of life as abnormal. Family climate, especially maternal distress, negatively affects both behavioral and psychosocial adjustment and quality of life. All these factors, including corticosteroid side-effects, had negative effect on emotional, psychosocial and behavioral domains of these children.

Mishra et al[12] selected 131 children aged 1.5 to 15 years with idiopathic nephrotic syndrome and 50 age and sex matched control group. Using child behavior checklist (CBCL) they compared children with nephrotic syndrome to their matched counterparts to explore behavioral abnormalities. Significantly higher mean scores were observed in idiopathic nephrotic syndrome patients compared to their matched controls for all the behavior dimensions such as withdrawn, anxious, somatic complaints, emotionally reactive, sleep problems, attention problems and aggressive behavior ($p<0.001$). Children from first episode of nephrotic syndrome (FENS) were assessed before and after steroid treatment. Prior to treatment, FENS patients showed significant increase in withdrawn behavior and somatic complaints in comparison to healthy controls ($p<0.01$). After 12 weeks of therapy these complaints significantly and significant increase in scores for anxiety/depression, emotional reactiveness, attention problems and aggression was observed.

Manti et al[13]conducted study on 41 patients with nephrotic syndrome (age 4.4-15.2 years) and compared them with age and sex matched controls to find out existing behavioral problems with the help of CBCL. Patient group showed more thought (23%) and withdrawal problems (9.8%), somatic complaints (12.8%), internalizing (25%) and total behavior problems (32%) as compared to controls. Externalizing problems and several somatic complaints were positively associated with the severity of the disease. 40% of those having a severe disease had CBCL somatic complaints T-scores > 69 i.e. in clinical range. Further, 33.3% with severe disease, 23.1% of those having a moderate disease, and 15.4% with mild disease had externalizing behavior T score >69.

In a prospective repeated measure study Youssef et al, 30 patients with SSNS were assessed for anxiety, aggression and depression with matched social level and duration of disease.[13] These children were evaluated at every 2nd week, i.e. 1, 3, 5 and 7th week of therapy for relapse. Highly significant differences were observed during 7 weeks of follow-up among cases.

Recently, Upadhyay et al, evaluated 45 children with first episode of idiopathic nephrotic syndrome (FENS).[15] 30 children were in 2–5 years and 15 children were in 6–14 years age group. They were compared with 60 controls for behavior problems using CBCL. Children with FENS were evaluated three times, i.e. before the treatment was started, after 6 weeks of daily prednisone administration dose and at completion of 12 weeks (6 weeks daily and 6 weeks alternate days) of therapy. In the lower age group, no significant difference was observed between controls and pre treatment condition. Significant differences were seen for attention problems ($P<0.001$) and aggression ($P<0.001$) when controls were compared after 6 weeks and 12 weeks of steroid treatment. Similarly, results of repeated measures showed that pre treatment condition differed significantly form 6 weeks and 12 weeks of treatment for attention problems and aggressive behavior.

In view of the above, the goal of comprehensive treatment should be, to provide assessment not only for disease but also for the behavioral problems. Those showing extreme behavior abnormalities should be referred to psychologist or psychiatrist for further intervention. A close interaction with the family and appropriate counseling should also be a part of the disease management. Unfortunately, problems are often either unrecognized or assessment or care is not available. Such opportunities may lead to normal, healthy lives of these children; therefore, there is a need to focus on improving the quality of their lives and preventing medical and psychological complications.

Objectives

After reviewing the above mentioned context the present study is focusing on the behavioral problems in children with chronic illness (nephrotic syndrome). Most of the children with chronic illness do have some sort of psychological issues such as anxiety, depression, conduct problem, withdrawal behavior. They do also face some social challenges such as stigmatization and labeling, which further decreases their psychosocial health resulting into more health complications and make the recovery difficult. Second objective of is to review parental stress in parents of children with chronic illness. Parental stress is another most ignored factor which exacerbate health condition of the child. Parents are confronted with stressors about their child's health including practical stressors for example managing daily medical routine and emotional challenges such as sadness and stress.

The most important part of the present study is to focus on the need of psychosocial intervention for parents and chronically children. This is much needed area to improve overall quality of life. If, chronically ill children and their parents are been provided with psycho-education and sociological support, then the holistic health can be achieved.

Discussion and Conclusion

Present study focused on the need of management and intervention of psychosocial issues in children with chronic illness and their family. It has been evidenced that about 15% of children and adolescents on an average have chronic physical health condition and these situations are risk factors for the development of *behavior*al problems. Assessment of behavioral problems in chronic illness and identifying risk factor is of practical relevance. This is because of the fact that assessing problems in these children help in the recognition of psychosocial consequences of chronic disease and provide valuable information that who should be screened for these problems. Behavioral abnormalities and affected cognitive functions have been observed as a undifferentiated part of chronic illness. This problem is often underappreciated by the treating physician and less reported by parents or children themselves.[3]

Children's chronic illness not just affects them; it affects emotional and physical wellbeing of whole family. According to Martires et al,[16] inclusion of close family members is a logical approach to enhance the efficacy of the treatment. 272 parents were studied in Dauma M et al[17] study and children with chronic illness were asked to complete an online questionnaire about the need and type of intervention which is needed for parents and children. They concluded that parents have a need for psychosocial support focusing on different themes such as illness management, parental self care, and relationship with other and practical support. This study adds very important contribution to the field, because the focus is on parents themselves. Face-to-face CBT approach (Op Koers; in English: On Track) was developed in the Emma Children's Hospital (Amsterdam University Medical Centers) and was proven to be effective in improving psychosocial functioning of the child.

Chronic illness is a major problem for children and families and is associated with outcomes ranging from reduced functioning and maladjustment to resilience. It usually has an impact on the psychological wellbeing of any individual. An illness of early onset, with necessity of frequent diagnostic and therapeutic interventions can adversely affect the behavioral adjustment of children.

Adding psycho-education and social support for child and family will provide them a positive experience. Studies have shown that if chronically ill children and their families are well prepared, psych0educated and know in advance what is coming next and what paths their disorders might take, and which preventative steps are best to follow, it enhances their adaptation or recovery.

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