



Strategies to Improve Quality of Life in Children with Nephrotic Syndrome

Nephrotic syndrome (NS) is one of the most common childhood kidney problems.¹ Although most children do go into remission and end-stage kidney disease is rare,² the relapsing-remitting nature of the disease increases the complexities of management.

Most of the children with NS have a prolonged course [Figure 1], resulting in risks of repeated steroid exposure, the need for steroid-sparing agents with attendant risks of side effects, dietary restrictions, and the requirement for frequent medical visits. All of these can affect quality of life (QoL). The review by Shukla *et al.*,³ consolidates the existing evidence of the burden on QoL in childhood NS in the current issue of the journal. The median QoL was significantly lower ($p=0.05$) compared to healthy children, affecting steroid-dependent or frequently relapsing NS, as well as steroid-resistant NS. However, it was more significant in the latter ($p=0.02$). QoL was affected across various parameters, including emotional, physical, social, and school functioning. The major contributors identified were the presence of edema,

recurrent relapses, prolonged illness, high steroid dosage, and multiple medications.

With robust evidence supporting decreased QoL among these children, it is imperative to focus on ways to improve the situation. Understanding and addressing the root causes not only improves QoL but also impacts clinical care and leads to better overall outcomes.

The first step to combating these challenges is raising awareness of the issue and implementing a comprehensive care plan encompassing medical and nonmedical strategies [Table 1].

Medical strategies

Edema due to relapse has been consistently identified as a factor that affects emotional and physical well-being. Infections and hypovolemia associated with NS relapse are the most common causes of morbidity and hospital admission. Regular home monitoring of urine for protein and recording in diaries can help in the early identification of relapse and ensure effective and rapid treatment initiation

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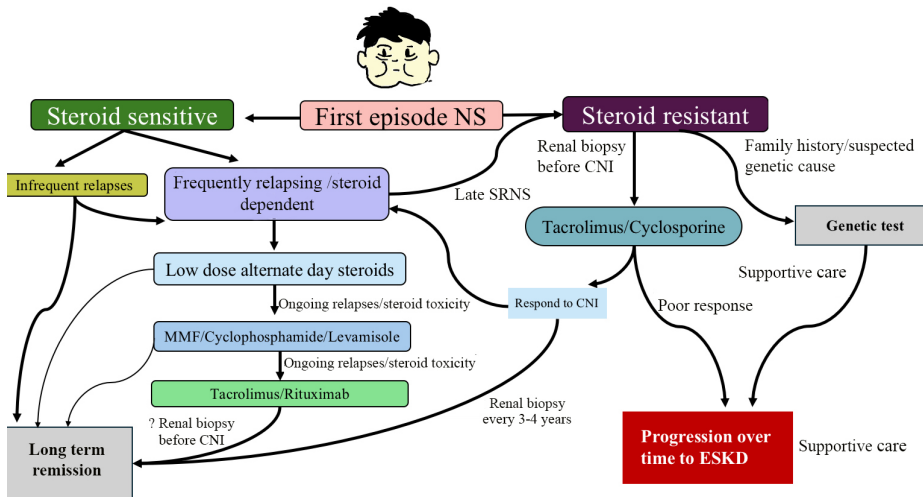


Figure 1: The treatment spectrum of children with nephrotic syndrome and factors affecting quality of life. The question mark indicates some disagreement regarding indication of kidney. NS: Nephrotic syndrome, SRNS: Steroid resistance nephrotic syndrome, CNI: Calcineurin inhibitor, ESKD: End stage kidney disease, MMF: Mycophenolate mofetil.

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Table 1: Medical and nonmedical support services for nephrotic syndrome children

Medical strategies	Nonmedical strategies
Home monitoring of urine protein and maintaining a nephrotic diary	Regular physical activities Mix with peers
Knowledge of potential complications and drug adverse effects	Salt restriction during relapse (not more than 15–35 mg/kg per day)
Early attendance in case of relapse or complication	Appropriate diet
Steroid minimization	Family education
Early use of steroid-sparing agents	Support groups
Up-to-date immunization	Meditation and yoga
Specialist–local physician joint care	Encourage school attendance or online school, if unable
Dispersal and implementation of guidelines	Creative activities

and significant edema and relapse complications can be prevented or limited.

Steroid toxicities, particularly obesity, short stature, and cushingoid features, are other factors that affect QoL. Steroid minimization by use of restricted courses of the alternate day rather than daily regimes for remission maintenance, utilization of brief periods (5–7 days) of low-dose daily steroids to prevent relapse during viral infections, and early use of steroid-sparing agents are all important strategies.⁴

Children with NS are predisposed to infections that also contribute to school absenteeism and social restrictions, all leading to the worsening of QoL. Ensuring routine immunizations (including vaccines against organisms such as pneumococcus), as well as including some vaccines that are not included in the Universal Immunization programs, such as influenza and chickenpox (the latter given when off immunosuppression), is vital for the control of vaccine-preventable diseases.⁴

Medical teams that follow uniform guidelines rather than practicing ad hoc treatment also have a prominent role in allaying confusion due to differing medical opinions and assuring the family of the best possible evidence-based treatment.

Nonmedical strategies

Family education and counseling play a vital role in disease management. Recognizing prognostic factors such as steroid response, disease severity, and age at onset and counseling the family regarding long-term outcomes help to allay anxiety in this recurring disease. The focus should be on maintaining as near an everyday life as possible so that the child grows up without a feeling of physical and mental handicap.

Some points to emphasize at every contact include the importance of home monitoring of urine protein, early recognition of relapse, and the need for monitoring for relapse or drug-related adverse effects so that complications can be avoided or rapidly managed.

Ensuring normal physical activity is integral to improving QoL, and physical activities should be encouraged even in an edematous state. Children with NS encounter difficulties while engaging in moderate or strenuous activities like running, sports, bathing, and household chores due to pain and easy fatigability⁵ and exhibit lower physical scores than healthy children ($p < 0.001$). The presence of edema significantly lowers the score. Increased mobility helps in edema control.⁵ Physical activity can benefit bone health improvement – team sports help make bonds with peer groups and improve mood.

Dietary salt restriction is a cheap and effective intervention for edema management but is often ignored. These children are advised a no-added salt diet while in relapse, however, excess restrictions that make food unpalatable should be avoided, and the diet should provide adequate nutrition. A nephrotic diet is sometimes mistakenly equated to a chronic kidney disease diet, and making both health professionals and dieticians aware of these could lead to the removal of various restrictions and better QoL for these children.

Psychological support through counseling or support groups can improve psychosocial well-being. Emotional dysfunctions such as disturbed sleep, difficulty in getting along with peers, and concerns regarding bullying are not only uncommon and multifactorial in origin and secondary to side effects of treatment but also a result of various social restrictions that are knowingly or unknowingly enforced on these children.⁵ Early judicious implementation of steroid-sparing strategy is important, but it is equally important to ensure peer support and increase awareness of the disease and its challenges among families and peers. Children should be encouraged to meditate and perform yoga and relaxing exercises to improve their mental health and well-being. Support groups can be helpful and may provide platforms for children with NS and their families to interact with other children or families facing similar challenges. No such support groups exist in India presently, but organizations such as Alport Syndrome Foundation and Nephcure have significantly helped patients in various world regions.

School functioning may be severely affected. Chronic absenteeism and dropping out of school due to the disease are common and can also result in low self-esteem. These are also more common among those with persistent edema and prolonged steroid usage. Special schools with facilities for home attendance and online classes might help to reduce absenteeism. The children

may be encouraged to do creative activities like drawing, painting, and craft making, as well as pursue indoor hobbies like playing chess. They require encouragement to achieve their best potential, and positive parenting should be emphasized.

Chronic diseases affect the family dynamics. Difficulties of traveling long distances to attend tertiary level clinics, the cost of medical care and travel, loss of days of parental work-related earnings, and depression among carers are important in every society, particularly in low- and middle-income countries (LMIC) like India.⁶ Strategies to address these barriers include building relationships between super-specialty and local physicians, educating and dispersing existing NS management guidelines within the medical fraternity, and encouraging families to follow up with local doctors. The acceptance of telemedicine post-COVID as a legally accepted mode of consultation can help reduce the frequency of travel, not only resulting in financial benefits but also ensuring school attendance and time for regular activities. All these might help in improving QoL in these children.

In conclusion, the poor QoL among children with NS is multifaceted, encompassing physical, emotional, and social

dimensions. Comprehensive care strategies that address these are the need of the hour.

Conflicts of interest

There are no conflicts of interest.

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