Quality of life assessment in pediatric nephrotic syndrome in North Sumatera Province: Parent-and-child proxy report

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Abstract

Background: Nephrotic syndrome (NS) is a pediatric kidney disease with a high recurrence rate, impacting patient quality of life (QoL). This study aimed to assess the QoL of NS children in North Sumatera using a parent-and-child proxy report.

Methods: This was a cross-sectional study (February–December 2023) in the nephrology and growth and developmental outpatient ward, Pediatrics Department, Adam Malik Hospital, and Prof. Dr. Chairuddin P. Lubis Universitas Sumatera Utara Hospital, Medan, Indonesia. The inclusion criteria for cases were children aged 5–18 who met the diagnostic criteria of NS. Cases were age-matched with healthy children as controls. The PedsQL 4.0 generic core scale instrument was used for the QoL assessment. Normally distributed continuous data were expressed as the mean and standard deviation; categorical data were expressed as proportions. Differences between the groups were analyzed using an independent t-test, and the correlation of illness duration and daily steroid dose with QoL was determined using the Pearson correlation test.

Results: A total of 44 NS pediatric patients were age-matched with 44 healthy children. A significant difference in QoL existed between the school scores of the NS and healthy groups in the parent proxy report (p = 0.001) and between the school score and total score of the child proxy report (p = 0.003 and p = 0.040, respectively). A significant difference in QoL existed in emotional scores between the remission and relapse groups in the parent-and-child proxy reports (p = 0.019 and 0.030, respectively). A significant negative correlation existed between the daily steroid dose and QoL in school and the total score of the parent proxy report (p = 0.025; r = –0.338).

Conclusion: The parent and child reports revealed a significant difference in QoL between the school scores of NS pediatric patients and healthy children. A significant difference in the emotional scores of NS pediatric patients in remission and relapse was also observed. The daily steroid dose was negatively correlated with the school score in the parent proxy report.
Keywords
child proxy report, nephrotic syndrome, parent proxy report, quality of life, North Sumatera

Introduction

Chronic kidney disease is a health problem affecting societies worldwide (Falhi et al. 2021). Nephrotic syndrome (NS) is a common chronic kidney disease in children and is characterized by proteinuria, hypoalbuminemia, and edema with or without hypercholesterolemia (Trihono et al. 2016). Worldwide, the prevalence of NS is 16 cases per 100,000 children, with an incidence of two to seven cases per 100,000 children (Hilmanto et al. 2022). Non-renal complications of NS are related to cardiovascular disease, anemia, infectious diseases (Al-Radeef 2020), growth disorders, endocrine disorders, psychosocial functioning, and quality of life (QoL) disturbance (Lee et al. 2020).

NS in children has a long-term impact on QoL due to the disease and the treatment received (Ruslie et al. 2021). Understanding QoL is critical to symptom improvement and patient care. Problems discovered from QoL reports can be used to modify and improve treatment and care or indicate deficiencies in the treatment provided (Haraldstad et al. 2019). QoL assessments should be based on parent and child reports, including physical, emotional, social, and school functioning (Varni 2020).

Several studies have reported on the QoL of pediatric NS patients. A study conducted at Haji Adam Malik Hospital, Medan, revealed an increase in the physical domain of QoL in NS children at the end of treatment compared to that at the initial treatment (Ruslie et al. 2021). Most QoL assessments of NS pediatric patients are based on parental reports; only a few studies include child reports. This study aimed to assess the QoL of NS pediatric patients according to parent and child reports across all domains.

Material and methods

This study enrolled 88 pairs of children aged 5–18 and their parents from February 2023 to February 2024, comprising NS pediatric patients who attended the nephrology and growth and developmental outpatient ward, the pediatric department at Adam Malik Hospital, and Prof. Dr. Chairuddin P. Lubis of Universitas Sumatera Utara Hospital, Medan, and healthy children as controls. This study was part of doctoral dissertation research. Ethical approval was obtained from the Health Research Ethics Committee of the Universitas Sumatera Utara, Medan, Indonesia, prior to the initiation of the study with number 85/KEPK/USU/2023 on January 27th, 2023. Verbal and written informed consent was obtained from each participant. The case group comprised 44 children diagnosed with NS, both old and new patients, who were in remission or relapse phases and had been taking steroids for at least 2 weeks. The control group comprised 44 healthy children not currently experiencing any infectious diseases.

QoL was assessed with the PedsQL 4.0 Generic Core Scales instrument in the Indonesian language, comprising 23 questions, including physical (eight items), emotional (five items), social (five items), and school (five items) functioning. This instrument consists of parent and child reports from children aged 5–7 years, 8–12 years, and 13–18 years (Desai et al. 2014). Completion involved using a 5-point Likert scale: zero (never a problem), one (almost never a problem), two (sometimes), three (often a problem), and four (almost always a problem). Scoring starts from zero to 100 in reverse: 0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0. The score was calculated by finding the average of each function and the total score. The higher the score obtained, the better the QoL will be (Varni 2001). The PedsQL 4.0 Generic Core Scales instrument based on parent and child reports had good reliability (Varni et al. 2005). QoL assessments can be divided into disturbances or not, with a cutoff of 70 points. A score less than 70 indicates disturbance, whereas a score above or equal to 70 indicates good QoL (Huang et al. 2009).

Statistical analysis

Statistical analyses were conducted with SPSS version 23.0, with p < 0.05 considered to indicate significance. The Kolmogorov-Smirnov test was used to analyze the normal distribution of continuous data. The data are presented as the mean and SD, and categorical data are presented as proportions. The difference in QoL between NS pediatric patients in remission and relapse phases and healthy children was analyzed using an independent t-test. The correlation between illness duration and daily steroid dose with QoL was analyzed using the Pearson correlation test.

Results

Most of the NS pediatric patients and healthy children were male (68.2% and 63.6%, respectively), in the adolescent age group (68.2% and 81.8%, respectively), and not firstborn (70.5% and 65.9%, respectively). The average weight and height of the NS pediatric patients were lower than those of healthy children. Most of the patients with a clinical status of NS experienced relapse (63.6%), with an average illness duration of 16.55 months and a daily steroid dose consumed at enrollment of 31.73 mg. The participant characteristics are listed in Table 1.
The assessment of QoL between NS pediatric patients and healthy children according to the parent proxy report revealed significant differences in the school score \((p = 0.001)\), whereas the physical, emotional, social, and total scores did not differ significantly. QoL differences according to the child proxy report were significant for the school and total scores \((p = 0.003\) and \(p = 0.040\), respectively), whereas the other parameters did not show a significant difference (Table 2).

### Table 2. QoL difference between the NS and HC groups according to the PedsQL™ 4.0 generic score scales.

<table>
<thead>
<tr>
<th>Parameters</th>
<th>Parent proxy report</th>
<th>Children proxy report</th>
<th>P-value</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical score</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NS</td>
<td>87.65 (14.26)</td>
<td>87.66 (14.25)</td>
<td>0.368</td>
<td></td>
</tr>
<tr>
<td>HC</td>
<td>90.00 (9.66)</td>
<td>89.93 (11.07)</td>
<td>0.406</td>
<td></td>
</tr>
<tr>
<td>Emotional score</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NS</td>
<td>76.93 (16.22)</td>
<td>72.84 (15.97)</td>
<td>0.873</td>
<td>0.269</td>
</tr>
<tr>
<td>HC</td>
<td>76.36 (16.89)</td>
<td>76.82 (17.56)</td>
<td>0.868</td>
<td>0.569</td>
</tr>
<tr>
<td>Social score</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NS</td>
<td>91.82 (11.57)</td>
<td>90.91 (12.82)</td>
<td>0.868</td>
<td>0.569</td>
</tr>
<tr>
<td>HC</td>
<td>92.77 (13.91)</td>
<td>92.39 (11.39)</td>
<td>0.887</td>
<td>0.569</td>
</tr>
<tr>
<td>School score</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NS</td>
<td>68.29 (22.12)</td>
<td>73.07 (19.48)</td>
<td>0.001*</td>
<td>0.003*</td>
</tr>
<tr>
<td>HC</td>
<td>82.84 (15.53)</td>
<td>84.09 (13.57)</td>
<td>0.001*</td>
<td>0.003*</td>
</tr>
<tr>
<td>Total score</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NS</td>
<td>81.19 (11.97)</td>
<td>81.14 (10.42)</td>
<td>0.067</td>
<td>0.040*</td>
</tr>
<tr>
<td>HC</td>
<td>85.38 (8.96)</td>
<td>85.82 (10.61)</td>
<td>0.067</td>
<td>0.040*</td>
</tr>
</tbody>
</table>

*Independent t-test.

The correlation between illness duration and QoL scores in the parent-and-child proxy report was not significant \((p > 0.05)\) for all functions. A correlation existed between the daily steroid dose consumed at enrollment and QoL scores in the child proxy report for all functions \((p > 0.05)\). Conversely, the parent proxy report revealed a significant negative correlation in the school and total scores \((r = -0.338, p = 0.025; \text{Fig. 1})\).
## Discussion

Most NS pediatric patients were male, with a ratio of 2:1. These results are consistent with those of several other studies (Eid et al. 2020; Mazahir et al. 2022). Currently, it is unclear why male children experience NS more frequently than female children. Most of the NS pediatric patients were in the adolescent group; this result is consistent with those of other studies (O. Pardede et al. 2019; Kartawijaya et al. 2022). Adolescence is an important human developmental stage, marked by puberty. The hormonal and immune changes that occur during puberty can affect kidney function and increase the risk of kidney disease. Most of the NS pediatric patients were not firstborn. Parents respond quickly and take their children to a health facility for treatment if they experience an illness that worries them. At the health facility, all data related to the child are recorded, including birth order.

The QoL assessment based on the parent report revealed a significant difference in school functioning between NS pediatric patients and healthy children (p = 0.001); however, no significant differences were found in the physical, emotional, social, or total scores. These results were inconsistent with those of studies conducted at Mansoura University Children’s Hospital, Mesir (Eid et al. 2020) and the Children’s Medical Centre, University of Medical Sciences, Iran (Abbas et al. 2022). The difference in QoL scores between NS pediatric patients and healthy children in terms of physical, emotional, social, and total scores was small, whereas the scores for school functioning differed considerably, nearing 15 points. The parents of NS pediatric patients tend to be more protective regarding their child’s health condition; thus, some of these parents opt for homeschooling, helping them monitor their child’s activities and food consumption.

The QoL assessment using the child report revealed a significant difference in school functioning (p = 0.003) and total (p = 0.040) scores between NS pediatric patients and healthy children; however, no difference existed in the other functioning categories. This result is consistent with those of a study on health facility tertiary care in India; differences in QoL scores existed for physical, social, school, and total functioning in that study (Mazahir et al. 2022). The difference in QoL scores reached 11 points. Individually, NS pediatric patients have difficulty concentrating at school, often forget to do schoolwork, and often miss school because they feel unwell and visit the doctor for treatment.

NS pediatric patients often experience relapses; thus, the QoL in the remission phase can differ from that during relapse. The QoL assessments based on the parent and child reports showed significant differences in emotional functioning (p = 0.019 and p = 0.030, respectively), while other functioning parameters did demonstrate differences. This result is inconsistent with that of a study conducted in Soba University Hospital, Khartoum, Sudan, which showed a significant difference in QoL in social, school, and total functioning (Allam et al. 2022). Emotional problems occur in NS pediatric patients; they often feel afraid, sad, and angry, struggle to sleep, and worry about their situation. This problem is related to steroid use, as the medication can affect emotions by increasing anxiety or irritability. Meanwhile, a relapse causes the children to experience emotional fluctuations, including despair and disappointment that the disease has not yet been completely cured.

Steroid use has been shown to affect QoL in the physical, emotional, social, and school functioning parameters (Khullar et al. 2021). In this study, a significant negative correlation existed between daily steroid dose and QoL, according to the parent report in school and total scores. Steroids can affect brain structure, particularly the areas involved in memory and attention. Structural changes in the brain can affect its ability to process information efficiently, interfering with the child’s performance at school.

The limitations of this study are that the data were collected at one time point without follow-up, and the results obtained do not represent the populations in other cities or provinces. These limitations can be used as a basis for further research.

## Conclusion

NS, a chronic pediatric kidney disease, can influence QoL. Parent and child reports revealed a significant difference in QoL in school scores between NS pediatric patients and healthy children. QoL differences were also observed in the emotional score between NS pediatric patients in remission and relapse. The daily steroid dose was negatively correlated with the school score in the parent proxy report. NS requires comprehensive management to improve QoL. Therefore, QoL assessments must be performed routinely every 3 to 6 months as part of NS pediatric patient management to assist in preventive and therapeutic measures.

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## References


