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Summary of Best Evidence for Disease Management of Primary Nephrotic Syndrome in Children

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Abstract: *Objective*: To retrieve, evaluate and summarize the best evidence for disease management in children with primary nephrotic syndrome. *Methods*: The relevant literatures on the management of primary nephrotic syndrome in children were systematically searched in comprehensive databases, relevant guidelines websites and professional society websites at home and abroad. The search time was from the establishment of the database to January 2025. Two researchers independently completed the quality evaluation, evidence extraction and integration of the literature. *Results*: A total of 16 articles were included, including 4 evidence-based guidelines, 5 expert consensuses, 1 systematic review, and 6 clinical decisions. A total of 34 best evidences were summarized and integrated, including management objectives, medication management, urine monitoring, diet management, infection prevention, lifestyle and recurrence assessment. *Conclusion*: This study summarizes the best evidence of disease management in children with primary nephrotic syndrome, and provides evidence-based basis for clinical medical staff to implement disease management and health education for children. Clinical medical staff should fully combine the clinical situation and the actual situation of the child when selecting evidence, transform it and apply it to clinical practice.

Keywords: Children; Primary nephrotic syndrome; Management; Best evidence summary; Evidence-based nursing

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1. Introduction

Primary nephrotic syndrome (PNS) in children is one of the most prevalent glomerular diseases among children, accounting for 90% to 95% o2,f pediatric nephrotic syndrome cases [1]. According to statistics, the global incidence rate of PNS in children is approximately (1.2 to 16.9) per 100,000, with an annual increase of 28,000 to 56,000 new cases in China [2,3]. Glucocorticoid therapy has long been the first-line treatment for this condition, but it is characterized by a long treatment cycle, a tendency to become protracted, and a high risk of recurrence [4,5]. This also makes it one of the primary causes of chronic renal failure in children [6].

Implementing effective disease management measures can help improve the quality of life for affected children, enhance long-term disease outcomes, and reduce the recurrence rate. While current guidelines and research have outlined treatment and management approaches for pediatric nephrotic syndrome, there is a lack of standardized, family-centered management plans specifically tailored to children with primary nephrotic syndrome. This study summarizes the best evidence for disease management in pediatric primary nephrotic syndrome through systematic retrieval, screening, quality assessment, extraction, and grading, aiming to provide evidence-based support for healthcare professionals in developing family-centered disease management plans.

2. Materials and methods

This study has been registered with the Evidence-Based Nursing Center at Fudan University (ES20246713).

2.1. Establishing evidence-based questions

Evidence-based questions were constructed following the PIPOST model of the Evidence-Based Nursing Center at Fudan University [7]. The details are as follows:

(1) Target population (Population, P): Pediatric patients with PNS (Primary Nephrotic Syndrome);
(2) Interventions (Intervention, I): Measures related to disease management applied to pediatric patients with PNS;
(3) Implementers of evidence application (Professional, P): Healthcare professionals or family caregivers;
(4) Outcome indicators (Outcome, O): Caregiving ability, unplanned readmission, infection rate, medication adherence, follow-up appointment adherence, satisfaction, etc.;
(5) Settings for evidence application (Setting, S): Hospitals, medical institutions, etc.;
(6) Study design or type (Study Design, T): Clinical practice guidelines, clinical decision-making, recommended practices, systematic reviews, evidence summaries, expert consensus, randomized controlled trials.

2.2. Evidence retrieval

Following the "5S" pyramid model, the search was conducted from top to bottom [8]. The Chinese search terms were "children/pediatric patients/infants", "nephrotic syndrome/ nephritic syndrome/ nephropathy", "diagnosis and treatment/ management/ therapy/ intervention/ nursing", and "guideline/ practice/ evidence summary/ systematic review/clinical decision-making/expert consensus/meta-analysis". The corresponding English search terms were"child/ children/ pediatric/ infant/ adolescent", "nephrotic syndrome/ nephritic syndrome/ nephropathy", "diagnosis/ treatment/ therapy/ management/ nursing/ nursing care/ nursing intervention", and "guideline/ practice/ systematic review/ consensus/ evidence summary/ meta-analysis".

The databases searched included CNKI, VIP, Wanfang Data, Chinese Biomedical Literature Database (CBM), PubMed, Web of Science, CINAHL, Cochrane Library, Joanna Briggs Institute (JBI) Evidence-Based Practice Database, Ovid, and Karger Medical Electronic Resource Database. Relevant guideline and professional society websites included UpToDate Clinical Advisor, BMJ Best Practice, National Institute for Health and Care Excellence (NICE), Chinese Society of Nephrology (CMA), International Society of Nephrology (ISN), International Pediatric Nephrology Association (IPNA), Medlive Clinical Guidelines, Guidelines International Network (GIN), MedSci, Scottish Intercollegiate Guidelines Network (SIGN), Registered Nurses' Association

of Ontario (RNAO), New Zealand Guidelines Group (NZGG), Chinese Medical Knowledge Base (Selected Guidelines Database), American Society of Nephrology (ASN), and Chinese Medical Journal Full-text Database (Guidelines Module). The search period spanned from the establishment of each database to January 2025. Chinese and English search strategies are shown in **Figure 1**.

English database retrieval formula -- taking PubMed as an example
#1 ((((child[MeSH Terms]) OR (children[MeSH Terms])) OR (pediatric[MeSH Terms])) OR (infant[MeSH Terms])) OR (adolescent[MeSH Terms])
#2 ((nephrotic syndrome[MeSH Terms]) OR (nephritic syndrome[MeSH Terms])) OR (nephropathy[MeSH Terms])
#3 ((((((diagnosis[Title/Abstract]) OR (treatment[Title/Abstract])) OR (therapy[Title/Abstract])) OR (management[Title/Abstract])) OR (nursing[Title/Abstract])) OR (nursing care[Title/Abstract])) OR (nursing intervention[Title/Abstract])
#4 (((((guideline[Title]) OR (practice[Title])) OR (systematic review[Title])) OR (consensus[Title])) OR (evidence summary[Title])) OR (meta-analysis[Title])
#5 (((#1) AND (#2)) AND (#3)) AND (#4)

Search query for Chinese databases—taking CNKI as an example:
#1 Subject = Children + Pediatric Patients + Infants
#2 Subject = Nephrotic Syndrome + Kidney Disease
#3 Title/Abstract/Keywords = Diagnosis and Treatment + Management + Therapy + Intervention + Nursing
#4 Title/Abstract/Keywords = Guidelines + Practice + Expert Consensus + Systematic Review + Evidence Summary + Clinical Decision-Making + Meta-Analysis
#5 #1 AND #2 AND #3 AND #4

Figure 1. Search formulas for PubMed and CNKI.

2.3. Literature inclusion and exclusion criteria

The inclusion criteria are as follows:

(1) Research content of the literature: measures related to disease management in children with PNS;
(2) Types of literature: guidelines, best practices, clinical decisions, expert consensus, systematic reviews, evidence summaries, randomized controlled trials;
(3) Outcome indicators: caregiving capacity, recurrence rate/unplanned readmission, infection rate, medication adherence, follow-up compliance, satisfaction, etc.;
(4) Time frame: literature published from the establishment of the database to January 2025, language: Chinese or English.

The exclusion criteria are as follows:

(1) Literature with incomplete data, duplicate publications, abstracts, or unavailable full texts;
(2) Literature that fails to meet the quality evaluation criteria.

2.4. Literature quality evaluation criteria

The quality of included guidelines will be evaluated using the Appraisal of Guidelines for Research and Evaluation II (AGREE II) [9]. Expert consensus will be evaluated using the JBI Evidence-Based Health Care Center's authenticity evaluation tool for opinion and consensus articles (2016 version) [10]. Systematic reviews and randomized controlled trials will be evaluated using the corresponding evaluation tools from the Australian JBI Evidence-Based Health Care Center (2016); clinical decisions, best practices, and evidence summaries will be traced back to the original literature and evaluated for quality using the corresponding evaluation tools [11,12].

2.5. Literature quality evaluation process

Two members of the research team, who have undergone systematic training in evidence-based nursing, independently evaluate the literature according to the literature quality evaluation criteria and conduct cross-

reviews. In cases of inconsistent or divergent evaluation opinions, a decision is made through consultation with a third team member.

2.6. Evidence extraction and summarization

Two researchers extract evidence based on the research topic and objectives. After evidence extraction, all team members participate in discussions to summarize the evidence. The principles for evidence summarization are as follows:

(1) When the content is consistent, select evidence that is more concise and better aligned with professional expressions;
(2) If the content is complementary, merge the evidence;
(3) When there are conflicting conclusions from evidence from different sources, prioritize evidence-based evidence, high-quality evidence, and recently published evidence.

The grading of evidence adopts the "JBI Evidence Pre-grading and Evidence Recommendation Level System (2014 Edition)" [13]. By tracing back to the original literature of the evidence, the evidence level is determined, encompassing a total of five levels, which decrease sequentially from 1 to 5. Additionally, under the guidance of the JBI FAME structure and in combination with the aforementioned recommendation level system (2014 Edition), the recommendation level of the included evidence-based guidelines is determined, with Level A representing strong recommendations and Level B representing weak recommendations.

3. Results

3.1. General characteristics of included literature

A preliminary search yielded 2,191 articles. After removing duplicates and excluding articles that did not meet the inclusion criteria by reviewing their titles, abstracts, and full texts, a final set of 16 articles was included, comprising 4 evidence-based guidelines, 5 expert consensuses, 1 systematic review, and 6 clinical decisions [5,14–28]. The general characteristics of the included literature are presented in **Table 1**, and the literature screening process is illustrated in **Figure 2**.

Table 1. General characteristics of included literature

No.	Literature	Database/ source	Type	Topic
1	Trautmann et al. 2022 [14]	CINAHL	Evidence-based Guideline	IPNA Recommendations for Diagnosis and Management of Steroid-Sensitive Nephrotic Syndrome in Children
2	Chinese Medical Association Pediatrics Branch Nephrology Group 2016 [5]	VIP	Evidence-based Guideline	Evidence-based Guidelines for Diagnosis and Treatment of Steroid-Sensitive, Relapsing/ Dependent Nephrotic Syndrome in Children
3	Kaku et al. 2015 [15]	PubMed	Evidence-based Guideline	General Treatment of Nephrotic Syndrome in Children
4	KDIGO 2012 [16]	PubMed	Evidence-based Guideline	Management and Treatment of Glomerular Diseases
5	Ehren et al. 2021 [17]	CINAHL	Expert Consensus	German Expert Consensus on Diagnosis and Treatment of Steroid-Sensitive Nephrotic Syndrome in Children

Table 1 (Continued)

No.	Literature	Database/ source	Type	Topic
6	Li Xiaozhong et al. 2019 [18]	CNKI	Expert Consensus	Expert Consensus on Vaccination for Children with Renal Diseases
7	Pasini et al. 2017 [19]	Yimaitong	Expert Consensus	Management of Nephrotic Syndrome in Children
8	Sinha et al. 2021 [20]	PubMed	Expert Consensus	Management Recommendations for Steroid-Sensitive Nephrotic Syndrome in Children
9	Sun Jinqiao et al. 2019 [21]	CNKI	Expert Consensus	Expert Consensus on Vaccination for Children on Immunosuppressive Therapy
10	Mi Xiufang et al. 2019 [22]	CNKI	Systematic Review	Efficacy of Calcium and Vitamin D in Preventing Steroid-Induced Bone Loss in Children with Nephrotic Syndrome
11	Boyer 2023 [23]	UpToDate	Clinical Decision Support	Evaluation of Proteinuria in Children
12	Niaudet 2023 [24]	UpToDate	Clinical Decision Support	Symptomatic Management of Nephrotic Syndrome in Children
13	Valentini 2022 [25]	UpToDate	Clinical Decision Support	Evaluation and Treatment of Edema in Children
14	Niaudet 2024 [26]	UpToDate	Clinical Decision Support	Treatment of Idiopathic Nephrotic Syndrome in Children
15	UpToDate 2025 [27]	UpToDate	Clinical Decision Support	Health Education for Patients with Nephrotic Syndrome
16	UpToDate 2025 [28]	UpToDate	Clinical Decision Support	Health Education on Low-Sodium Diet for Children

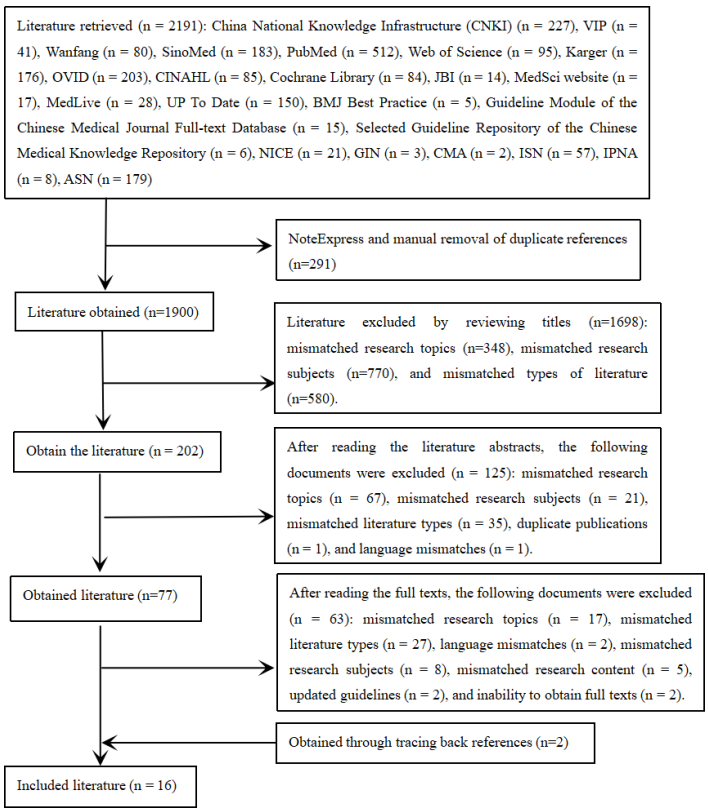

Figure 2. Flowchart of literature screening process.

3.2. Results of literature quality assessment

3.2.1. Quality assessment of guidelines

Four guidelines were included, all of which received high-quality assessments and were thus included. The standardized percentage scores and recommendation levels for each field are provided in **Table 2**.

Table 2. Quality assessment results of included guidelines (n = 4)

Included guidelines	Domain score percentage (%)						Number of domains		Recommendation level
	Scope & purpose	Stakeholder involvement	Rigor of development	Clarity of presentation	Applicability	Editorial independence	≥ 60%	≥ 30%	
Trautmann et al. [14]	100	100	70.83	90.48	66.67	100	6	6	A
Chinese Medical Association Pediatrics Branch Nephrology Group [5]	94.44	63.89	79.17	97.22	62.50	100	6	6	A
Kaku et al. [15]	100	97.22	81.25	100	52.08	95.83	5	6	B
KDIGO [16]	100	58.34	69.79	100	81.25	100	5	6	B

3.2.2. Quality assessment of expert consensuses

Five expert consensuses were included, all of which received favorable quality assessments and were thus approved for inclusion. The assessment results are shown in **Table 3**.

Table 3. Quality assessment results of included expert consensuses (n = 5)

Literature	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6
Ehren et al. [17]	Yes	Yes	Yes	Yes	Yes	Yes
Li et al. [18]	Yes	Yes	Unclear	Yes	Yes	Yes
Sun et al. [21]	Yes	Yes	Unclear	Yes	Yes	Yes
Pasini et al. [19]	Yes	Yes	Yes	Yes	Yes	Yes
Sinha et al. [20]	Yes	Yes	Unclear	Yes	Yes	Yes

3.2.3. Quality assessment of systematic reviews

A total of one systematic review was included [22]. In its quality assessment, item 7, "Were measures taken to minimize errors during data extraction?" was rated as "No"; item 11, "Were appropriate suggestions made regarding specific directions for future research?" was rated as "Unclear"; all other items were rated as "Yes". The quality assessment was favorable, and the review was approved for inclusion.

3.2.4. Quality evaluation of clinical decisions

A total of six clinical decisions were included, all sourced from the UpToDate clinical decision-making system [23–28]. This system is an internationally recognized authoritative evidence-generating institution, with its evidence content confirmed through international peer review, ensuring high evidence quality. Therefore, all decisions were approved for inclusion.

3.3. Evidence description and summary

This study summarized seven themes: management objectives, medication management, urine testing, dietary management, infection prevention, lifestyle, and recurrence assessment, culminating in a total of 34 pieces of best evidence (**Table 4**).

Table 4. Summary of best evidence for disease management in pediatric patients with PNS

Evidence theme	Evidence content	Level
Management Goals	1. Achieve relapse-free status, minimize adverse effects, and improve quality of life [14].	1a
	2. Prevent or minimize complications of the underlying NS [2].	1a
Medication Management	3. Common adverse effects: Obesity/weight gain, hypertension, diabetes, behavioral/mental disorders, sleep disruption, growth impairment, Cushingoid appearance, striae, glaucoma, cataracts, bone pain, femoral head necrosis [14].	1a
	4. Regular monitoring recommended: Blood pressure, height, weight (quarterly) [14,23].	1b
	5. Regular ophthalmologic examinations recommended during steroid therapy [14,15].	2d
	6. Prophylactic use of calcium and vitamin D to prevent bone loss during PDN therapy [14,22].	1a
	7. Guide parents to keep a medication record [20].	5b
Urine Monitoring	8. Random urine samples (preferably first morning or 24-hour specimens) recommended for assessing proteinuria [14].	1a
	9. Educate parents/caregivers: Use dipstick test to monitor urine protein levels [1–3,6-7].	5b
	10. Continue monitoring proteinuria after effective PDN treatment to detect early relapse, initiate timely treatment, and prevent significant edema and complications [23].	1b
	11. Monitoring frequency/timing: (1) Daily home dipstick testing until remission after discharge [14,23]. (2) Home dipstick testing at least twice weekly in the first year, then individualized [14,19]. (3) Daily testing if dipstick shows 1+ protein or more, during fever/infection, or if relapse is suspected [14,19].	5b
	12. Advise children to urinate before bed and remain recumbent before collecting the first morning sample [23].	5c
	13. Do not use dipstick tests for at least 24 hours after contrast imaging [23].	5c
Dietary Management	14. Low-salt diet recommended during edema [14,15,19,24,25,27,28]; daily sodium intake limited to 2-3 mEq/kg body weight, up to 90 mEq/day (2000 mg) for older children [14,25]; fluid restriction should be based on effective circulating volume [14,15,19,23,25,28].	5b
	15. Ensure healthy nutrition during PDN therapy, avoiding high-fat/high-calorie foods. Caloric intake should be age-appropriate [14,15].	1b
	16. Dietary measures limiting excessive caloric intake (including low-fat diet) help prevent significant weight gain. Therefore, guiding families on reasonable diet is important for obesity prevention [15,24].	5a
	17. For PNS children with normal renal function, protein intake should be based on the nutritional requirements of healthy peers [15]. Protein intake should reach 130%-140% of the Recommended Daily Allowance [23].	2b
	18. Ensure adequate dietary calcium; children with insufficient intake should receive oral calcium supplements [14].	1a
	19. Where possible, involve a dietitian to advise children and families on appropriate low-salt, low-fat diet during relapse [14].	1a

Table 4 (Continued)

Evidence theme	Evidence content	Level
Infection Prevention	20. Routine prophylactic antibiotics are not recommended [1].	1a
	21. Inform families about the increased infection risk due to immunosuppressive therapy [3].	5b
	22. In case of suspected bacterial infection, seek immediate medical care for timely antibiotic therapy [14,19].	5b
	23. Vaccination is the primary means of infection prevention [24].	1b
	24. Children on immunosuppressive therapy can receive inactivated vaccines [13] and are recommended to complete age-appropriate inactivated vaccinations [14,15,20,24].	5b
	25. Administration of live attenuated vaccines should follow national guidelines [1,13]. It is advised to postpone live attenuated vaccines during high-dose immunosuppressive therapy [19,21].	5b
	26. Live vaccines are contraindicated during immunosuppressive therapy [14,15].	1a
	27. Annual influenza vaccination is recommended for the child and close household contacts [1,6,9,16]. Unimmunized children should receive pneumococcal vaccines [2,15,16].	4b
	28. Timely vaccination of healthy household contacts, especially against varicella and influenza, is recommended to minimize the child's infection risk [4,6,15].	1b
	29. Avoid direct contact of the child with GI, urinary, or respiratory secretions of household members who have received a live vaccine within the prior 3-6 weeks [16].	1a
Lifestyle	30. Avoid excessive restriction of physical activity to prevent thrombosis, bone loss, and obesity [14,24].	4a
	31. Restrict activity during acute phase if there is abnormal blood pressure and/or severe pulmonary edema [15].	4d
	32. Adequate sun protection is recommended for children on long-term immunosuppressants [14,17], including reducing UV exposure, avoiding sunbathing, covering skin, and using high-SPF sunscreen [14].	5b
Relapse Assessment	33. Relapse is defined in a previously fully remitted patient as dipstick urine protein ≥3+ (or uPCR ≥200 mg/mmol / 2 mg/mg) for 3 consecutive days, with or without edema [5,14].	1b
	34. Signs of potential relapse requiring evaluation include fever ≥38°C, decreased urination frequency, and worsening swelling [27].	5c

Note: NS refers to Nephrotic Syndrome, PNS refers to Primary Nephrotic Syndrome, and PDN refers to Prednisone or Prednisolone.

4. Discussion

4.1. Family-centered approach: Leveraging the vital role of family caregivers

Due to the unique characteristics of children with PNS, such as their young age and limited self-care abilities, they primarily rely on family caregivers for disease management. Multiple items in the compiled evidence explicitly highlight the crucial role of family caregivers in managing the child's illness. For instance, evidence item 7 recommends instructing family caregivers to keep medication records during the child's pharmacological treatment; evidence item 9 suggests educating the child and their parents or caregivers and guiding them to monitor the child's urinary protein levels using dipstick tests; evidence item 19 proposes that not only should children be educated on dietary management, but family members also play a pivotal role in dietary adjustments; evidence item 21 advises informing family members that the child's risk of infection increases due to immunosuppressive therapy, necessitating the cooperation of family caregivers to implement measures to prevent infections [14,19,20,13].

In summary, family caregivers play a vital role in medication management, urine monitoring, dietary management, and infection prevention for the child. Evidence items 1 and 2 summarize that effective disease

management can prevent relapse, minimize adverse reactions, reduce complications caused by underlying nephrotic syndrome (NS), and improve the child's quality of life [14,23]. Therefore, in future clinical practice, healthcare professionals can fully leverage the initiative of family caregivers of pediatric patients, encouraging their participation in the child's disease management to improve the child's long-term prognosis and enhance their quality of life.

4.2. Strengthening medication management is crucial for pharmacological treatment

Evidence items 3 to 7 summarize the content related to medication management in children with PNS. Guidelines and clinical decisions outline common adverse reactions during corticosteroid therapy and corresponding measures [14,15,23]. For adverse reactions such as obesity or weight gain, hypertension, and growth disorders, children require regular monitoring of blood pressure, height, and weight. During corticosteroid therapy, children also face risks of glaucoma and cataracts, necessitating regular ophthalmologic examinations to promptly assess ocular conditions. Research also indicates that children undergoing prednisone (PDN) therapy can prophylactically use calcium and vitamin D to prevent drug-induced bone loss [22]. Additionally, expert consensus recommends that healthcare professionals should guide parents in keeping medication records [20]. Collectively, regular monitoring and examination of relevant indicators are key to prevention in the medication management of children with PNS; prophylactic use of relevant medications and the involvement of family caregivers are important components of management.

4.3. Emphasizing urine monitoring for timely identification of relapse

Evidence items 8 to 13 summarize the methods and specific content of urine monitoring in children with PNS. The degree of proteinuria is closely related to the onset and prognosis of the disease in children and is considered one of the important predictors of relapse [29]. Other studies have shown that continuous monitoring of urinary protein facilitates early detection of relapse and initiation of treatment, thereby preventing significant edema and minimizing related complications [23]. Currently, clinicians primarily rely on urine test results reported by pediatric patients and their caregivers during medical visits to assess the prognosis of these patients after discharge. However, research has found issues such as poor monitoring compliance and untimely medical visits [30]. Therefore, strengthening health education on urine monitoring for pediatric patients and their family caregivers to enhance their awareness and compliance is of great significance for the disease prognosis of these patients.

Guidelines recommend prioritizing the use of first morning urine or 24-hour urine specimens for assessing proteinuria, followed by random urine samples [14]. Family caregivers can be encouraged to actively participate in the urine monitoring and management of pediatric patients. It is recommended that healthcare professionals provide health education to pediatric patients and their family caregivers, instructing them on how to use test strips to monitor the urinary protein levels of pediatric patients, and informing them about the timing, frequency, and precautions of urine monitoring [14,19,20,23]. Simultaneously, pediatric patients and their family caregivers should be instructed on how to identify disease recurrence. The guidelines recommend that when a pediatric patient who has previously achieved complete remission exhibits a random urine or first morning urine test strip result of ≥ 3+ for three consecutive days, or a urine protein/creatinine ratio of ≥ 200 mg/mmol (2 mg/mg), with or without edema, it indicates recurrence, and they should seek medical attention promptly. If symptoms of infection, a decrease in urination frequency compared to usual, or increased swelling occur, it may also indicate recurrence, and medical attention should also be sought promptly [5,14,27].

4.4. Emphasizing the supportive role of diet and lifestyle in pediatric patients

Articles 14 to 19 and 30 to 32 summarize the management of diet and lifestyle for pediatric patients with PNS. During periods of edema, a low-salt diet is recommended with daily intake adjusted according to body weight and limited to 2-3 mEq/kg, with a maximum of 90 mEq (2000 mg) for older children [14,15,19,24,25,27,28]. However, fluid intake restriction should be determined based on effective circulating blood volume [14,15,19,23,25,28]. Regarding caloric intake, guidelines recommend maintaining healthy nutrition during PDN treatment, avoiding high-fat and/or high-calorie foods [14,15]. Caloric intake should be tailored to the patient's age, and dietary measures to limit excessive calorie intake can help prevent significant weight gain in children.

Studies have shown that guiding families on proper dietary arrangements is crucial for preventing obesity [24]. When feasible, it is recommended that a dietitian provide advice to children and their families who require a moderately low-fat and low-salt diet during relapse [14]. In terms of protein intake, guidelines suggest that protein consumption in PNS children with normal renal function should be based on the nutritional needs of healthy children of the same age, reaching 130% to 140% of the daily recommended intake [15,23]. Additionally, regarding lifestyle, reasonable exercise can prevent complications such as thrombosis, decreased bone mass, and obesity, but children with abnormal blood pressure and/or severe pulmonary edema during the acute phase should limit physical activity [14,15,24]. Children receiving long-term immunosuppressive therapy should also be adequately protected from sun exposure [14,17].

4.5. Popularize knowledge about vaccination and strengthen the prevention of infections

Evidence from Articles 20 to 29 summarizes content related to infection prevention and management in children with PNS. Due to the long-term use of corticosteroids and other immunosuppressive agents in children with PNS, their immune function is prone to decline, making them susceptible to infections. Infections are not only a major complication of childhood PNS but also one of the risk factors for PNS relapse, posing a persistent challenge in PNS treatment [31–33]. Guidelines and expert consensus recommend that children and their families should be informed of the increased risk of infection during treatment and instructed on how to take effective measures to prevent infections [14,19].

In cases of suspected bacterial infection, immediate medical attention is advised to initiate antibiotic therapy promptly; however, routine prophylactic use of antibiotics is not recommended. Studies indicate that vaccination is a primary means of preventing infections [24]. However, live vaccine administration is contraindicated under immunosuppressive therapy [16,17]. Children receiving immunosuppressive therapy can receive inactivated vaccines, and it is recommended that they complete inactivated vaccine vaccinations according to age-appropriate standards [14,15,20,21,24]. The administration of live attenuated vaccines should adhere to the corresponding principles outlined in national vaccination guidelines, and it is recommended that children undergoing high-dose immunosuppressive therapy delay vaccination [14,19,21].

Timely vaccination of family members who have long-term contact with pediatric patients is also crucial to minimize the risk of infecting the children, particularly with vaccines for varicella and influenza [15,16,20]. It is recommended that both pediatric patients and their family members with long-term contact receive annual influenza vaccinations, and that pediatric patients who have not been immunized should also receive pneumococcal vaccines [5,14,16,20,23,24]. Additionally, guidelines recommend that pediatric patients should avoid direct contact with gastrointestinal, urinary, or respiratory secretions from family members who have received live vaccines within the past 3 to 6 weeks [16].

5. Conclusion

This study summarized the disease management aspects for pediatric patients with PNS across seven dimensions, including management objectives, medication management, urine testing, dietary management, infection prevention, and lifestyle. In the future, based on the evidence summarized and in conjunction with actual clinical conditions, disease management measures for pediatric patients with primary nephrotic syndrome will be developed to provide evidence-based support for clinical healthcare professionals in implementing disease management and health education for pediatric patients. However, this study has certain limitations, including a limited variety of included literature types and a lack of high-quality randomized controlled trials. Future research could expand search resources and enrich the types of literature. Clinical healthcare professionals should fully consider clinical conditions and the actual situations of pediatric patients when selecting evidence, transforming it, and applying it to clinical practice.

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Disclosure statement

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