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A Mixed-Methods Study on the Diagnosis and Management Status and Family Care Needs of Children with Allergic Rhinitis Based on the TQM Concept

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Abstract

Objective: To investigate the disease knowledge level of family caregivers, medication adherence of children, and satisfaction with medical services among families of children with allergic rhinitis (AR), and to explore in depth the core difficulties and support needs of caregivers in the whole-process disease management, thereby providing empirical evidence for constructing a family-centered, whole-process health management model guided by the Total Quality Management (TQM) concept. **Methods:** An explanatory sequential mixed-methods design was employed. From April to September 2025, convenience sampling was used to conduct a questionnaire survey of 350 caregivers of children with allergic rhinitis at the pediatric outpatient clinic of a tertiary maternity and child healthcare hospital in Shenzhen. From October to December 2025, semi-structured in-depth interviews were conducted with 15 caregivers selected through purposive sampling. Quantitative data were analyzed using descriptive statistics, and qualitative data were analyzed using Colaizzi's 7-step method. **Results:** Among the 350 caregivers, mothers accounted for 76.9%, and the mean disease duration of children was (3.5 ± 2.1) years. The total disease knowledge score was (12.50 ± 3.20). The lowest awareness rates were found in complication prevention (31.7%) and environmental control (38.7%). The medication adherence score was (5.20 ± 1.80), with 62.9% showing poor adherence. The overall satisfaction score was (3.40 ± 0.60), with the lowest ratings for "follow-up convenience" and "accessibility of health education materials". Qualitative analysis identified four themes: ambiguity in disease cognition and the need for structured education; fragmentation of healthcare processes and the need for proactive navigation; isolation in home management and the need for accessible, immediate support; and lack of participation in decision-making and the need for collaborative communication. **Conclusion:** Families of children with AR face significant challenges in disease knowledge, medication adherence, and service experience. Caregivers urgently desire systematic, continuous, and collaborative health management support. These findings provide a reference for the future development of a whole-process management model for children with AR grounded in the TQM concept.

Keywords

Allergic rhinitis; children; family caregivers; diagnosis and management; total quality management; mixed-methods research

1. Introduction

Allergic rhinitis (AR) is one of the most common chronic respiratory diseases in children, with a globally increasing prevalence that has made it a significant public health concern [1]. A meta-analysis conducted in China reported an

overall prevalence of 18.46% among children and adolescents with AR between 2001 and 2021 [2]. The disease not only causes recurrent symptoms such as nasal congestion, runny nose, nasal itching, and sneezing, but also seriously affects their sleep quality, learning efficiency, and mental health. It is also a key risk factor that induces or aggravates complications such as bronchial asthma and sinusitis, and brings long-term and heavy disease burden to children and their families [3-5]. However, at present, the diagnosis and treatment management of AR in children is still dominated by acute symptom control, and there is a lack of systematic management strategies throughout 'pre-hospital-hospital-post-hospital'. Problems such as insufficient knowledge of family diseases, low medication compliance of children, and lack of follow-up management are common [6, 7]. Medical services are characterized by 'short-term and fragmentation' [8]. At the same time, clinical practice focuses more on the treatment of the disease itself and lacks systematic attention to the actual needs of caregivers in terms of disease cognition, care skills, and psychological support [9]. There is a gap in the patient- and family-centered care concept. The Total Quality Management (TQM) concept seeks to create a "patient-centered," safe, effective, and satisfactory healthcare environment through continuous improvement across the whole process, all aspects, and all members' participation [10]. TQM emphasizes customer demand orientation through systematic design, control, and continuous improvement of the whole process of service to achieve quality optimization, which provides an ideal theoretical framework for examining and optimizing the current children's AR health management system. At present, this concept is mostly used to improve the quality of the process system, and less used for disease management. However, the TQM concept is consistent with the purpose of managing children with AR, and has strong applicability and practicability for the management of children with AR.

Therefore, this study takes the three elements of 'whole process, all-aspect, and all-member participation' of TQM as the guiding framework, and adopts an interpretative sequential mixed-methods research method. Firstly, the disease knowledge level of family caregivers of children with AR, the current situation of medication compliance of children, and their satisfaction with existing medical services are objectively described through quantitative research. Combined with qualitative research, the core dilemma, emotional experience, and specific needs of the ideal support mode encountered by family caregivers in participating in the whole-course health management of children were deeply explored. Finally, the three elements of TQM are used as the analysis framework to integrate quantitative and qualitative findings, identify the breaking points of the current management system at the three levels of process, dimension, and subject, and provide an empirical basis for the subsequent construction of the whole-process health management program for children with allergic rhinitis with family empowerment as the goal.

2. Subjects and Methods

2.1 Subjects

This study employed an explanatory sequential mixed-methods design, consisting of quantitative and qualitative phases.

2.1.1 Quantitative Phase

A convenience sampling method was used. Caregivers of children with AR attending the pediatric outpatient clinic of a tertiary maternity and child healthcare hospital in Shenzhen from April to September 2025 were recruited. Inclusion criteria for children with AR were: (1) age 3 to 14 years; (2) meeting the diagnostic criteria for AR as specified in the Guidelines for the Diagnosis and Treatment of Allergic Rhinitis in Children (2022 Revised Edition) [11]; and (3) disease duration of at least 3 months. Exclusion criteria for children were: (1) combined with autoimmune diseases; (2) combined with heart, kidney, liver, and other important organ diseases; (3) patients with incomplete data. Inclusion criteria for family caregivers were: (1) age ≥20 years; (2) clear consciousness; can independently complete the survey; (3) Informed consent and voluntary participation in this study. Exclusion criteria for caregivers were severe mental illness or communication barriers.

The questionnaire contains 60 items. This study uses descriptive analysis as the main purpose, refers to the sample size estimation method of similar cross-sectional studies, and combines the empirical rule of multivariate analysis (5-10 times the number of independent variables). Considering 10% of invalid questionnaires, the minimum sample size is calculated to be 330 cases. A total of 370 questionnaires were distributed during the study period, and 350 valid questionnaires were recovered, with an effective recovery rate of 94.6%.

2.1.2 Qualitative Phase

From October to December 2025, semi-structured interviews were conducted using the 'maximum difference method' in purposive sampling, considering the role of caregivers, education level, course of disease, and severity of disease. The inclusion and exclusion criteria of the subjects were the same as in the quantitative study. Finally, a total of 15

family caregivers were interviewed on the principle of information saturation. During the sampling process, the researchers recorded the basic characteristics of each respondent and continuously assessed the distribution of the samples on key variables (caregiver role, education level, place of residence, course of disease, and severity of the child). Urban residents accounted for a relatively high proportion (11/15), and college degree or above accounted for the majority (11/15). This distribution was generally consistent with the trend observed in the overall quantitative sample (64.9% urban residents, 58.5% with college degree or above), yet it still carried the limitation of underrepresentation of rural and less-educated caregivers. The operational definition of data saturation was set as no new themes or codes emerging from the interviews of three consecutive participants. Ultimately, based on the principle of information saturation, a total of 15 family caregivers were interviewed.

2.2 Research Instruments

2.2.1 Quantitative Research Instruments

2.2.1.1 General Information Questionnaire

This was self-designed to collect sociodemographic data of caregivers (relationship with the child, age, highest educational attainment, occupation, average monthly family income, and place of residence), demographic data of children (age and sex), and disease characteristics (disease duration, disease severity, presence of other allergic diseases, and primary allergens).

2.2.1.2 Children's Allergic Rhinitis Disease Knowledge Questionnaire

This was developed by the research team following a systematic review of clinical guidelines and group discussions. It covers 6 dimensions of disease essence cognition, typical symptom recognition, treatment principle, drug use, environmental control, and complication recognition, with a total of 22 judgment questions. The total score was 22 points. The higher the score, the higher the level of knowledge. The Cronbach's α coefficient of the questionnaire in this study was 0.86.

2.2.1.3 Chinese Version of the Morisky Medication Adherence Scale (MMAS-8)

The revised Chinese version of the international common scale was adopted. The total score was 0-8 points; < 6 points were poor compliance, 6- < 8 points were medium, and 8 points were good. The Cronbach's α coefficient in this study was 0.83.

2.2.1.4 Satisfaction with Healthcare Services Scale

This self-designed scale assesses caregivers' satisfaction with medical services. The scale includes 15 items in four dimensions: service accessibility, clinician-patient communication, continuity and support services, and environmental support. A 5-point Likert scale was used. The higher the score, the higher the satisfaction. The Cronbach's α coefficient in this study was 0.92.

2.2.2 Qualitative Interview Guide

Based on the quantitative findings, the research team developed an initial interview guide through extensive discussion. Four caregivers were recruited for a pilot interview, and the guide was revised and refined based on the pilot results and input from clinical physicians. The final interview guide consisted of the following questions: (1) From the earliest symptoms of the child to the later diagnosis of AR, what is the most impressive or difficult thing to impress you in the whole process? (2) What are the greatest challenges or pressures you face in the long-term care of your child? (3) Reflecting on the entire healthcare-seeking process, which aspects have been satisfactory and which require improvement? (4) What questions or concerns do you still have regarding the disease itself? (5) What support would you most like to receive from the hospital or healthcare providers that you currently do not have access to? (6) In your view, what would an "ideal" management or service model for children with AR look like?

2.3 Data Collection and Quality Control

2.3.1 Quantitative Data Collection

Data were collected by the principal investigator using questionnaires. After obtaining informed consent from caregivers, the investigator distributed the questionnaires and provided standardized instructions. Questionnaires were collected on-site and reviewed item by item; any missing responses were completed by the caregiver at the time of collection.

2.3.2 Qualitative Data Collection

Caregivers were contacted by telephone, and after receiving informed consent, interview appointments were scheduled. One-on-one, face-to-face interviews were conducted in a quiet consultation room by a researcher trained in qualitative research methods. Caregivers were encouraged to express themselves freely, and non-verbal information was recorded. All interviews were audio-recorded, with each interview lasting 30 to 75 minutes. Audio recordings were transcribed verbatim within 24 hours of the interview.

2.4 Statistical Analysis

2.4.1 Quantitative Data Analysis

SPSS version 26.0 software was used. Continuous variables were described as mean ± standard deviation, and categorical variables as frequencies and percentages.

2.4.2 Qualitative Data Analysis

Transcribed texts were analyzed using Colaizzi's 7-step method: (1) reading and reviewing the interview data; (2) extracting significant statements relevant to the research topic; (3) formulating meanings from these statements and coding recurrent ideas; (4) clustering codes into categories and themes; (5) integrating themes into a comprehensive description of the phenomenon; (6) constructing the fundamental structure of the phenomenon; and (7) validating the findings with participants and incorporating feedback. Two researchers independently coded and categorized the data; disagreements were resolved through group discussion among the research team.

2.4.3 Mixed-Methods

Integration: In the results and discussion sections, qualitative themes were connected with and used to interpret quantitative findings, allowing for triangulation and synthesis of the data.

2.5 Ethical Considerations

This study was approved by the Medical Ethics Committee of the hospital (Approval No.: LGFYKYXMLL-2025-37). All participants provided informed consent.

3. Results

3.1 Quantitative Results

3.1.1 General Characteristics of Children with AR and Their Caregivers

The caregivers' mean age was (34.5 ± 5.2) years. Mothers constituted the largest proportion of caregivers (76.9%). The majority of caregivers had educational attainment of a college degree or above (48.0%) or senior high school/secondary school (28.9%). The children's mean age was (7.2 ± 2.8) years, and the mean disease duration was (3.5 ± 2.1) years. Disease severity was predominantly moderate (52.9%) and mild (31.4%). The most common allergens were dust mites (68.6%) and pollen (32.9%). Detailed characteristics are presented in Table 1.

Table 1. General characteristics of children with AR and their caregivers (N = 350)

Characteristic	Category	Number (N)	Percentage (%)
Child Characteristics			
Gender	Male	205	58.6
	Female	145	41.4
Disease duration (years)	≤1	66	18.9
	1 ~ 3	160	45.7
	>3	124	35.4
Disease severity (Physician	Mild	110	31.4
Assessment)	Moderate	185	52.9
	Severe	55	15.7

Table 1 Continued

Characteristic	Category	Number (N)	Percentage (%)
Comorbid allergic disease	Yes	162	46.3
	No	188	53.7
Primary allergens (multiple responses)	Dust mites	240	68.6
	Pollen	115	32.9
	Mold	64	18.3
	Animal dander	51	14.6
	Other (food, etc.)	76	21.7
Caregiver characteristics			
Relationship to child	Mother	269	76.9
	Father	64	18.3
	Grandparent	17	4.8
Educational level	Middle school or below	44	12.6
	Senior high/secondary	101	28.9
	College/University	168	48.0
	Master's degree or above	37	10.5
Average monthly family income (CNY)	< 5000	57	16.3
	5000-10000	144	41.1
	> 10000	149	42.6
Place of residence	Shenzhen City	227	64.9
	Other cities in Guangdong	78	22.3
	Other provinces	45	12.8

3.1.2 Disease Knowledge, Medication Adherence, and Satisfaction with Healthcare Services

The caregivers' total disease knowledge score was (12.50 ± 3.20), with an overall awareness rate of 56.8%. Dimension-specific awareness rates are shown in Table 2. The two dimensions with the lowest awareness rates were "complication identification and prevention" (31.7%) and "environmental control methods" (38.7%).

The children's medication adherence (MMAS-8) total score was 5.20 ± 1.80. Adherence was classified as good in 35 participants (10.0%), moderate in 95 (27.1%), and poor in 220 (62.9%).

The caregivers' overall satisfaction score was (3.40 ± 0.60). Dimension scores in descending order were: clinician-patient communication (4.00 ± 0.80), environmental support (3.90 ± 0.90), service accessibility (3.50 ± 1.00), and continuity and support services (3.20 ± 1.10). Within the continuity and support services dimension, the two lowest-rated items were "convenience of follow-up appointment arrangements" (3.00 ± 1.10) and "accessibility of health education materials" (3.10 ± 1.00).

Table 2. Dimension-specific awareness rates of disease knowledge among caregivers of children with AR (N = 350)

Knowledge Dimension	Number of Items	Correct responses (total)	Awareness rate (%)	Rank
Symptom recognition	4	1260	90.0	1
Basic disease understanding	4	980	70.0	2

Table 2 Continued

Knowledge Dimension	Number of Items	Correct responses (total)	Awareness rate (%)	Rank
Treatment principles	4	840	60.0	3
Medication use	4	700	50.0	4
Environmental control methods	3	406	38.7	5
Complication identification and prevention	3	333	31.7	6
Total	**22**	**4519**	**56.8**	**-**

3.2 Qualitative Results

3.2.1 General Information of Interview Participants

Fifteen caregivers of children with AR were interviewed. The participants included 11 mothers, 3 fathers, and 1 grandmother. Their ages ranged from 24 to 58 years. The children's disease duration was <1 year for 3 participants, 1-3 years for 6 participants, and >3 years for 6 participants. Disease severity was predominantly mild to moderate (13 cases), with 2 cases classified as severe. This sample reflected diversity in caregiver role, geographic residence, cultural background, and child disease duration, aiming to capture a broad range of caregiving experiences and management needs. Detailed characteristics are presented in Table 3.

Table 3. General characteristics of qualitative interview participants (N = 15)

ID	Relationship	Age (years)	Education	Residence	Child's disease duration	Disease severity
P1	Mother	32	College	Urban	<1 year	Moderate
P2	Father	35	Senior high	Rural	<1 year	Mild
P3	Mother	29	Master's	Urban	>3 years	Moderate
P4	Grandmother	58	Middle school	Rural	1–3 years	Moderate
P5	Mother	30	Senior high	Urban	1–3 years	Severe
P6	Father	38	Bachelor's	Urban	>3 years	Moderate
P7	Mother	34	Master's	Urban	>3 years	Severe
P8	Mother	28	Senior high	Urban	<1 year	Moderate
P9	Mother	31	Senior high	Rural	1–3 years	Moderate
P10	Mother	36	Middle school	Rural	>3 years	Mild
P11	Father	40	Bachelor's	Urban	1–3 years	Moderate
P12	Mother	33	Bachelor's	Urban	>3 years	Mild
P13	Mother	29	Senior high	Urban	1–3 years	Moderate
P14	Mother	31	College	Urban	1–3 years	Moderate
P15	Mother	37	Bachelor's	Urban	>3 years	Moderate

3.2.2 Thematic Analysis

Four core themes were identified through thematic analysis, revealing the caregivers' core challenges and corresponding needs in managing their children's AR.

Theme 1: Ambiguity in disease cognition and the need for continuous education

Most caregivers' understanding of the disease remained at the symptom level, with insufficient comprehension of its chronic, immune-mediated nature and long-term consequences. P3 stated: "The doctor diagnosed allergic rhinitis, but I don't understand why it can't be cured. What's the difference between this and an ordinary cold? Not knowing what causes it makes me feel that the treatment is useless." Information sources were fragmented and inconsistent in authority, contributing to cognitive confusion and diminished confidence in management. P12 explained: "What we need is not scattered pieces of information. We want to know the goals, methods, and possible risks at each stage from diagnosis to maintenance." Caregivers universally desired systematic, phased, and clinically integrated authoritative guidance. P8 remarked: "The nurse demonstrated the nasal spray once, but that was it. At home, I keep wondering: can I stop when symptoms improve? How long is this steroid really safe to use? I truly wish there were a detailed, phased family booklet telling us what to do and what to watch for at each step."

Theme 2: Fragmentation of healthcare processes and the need for humanized navigation

Caregivers commonly reported fragmented healthcare experiences, particularly when involving consultations across multiple specialties, diagnostic tests, and follow-up arrangements. P5 described: "Taking my child to see a doctor feels like running an obstacle course—registration, waiting, check-ups, picking up medication—I have to figure out each step myself. If the hospital had a clear electronic guide, or if there were a designated nurse to guide us at key points, it would be a tremendous help to parents like us who are unfamiliar with the process." Unclear procedures and poor inter-visit connections consumed substantial time and energy, reducing both efficiency and satisfaction. P11 noted: "Sometimes doctors in different departments give slightly inconsistent advice. We're caught in the middle, not knowing how to weigh things. It would be great if there were a platform to integrate a unified care plan for us." P14 added: "The doctor said to come back for regular follow-ups, but getting appointments is hard, and scheduling is difficult. If follow-ups could be more intelligent and proactive—with reminders and appointment assistance—it would relieve a lot of burden."

Theme 3: Isolation in home management and the need for accessible, immediate support

After discharge, families became the primary executors of caregiving tasks. They often felt isolated when managing medication use, symptom assessment, environmental control, and acute exacerbations—particularly when daily caregiving responsibilities conflicted or when symptoms worsened at night. P2 expressed: "What I worry about most is when my child's nasal congestion worsens at night, and his breathing sounds heavy. I can't judge how serious it is. Should I give more medication or go to the hospital? At moments like that, I really wish there were an online consultation channel accessible anytime through my phone—even if I had to pay for it—just to give us some peace of mind. (Covers face)" P7 explained: "Nasal irrigation is a skill, and my child resists it strongly. When he fights it, we feel both distressed and helpless, and our technique easily gets compromised. If there were a platform where we could upload a video of our procedure and have a nurse provide feedback online, it would make a real difference." P4 stated: "At my age, I often forget when and how to give medication. I wish there were a user-friendly mobile reminder program with large fonts and clear images."

Theme 4: Lack of participation in decision-making and the need for collaborative communication

Many caregivers felt that they were not adequately involved in developing treatment and management plans, and that their family's actual circumstances, the child's individual differences, and their own preferences were insufficiently considered. P1 commented: "The doctor recommends taking medication at fixed times twice a day. But in the morning, the child has to catch the school bus, and it's easy to miss a dose; at night, he sleeps so soundly that waking him for the spray is really difficult." Caregivers expressed a desire for equal, collaborative relationships with healthcare providers to jointly develop practical, individualized plans. P9 noted: "The doctor recommended desensitization therapy, but the three-year course, frequent hospital visits, and the high cost place a lot of pressure on us. It's not that we're refusing treatment—we want the doctor to understand our real-life constraints and discuss whether there might be more flexible options, or phased goals, so we can make a choice that works for us together." P15 said: "We know our child's daily responses best. If the plan could be made considering our daily schedule, with adjustments to reach a more workable solution, we would be much more willing to stick with it."

3.3 Mixed-Methods Integration

The quantitative phase provided a macro-level profile of the current challenges facing families of children with AR in terms of disease knowledge, medication adherence, and satisfaction with healthcare services. The qualitative phase provided micro-level insights into the underlying reasons, contextual factors, and emotional dimensions behind these quantitative patterns, while also offering specific projections for future improvement.

The two phases showed the relationship of explanation and complementarity: the information fragmentation (theme 1), skill anxiety and lack of support (theme 3), and the scheme divorced from reality (theme 4) found in qualitative research effectively explained the internal motivation behind the low knowledge awareness rate and poor medication compliance in quantitative results. The cumbersome and fractured medical treatment process revealed by qualitative research (theme 2) provides an explanation for the low satisfaction with continuity and supportive services and out-of-hospital support in quantitative results.

Integrating quantitative and qualitative findings, the core defect of the current children's AR management model is not a single link problem, but a systematic fracture. Specifically, this fracture exists in four dimensions at the same time : First, the systematic fracture of knowledge transmission, that is, the information obtained by caregivers is fragmented, and it is difficult to integrate into a cognitive framework that can guide practice (corresponding to the knowledge-attitude-practice fault); The second is the continuous fracture of behavioral support, the children face a vacuum of professional support after leaving the hospital, and lack of immediate guidance for home management behavior (corresponding to the fault inside and outside the hospital); The third is the convergence fracture of the service process, the lack of effective coordination between multiple departments in the hospital, and the separation of pre-hospital, in-hospital and post-hospital links (corresponding to horizontal and vertical faults) ; fourth, the participatory rupture of the doctor-patient relationship, the family is marginalized in the treatment decision-making, and its empirical knowledge and value preference are not included in the program formulation process (corresponding to the decision-making power fault). This systematic diagnosis precisely points to the improvement targets corresponding to the three elements of TQM's 'whole process, all-aspect and all-member participation'. In addition, the qualitative findings clearly put forward the strong expectation of the family for the integrated service model of systematic education, personalized navigation, instant support, and collaborative decision-making, which provides direct and clear caregiver needs for optimizing the existing management system based on the TQM concept.

4. Discussion

4.1 Structural Knowledge Deficits and Behavioral Adherence Barriers: Toward a Standardized, Phased Cognitive Intervention Framework

From the perspective of the TQM 'whole process' management concept, the health management of children with AR should cover the complete chain of pre-hospital prevention and screening, standardized diagnosis and treatment in hospital, and continuous follow-up after hospital. However, this study found that the lack of family awareness of core management knowledge and the low medication compliance of children coexisted, suggesting that there were obvious breaks in the information transmission and behavioral support links of 'pre-hospital-hospital-post-hospital'.

Qualitative interviews revealed that this lack of knowledge is not simply a matter of information, but a lack of a systematic cognitive framework that links disease mechanisms, treatment logic, daily operations, and long-term prognosis. According to the Knowledge-Attitude-Behavior (KAB) theory, knowledge is the basis of behavior change, and attitude is the driving force of behavior change [13]. When the family lacks a systematic understanding of the pathogenesis, drug treatment principles, and long-term management objectives of allergic rhinitis, it is easy to reduce or discontinue the treatment after the symptoms are relieved, or to discontinue the treatment when the symptoms fluctuate due to a lack of understanding of disease changes. In addition, if you do not master the specific methods of environmental control, the relevant measures will be difficult to implement effectively. This suggests that improving compliance must focus on building a family's holistic cognition and self-efficacy for disease management.

Based on the standardized thinking of TQM, nursing practice should lead the development and implementation of the 'structured health education path for children with AR'. The pathway should be closely integrated with the diagnosis and treatment process, and provide targeted and diversified educational content at different clinical decision-making points.

4.2 Fragmented Healthcare Processes and Lack of Continuity Support: Strengthening the Care Coordination Hub

The 'all-aspect' concept of TQM requires the management system to cover all relevant aspects of medical services, including process convergence, information sharing, and multi-role collaboration. The satisfaction of the items related to 'continuity and supportive services' in the quantitative results was at the bottom, which echoed the strong sense of 'separation' and 'isolation' in the qualitative research, indicating the two major fracture problems in the current service system: the horizontal department/department synergy fracture in the hospital [14], and the vertical continuous care fracture between the hospital and the family [15, 16].

The core of TQM is to optimize the process to improve overall efficiency and customer experience. The establishment of a full-time nursing coordinator or case manager is the key to solving these two major problems [17]. This role should act as a fixed-responsibility liaison for the family throughout the medical process. Its function is to provide medical coordination and process guidance in the hospital, and to provide continuous support through regular follow-up and remote platforms outside the hospital [18]. The establishment of this role can integrate scattered and passive service nodes into a dedicated, active, and continuous service chain, and truly realize the transformation from fragmented medical care to continuous care.

4.3 Insufficient Family Participation in Decision-Making and Lack of Individualized Plans: Advancing Toward a Shared Decision-Making Clinical Practice Model

The 'all-member participation' concept of TQM emphasizes that all stakeholders, including patients and families, should become active participants in the management process. However, more than half of the interviewees expressed a lack of participation in decision-making, which corresponded to poor medication compliance of up to 62.9%. When families perceive treatment plans as imposed directives disconnected from their daily realities, their intrinsic motivation to adhere to the plan diminishes.

Contemporary medical models are shifting from paternalistic decision-making toward Shared Decision-Making (SDM) [19]. In this process, nurses are naturally in an ideal position to promote SDM because of their frequency and depth of contact with patients and families. Nurses should serve as collaborators and enablers, using decision aids to help families understand the trade-offs of different treatment options, acting as a bridge for communication between families and physicians, and ensuring that the final treatment plan represents a consensus among the clinician, nurse, and family. This practice of incorporating the 'empirical knowledge' of the family into the decision-making process is the practical basis for improving the feasibility and compliance of the program.

5. Conclusions

This mixed-methods study systematically assessed the disease knowledge, medication adherence, and satisfaction with healthcare services among families of children with AR, while also exploring in depth the core challenges and needs of caregivers in whole-process management. The quantitative findings showed that families had insufficient knowledge of core management, the medication compliance of children was generally low, and the satisfaction with continuity and support services was the lowest. The qualitative findings extracted four challenges: ambiguity in disease cognition, fragmentation of healthcare processes, isolation in home management, and lack of participation in decision-making. The current management system shows substantial deficiencies in the systematicity of knowledge transfer, accessibility of behavioral support, coherence of service processes, and participation of families in decision-making. This study is a single-center cross-sectional survey. The qualitative interview sample had a relatively high proportion of urban residents and caregivers with higher educational levels, which may not fully reflect the caregiving experiences and needs of rural or less-educated caregivers. Therefore, the extrapolation of the conclusions needs to be further verified by multi-center studies. Future research should be based on the concept of TQM, focusing on core elements such as structured education, nursing coordination roles, and shared decision-making models to construct and verify the effectiveness of the whole-process health management program for children with AR.

Ethical Approval

This study was approved by the Medical Ethics Committee of the hospital (Approval No.: LGFYKYXMLL-2025-37). All participants provided informed consent.

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