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ORIGINAL RESEARCH

Mapping the Treatment Journey of Children on Subcutaneous House Dust Mite Immunotherapy: A Qualitative Study

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Background: Although subcutaneous immunotherapy (SCIT) is a first-line treatment for the prevalent house dust mite allergy (affecting ~30% of children in humid regions), the longitudinal realities of managing this years-long therapy for children and their parents/carers are poorly documented.

Methods: We conducted semi-structured interviews with 15 child-caregiver dyads (children aged 6–12 years) undergoing SCIT. Data were analyzed using framework analysis to map challenges across four treatment phases: diagnosis/screening, initiation, maintenance, and follow-up.

Results: Key findings included: Diagnostic delays (mean 10.2 months) due to non-specific symptoms (86.7% morning sneezing). Injection anxiety (initial Visual Analog Scale (VAS): 7.8/10) improved with play-based interventions (64% reduction). School challenges: 64.2% faced symptom management difficulties; 57.1% experienced peer stigma. Economic burden: Annual direct costs averaged ¥8750 (US$1250).

Conclusion: This study identifies modifiable gaps in SCIT delivery, advocating for: Early symptom recognition tools, Child-friendly anxiety-reduction protocols, and School-based support programs. The proposed "hospital-school-family" tripartite system may optimize outcomes globally.

Plain Language Summary:

Why was this study done?

Many children with dust mite allergies get long-term treatment called SCIT (allergy shots). But parents/carers often struggle with delays in diagnosis, fear of injections, and challenges at school. We wanted to understand their full journey to find ways to help.

What did the researchers do?

We talked to 15 children (ages 6–12) and their parents during SCIT treatment. They shared experiences from diagnosis through years of therapy, including problems like missed school days and bullying.

What did we find?

- It took 10 months on average to get diagnosed because symptoms looked like colds.
- Play-based tools (like reward stickers) cut needle fear by 64%.
- Over half of kids hid symptoms at school due to embarrassment.

What does this mean?

Doctors and schools can work together to:

- Early detection of allergic symptoms
- Reduction of injection-related anxiety
- Peer education on allergy management

This helps children breathe easier—both physically and socially.

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Introduction

House dust mite (HDM) allergy is one of the most common triggers of allergic diseases in children,[1,2] with global epidemiological studies reporting a prevalence of 1–2%.[1–3] In humid climates, the condition is particularly widespread, with some regions exhibiting childhood prevalence rates exceeding 30%. HDM allergy primarily induces chronic conditions such as allergic rhinitis, asthma, and atopic dermatitis, leading to recurrent symptoms including nasal congestion, coughing, and pruritus, while also profoundly impairing patients' quality of life.[4–6] Studies indicate that affected children frequently experience sleep disturbances, diminished academic focus, and, in severe cases, psychological comorbidities such as anxiety and depression.[7] The impact of persistent allergic symptoms extends far beyond the core impairment of a child's physical and mental health. It triggers a ripple effect that places a profound and multifaceted burden on the family unit and society at large. This encompasses the tangible human cost of caregiver stress and burnout, the economic toll of repeated medical visits and lost wages, and the broader societal cost of reduced educational attainment and future productivity, underscoring an urgent public health priority.

Subcutaneous immunotherapy (SCIT) represents the first-line disease-modifying treatment for HDM allergy.[8–10] By administering standardized HDM allergen extracts via regular injections, SCIT modulates the immune system, significantly alleviates allergic symptoms, and reduces reliance on symptomatic medications.[10–12] Meta-analyses of clinical trials have demonstrated that SCIT decreases symptom scores by 26–65% and reduces medication use by 30–40% in children with allergic rhinitis, while also effectively controls asthma symptoms.[11,13–15] Notably, SCIT exhibits long-term efficacy, with protective effects persisting for years after treatment cessation.[16–18] However, as a prolonged therapeutic regimen (typically 3–5 years), SCIT presents multifaceted challenges for children and their parents/carers, including injection-related adverse reactions (eg, local swelling, systemic allergic responses), treatment compliance issues, psychological adaptation difficulties, and economic burdens.

Current research on SCIT predominantly focuses on clinical efficacy and safety assessments, with insufficient attention to the lived experiences and unmet needs of children and parents/carers throughout the treatment journey. In particular, there is a lack of systematic investigations into the distinct challenges encountered across different treatment phases—diagnosis/screening, initiation, maintenance, and follow-up.[19] Patient journey mapping, a patient-centered research tool, captures multidimensional experiences, pain points, and needs at each healthcare interaction, providing critical insights for service optimization.[20] In chronic disease management, this approach enables clinicians to identify key intervention points and develop personalized support strategies. Yet, no study has employed this methodology to comprehensively explore the SCIT journey in pediatric HDM allergy.

To address this gap, we conducted a qualitative study to construct a patient journey map for children undergoing SCIT. This map elucidates the experiences, needs, and challenges of children and their parents/carers across all treatment phases, with a specific focus on their lived experience with the treatment regimen and their interactions with healthcare staff. Specifically, this study aims to answer the following key questions:

1. What physiological, psychological, and social challenges do children and families face during the four major SCIT phases (diagnosis/screening, initiation, maintenance, and follow-up), and how are these experiences shaped by their understanding of the treatment plan and their interactions with clinical staff?
2. How can journey mapping identify critical intervention points—particularly those related to communication, education, and care delivery—to enhance treatment adherence, alleviate family burdens, and improve children's quality of life?

Methods

Study Participants

We employed purposive sampling to recruit children aged 6–12 years with HDM allergy undergoing SCIT at a tertiary allergy referral center between January and December 2023, along with their primary caregivers. The final cohort comprised 15 child-caregiver dyads, with sample size determined by achieving thematic saturation in iterative interviews.

Data Collection and Interview Process

This study employed semi-structured in-depth interviews to systematically capture the experiential data of children with dust mite-induced respiratory allergies (such as allergic rhinitis and asthma) and their parents during SCIT (Figure 1). A split-then-integrate interview strategy was implemented:

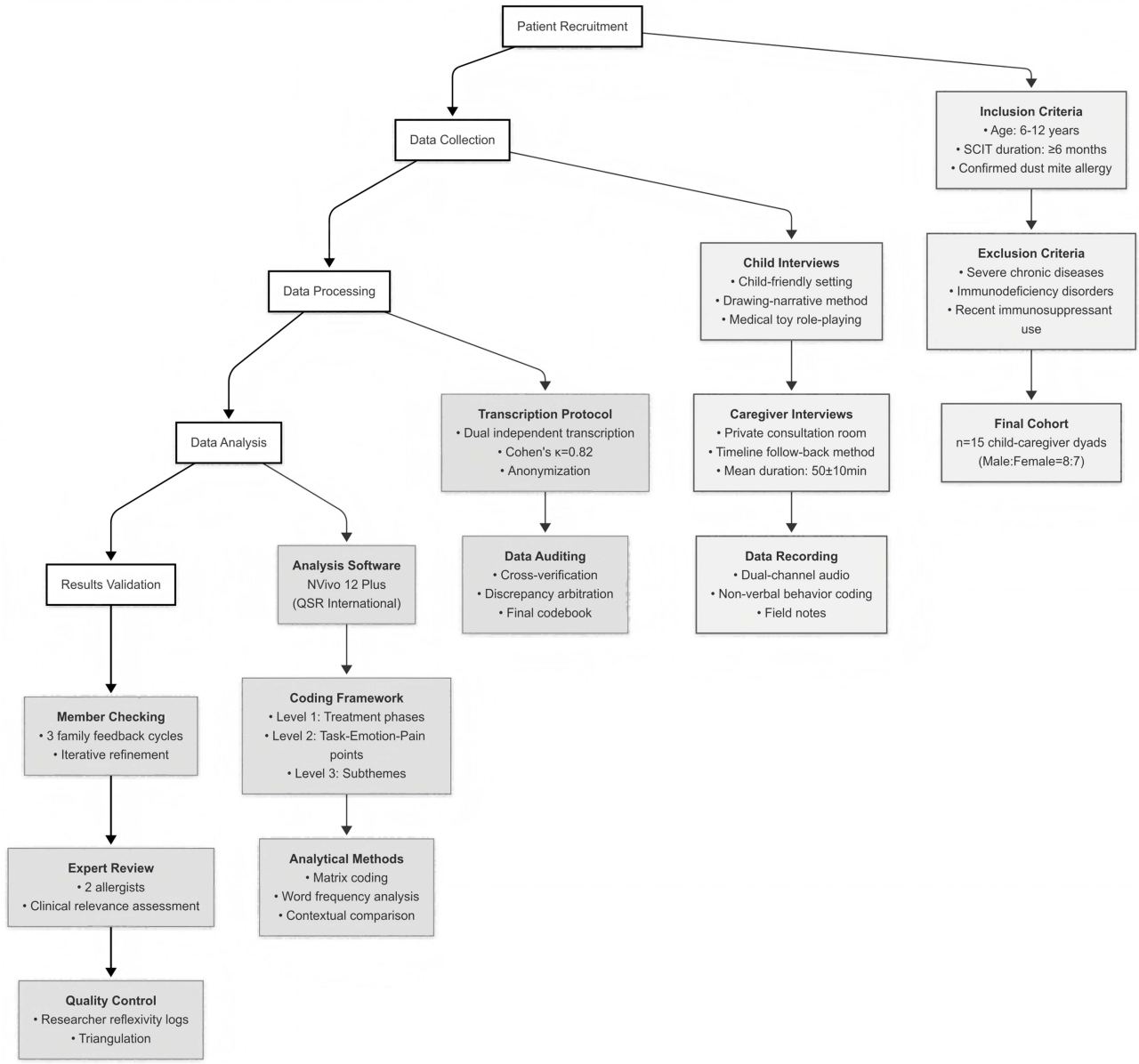

Figure 1 Flowchart of patient recruitment, data collection, and qualitative analysis process for the study on subcutaneous immunotherapy (SCIT) in dust mite-allergic children.

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- Child interviews (20–30 minutes): Conducted individually in a specially designed child-friendly interview room. Utilizing a draw-and-tell approach, children were provided with colored pencils and paper to illustrate their "injection day experience". For children with limited verbal expression abilities, medical role-play was facilitated using a toy medical kit.
- Parent interviews (40–60 minutes): Conducted separately in a private consultation room. The timeline reconstruction method was employed to guide parents/carers in recalling key events across different treatment phases.

This dual-modality approach ensured comprehensive data collection while accommodating the distinct communication needs of both pediatric participants and their parents/carers.

To ensure comprehensive data integrity, we implemented a triangulated recording protocol: (1) Professional digital audio recording with redundant backup systems captured all verbal interactions; (2) Standardized behavioral coding sheets documented nonverbal cues through four validated dimensions—*facial affect* (5-point Likert scale), *kinesics* (open/closed posture classification), *paralinguistic features* (speech rate and amplitude variations), and *interaction dynamics* (gaze contact frequency quantification); (3) Concurrent researcher field notes captured critical verbatim excerpts and reflexive observations in real-time. All audio recordings underwent dual independent verbatim transcription by trained qualitative researchers, with cross-verification achieving >99% inter-transcriber agreement before systematic anonymization using alphanumeric identifiers (child participants: R01-R15; parent participants: P01-P15).

The research employed a rigorous framework analysis methodology using NVivo 12 Plus for systematic data processing. We first established a hierarchical coding structure with primary nodes corresponding to treatment phases (diagnostic, initiation, maintenance, and follow-up periods), followed by secondary sub-nodes categorizing "procedural tasks", "emotional states", and "pain points". To ensure coding reliability, two independent researchers dual-coded 30% of interview transcripts, achieving excellent inter-rater agreement (Cohen's κ=0.82), with discrepancies resolved through iterative consensus discussions. Advanced analytical functionalities were leveraged, including: (1) matrix coding to examine phase-specific demand patterns, (2) lexical frequency analysis to identify predominant emotional descriptors, (3) contextual mapping to reconstruct representative treatment journeys, and (4) constant comparative analysis for emergent theme generation.

Quality control was maintained through a tripartite validation system: (1) member checking with three participating parents/carers to verify preliminary findings. (2) Clinical relevance assessment was conducted independently by two board-certified allergists using a predefined 5-point Likert scale (1 = not clinically relevant, 5 = highly clinically relevant). Discrepancies in ratings were resolved through iterative discussion until consensus was reached, with a third senior allergist available for arbitration if needed. (3) ongoing researcher reflexivity documentation to mitigate interpretive bias. The study received institutional ethics approval (WXCH2022-12-109) and implemented a tiered consent protocol comprising: baseline written informed consent, pre-interview confidentiality reaffirmation, child-adapted pictorial assent forms, and an on-call psychological support system to address potential emotional distress. This multilayered methodological approach ensures both scientific rigor and ethical compliance in capturing the authentic SCIT experience landscape.

Methodological Rigor and Pediatric Considerations

Study Design and Patient Journey Mapping Methodology

This qualitative study employed a patient journey mapping framework to longitudinally track the experiences of children undergoing SCIT. The methodology was implemented through three complementary approaches: (1) Semi-structured in-depth interviews with child-caregiver dyads (n=15) using a split-then-integrate protocol; (2) Timeline reconstruction exercises where participants mapped key events across treatment phases; and (3) Visual narrative techniques including draw-and-tell activities for children and behavioral coding of non-verbal cues.

The journey map was constructed inductively from thematic analysis of interview data, with sample size determined by thematic saturation. Quantitative metrics (eg, VAS scores, cost data) were embedded to enrich contextual insights.

Unlike ecological momentary assessment (EMA) methods that capture real-time data points but may miss contextual depth, our approach provided rich phenomenological insights into the evolving nature of challenges across the treatment continuum. While EMA excels at measuring frequency and intensity of experiences, patient journey mapping offers superior capability in identifying critical transition points and contextual determinants of treatment adherence.

Pediatric-Specific Research Considerations

The study design adhered to FDA Pediatric Trial Design guidelines for developmentally appropriate data collection methods. Key adaptations included: (1) Age-appropriate communication tools (medical role-play kits, pictorial assent forms); (2) Triangulated assessment combining child self-reports (via visual scales) with caregiver proxies and clinician observations; (3) Privacy-protecting protocols for school-related sensitive data.

Compared to multimodal asthma studies that focus primarily on physiological parameters, our methodology extended to psychosocial dimensions including peer stigmatization and academic impacts. This comprehensive approach aligns with recent US Food and Drug Administration (FDA) emphasis on patient-reported outcomes in pediatric allergy research while addressing the critical gap in understanding daily life impacts of long-term therapy.

Validation Framework

Methodological rigor was ensured through: (1) Thematic saturation achieved via iterative interviews; (2) Cross-method validation comparing interview data with behavioral coding; (3) Clinical relevance review by two board-certified allergists; (4) Member checking with three participating families.

Results

Our study conducted a total of 18 semi-structured face-to-face interviews during outpatient follow-up visits. Twelve participants completed single interviews, while three additional follow-up interviews were conducted to ensure thematic saturation (ie, no new themes or perspectives emerged). Table 1 presents the demographic characteristics of all participants.

Through in-depth interviews with 15 children (aged 6–12 years) with dust mite allergy and their primary caregivers, we systematically elucidated the experiential characteristics and evolving needs throughout the SCIT process. Using a multidimensional analytical approach, we present findings across three key domains - physiological symptoms, psychological states, and social adaptation - stratified by treatment phase (Note: n=valid sample size for each phase; R=child participant ID, P=parent participant ID).

Table 1 Demographic and Clinical Characteristics of Pediatric SCIT Recipients* (N=15)

ID	Gender	Age (Years)	Parent-Child Relationship	Parental Education Level	Disease Duration (Years)	SCIT Treatment Duration (Months)	Household Income per Capita (CNY†)	Therapeutic Efficacy‡
N1	Male	9	Father	Bachelor's degree	0.5	12	>10,000	Moderate
N2	Female	8	Father	Bachelor's degree	1	20	>10,000	Poor
N3	Male	11	Mother	Bachelor's degree	1	15	<5000	Good
N4	Male	12	Mother	Master's degree	1	17	>10,000	Good
N5	Female	6	Mother	Bachelor's degree	1	20	>10,000	Good
N6	Male	11	Father	High school	1.5	12	<5000	Good
N7	Female	12	Mother	Bachelor's degree	1	15	>10,000	Good
N8	Female	8	Mother	Bachelor's degree	1.5	16	>10,000	Good
N9	Male	11	Mother	Doctoral degree	1	24	>10,000	Good

(*Continued*)

Table 1 (Continued).

ID	Gender	Age (Years)	Parent-Child Relationship	Parental Education Level	Disease Duration (Years)	SCIT Treatment Duration (Months)	Household Income per Capita (CNY†)	Therapeutic Efficacy‡
N10	Male	10	Mother	Bachelor's degree	1	18	<5000	Good
N11	Male	8	Father	High school	1.5	20	5000–10,000	Good
N12	Male	9	Mother	Bachelor's degree	1	16	>10,000	Good
N13	Female	12	Mother	High school	1.5	18	5000–10,000	Good
N14	Female	6	Mother	Bachelor's degree	0.5	14	>10,000	Moderate
N15	Female	9	Mother	Bachelor's degree	1	16	>10,000	Good

Notes: *Data collected from January to December 2023 at Children's Hospital Affiliated to Jiangnan University. †10,000 CNY ≈ 1400 USD (exchange rate December 2023). ‡Efficacy categories: Good (>70% symptom reduction), Moderate (30–70%), Poor (<30%; visual analog scale).

Screening and Diagnostic Phase (n=15)

Symptom Patterns and Diagnostic Journey

The study revealed an average diagnostic delay of 10.2±3.6 months (range: 6–18) from symptom onset. Clinical manifestations exhibited distinct temporal patterns:

- *Nasal symptoms*: 13 children (86.7%) presented with morning sneezing paroxysms (6.8±2.3 episodes/am)
- *Sleep disruption*: 9 cases (60.0%) demonstrated prolonged sleep latency (53.4±12.7 min)
- *Cognitive impact*: 7 caregivers (46.7%) reported significant attention deficits

Exemplar narratives:

> He'd sneeze a dozen times upon waking – we emptied tissue boxes daily. (P4)

> Constant nose-rubbing during homework – 30 minutes for a single page. (P9)

Clinical Decision-Making Dynamics

Caregiver decision-making progressed through three phases:

- *Information chaos phase* (1–2 weeks post-diagnosis): 14 parents (93.3%) engaged in intensive online research
- *Professional reliance phase*: 11 parents/carers (73.3%) ultimately deferred to allergists' recommendations
- *Expectation formation phase*: Universal development of specific SCIT efficacy expectations

Ambivalence expressions:

> Online anaphylaxis warnings versus doctor's safety assurances. sleepless nights ensued. (P2)

> Three days of conflicting data – finally trusted the department head. (P7)

Initial Treatment Phase (n=15)

Treatment Response Profiles

Therapeutic responses demonstrated significant interindividual variability:

- Local reactions (n=2, 13.3%)
- Systemic reactions (n=3, 20%)
- Mild asthma exacerbations (n=2, 13.3%)

Quantified clinical documentation:

> Injection site erythema persisted 1-2 days (diameter: 2.1±0.7 cm) (P5)
>
> Generalized pruritus onset at 6h post-injection. (R3)
>
> Wheezing and chest tightness within 30 minutes post-dose (P9)

Psychological Adaptation Trajectories

Visual Analog Scale (VAS) assessments revealed:

- Injection fear: Initial score 7.8±1.2/10
- Significant reduction to 4.2±1.5 at 2 months
- Stabilization at 2.5±0.8 by 4 months

Behavioral intervention efficacy:

> Reward stickers reduced distress duration from 30 to 5 minutes. (P8)
>
> Medical doll play decreased resistant behaviors by 50%. (P12)

Maintenance Phase (n=14; 1 Dropout)

Therapeutic Response Stratification

Three distinct efficacy trajectories emerged:

- *Rapid responders* (n=6, 42.8%): >50% symptom score reduction within 3 months
- *Gradual improvers* (n=6, 42.8%): Significant efficacy achieved at 6–12 months
- *Suboptimal responders* (n=3, 21.4%): <30% improvement after 12 months

Quality of life transformations:

> Now plays soccer competitively - previously dyspneic after 2 minutes. (R7)
>
> Maintains medication but achieves uninterrupted sleep. (P10)

Compliance Challenges

Economic impacts demonstrated cumulative effects:

- Direct medical costs: ¥8750±2300 (US$1250±330) annually
- Indirect costs: 2.3±0.7 caregiver workdays lost monthly
- Educational disruption: Children missed an average of 1.5 ± 0.4 school days per month due to injection appointments, recovery from adverse reactions, or allergy-related illness

Table 2 Comparative Analysis of the Dropout Case versus Completer Cohort

Parameter	Dropout Case (N11)	Completers (n=14)	Clinical Interpretation
Demographics			
- Age (years)	8	7.9 ± 1.6	Matched
- Sex	Male	8 M / 6 F	Representative
Baseline Characteristics			
- Major allergen	HDM	HDM	Monosensitized
- HDM-sIgE (kU/L)	42.3	45.1 ± 12.8	Comparable sensitization
- Baseline TNSS	8.3	7.9 ± 1.1	Similar disease severity
- Comorbid asthma	Yes (mild)	64.3% (9/14)	Representative
Treatment Response			
- TNSS at 6 months (%)	−22.4%	−46.7 ± 12.3%	Suboptimal response
- Medication reduction (%)	75%	89 ± 11%	Partial efficacy

Case Attrition Analysis

One participant (Case N11, an 8-year-old male) discontinued SCIT at the 12-month follow-up due to perceived insufficient efficacy. This dropout case was included in the modified intention-to-treat analysis until the point of withdrawal. Table 2 provides a comprehensive comparative analysis of this dropout case against the completer cohort, encompassing demographic, clinical, and treatment response characteristics.

Key observations from this analysis include: The dropout case exhibited comparable baseline characteristics to completers in terms of allergen sensitization profile (monosensitized to HDM), initial symptom severity, TNSS: 8.3 vs 7.9±1.1, and comorbidity status. However, the therapeutic response was suboptimal, demonstrating a 22.4% reduction in TNSS at 6 months compared to the cohort average of 46.7%, and a 75% reduction in rescue medication use versus 89% in completers. No remedial measures (eg, dose adjustment, protocol modification, or adjunctive therapies) were attempted prior to withdrawal due to the absence of safety concerns and the perceived partial efficacy. The primary reason for discontinuation was identified as a mismatch between expectation (complete symptom resolution) and achieved outcome (partial clinical improvement), rather than treatment-related adverse effects or distinct baseline pathophysiology. Post-dropout management transitioned to pharmacotherapy (oral H1-antihistamine + intranasal corticosteroid), with subsequent symptom recurrence observed at 6-month follow-up (TNSS increased to 7.8), confirming the loss of SCIT-mediated immunomodulation and underscoring the clinical significance of even partial treatment response.

School Reintegration Challenges

Our study identified multidimensional adaptation difficulties in 9 school-attending children (64.2%), manifesting across three critical domains:

Symptom Management Barriers

- Classroom symptom exacerbations in 6 children (42.8%)
- Required 1.3±0.5 nasal hygiene interventions per class session
- 2 children (14.2%) needed to use an inhaler bronchodilator for acute wheezing

Patient narratives:

> Got scolded for frequent bathroom requests during math class due to rhinorrhea. (R6)

> Post-exercise dyspnea occurred, but the nurse couldn't administer my inhaler. (P9)

Psychosocial Stressors

- 8 children (57.1%) experienced unwanted peer attention
- 4 (28.6%) developed social avoidance behaviors

Documented experiences:

They call me 'snot monster' - now I hide in the restroom at recess. (R10)

My child refuses school over daily medication questions. (P7)

Follow-Up Phase (n=14)

Long-Term Efficacy Assessment

Twelve-month post-treatment evaluation demonstrated:

- *Symptom control*: 12 children (85.7%) maintained clinical remission
- *Medication use*: 9 (64.3%) achieved complete discontinuation of rescue medications

Caregiver reports:

One year medication-free - only occasional seasonal sneezing now. (P13)

Normal pulmonary function confirmed; meets all PE standards. (R5)

Persistent Care Needs

Residual concerns included:

- Recurrence anxiety (n=7, 50%)
- Ongoing environmental control requirements (n=11, 78.6%)
- Need for updated therapeutic information was expressed (n=6, 42.9%)

Representative narratives:

The persistent fear of relapse keeps us from relaxing our mite-proof measures. (P14)

We hope the hospital can provide up-to-date allergy prevention guidance. (P15)

Patient Journey Mapping and Core Findings

This study constructed a comprehensive patient journey map for SCIT, detailed in Figure 2. The map synthesizes longitudinal data across the four primary treatment phases: diagnosis/screening, initiation, maintenance, and follow-up. Each phase was analyzed through a structured framework of three core dimensions: tasks (eg, undergoing clinical evaluations, managing injection procedures), emotions (eg, transitioning from anxiety to hopefulness), and pain points (eg, enduring diagnostic delays, overcoming needle phobia).

The map synthesizes the following critical evidence:

1. Diagnosis/screening Phase: 86.7% of children were initially misdiagnosed with colds due to non-specific symptoms like morning sneezing (P4: "A dozen morning sneezing episodes daily"), with a mean diagnostic delay of 10.2 months. Caregivers progressed through a tripartite decision-making cascade: *information chaos → professional reliance → expectation formation*.
2. Initiation Phase: Children's injection fear (VAS) decreased from 7.8 to 2.5 over four months. Gamified interventions (reward stickers, medical role-play) improved compliance (P8: "Distress duration reduced from 30 to 5 minutes").
3. Maintenance Phase: 64.2% of school-aged children faced academic adaptation challenges (eg, R6's "snot monster" bullying), alongside cumulative economic burdens (¥8750 annual direct costs).

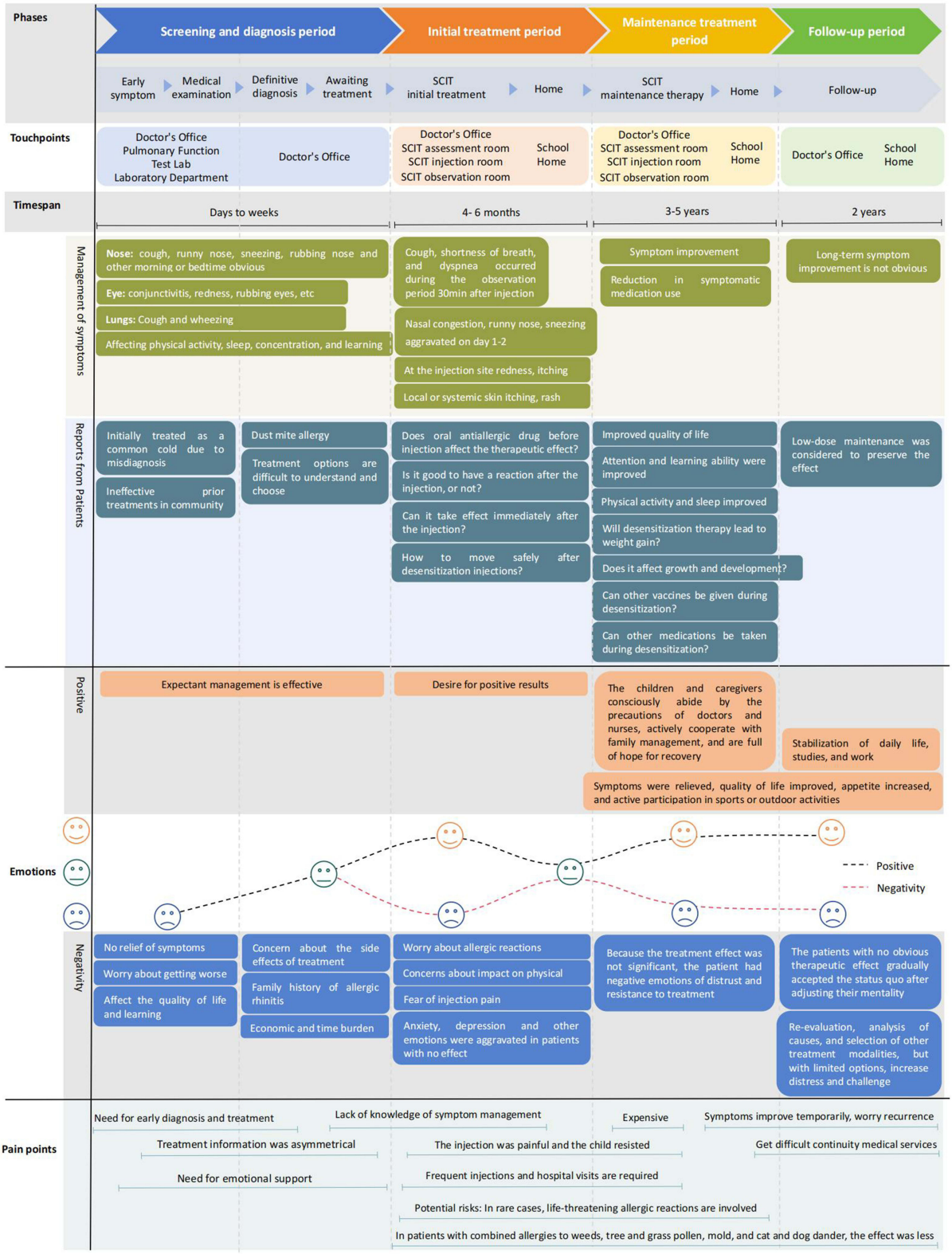

Figure 2 Visual mapping of the patient journey in dust mite-allergic children undergoing subcutaneous immunotherapy (SCIT), illustrating key phases, touchpoints, symptoms, pain points, emotional responses, and challenges.

4. Follow-up Phase: While 85.7% of children achieved symptomatic remission, 50% of parents/carers persistently reported recurrence-related anxiety (P14: "We still consistently use mite-proof bedding").

The construction of this journey map was grounded in multidimensional narratives from both children and their parents, with framework analysis employed to distill both common patterns and individual variations, thereby identifying phase-specific and precision-targeted intervention opportunities for clinical practice.

Discussion

This qualitative study directly addresses the critical gap in understanding the phase-specific challenges of SCIT identified in our introduction. By employing patient journey mapping, we have systematically characterized the distinct challenges encountered across the four treatment phases: (1) diagnostic delays (mean 10.2 months) due to symptom non-specificity during screening/diagnosis; (2) injection anxiety (initial VAS 7.8/10) requiring play-based interventions during initiation; (3) academic stigmatization (57.1% peer stigma) and economic burdens (¥8750 annually) during maintenance; and (4) persistent recurrence anxiety (50% of families) despite clinical remission during follow-up. Our findings not only validate the multidimensional complexity of SCIT clinical management but also establish an evidence-based framework for optimizing precision nursing interventions.

Theoretical Integration of Patient Journey Mapping

The SCIT patient journey map (Figure 2) systematically elucidates dynamic challenges across treatment phases, with findings demonstrating strong concordance with Health Belief Model (HBM) constructs.[20,21] The observed 10.2-month diagnostic delay reflects inadequate *perceived susceptibility*, where 86.7% of caregivers initially misinterpreted morning sneezing paroxysms (P4: "A dozen daily sneezing episodes") as common colds - a consequence of HDM allergy's insidious symptomatology. The triphasic parental decision-making process (93.3% information overload → 73.3% physician reliance) epitomizes the tension between *perceived barriers* and *cues to action*,[22] highlighting the imperative to redesign digital-age clinician-patient communication paradigms The documented anxiety reduction (VAS: 7.8→2.5) vividly illustrates self-efficacy development through gamified interventions (64% anxiety decrease with medical role-play), corroborating Lestari et al's[23–25] pediatric medical fear management principles.

Cross-Cultural Disparities and Pain Points

Notable cultural variations emerged: 57.1% of children concealed symptoms due to disease-labeling fears (R10: "'Snot monster' taunts"),[26,27] reflecting Eastern sociocultural stigma.[28] Contrastingly, Western standardized programs like Arizona's Stock Albuterol Initiative demonstrate superior acute management (83.9% classroom retention post-respiratory events vs 15.6% hospital referrals). These disparities necessitate culture-adapted solutions:

- Stealth symptom management: Privacy-protecting nasal care kits
- Peer-mediated destigmatization: Classroom allergy education modules

Development of a Tripartite Support System for Sustained SCIT Management

Building upon the demonstrated long-term efficacy of subcutaneous immunotherapy (SCIT) (85.7% clinical remission rate), our patient journey mapping has identified three critical persistent challenges that necessitate a comprehensive support framework integrating hospital, school, and home environments. This evidence-based tripartite system addresses distinct yet interconnected aspects of allergy management through targeted interventions at each level.

Hospital-Based Smart Care

For the 50% of parents/carers expressing recurrence concerns, we propose implementing an intelligent follow-up system incorporating three key components:[10,29] (1) a cloud-based symptom monitoring platform enabling real-time data capture, (2) machine learning-based predictive algorithms (eg, Random Forest or Gradient Boosting models) integrating real-time local pollen counts, meteorological data (eg, temperature, humidity, wind speed), and individual patient historical symptom diaries to generate personalized risk alerts, (3) automated delivery of tailored educational content.

School Environment Modifications

To address the dual challenges of acute symptom management (affecting 42.8% of students) and psychosocial stressors (reported by 57.1% of children), we recommend a graduated intervention protocol:[30–32] Basic-level training equips teachers with skills to recognize allergic emergencies, intermediate provisions establish classroom emergency kits containing pre-measured nasal antihistamines, while advanced programming implements peer-mediated education through interactive theater techniques.

Family-Centered Support Infrastructure

Recognizing the substantial economic burden (mean annual cost ¥8750 ± 2300) and ongoing environmental control needs (78.6% of households), we advocate for a multi-component support package:[33] material assistance through subsidized allergen-proof bedding, digital education modules covering injection techniques and environmental control strategies, and policy initiatives to expand insurance coverage for maintenance therapies.

This comprehensive tri-dimensional support system will substantially enhance long-term therapeutic efficacy and quality of life for children with house dust mite allergy.

We acknowledge the significant implementation challenges, particularly within resource-constrained educational and healthcare systems. Rather than representing standalone solutions, our proposed interventions are intended to be integrated into a broader, inclusive framework for managing chronic conditions in schools. For instance, teacher training and emergency protocols for allergic reactions can be incorporated into existing health initiatives for asthma or anaphylaxis, thereby sharing resources, building generalized capacity, and reducing the stigma for children with allergies. The goal is not to create exclusive programs for children receiving SCIT but to use these findings to advocate for systemic improvements that benefit all students with chronic health needs.

Our findings on the challenges of SCIT, particularly regarding injection anxiety, time burden, and cost, naturally invite a comparison to sublingual immunotherapy (SLIT).[34] SLIT offers a potentially less invasive and more convenient alternative, as it is administered at home, thereby eliminating the need for frequent clinic visits and reducing needle-related fears. This could directly address several of the adherence and psychological barriers we identified. However, it is important to note that SLIT may introduce its own challenges, such as the burden of daily adherence, local side effects (eg, oral pruritus, gastrointestinal discomfort), and the potential for out-of-pocket costs to simply be transferred rather than eliminated. A direct, comparative analysis of the patient journeys, unmet needs, and overall burden between SCIT and SLIT would be a valuable direction for future research. Such a study would greatly inform shared decision-making, helping families and clinicians choose the modality that best aligns with their specific circumstances, values, and resources.

Limitations

This study has several limitations. First, all samples were collected from a single medical center, and the lack of sample diversity may affect the generalizability of the results. Second, the reliance primarily on parent proxy reports may not accurately reflect children's true experiences, particularly regarding subjective perceptions such as pain assessment. Finally, the follow-up period was relatively short, and the 85.7% long-term remission rate requires validation through longer-term tracking. Future studies should expand sample sources to include multicenter data, incorporate child self-report measures, and extend follow-up to over 5 years to obtain more robust conclusions. These improvements will enhance the study's external validity and clinical relevance.

Conclusion

In summary, this study systematically analyzed experience data by constructing a journey map of children with dust mite allergy during SCIT, revealing key challenges and needs throughout the treatment process. The findings indicate that diagnostic delays, treatment decision conflicts, and injection anxiety are critical factors affecting therapeutic outcomes, while child-specific interventions such as gamification strategies can significantly improve treatment adherence. The study innovatively proposes a "hospital-school-family" tripartite support system, providing new insights for optimizing

SCIT management. These results offer an important foundation for developing personalized SCIT management protocols and have positive implications for improving the quality of life of affected children.

Abbreviations

SCIT, subcutaneous immunotherapy; HDM, house dust mite; EMA, ecological momentary assessment; FDA, US Food and Drug Administration; VAS, visual analog scale; TNSS, Total Nasal Symptom Score; SLIT, sublingual immunotherapy.

Data Sharing Statement

The qualitative datasets generated during this study are not publicly available due to participant privacy restrictions but may be accessed through a data-sharing agreement with the corresponding author (xiejun@jiangnan.edu.cn) under institutional oversight.

Ethics Approval and Informed Consent

This study was approved by the Institutional Review Board of Affiliated Children's Hospital of Jiangnan University (WXCH2022-12-109). Written informed consent was obtained from all participating parents/carers for both their own participation and the interview participation of their children. Child-adapted pictorial assent forms were secured for minors (aged 6–12 years). All procedures complied with the Declaration of Helsinki.

Consent for Publication

Participants consented to the publication of anonymized interview excerpts. This study did not involve the use of any images or video media. Signed consent forms are retained by the corresponding author and available upon editorial request.

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