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Care Experiences and Support Needs of Families of Children with Tic Disorders during Traditional Chinese Medicine Treatment: A Qualitative Study

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Abstract

Background: Tic disorders (TD) are a common childhood-onset neuropsychiatric condition that typically requires long-term, comprehensive management. Traditional Chinese medicine (TCM) is increasingly used to treat TD, and because TCM management is long-term and depends heavily on family participation, families play a central role in daily care. However, little is known about the caregiving experiences and support needs of families managing TD through TCM treatment.

Methods: This descriptive qualitative study used purposive sampling to recruit 14 primary caregivers of children with TD from the Department of Traditional Chinese Medicine at Shenzhen Children's Hospital between April and July 2026. Semi-structured interviews were conducted and analyzed using Braun and Clarke's six-phase thematic analysis framework, with the assistance of NVivo 12 software for data management and coding. This study followed the Standards for Reporting Qualitative Research (SRQR) and the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.

Results: Three themes and ten subthemes were identified: (1) cognitive dilemmas and decision-making pathways in family caregiving (delayed disease recognition and multi-source information trust dilemmas; treatment choices dominated by the perception of TCM as "safe and root-treating"; mother-dominated family decision-making); (2) multidimensional dilemmas in TCM treatment experience and home care (differentiation in treatment adherence across modalities and individual variation; multidimensional

difficulties in executing home care; imbalance in family support systems and maternal caregiving burden); and (3) evolution of psychological trajectories and support service needs (nonlinear evolution of parents' psychological trajectories; structural pressure from financial burden and healthcare accessibility; expectations for healthcare support and service model reconstruction; and persistent distress from fear of relapse and future uncertainty).

Conclusions: Families of children with TD face multiple cognitive, behavioral, psychological, and systemic challenges during TCM treatment. There is an urgent need to build a TCM-based family care support system centered on "specialized nursing clinics + professional parent groups + systematic health education + psychological support services + community-based early screening," with priority given to the initial diagnosis period and periods of symptom recurrence, together with mechanisms for transitioning to adult healthcare to address the gap in care access that arises once patients age out of pediatric services.

Keywords: Tic disorders; Child; Traditional Chinese medicine; Family caregiving; Caregiver experience; Qualitative research; Pediatric nursing

Background

Tic disorders (TD) are a childhood-onset neuropsychiatric condition characterized by involuntary, sudden, rapid, recurrent, and non-rhythmic motor and/or vocal tics [1]. Epidemiological studies indicate that the prevalence of TD among children is approximately 0.3–1.6% and has been rising in recent years [2]. TD tends to follow a protracted, relapsing course and is frequently comorbid with attention-deficit/hyperactivity disorder, obsessive-compulsive disorder, and anxiety disorders, exerting a profound impact on children's learning, social functioning, mental health, and family functioning [3].

Traditional Chinese medicine (TCM) has become an important component of comprehensive TD management, with clinical evidence supporting its distinctive advantages in alleviating tic symptoms, improving comorbidities, and regulating the child's overall constitution [4,5]. TCM treatment for TD is characterized by its long-term, comprehensive, and family-participatory nature: beyond acupuncture, tuina (Chinese therapeutic massage), and herbal medicine administered during clinic or hospital visits, it requires

sustained home-based care across multiple domains, including diet, sleep, emotion, and physical activity [6]. However, existing research has focused predominantly on evaluating TCM clinical efficacy and optimizing treatment protocols [7,8], with limited attention to families' caregiving experiences, psychological trajectories, and support needs across the full course of treatment. International studies show that parents of children with chronic illness commonly experience cognitive conflict, emotional distress, and decisional dilemmas during caregiving, and that inadequate social support may compromise treatment adherence and child outcomes [9,10]. Although some studies in China have examined the mental health of parents of children with TD [11], systematic qualitative research on family caregiving experiences specifically within the context of TCM treatment remains scarce.

Braun and Clarke's six-phase thematic analysis is a systematic and flexible method of qualitative data analysis that can reveal participants' authentic experiences through six phases: familiarizing with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report [12]. This method has been widely applied in qualitative research on chronic disease management and care experiences [13]. Therefore, this study used a descriptive qualitative design guided by Braun and Clarke's six-phase thematic analysis framework to explore in depth the care experiences and support needs of families of children with TD during TCM treatment, with the aim of providing an evidence base for developing a systematic TCM-based family care support system.

Methods

Study design

This was a descriptive qualitative study.

Setting and participants

Between April and July 2026, primary caregivers of children with TD were recruited from the inpatient unit of the Department of Traditional Chinese Medicine at Shenzhen Children's Hospital using purposive sampling.

Inclusion criteria were: (1) the child met the diagnostic criteria for TD in the International

Classification of Diseases, 11th Revision (ICD-11) [14], as confirmed by an attending physician or above in the Department of Traditional Chinese Medicine; (2) the child was aged 4–18 years and currently receiving TCM treatment (outpatient or inpatient); (3) the caregiver was the child's primary day-to-day caregiver (providing ≥8 hours of care per day); and (4) the caregiver gave informed, voluntary consent to participate. Exclusion criteria were: (1) caregivers with a communication or cognitive impairment; and (2) children with a severe comorbid organic disease, schizophrenia, or other major illness.

To maximize the diversity of family backgrounds and experiences represented, maximum-variation sampling was applied across two dimensions: sociodemographic characteristics (age, education, occupation, family structure) and clinical characteristics (child's age, disease duration, treatment stage, comorbidities). Sample size was guided by data saturation; after saturation appeared to be reached, two further interviews were conducted to confirm it. Fourteen caregivers (coded P1–P14) were ultimately enrolled; their characteristics are shown in Table 1. This study was approved by the Ethics Committee of Shenzhen Children's Hospital (approval no. SCH-IRB-202603401), and all participants provided written informed consent. To protect participant confidentiality, potentially identifying details were removed or aggregated: caregivers' ages are not reported, children's ages are presented as ranges, place of residence is reported at region level, and occupations are collapsed into broad categories (Table 1).

Table 1 General characteristics of participating caregivers (n = 14)

Code	Relationship	Education	Occupation	Region of residence	Child's age band (years)	Disease duration (years)	Main treatment modalities	Comorbidities
P1	Mother	Bachelor's degree	Self-employed	Shenzhen	7–9	1	Herbal medicine + tuina + gua sha	ADHD
P2	Mother	Bachelor's degree	Homemaker	Shenzhen	7–9	1	Herbal medicine + tuina + transcranial magnetic stimulation	Attention deficit
P3	Mother	Bachelor's degree	Self-employed	Shenzhen	7–9	2	Herbal medicine + tuina + acupuncture	–

Code	Relationship	Education	Occupation	Region of residence	Child's age band (years)	Disease duration (years)	Main treatment modalities	Comorbidities
P4	Grandmother	Primary school	Retired	Shenzhen	7–9	1	Herbal medicine + tuina + acupuncture	–
P5	Mother	Associate degree	Employed	Shenzhen	13–18	5	Herbal medicine + tuina + acupuncture	Social anxiety
P6	Mother	Bachelor's degree	Employed	Elsewhere in Guangdong Province	7–9	2	Herbal medicine + tuina	Allergic rhinitis
P7	Mother	Associate degree	Employed	Elsewhere in Guangdong Province	4–6	2	Herbal medicine + tuina + acupuncture	Food intolerance
P8	Mother	Bachelor's degree	Self-employed	Shenzhen	10–12	2	Herbal medicine + tuina + acupuncture + magnetic therapy	Rhinitis
P9	Mother	Associate degree	Employed	Elsewhere in Guangdong Province	7–9	1	Herbal medicine + tuina + acupuncture	Urticaria
P10	Mother	High school	Employed	Outside Guangdong Province	7–9	5	Herbal medicine + tuina + acupuncture + fire-dragon cupping	ADHD
P11	Father	Bachelor's degree	Employed	Shenzhen	7–9	4	Herbal medicine + tuina + acupuncture	–
P12	Mother	Bachelor's degree	Employed	Shenzhen	4–6	1	Herbal medicine + tuina + acupuncture	–
P13	Mother	Bachelor's degree	Employed	Shenzhen	4–6	1	Herbal medicine + tuina + acupuncture	Attention deficit
P14	Father	Bachelor's degree	Employed	Shenzhen	13–18	5	Herbal medicine + tuina + acupuncture	Rhinitis

Note: To protect participant anonymity, caregivers' ages are not reported; children's ages are presented as ranges; place of residence is reported at region level; and occupations are collapsed into broad categories. Disease duration refers to the interval between the child's first confirmed diagnosis of tic disorders and the interview. TCM, traditional Chinese medicine; ADHD, attention-

deficit/hyperactivity disorder.

Interview guide development

The interview guide was developed specifically for this study and has not been published elsewhere. It was based on a review of domestic and international literature on family caregiving in TD, adherence to TCM treatment, and chronic disease family management [15–17], and covered nine core domains: disease discovery and diagnosis, decision-making around TCM treatment, treatment experience and adherence, home care practices, family support systems, psychological trajectory, financial burden and healthcare access, expectations for healthcare support, and future concerns. Three caregivers were interviewed in a pilot phase prior to formal data collection, and the guide was revised accordingly. The final interview guide included the following questions: (1) When and how did you first notice your child's abnormal movements? (2) How did you feel when your child was diagnosed, and how did you learn about this condition? (3) Why did you choose TCM treatment, and did family members agree? (4) Does your child cooperate during treatment? Which treatments does he/she like, and which does he/she resist? (5) How well have you actually been able to implement home care (diet, sleep, exercise, emotion), and which aspects have been hardest to sustain? (6) What has your psychological journey been like, and which stage was hardest? (7) Have you encountered financial or healthcare-access difficulties? (8) What kind of support would you most like to receive from healthcare professionals? (9) What hopes or concerns do you have about your child's future treatment? Non-directive probing questions were used during the interviews based on participants' responses. The complete guide, including the opening statement, probes and closing questions, is provided as Additional file 1.

Data collection

Semi-structured, face-to-face interviews were conducted. Interviews were led primarily by specialist TCM nurses and nursing graduate students who had received systematic training in qualitative research methods. Before each interview, the researcher explained the study's purpose, expected duration, and confidentiality principles, and clarified the necessity of audio recording. Interviews were conducted in a

private doctor–patient communication room within the department. Throughout the interviews, researchers maintained a neutral stance, avoided expressing personal opinions or biases, listened attentively to participants' feelings, and attended to non-verbal cues such as facial expression and tone of voice, in order to understand participants' views and feelings comprehensively and accurately. Each interview lasted 20–33 minutes (mean, 26 minutes). Audio recordings were transcribed verbatim into text within 24 hours of each interview.

Data analysis

Interview transcripts were imported into NVivo 12 software and analyzed using Braun and Clarke's six-phase thematic analysis method [12]: (1) familiarization with the data – researchers repeatedly read all transcripts to develop an overall understanding; (2) generation of initial codes – meaningful semantic units were coded line by line, with each code annotated with a verbatim excerpt, source file, and line number; (3) searching for themes – related codes were grouped into candidate themes to construct a preliminary thematic map; (4) reviewing themes – themes were reviewed against four criteria (coherence, distinctiveness, relevance, and saturation) and merged or split as needed; (5) defining and naming themes – a clear definition and name were developed for each theme; and (6) producing the report – the analysis was written up together with illustrative quotations. Two researchers coded the data independently, and inter-rater agreement was calculated using Cohen's kappa ($\kappa = 0.85$), indicating strong agreement; any disagreements were resolved through discussion or, where necessary, consultation with a third researcher. No new analytic dimensions emerged by the twelfth interview; two further interviews were conducted to confirm data saturation before data collection was concluded.

Results

Systematic analysis of the 14 caregiver interviews yielded three themes and ten subthemes (Table 2).

Table 2 Themes and subthemes of TCM-related care experiences among families of children with tic disorders

Theme	Subthemes
Theme 1: Cognitive dilemmas and decision-making pathways in family caregiving	1.1 Delayed disease recognition and multi-source information trust dilemmas 1.2 Treatment choices dominated by the perception of TCM as "safe and root-treating" 1.3 Mother-dominated family decision-making
Theme 2: Multidimensional dilemmas in TCM treatment experience and home care	2.1 Differentiation in treatment adherence across modalities and individual variation 2.2 Multidimensional difficulties in executing home care 2.3 Imbalance in family support systems and maternal caregiving burden
Theme 3: Evolution of psychological trajectories and support service needs	3.1 Nonlinear evolution of parents' psychological trajectories 3.2 Structural pressure from financial burden and healthcare accessibility 3.3 Expectations for healthcare support and service model reconstruction 3.4 Persistent distress from fear of relapse and future uncertainty

Theme 1: Cognitive dilemmas and decision-making pathways in family caregiving

1.1 Delayed disease recognition and multi-source information trust dilemmas

The initial symptoms of TD are often non-specific behaviors such as blinking, sniffing, or neck-twisting, which parents commonly misattribute to conjunctivitis, rhinitis, a stiff neck, or post-cold sequelae, resulting in visits to the wrong department and an average diagnostic delay ranging from six months to five years. P1: “After his cough stopped, he started blinking. He just kept blinking, and we didn't think much of it.” P2: “It was happening so often — he kept tilting his head back... at first we thought he'd just slept on his neck wrong.” P13: “I didn't notice it myself at first — we ended up seeing an ENT specialist about it, for years.” In the course of seeking a diagnosis, parents commonly went through experiences of moving between hospitals, cities, and departments; one parent visited four different hospitals, and another traveled from another province specifically to seek treatment in Shenzhen.

After diagnosis, online platforms (Douyin, Baidu, Doubao AI, and Xiaohongshu) became parents' overwhelmingly dominant channel for obtaining disease-related information, with 12 parents explicitly reporting that they searched these platforms for information. However, algorithm-driven recommendations

frequently exposed parents to severe or seemingly incurable cases, intensifying their anxiety. P5: “Whenever I scroll through videos... I really, truly — I can't. When I hear that kind of thing I just feel like crying. It's truly overwhelming.” Some parents developed psychological distress after seeing severe cases and consequently withdrew from parent support groups on their own initiative. P3: “His was mild, but sometimes seeing children with more severe cases scared me too, so I left the group.” Accounts of relapse shared within parent groups were also a common source of contagious anxiety. P9: “Joining the group actually made me more anxious... because so many parents said things like, ‘Mine keeps relapsing, over and over, and nothing works.’” Despite investing considerable time in online searching, parents' disease-related knowledge remained fragmented and superficial; most self-rated their understanding of the disease at only 50–60%, and even parents whose children had been in treatment for more than five years still reported feeling “without a clear sense of direction.”

1.2 Treatment choices dominated by the perception of TCM as “safe and root-treating”

Roughly half of the parents turned to TCM after Western medicine treatment proved ineffective (poor efficacy, recurrent symptoms) or after becoming concerned about side effects (effects on the nervous system, suppression of learning ability, liver or kidney damage). P1: “We took it for eight or nine months — more than a year — and it had no effect at all, and it even suppressed his nervous system, which slowed down his ability to learn.” P5: “Everyone says medicine — any medicine — comes with some toxicity, right? So afterward we switched to Chinese herbal medicine.” Parents generally positioned TCM as a “safe, natural, gentle, and root-treating” approach, believing that by regulating the spleen and stomach and calming internal wind, it improves the child's constitution at a fundamental level. P10: “It's relatively safe, and it can treat the problem at its root.” P2: “It's relatively natural. I don't have any worries — no concerns about side effects.” This belief became an important psychological anchor sustaining continued TCM treatment. As for how families first encountered TCM treatment, nearly half of the parents were referred through networks of friends, neighbors, kindergarten teachers, or classmates. P2: “It was because of a friend of mine — her child's case was much more severe than ours... and the results were obvious.” P9: “It just came up in conversation with a teacher... she mentioned that a child in the class next door had the same

thing.” Online reputation was another important pathway: P8: “The online reviews of one senior TCM physician were quite good, so I booked an appointment with him right away.”

1.3 Mother-dominated family decision-making

In 12 of the 14 families, the mother took the lead in decisions about TCM treatment, while fathers more often played a supporting role described as “hands-off,” “standing by,” or “helping to carry things out.” P2: “I just decide on my own.” P2: “The rest of the family doesn't see it as that serious a problem, because it's mainly me who's affected by it.” As both the primary caregiver and primary decision-maker, mothers carried a disproportionate share of the psychological and caregiving burden. Insufficient spousal support took various forms: some spouses “stood by and did nothing,” while others believed that “children are just mischievous — he'll grow out of it.” P7: “It's not that he doesn't love him. But he thinks kids are just mischievous... he just can't understand the kind of pain I'm going through.” Families seeking treatment away from home also faced the practical difficulty of family separation. P10: “I live in another province... I came here specifically to be hospitalized for treatment.”

Theme 2: Multidimensional dilemmas in TCM treatment experience and home care

2.1 Differentiation in treatment adherence across modalities and individual variation

Adherence differed markedly across TCM treatment modalities. Body-surface manual therapies such as tuina, massage, gua sha, and fire-dragon cupping were the most readily accepted, with children commonly reporting that they felt “comfortable, relaxed, and less stiff.” P11: “After the gua sha and the massage on his back, he says he feels very relaxed.” P8: “When he's having an episode, he feels really stiff all over. After the tuina and acupuncture, he says he feels — he feels very relaxed.” Acupuncture, because of the associated pain, was the treatment children resisted most; nearly all parents reported that their child showed fear, crying, or avoidance in response to acupuncture. P3: “He's a bit resistant to acupuncture — the needles, right? So he says if he doesn't have to, he won't do it.” P9: “Yesterday was his first time doing acupuncture, and he'd never done it before. He was quite frightened, so we stopped.” Taking herbal medicine generally required parents to coax, reward, or negotiate with the child. P8: “Honestly, he's never

cooperated — he still doesn't cooperate now. Even now, getting him to drink his herbal medicine means he holds the cup, walks around, fetches a piece of dried tangerine peel, then a bottle of water, and we have to count to three before he'll drink it."

The effectiveness of TCM treatment showed marked individual variation: some children improved within 2–3 days (described by parents as "miraculous"), while others showed no improvement after more than a month. P8: "After seeing that physician, by the second or third day the child was basically fine." P9: "It's been more than a month and there's been no improvement at all." Differences in treatment plans among children sharing the same hospital room also intensified parents' comparison-driven anxiety. "How long to take the medicine, when to stop, and how long to wait before resuming" were the most common sources of confusion for parents; physicians' answers were often along the lines of "take it until he improves" or "stop once he's better," without a clear treatment-course endpoint. P1: "How long should he take the herbal medicine, and how long should we stop before starting again — what would work better?" P9: "I don't even know how long he's supposed to take this medicine for... they said just keep taking it until you're better, until you recover."

2.2 Multidimensional difficulties in executing home care

Home-based TCM care spans multiple domains — diet, sleep, exercise, emotion, and electronic device use — and parents faced a systematic gap between "knowing what should be done" and "actually being able to do it." Dietary control faced a triple bind of "the child's cravings being hard to refuse, limited types of allergen testing available, and confusing information about dietary restrictions." P9: "We try to tell him not to eat that kind of thing, but he insists on eating it. Actually it's cold foods we're not supposed to have." P7: "For food intolerance testing, the range of items the hospital tests for is too limited." P4: "He can eat anything, just not too much of it." Sleep management showed intergenerational spillover, with the whole family commonly going to bed later than 22:00. P2: "We can't control his sleep... it's because — neither being gentle nor strict works, because he just can't fall asleep, he simply can't." P13: "Because when they haven't fallen asleep yet and their dad comes home, they get all excited." Restricting electronic-device use ran into the practical tension between "learning needs, peer pressure, and the child's limited self-control."

P3: “Electronic devices really do have a big impact... but he still needs his phone for schoolwork.” Families relying on grandparents for co-caregiving commonly reported that the older generation was unable to effectively manage the child's diet, sleep, or device use. P5: “His grandmother definitely can't manage it... she'll listen, but she can't actually follow through — she won't try to control him.” P12: “The grandparents can't control him. He doesn't listen to them — he'll go raid the fridge on his own.”

2.3 Imbalance in family support systems and maternal caregiving burden

Caregiving for children with TD showed an imbalanced structure of “mother-led, spouse-absent, and limited grandparental assistance.” Of the 14 parents interviewed, 12 mothers served as both the primary caregiver and decision-maker, shouldering comprehensive responsibilities including accompanying the child to medical visits, supervising medication, managing diet, providing emotional reassurance, and communicating with the school. P2: “The rest of the family doesn't see this as such a serious problem, because it mainly affects me — I'm the one who usually sits with him doing homework.” Spousal support followed several patterns, including “standing by and doing nothing,” “not regarding it as serious,” and “providing financial support but being emotionally absent”; the gap between spouses' perception of the severity of the child's condition, together with a lack of understanding of the mother's anxiety, intensified mothers' sense of helplessness and marital strain. P7: “It's not that he doesn't love him. But he thinks kids are just mischievous... he just can't understand the kind of pain I'm going through.” Some families faced separation due to seeking treatment away from home. P10: “At a hospital in our home region, a single course of medicine cost several thousand yuan... it comes to six or seven thousand yuan a month.”

Theme 3: Evolution of psychological trajectories and support service needs

3.1 Nonlinear evolution of parents' psychological trajectories

Parents' psychological trajectories followed a nonlinear evolution of “diagnostic shock → repeated turmoil → self-adjustment → acceptance and coexistence.” The early period after diagnosis and periods of symptom worsening were the stages of most intense anxiety, during which some parents reported hiding to cry, insomnia, and self-doubt. P10: “The hardest time was when his symptoms were especially frequent,

especially bad... I would sometimes hide away and cry a little." P7: "The kind where you lie awake all night, night after night. Extremely, extremely anxious." Symptom recurrence — relapsing after having improved — was consistently identified as the most difficult moment of all, far exceeding the initial shock of diagnosis. P8: "The hardest part is when he gets better and then relapses again. Then after the relapse, some time passes and it feels like it won't get better as easily this time." P13: "...it's the relapses. He'll get better, and then the next time it comes back and doesn't get better again."

Self-management was the predominant coping strategy; a few parents confided in their spouse, but a lack of understanding from the spouse often caused secondary hurt. Very few parents received support from friends or professional psychological services. P3: "Who would I even go to for that? I just work through it myself." P7: "Where would I even go... yes, it's very isolating." None of the 14 parents had ever sought professional psychological counseling, citing reasons such as "no need for it," "not knowing where to find it," and "focus being on the child." However, when asked whether they would be willing to attend a psychological support clinic for parents if one were offered, most responded "if time allows" or "yes, I'd be willing," suggesting a latent unmet need. P13: "No, because I don't feel I need it."

3.2 Structural pressure from financial burden and healthcare accessibility

TCM treatment is characterized by its long duration, cross-regional nature, and high proportion of out-of-pocket cost, creating a cumulative financial burden for families. P2: "Going to the outpatient clinic is a financial strain, because when he was on both Western and Chinese medicine, a single treatment cost one or two hundred yuan, and it came to over a thousand yuan a month." P9: "That medicine — the patch — is quite expensive. It's a premium herbal formulation." P13: "Of course there's pressure — with two kids, it's no small amount every month." Families seeking treatment away from their home region commonly faced low insurance reimbursement rates (only about 30%), non-reimbursable outpatient costs, and complex reimbursement procedures. P10: "Apparently, because ours is out-of-area insurance, it only reimburses about 30% of the eligible costs." Limited appointment slots with well-known specialists (sold out within seconds), out-of-town parents queuing in the early hours, and the need to book follow-up visits well in advance were prominent problems. P9: "Appointments open at 5 o'clock, and I was there right on time —

they were gone in ten, twenty seconds." P13: "There was nothing to be done — I just had to take time off work."

3.3 Expectations for healthcare support and service model reconstruction

Parents' expectations for existing healthcare support reflected a need for multidimensional reconstruction encompassing "professional guidance, systematic health education, integration of online and offline formats, professionally led parent groups, dedicated nursing clinics, and needs-based ongoing support." Because of high patient volumes and limited time, outpatient physicians found it difficult to provide in-depth health education or psychological support, often following a rapid "prescribe – dispense medicine – next patient" pattern. P9: "There's not much communication about the professional side of things, because the doctor I see has a lot of patients and doesn't say much." P2: "They're probably very busy — they just flag up a few of the more obvious issues without really explaining them in depth."

Parents commonly expressed a desire for systematic, detailed health education covering disease knowledge, medication guidance, home care, relapse prevention, and psychological guidance. P2: "The more detailed the better, because then... I could guide him myself." Preferences for the format of health education were diverse: official social media accounts (most convenient), printed brochures (easy to browse), short videos (intuitive), face-to-face explanations (more interactive), and telephone follow-up (personalized). P8: "An official account. And also, if staffing allows, a phone call would be good." P1: "I think if everyone could actually see the doctor, then face-to-face would definitely be best."

Parents were generally reserved about purely peer-led parent groups but expressed strong interest in parent groups with professional healthcare involvement. P1: "There would definitely need to be a professional there to give us proper guidance." P12: "Too much of it is just idle chat... what I want is guidance on how to actually treat this condition." Most parents responded positively to the idea of a dedicated TCM nursing clinic (a health-guidance clinic for families of children with TD), hoping to receive guidance on appropriate TCM techniques such as acupoint patch therapy, massage techniques, seasonal health preservation, and pattern-based dietary therapy. P2: "I'd hope for systematic health education — essentially, popular science, promoted as such." Parents generally opposed a "one-off, all-at-once" format

of education, preferring to access information as needed or receive it through periodic, ongoing outreach. P1: “I think it should be available whenever there's a need... because the way you handle things may differ at different stages.” P2: “The earlier, the better.”

3.4 Persistent distress from fear of relapse and future uncertainty

Fear of relapse ran throughout the entire course of treatment and was the most persistent and difficult psychological burden for parents. P1: “What worries me now is that if he stops taking the medicine, if he stops all treatment, will he slowly slip back to how he was before?” P11: “I worry — I just worry that he'll relapse.” Starting school (especially first grade) was a common trigger for symptom worsening, with academic pressure, teachers' attitudes, and peer acceptance identified as three major sources of stress. P3: “What worries me is that I've seen so many cases where, without timely intervention, things later progressed to a severe stage.” P4: “The psychological pressure of first grade... it's just too much pressure.” Ridicule, lack of understanding, and stares from classmates were a shared psychological burden for both parents and children. P5: “He's started avoiding it himself, because at school other kids might laugh at him.” Some parents were aware that TD “might be curable, or might last a lifetime,” and this uncertainty became a deep-seated source of anxiety. P2: “I know that with this condition... it could be cured, or it could last a lifetime.” The age limit for treatment at children's hospitals (18 years) meant that some patients faced a gap in access to care upon reaching adulthood. P14: “I have a problem right now... my child is about to reach the upper age limit for treatment at a children's hospital. Once he turns 18, we won't be able to get an appointment anymore.”

Discussion

Addressing cognitive dilemmas in family caregiving: building systems for early recognition and information support

This study found that the initial symptoms of TD are often misattributed to ophthalmological or otolaryngological conditions, with an average diagnostic delay ranging from six months to five years, consistent with several previous studies conducted in China [18,19]. Diagnostic delay not only forfeits the

optimal window for early intervention but may also lead to symptom worsening and the emergence of comorbidities, further complicating treatment [20]. The underlying causes of diagnostic delay include low public awareness of TD, the non-specific nature of initial symptoms, and limited recognition capacity among primary-care physicians. We therefore suggest conducting early public education on TD in community, kindergarten, and primary school settings, informing families of children in the high-risk age range of 3–5 years about key warning signs to improve parents' capacity for early recognition [21]. In parallel, training in TD recognition should be strengthened among primary-care physicians (general practitioners, pediatricians, ophthalmologists, and otolaryngologists), and a "primary-care recognition – specialist referral" fast-track pathway should be established to shorten the time to diagnosis.

This study also found that the internet has become parents' overwhelmingly dominant channel for obtaining TD-related information, but that this channel carries a double-edged-sword effect of "rich information but heightened anxiety," consistent with the findings of Handelsman et al. [22]. Algorithm-driven content recommendation frequently exposes parents to severe cases, intensifying their anxiety. We therefore suggest that healthcare institutions proactively build an authoritative, systematic, and accessible information-support system for TD, including official social media accounts and mini-programs that regularly disseminate educational articles and short videos; mechanisms to verify information and correct online misinformation; and personalized information consultation services to prevent parents from becoming lost amid an overwhelming volume of information. Attention should also be paid to parents' emotional fluctuations during information-seeking, with timely provision of psychological support [23].

Addressing adherence to TCM treatment and difficulties in home care: building a systematic TCM nursing support system

This study found marked differences in adherence across TCM treatment modalities: tuina had the highest acceptance, acupuncture was widely resisted, and herbal medicine required active inducement. This is consistent with clinical observations in TCM pediatrics [24]. Resistance to acupuncture emerged as a major barrier to treatment adherence, suggesting that healthcare providers should pay closer attention to

children's treatment experience and explore comprehensive interventions such as pain-reduction strategies (e.g., laser acupuncture or auricular acupoint pressure as alternatives), psychological approaches (e.g., gamifying treatment, reward mechanisms), and parental involvement (e.g., accompanying and comforting the child) [25]. Individual variation in treatment effectiveness and ambiguity around treatment protocols were also important sources of distress; we recommend strengthening doctor–patient communication to clearly convey expected treatment duration, adjustment milestones, and criteria for discontinuation, thereby reducing parents' uncertainty-related anxiety [26].

Home-based care revealed a systematic gap between "knowing what should be done" and "actually being able to do it," consistent with findings from research on chronic disease family management [27]. Dietary control, sleep management, restriction of electronic-device use, and limited caregiving capacity among grandparents constituted the core of these multidimensional difficulties. We recommend building a TCM-based family care support system centered on "specialized nursing clinics + systematic health education + home visits," including: establishing a dedicated TCM nursing clinic where specialist nurses provide guidance on appropriate TCM techniques such as acupoint patch therapy, massage techniques, seasonal health preservation, and pattern-based dietary therapy; developing tiered, age-appropriate home-care manuals (basic, standard, and advanced versions); establishing a home-visit program to assess the implementation of home care and provide individualized guidance; and incorporating all caregivers, including grandparents, into a structured education program to build family caregiving capacity [28].

Addressing parents' psychological trajectories and family support: building diversified psychological support services

This study found that parents' psychological trajectories followed a nonlinear evolution of "diagnostic shock → repeated turmoil → self-adjustment → acceptance and coexistence," that relapse was consistently identified as the most difficult moment, that self-management was the predominant coping strategy, and that use of professional psychological support was extremely low. These findings are consistent with Hansen et al.'s research on the mental health of parents of children with chronic illness [29]. Family

caregiving showed an imbalanced structure of "mother-led, spouse-absent, and limited grandparental assistance," with mothers bearing a disproportionate psychological and caregiving burden. We therefore recommend building a diversified psychological support system centered on "a psychological support clinic for parents + peer support groups + spousal education and participation + information on financial assistance," including: establishing a dedicated psychological support clinic for parents of children with TD, offering individual counseling and group psychological support; establishing parent peer-support groups with the involvement of professional healthcare staff to share successful experiences and provide expert guidance; incorporating spouses (particularly fathers) into family health education to strengthen their disease awareness and capacity for emotional support; and providing practical support such as information on financial assistance, guidance on insurance policy, and support for accessing care away from home [30].

Addressing fear of relapse and future uncertainty: exploring mechanisms for long-term management and transition

Fear of relapse pervades the entire course of treatment, with school-age academic impact, social stigma, the possibility of lifelong persistence, and the gap in care access after aging out of pediatric services constituting deep-seated sources of anxiety. This is closely related to the chronic, relapsing nature of TD [31]. We therefore recommend building a long-term management mechanism centered on "relapse early-warning – long-term follow-up – school collaboration – transition to adult healthcare," including: establishing a system of early-warning indicators to help parents recognize early signs of relapse (e.g., colds, emotional fluctuations, excessive use of electronic devices); establishing a long-term follow-up program to regularly assess children's symptoms, psychological status, and academic functioning; establishing collaborative mechanisms with schools, including teacher training on TD to foster an accepting school environment; and exploring a "pediatric-to-adult healthcare" transition mechanism, including a referral pathway for patients over 18 years of age, to address the gap in care access after aging out of pediatric services [32].

Study limitations

This study has several limitations. First, the sample was drawn from a single source — all 14 caregivers were recruited from the inpatient unit of the Department of Traditional Chinese Medicine at Shenzhen Children's Hospital, without a comparison group from outpatient settings or other hospitals, which may introduce selection bias. Second, interviews were led by TCM nursing staff, and parents' responses may reflect social desirability bias arising from the healthcare provider–patient relationship, potentially skewing their evaluations of TCM treatment in a more positive direction. Third, this was a cross-sectional qualitative study reflecting parents' experiences only at the time of interview, without longitudinal tracking of treatment outcomes. Fourth, this study focused on the parental perspective and lacked triangulation with children's own experiences or the perspectives of healthcare providers. Future research should expand the sample size, incorporate multicenter comparison, and add longitudinal follow-up to strengthen the credibility and transferability of these findings.

Conclusions

Through in-depth interviews with 14 caregivers of children with TD, this study systematically revealed families' care experiences and support needs during TCM treatment. Families face multiple challenges, including cognitive dilemmas (delayed disease recognition, difficulty trusting information sources), decisional dilemmas (mother-dominated decision-making, spousal absence), treatment-related dilemmas (differentiated adherence, individual variation in response), home-care dilemmas (multidimensional difficulties in implementation), psychological dilemmas (nonlinear trajectories, reliance on self-management), and systemic dilemmas (financial pressure, limited healthcare accessibility), with fear of relapse and future uncertainty constituting a persistent source of distress. We recommend building a TCM-based family care support system centered on “specialized nursing clinics + professional parent groups + systematic health education + psychological support services + community-based early screening,” with priority given to the initial diagnosis period and periods of symptom recurrence, together with mechanisms for transitioning to adult healthcare to address the gap in care access after patients age out of pediatric services. Future research should expand the sample size, incorporate multicenter comparison, and conduct

longitudinal follow-up to further verify and deepen these findings.

List of abbreviations

TD: Tic disorders; TCM: Traditional Chinese medicine; ADHD: Attention-deficit/hyperactivity disorder; OCD: Obsessive-compulsive disorder; ICD-11: International Classification of Diseases, 11th Revision; DSM-5: Diagnostic and Statistical Manual of Mental Disorders, 5th Edition; SRQR: Standards for Reporting Qualitative Research; COREQ: Consolidated Criteria for Reporting Qualitative Research.

Declarations

Ethics approval and consent to participate

This study was approved by the Ethics Committee of Shenzhen Children's Hospital (approval no. SCH-IRB-202603401) and was conducted in accordance with the Declaration of Helsinki. All participants provided written informed consent prior to participation.

Consent for publication

Written informed consent for publication of anonymized interview excerpts was obtained from all participants. No identifying information of any individual is included in this manuscript. Quotations are labelled with participant codes only, and potentially identifying details, including the names of treating physicians, specific cities and exact dates, have been removed or generalized.

Availability of data and materials

The interview transcripts generated and analyzed during the current study are not publicly available, in order to protect participant privacy and confidentiality, but de-identified excerpts are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

XQZ and RNY contributed equally to this work and should be considered co-first authors. XQZ designed the study, conducted data collection and analysis, and drafted the manuscript. RNY contributed to the study design, supervised data analysis, and critically revised the manuscript. HY (corresponding author) conceived the study, supervised all aspects of the research, and finalized the manuscript. LJW contributed to interview guide development and participant recruitment. GMQ contributed to data interpretation and manuscript revision. All authors read and approved the final manuscript. Correspondence: Hong Yu, Department of Traditional Chinese Medicine, Shenzhen Children’s Hospital, No. 7019 Yitian Road, Futian District, Shenzhen, Guangdong 518026, China. Email: 1094713269@qq.com.

Supplementary Materials

Additional file 1: Semi-structured interview guide (English version) used in this study.

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