Additional File 1

Semi-structured Interview Guide (English version)

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

Development of the guide

This interview guide was developed specifically for the present study and has not been published elsewhere. It was constructed on the basis of a narrative review of the domestic and international literature on family caregiving in tic disorders, adherence to traditional Chinese medicine (TCM) treatment, and family management of chronic childhood conditions. The draft guide was pilot-tested with three primary caregivers who met the same eligibility criteria as the main sample. Pilot interviews were used to revise the wording, sequencing and probing questions of the guide. No further changes were made to the guide after formal data collection began.

Structure and administration

The guide covers nine core domains corresponding to the study aims: (1) disease discovery and diagnosis; (2) decision-making around TCM treatment; (3) treatment experience and adherence; (4) home care practices; (5) family support systems; (6) psychological trajectory; (7) financial burden and healthcare access; (8) expectations of healthcare support; and (9) future concerns. Each domain contains one opening question followed by non-directive probes. Probes were used flexibly according to participants' responses; interviewers avoided leading questions and personal judgement. All interviews were conducted face-to-face in a private room, audio-recorded, and lasted 20–33 minutes (mean 26 minutes).

Part A. Opening statement (read before the interview)

- Thank you for agreeing to take part in this study. I am a TCM nursing specialist involved in the care of children with tic disorders.
- We would like to hear, in your own words, about your experiences of caring for your child since the onset of tics, and about the support you and your family need during TCM treatment.
- There are no right or wrong answers. Everything you say will be treated confidentially; the recording will be used only for transcription and analysis, and your name will not appear in any report or publication. You may stop at any time or decline to answer any question.
- The interview will take about 20 to 35 minutes. Do you have any questions before we begin?

Part B. Core interview questions and probes

Domain 1. Disease discovery and diagnosis

Main question: When and how did you first notice your child's abnormal movements?

– What did the movements look like at the time?
– What did you think might be causing them?
– Where did you first seek help, and what was explained to you?
– How much time passed before a diagnosis was made?

Domain 2. Diagnosis experience and sources of information

Main question: How did you feel when your child was diagnosed, and how did you learn about this condition?

– Who first told you about tic disorders?
– Where did you go for information afterwards (hospital, internet, other parents)?

– Which sources did you trust most, and which confused you?
– How would you rate your current understanding of the condition?

Domain 3. Decision-making about TCM treatment

Main question: Why did you choose TCM treatment, and did family members agree?

– What treatments had you tried before choosing TCM?
– What were your main hopes and main worries at that point?
– How did other family members react to the decision?
– Who made the final decision in your family?

Domain 4. Treatment experience and adherence

Main question: Does your child cooperate during treatment? Which treatments does he or she like, and which does he or she resist?

– How does your child respond to acupuncture / tuina / herbal medicine / other modalities (ask about each one received)?
– How do you manage it when your child refuses?
– Have you noticed any change in the tics? How quickly?
– Has anyone explained how long the treatment course should last, or when it can be stopped?

Domain 5. Home care and daily management

Main question: How well have you actually been able to carry out home care (diet, sleep, exercise, emotion), and which aspects have been hardest to sustain?

– What changes have you made to your child's diet, and what has been difficult about it?
– How is your child's sleep, and what affects it?
– How do you manage screen time and electronic devices?
– Who else helps with daily care at home, and how well does that work?

Domain 6. Family support and psychological trajectory

Main question: What has your psychological journey been like, and which stage was hardest?

– When was the most difficult moment for you?
– What did you do to cope at that time?
– Did you talk to anyone, or seek professional psychological help? Why or why not?
– If a psychological support service for parents were available, would you use it? What would make it easier?

Domain 7. Financial burden and healthcare access

Main question: Have you encountered financial or healthcare-access difficulties?

– What does treatment cost your family each month?
– How much is reimbursed through insurance, and what is paid out of pocket?
– Have you had difficulty booking appointments or travelling for care?
– Has treatment affected your work or the family's daily routine?

Domain 8. Expectations of healthcare support

Main question: What kind of support would you most like to receive from healthcare professionals?

– What information or guidance do you wish you had received earlier?
– How would you prefer to receive it (official account, leaflet, short video, face-to-face, telephone follow-up)?
– What do you think of parent support groups, and of a dedicated TCM nursing clinic?
– When would be the best time to receive this support?

Domain 9. Hopes and concerns about the future

Main question: What hopes or concerns do you have about your child's future treatment?

– What worries you most about the possibility of relapse?
– How has school affected your child's symptoms and your family?
– Are you concerned about stigma or how others respond to your child?
– What happens when your child becomes too old for a children's hospital?

Part C. Closing questions

- Is there anything we have not talked about that you think is important for us to know?
- Is there anything you would like to ask us?
- Would you be willing to be contacted again if we need to check anything in the transcript?

Part D. Post-interview field notes (completed by the interviewer)

- Setting, date, duration, and who was present.
- Apparent emotional state of the participant and any notable non-verbal cues.
- Anything that interrupted the interview or may have affected the participant's openness.
- Initial impressions and points to follow up in subsequent interviews.

Note: Participant sociodemographic and clinical characteristics (relationship to the child, education, occupation, region of residence, child's age band, disease duration, treatment modalities received, and comorbidities) were collected separately using a short structured form before the interview. To protect participant anonymity, ages were recorded as ranges and place of residence was recorded at province/region level only.