RESEARCH ARTICLE

"Mental Health with Social Challenges" and "Support Systems with Coping Mechanisms" Among Chinese Adults with Tourette Syndrome in three Locales: A Qualitative Study

Tsung-Yu Tseng[1,#], Kuo-Yu Chao[2,3,#] and Wei Cheng[4,5,6,*]

[1]Graduate Institute of Education, National Chung Cheng University, Chiayi, Taiwan; [2]Department of Nursing, Chang Gung University of Science and Technology, Taoyuan, Taiwan; [3]Division of Colon and Rectal Surgery, Chang Gung Memorial Hospital, Linkou, Taiwan; [4]Department of Pathology, Kee-Lung Hospital, Ministry of Health and Welfare, Kee-Lung, Taiwan; [5]School of Nursing, National Taipei University of Nursing and Health Sciences, Taiwan; [6]Department of Nursing, Deh Yu College of Nursing and Health, Kee-Lung, Taiwan

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Abstract: ***Background and Objective*:** Tourette Syndrome (TS) typically appears in childhood. The adverse childhood experiences of individuals with TS may influence their adult well-being. The social adjustment problems of adults with TS are often ignored in clinical practice. This study explored how Chinese adults with TS in Taiwan, Hong Kong, and Mainland China understand and are affected by TS.

***Methods*:** We recruited 19 individuals with moderate-to-severe TS from ad hoc TS support groups in Taiwan, Hong Kong, and Mainland China and conducted semi-structured in-depth interviews between April 2015 and January 2016, and between June and September 2022. A total of 9 participants completed three quantitative scales: Gilles de la Tourette syndrome - quality of life scale (GTS-QoL) and two self-assessments, namely the severity of TS symptom index (S-TS-I) and satisfaction with life index (SL-I).

***Results*:** We identified ten resilience factors, which were categorized into two main categories. The first category, "Mental Health with Social Challenges" included lack of family support, struggles to adapt to social expectations of normal behavior, bullying from peers, friends, or teachers, and negative thoughts about TS. The second category, "Support Systems and Coping Mechanisms," encompassed support from families, support from teachers and friends, positive thoughts about TS, professional guidance, life goals, and coping strategies. We found that adults with TS who had more "Support Systems with Coping Mechanisms" than "Mental Health with Social Challenges" were more satisfied with their lives. Surprisingly, GTS-QoL was correlated with S-TS-I (TS severity) but not with SL-I scores (TS satisfaction). The participants exhibited differences in cultural beliefs and perceptions of TS depending on the locale.

***Conclusions*:** Two prominent categories were identified pertaining to how Chinese people with TS understand, are affected by, and cope with their condition.

Keywords: Tourette syndrome, adverse experience, resilience, Chinese, qualitative interview.

1. INTRODUCTION

Tourette Syndrome (TS) is a chronic neurological disorder. TS is diagnosed when a person has multiple motor tics and at least one phonic tic that persists for at least 1 year. Symptoms of TS usually appear between 5 and 8 years of age, with tic severity generally peaking between the ages of 10 and 12 years [1]. Children with TS are bullied and victimized more than children without TS [2]. TS negatively affects the social and emotional quality of life (QoL) of both children and adults [3].

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*Address correspondence to this author at the Department of Pathology, Kee-Lung Hospital, Ministry of Health and Welfare, Kee-Lung, Taiwan; E-mail: kln8301@kln.mohw.gov.tw

[#] *These authors contributed equally to this work.*

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Although tic symptoms in TS typically begin in early childhood, they can continue to affect individuals into adulthood. Estimates of TS prevalence among children have ranged from 0.4% to 5.0% in community samples [4]. TS affects 0.4%–0.8% of the population in the United States [5] and 0.56% of Taiwanese schoolchildren [6]. In Hong Kong, the prevalence of TS among children from a lower-middle social class is 0.4% [7]. In Mainland China, the prevalence of tic disorders (TD) in children is approximately 2.46%, according to a first-of-its-kind national survey [8].

TS primarily affects male individuals. The ratio of boys to girls with TS aged 4–6 years is approximately 4:1 [9]. In Taiwan, the male-to-female risk ratio is 3.65 [10]. In Mainland China, the ratio of boys to girls with tic disorders (TD) is 1.51, while for TS specifically, it is 2.45 [11].

Furthermore, TS is usually accompanied by comorbidities, which may complicate the conditions. The lifetime prevalence of one or more psychiatric comorbidities among individuals with TS is 85.7%, and 57.7% of the population has two or more psychiatric disorders [12]. Among people with TS, 72.1% have either Obsessive-Compulsive Disorder (OCD) or Attention-Deficit/Hyperactivity Disorder (ADHD) [12]. Other disorders, including those related to mood, anxiety, and disruptive behavior, occur in approximately 30% of individuals with TS [12].

TS typically appears in childhood. However, due to their age, the social adjustment challenges faced by adults with TS are often overlooked in clinical nursing practice. Misrepresentations of TS in the media and education are common. Discussions of TS are typically not included in academic curricula [13]. Most Chinese people (possibly including people in Hong Kong and Taiwan) believe children with TS symptoms to be misbehaved and unable to control their motor and phonic tics [13]. Chinese culture, particularly its traditional health beliefs and practices, influences the perception and the management of mental illnesses and related behaviors. Because of differences in knowledge of TS and cultural traditions, Chinese people with TS may have different experiences from Western people with TS.

It is known that the symptoms and severity of TS are often associated with childhood adversity [11], stress [14], resilience, QoL, and social functioning in clinical practice [3, 15]. By understanding the effects of culture, clinical nurses can help clients adapt to various challenges.

Therefore, this study explored how Chinese adults with TS in Taiwan, Hong Kong, and Mainland China understand and are affected by TS. We asked participants whether they experienced difficulties with academic work, social interactions, and emotional well-being in school or their careers, as well as how they coped with these challenges. We also investigated the risk factors for TS-related adversity and the protective factors of resilience, which the participants thought would be helpful for their peers with TS. Understanding these factors may help healthcare providers, particularly nurses, manage their interactions with clients with TS and improve daily QoL clinical nursing practice. The innovation in this study lies in its comprehensive and culturally contextualized approach to understanding TS among Chinese adults in Taiwan, Hong Kong, and Mainland China.

2. MATERIALS AND METHODS

2.1. Process

We conducted semi-structured, in-depth interviews with 19 individuals with moderate-to-severe TS from Taiwan, Hong Kong, and Mainland China. We conducted the interviews over a 10-month period, between April 2015 and January 2016, and a 3-month period, between June and September 2022. The criteria for inclusion were diagnosis of TS by a physician or health-care provider in accordance with the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*; strong communication abilities, and age of over 18 years.

2.2. Research Design

In this study, we used both qualitative methods (interviews) and a quantitative approach (three quantitative scales). Mixed-methods designs were used to compensate for weaknesses of the individual methods, to improve the scope of the results, and to provide a comprehensive insight into the topic [16]. Studies that assess quality of life allow individuals to express which aspects are most important to them, providing valuable insights for better intervention strategies [17].

2.3. Data Collection

A total of 19 participants participated in the qualitative study. After providing written informed consent, each interviewee participated in a Narrative Inquiry and semi-structured in-depth interview for approximately 2–3 hr. The interviews were facilitated by the first author [18], who also has TS. Participants were interviewed individually in order to enable them to speak freely. The interview protocol (provided in Supplementary File 1) consisted of the following parts: (1) demographic information, including gender, age, occupation, and other relevant details, and (2) 19 questions focused on the interviewees' perceptions of their TS experience. Interviews were translated verbatim for 19 participants. Translated interview data were analyzed with initial coding, and each interview was examined line-by-line. Open coding was applied to identify and document the relationships between concepts to ensure that no important ideas were ignored. Initial categories were developed, tentative relationships between categories were established, and the first level of abstraction was conceptualized. Theoretical sampling guided data collection with each subsequent interview in order to confirm emerging concepts or categories. The research team held regular meetings to reflect on and discuss the entire research process. The research team critically examined the role and continuously made self-reflections to ensure the absence of biases and tried to maintain neutrality in the process of analyzing and interpreting the research results.

2.4. Data Analysis

A total of 9 interviewees participated in the quantitative study, selected through purposive sampling based on a discrepancy between their satisfaction with TS and their quality of life. We used three quantitative scales, namely (1) the Gilles de la Tourette syndrome Quality of Life scale (GTS-QoL) (*no problem* = 1 to *extreme problem* = 5 of 27 items, with scores ranging from 27 to 135) [19]; (2) The Self-Assessment of Severity of TS Symptom Index (S-TS-I) (*mild* = 1 to *severe* = 100); and [3] the Self-Assessment of Satisfaction with Life Index (SL-I) (*strongly satisfied* =1 to *strongly dissatisfied* = 100). Statistics were performed using Pearson Correlation.

2.5. Ethical Considerations

The Ethics Committee of Taipei Hospital, Ministry of Health and Welfare approved the study (TH-IRB-0022-0009). All study procedures were performed in accordance with the ethical standards of the Ethics Committee of Taipei Hospital, Ministry of Health and Welfare, and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

3. RESULTS

3.1. Socio-demographic Profile of the Participants

We recruited 19 interviewees. Twelve interviewees were from Taiwan, one was from Hong Kong, and six were from Mainland China. Sixteen were men (84.2%), and three were women. Eighteen of the interviewees had comorbid OCD or ADHD; the other participant only had TS (Table **1**).

Participants were excluded if they were unable to communicate, had a diagnosis of substance use or dependence, or had a lifetime diagnosis of mania or psychosis. The mean age of the interviewees was 31.3 years, with a range of 21 to 52 years. The ratio between men and women was 5.33:1. Table **1** provides details of the participants. The mean duration of TS was 23.26 ± 8.59 years. A total of 16 participants were assessed using the Yale Global Tic Severity Scale (YGTSS), with moderate to severe symptoms (n = 16, 84.21%). Additionally, 10 participants were still taking medication (n = 10, 52.63%). All data were anonymized.

3.2. Categories of “Mental Health with Social Challenges” and “Support Systems with Coping Mechanisms”

We identified ten factors from the interviews and categorized them into two categories, namely “Mental Health with Social Challenges” representing adverse experiences, and “Support Systems with Coping Mechanisms” reflecting factors that influence resilience (Table **2**). The themes of “ Mental Health with Social Challenges” included lack of family support, struggles to adapt to social expectations of normal behavior, bullying from peers, friends, or teachers, and negative thoughts about TS. The themes of “Support Systems with Coping Mechanisms” included support from families, support from teachers and friends, positive thoughts about TS, professional guidance, life goals, and coping strategies. Table **3** provides a summary of the factors and representative quotes.

Table 1. Characteristics of the study participants.

Demographics						Diagnosis		Chinese Culture	
Cases	**Age**	**Sex**	**Place of Residence**	**Education**	**Occupation**	**OCD**	**ADHD**	**Seek Herbal Medicine, Religious Healer, or Divine Advice**	**Fatalism**
F1	24	F	Taiwan	Bachelor	Student in USA	Yes	No	-	-
F2	34	F	China	Bachelor	Freelancer	No	Yes	Yes	-
F3	34	F	Taiwan	N/A	English teacher	No	No	Yes	Yes
M1	33	M	Taiwan	Master	Special education teacher	No	Yes	-	-
M2	36	M	China	Bachelor	Director	Yes	No	-	-
M3	28	M	Taiwan	Bachelor	English teacher	No	Yes	Yes	-
M4	39	M	Taiwan	Master	Florist	Yes	No	Yes	Yes
M5	27	M	Taiwan	Bachelor	-	Yes	No	-	Yes
M6	23	M	Hong Kong	Vocational high school	-	No	Yes	-	-
M7	52	M	Taiwan	Junior college	Trader	Yes	No	Yes	-
M8	46	M	Taiwan	Vocational high school	Farmer	Yes	No	Yes	-
M9	21	M	Taiwan	Bachelor	Student	Yes	Yes	Yes	Yes
M10	36	M	Taiwan	Master	-	Yes	Yes	Yes	Yes
M11	22	M	China	Master	Student	Yes	Yes	Yes	Yes
M12	25	M	China	Bachelor	Software Engineer	No	Yes	Yes	Yes
M13	35	M	China	Bachelor	-	Yes	No	Yes	-
M14	22	M	Taiwan	Bachelor	Employee	No	Yes	Yes	Yes
M15	21	M	China	University Student	Part-time job	No	No	Yes	Yes
M16	36	M	Taiwan	Senior high school	Part-time job	Yes	No	Yes	Yes

3.3. Category 1: Mental Health with Social Challenges (Adverse Experiences)

When discussing their experience of living with TS, most participants stated that they usually felt embarrassed, worried, and irritated. Four themes emerged from their accounts of adverse situations.

A total of 11 participants said their families did not support them. A 24-year-old woman said, "*My parents' words are like whips. They say the most stinging things to hurt me.*" A 34-year-old woman blamed herself for her problems: "*My parents had fights because of my condition, and they even planned to divorce.*" A 27-year-old man said, "*In fact, my father hated me very much. He wanted my mother to have an abortion when she was pregnant with me. He hated me because of my TS.*"

A total of 14 participants struggled to adapt to society's expectations of normal behavior. A 33-year-old man shared his experience: "*On the bus, an old woman whispered to her daughter-in-law in Taiwanese, 'He is possessed by a ghost.'*" A 34-year-old woman said she would hide her symptoms in public and in front of her parents: "*I hide the symptoms as much as possible to prevent conflict with my family.*"

A total of 18 participants had experienced bullying from classmates, friends, or teachers as

Table 2. Categories of "Mental Health with Social Challenges" and "Support Systems with Coping Mechanisms" from the narrative interviews.

Categories	Mental Health with Social Challenges				Support Systems with Coping Mechanisms						Suicide Ideation/ Attempts
Themes	Lack of Support from Families	Struggling to Fit into Society's Expectations of Normal Behaviors	Bullied by Classmates, Friends, or Teachers	Negative Thinking of TS	Support from Family	Support from Classmates, Friends, or Teachers	Positive Thinking of TS	Professional Abilities	Life Goals	Good Coping Strategies	
F1	●	●	●	●	-	-	-	-	-	-	-
F2	●	●	●	●	-	○	○	-	○	-	Yes
F3	-	-	●	●	○	○		○	-	Suppressing symptoms	Yes
M1	-	●	●		○	○	○	○	○	○	-
M2	-	-	●	-	○	-	○	○	○	○	-
M3	-	-	●	-	○	○	○	○	○	○	-
M4	-	●	-	-	-	-	○	○	-	○	-
M5	●	●	●	-	-	○	○	-	○	-	-
M6	●	●	●	●	-	-	-	-	-	-	Yes
M7	-	-	●	-	○	○	○	○	-	-	Yes
M8	●	●	●	●	-	-	-	-	○	-	Yes
M9	●	●	●	●	○	○	○	○	-	○	Yes
M10	●	-	●	●	○	○	○	○	○	○	Yes
M11	●	●	●	●	-	○	-	○	○	Suppressing symptoms	Yes
M12	●	●	●	●	-	○	-	○	-	-	Yes
M13	●	●	●	●	-	-	-	-	-	-	-
M14	-	●	●	●	○	○	-	-	-	Suppressing symptoms	Yes
M15	●	●	●	●	-	-	-	-	-	-	Yes
M16	-	●	●	●	○	-	-	-	-	-	Yes

children, with one stating, "*My elementary school teacher dragged me to the restroom and locked me in because I kept making noises. My classmates disliked me and didn't want to play with me because of my teacher.*"

A total of 13 participants had negative attitudes toward TS because of the motor and phonic symptoms. A 24-year-old woman said, "*TS is a greedy monster.*" A 34-year-old woman said being a woman with TS was more difficult: "*I'm a girl with TS. People often criticize me for not being elegant and for not behaving.*" A 23-year-old man complained, "*TS is like a barking dog. It attracts unwanted attention, and it's annoying.*"

3.4. Category 2: Support Systems with Coping Mechanisms (Resilience)

A total of 9 participants were thankful for their families' support and love. A 33-year-old man said, "*The affirmation and support from my family are very important to me. My father thinks that it's okay to have TS because I don't do bad things or steal.*" A 28-year-old man described his mother's support: "*Many people helped when I had difficulties.*

Table 3. Summary of the narrative interviews: Categories, description, and contents.

Categories	Description	Contents
Mental Health with Social Challenges • Lack of support from families • Struggling to fit into society's expectations of normal behaviors • Bullied by classmates, friends, or teachers • Negative thinking of TS	• Lack of family support as an important cause of psychological distress • Loss the harmony with the environments • Misunderstood and isolated • Pessimistic	• Parents' words hurt me. • Parents quarreled and intended to divorce because of me • I experience stigma in public. • It is difficult for me to stop tics in crowded spaces. • My teacher dragged and locked me away because I had tics. My classmates would not play with me. • To me, TS is a greedy monster or a barking dog. • My suicide ideation, my loneliness, and my being isolated by others are because of TS.
Support Systems with Coping Mechanisms • Support from family • Support from classmates, friends, or teachers • Positive thinking of TS • Professional abilities • Life goals • Good coping strategies	• Responsibility and obligation towards family and group • Understood and accepted • Optimistic • Good intellectual functioning in society • Having contributed to the society • Decreasing the misunderstanding and increasing the acceptance by others	• My parents never stopped teaching and helping me. • My teacher and classmates thought I was special and had talents. • TS is only a part of me. • TS is just like color blindness. It is only a small defect. No one is perfect. • People accept me as a famous florist. They understand TS is merely a health condition. • I have marketable language skills. • My goal is to teach children the diversity of life experiences. • My goal is to produce films about TS to communicate to society about TS. • I try to overlook my symptoms of TS and focus on other important things. • I tell others that I have TS in advance. • My friend accompanies me when I go to public places.

My mother never gave up on teaching and helping me.”

Although people with TS encountered bullying in school, 11 of them also felt included and supported by teachers and friends. A 33-year-old man said, “*My art teacher in my senior high school discovered that I was talented in art. My teacher's validation gave me a lot of motivation to keep moving forward.*” He also had friends who accepted him, as he described: “*My high school classmates thought I was special, and they didn't think of TS as a disease but as a personality trait.*”

A total of 9 participants did not have negative attitudes toward_their TS. A 36-year-old man said, “*TS is just like color blindness. It's only a small defect. No one is perfect.*” A 28-year-old man was glad to have TS: “*TS is a gift for me. I am unique and special.*” A 39-year-old florist said, “*TS is only a part of me. I can market myself with my TS.*” A 52-year-old man said, “*I have better acuity and insight because I have TS.*”

A total of 10 Participants with successful careers had a strong sense of confidence and felt satisfied with their lives. The 39-year-old florist said, “*When I became a famous florist, people accepted me because of my professional success. I introduce myself as a florist and also as a person with TS. People accept me and understand that TS is only a health condition.*”

Life goals were also crucial for 8 participants because achieving them is rewarding and generates a sense of purpose and meaning. A 33-year-old special education teacher said, “*My elementary school teacher said that I was very special, and I understood myself more (than people without TS) when I entered the field of special education.*” A 36-year-old director said, “*I directed films about TS and used them to educate society about TS and* *help everyone appreciate diversity.*" A 28-year-old English teacher stated, "*I'm a teacher, and I enjoy teaching. I hope I can give children life experiences that are different from my own and help others, just like the many people who helped me during my childhood.*"

Coping strategies are cognitive responses to threats. A total of 6 participants who had effective coping strategies felt positive about life. A 33-year-old man said, "*I never hide my motor or phonic tics. I just let them happen. But I would tell others that I had TS beforehand and explain TS to anyone who asked.*" A 36-year-old man was unbothered by the stigma attached to TS: "*Rude behavior toward me because of my TS does not affect me because the things I want to achieve are far more important than that pain.*" He also said, "*I try to overlook the symptoms of TS and focus on what I want to do.*" The 39-year-old florist said, "*I take the MRT or buses when they're less crowded. I arrive at my destinations earlier, familiarize myself with the environment, and try to eliminate factors that may trouble others before entering. I also tell others that I have TS beforehand.*" However, three interviewees indicated that they suppressed their tics and symptoms in public, which caused them stress and anxiety. This was not considered a beneficial coping strategy (Table **2**).

3.5. Support Systems Against Suicidal Ideation

People with TS and certain risk factors, such as childhood adversity, social disadvantage, and psychiatric morbidity, tend to experience suicidal ideation. Twelve of the 19 interviewees (63.2%) had experienced suicidal ideation or attempted suicide in their lifetime because of bullying from teachers and classmates or TS-related stigma during childhood. These interviewees said that support systems, such as support from family, teachers, classmates, and friends, can prevent suicidal behavior.

A 46-year-old man who had been on the verge of suicide thought of his mother and decided against suicide: "*I wanted to commit suicide once. Fortunately, I didn't follow through. I knew my death would hurt my mom. Although I'm not successful, I often tell myself that there's still hope.*"

A 34-year-old woman was thankful for her teacher's help: "*I didn't want to live, and I wanted to die on three occasions. My teacher's words saved me. He said that no one would understand my pain if I were dead and that I could do meaningful things only if I were alive.*"

Moreover, thinking of his parents' love stopped a 52-year-old man from attempting suicide, as he described: "*I actually tried to commit suicide. I tried to walk into the sea in the middle of the night. But when the water reached my waist, I stopped. I suddenly thought of all the good things happening in my life. I wasn't that miserable. I also thought of my parents, who loved me, so I decided I didn't want to die.*"

3.6. Quality of Life and Severity of Symptoms

In 2008, Cavanna *et al.* developed the GTS-QoL scale, a specialized questionnaire that measures QoL in people with TS [19]. It was first validated in adults and later in children and adolescents [20]. We performed a quantitative analysis of the GTS-QoL responses from nine interviewees, selected through purposive sampling based on a discrepancy between their satisfaction with TS and their quality of life. The goal was to determine whether GTS-QoL scores could predict the severity of TS in the daily lives of patients from Mainland China and Taiwan. The interviewees also self-assessed the severity of their TS symptoms index (S-TS-I; *mild* = 1 to *severe* = 100) and SL-I (*strongly satisfied* = 1 to *strongly dissatisfied* = 100).

Pearson Correlation was used to understand the correlation between quality of life, severity, and satisfaction with life. The Pearson Correlation of GTS-QoL (mean=76.00±25.60) and S-TS-I (mean=66.67 ± 22.36) was 0.759 with statistical significance (*p* = 0.018). However, no statistical significance was observed between SL-I (mean = 68.11 ± 16.23) and S-TS-I (r = -0.66, *p* = 0.866), or between GTS-QoL and SL-I (r = 0.193, *p* = 0.620). The GTS-QoL correlated with the self-assessment of the severity of TS. Therefore, it supported our findings that, although GTS-QoL correlated with the self-assessment of TS severity, neither GTS-QoL nor the self-assessment of TS severity correlated with self-assessment of satisfaction with life (Table **4** and Fig. **1**).

One interviewee (M10), an English teacher, was satisfied with life despite his higher GTS-QoL scores (low QoL) and higher S-TS-I scores (moderate to marked severity of self-assessed TS symptom) (Table **4** and Fig. **1**). He said a supportive factor was proficiency in English. He could use English to explain TS to his foreign friends and avoid discrimination, which made him more confident.

Table 4. Scores of GTS-QoL and self-assessments of S-TS-I and SL-I in 9 participants.

-	Scores		
	GTS-QoL (27-135) QoL (Better-Worse)	Self-assessments	
		S-TS-I (1-100) Symptom (Mild-Severe)	SL-I (1-100) Satisfaction (Yes-No)
F3	45	50	70
M9	123	80	70
M10	99	95	75
M11	47	30	85
M12	56	40	50
M13	72	90	45
M14	81	75	78
M15	70	65	50
M16	91	75	90

On the contrary, two interviewees (F3 and M11) were less satisfied with their lives even though they had lower GTS-QoL scores (better QoL) and low S-TS-I scores (mild severity of self-assessed TS symptom) (Table **4** and Fig. **1**). They described that they always hid their symptoms in public, which made them anxious.

3.7. Effects of Culture on Perceptions of TS

For some participants, Chinese culture affected their TS experience. A total of 14 participants, on their own or as a result of others' encouragement, sought herbal medicine, religious healers, or divine advice, and some exhibited fatalism (n = 10; Table **1**). Though fatalism (the propensity of individuals or groups to believe that their destinies are ruled by an unseen power or are played out inevitably rather than by their will) is mentioned in different cultures and countries [21], these experiences may differ from those of Western people with TS. Although the participants were all Chinese, their cultural beliefs and perceptions of TS differed in each area.

A 24-year-old Taiwanese woman said, "*I am very afraid of what people think of me. So, I take Western medicine to make myself normal. I suffer*

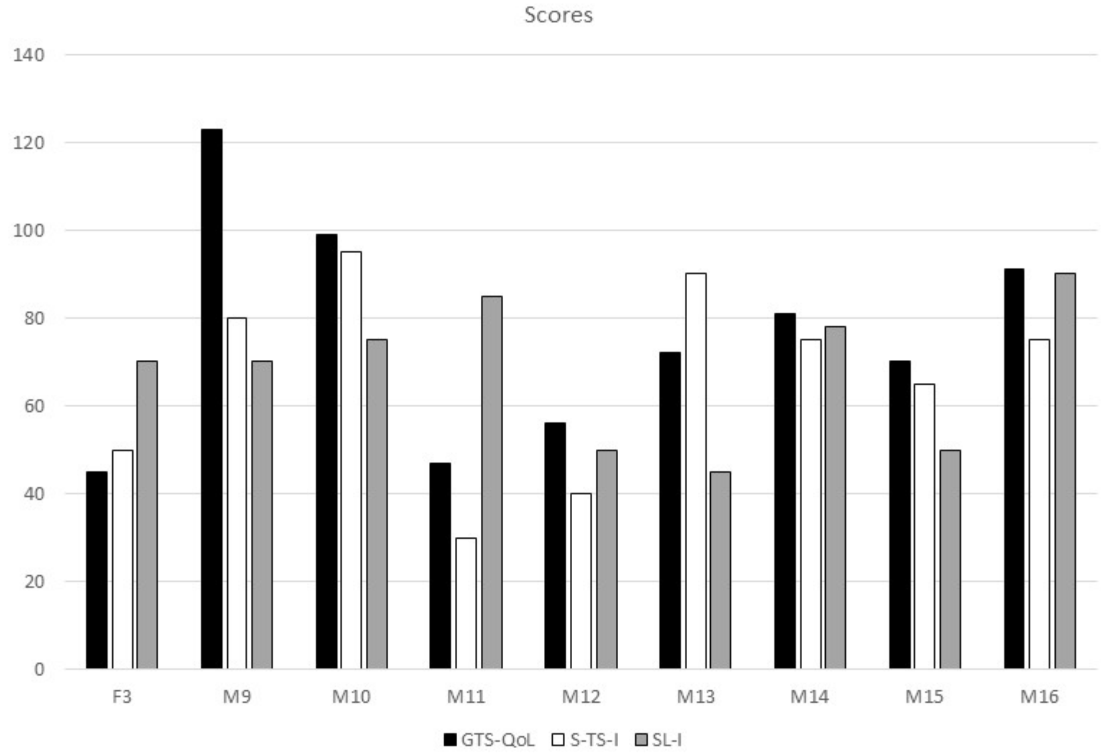

Fig. (1). Graph of scores of GTS-QoL and self-assessments of S-TS-I and SL-I in 9 participants with TS. (*A higher resolution / colour version of this figure is available in the electronic copy of the article*).

from the side effects of the medicine, which makes me very uncomfortable."

A young man from Taiwan said, "*In Taiwan, there is sympathy (toward people with TS), but not empathy. People in Taiwan are different from people in the United States. Americans have empathy, although they may not pay attention to you. When I rode buses in the United States, they would look at me once, and they would not stare at me or talk about my symptoms. That's good for people with TS. We feel at ease when people pay less attention to us*."

A 36-year-old man from China was thankful to his parents, "*Fortunately, my parents figured out that the medicine was not good. They maintained a positive and optimistic attitude about the future. They always put themselves in my shoes and tried to understand and listen to me*."

A young man from China complained, "*In China, there are still many people who are ignorant about TS. My years in school were full of conflict. The teachers treated me like a freak. They said I was hopeless. No one really understood what I went through*."

A young woman from China worried about her marriage: "*TS affects marriages. Almost 90% of people with severe TS I know are not married. I am a woman with TS. Women with TS have more problems in marriage because Chinese women are required to be elegant and gentle; they should behave and meet social expectations. My boyfriend's mother does not like me*."

A young man from Hong Kong shared a negative experience: "*My family moved three times because I made a lot of noise because of TS. The neighbors couldn't tolerate my noise, partly because their houses were narrow and very close to ours, and our Chinese neighbors thought I couldn't live up to the standards of society*."

4. DISCUSSION

The interviews revealed two prominent categories, "Mental Health with Social Challenges" and "Support Systems with Coping Mechanisms", regarding how Chinese people with TS understand, are affected by, and cope with TS. Although most interviewees had experienced suicide ideation and were less satisfied with their lives than people without TS, having supportive systems may have helped them feel better, gave them the courage to address TS-related problems in their lives, and contributed to their resilience. This information is important for the care providers, especially nurses, to manage the Chinese clients of TS.

Resilience involves the interplay of risk and protective factors. It pertains to the maintenance of stability in the face of adversity and challenging situations [22]. People with TS often encounter adversity because of their motor and vocal tics, other symptoms, comorbidities, and coexisting psychopathologies. Close relationships with caring parental figures within the family are essential for resilience in children and adolescents who experience adversity. Healthy family functioning, including family cohesion (a supportive factor presented in Table **2**), was independently associated with lower depressive symptoms, regardless of life events, illustrating a compensatory effect [23].This is true for Chinese children and adolescents with TS. The interviewees who were satisfied with their lives had strong relationships with and were supported by their families. Those who did not have support from their families (a challenging factor presented in Table **2**) were less satisfied with their lives.

In addition to family support, supportive factors of resilience include social competence with peers and teachers, high self-esteem, good intellectual functioning, positive thinking [22], and a sense of purpose. Interviewees who had support from classmates, friends, or teachers, positive thinking regarding TS, professional skills, life goals, and coping strategies (Table **2**) were more satisfied with their lives, which supports the findings of the literature. Support systems can also help prevent suicidal ideation among individuals with Tourette Syndrome (TS). Despite having mild TS symptoms, F3 and M1 experienced lower mood, as assessed using the GTS-QoL, S-TS-I, and SL-1 scales to explore potential correlations. Our findings revealed that life satisfaction was not correlated with the severity of Tourette Syndrome. We also found that enhancing "Support Systems with Coping Mechanisms" could help reduce stress in TS patients. This was the key contribution of our quantitative study.

Family is a central aspect of Confucianism, which is based on the principles of the good life, loyalty, respect for older people and family, and harmony and altruism [24]. Family support is also a crucial protective factor contributing to the resilience of Chinese people with TS. Chinese people often hold a sense of responsibility and obligation toward their family and group [25]. Confucian thought regards the lack of family support as a major cause of psychological distress [25].

In Chinese societies, to be a person is to fit external behavior to the interpersonal standards of society and culture [25]. Motor and phonic tics that occur in public are regarded as improper conduct that violates social standards [26]. Stigma resulting from misunderstanding can influence how Chinese individuals view psychological distress. For example, Hong Kong Chinese reported significantly higher levels of stigma toward mental illness and perceived barriers to help-seeking compared to Chinese Americans, who, in turn, exhibited significantly higher levels than European Americans [27]. This highlights the need for public education about TS in Chinese societies.

In Chinese communities, when someone is mentally ill, family plays a key role in coping and assistance. In a model of the typical stages of how Chinese families interact with family members with mental illness, first, when a family member is mentally ill, the family attempts to reverse the abnormal behavior. Then, the family invites outside specialists, such as herbalists, physicians, or religious healers to treat the mental illness [28]. The family may relinquish hope and reconcile with the fate of having a member with a mental illness [29]. Since mental illness is often perceived as hereditary and indicative of ancestral misconduct, both the afflicted individual and their siblings may be deemed unfit for marriage and childbearing. Caregivers, particularly nurses, expressing empathy to patients and their siblings in a culturally sensitive manner should first understand how traditional cultural values inform their attitudes [25].

In Taiwan, people with TS experience sympathy but lack empathy, leading some to rely on Western medicine, which causes discomfort due to side effects. In China, TS is heavily stigmatized, especially in schools where individuals are treated as outcasts. However, some families provide support, showing understanding and optimism. Chinese women with TS face additional challenges in marriage due to societal expectations of elegance, with many unable to marry. In Hong Kong, TS sufferers face intolerance from neighbors, leading to multiple relocations due to the noise caused by their symptoms. These experiences reflect cultural tensions between societal norms and acceptance of TS.

Chinese culture varies across communities. It is constantly changing despite the common belief that it has been unchanged for thousands of years. It changes over time and through contact with outside influence. Eliminating challenging factors and strengthening supportive factors may help people with TS in their daily lives. Healthy family functioning and public education about TS are crucial for the well-being of Chinese individuals with TS. School-based interventions that promote positive attitudes toward TS can help children with the condition embrace their identity [30]. In addition, positive thinking, good coping strategies, professional achievement, and life goals are useful factors that strengthen resilience in people with TS.

Beyond cultural influences, the severity of TS did not correlate with satisfaction with TS, particularly among individuals with stronger support systems and coping mechanisms, such as self-esteem, perceived social support, and job satisfaction. This pattern held true in Chinese individuals as well [31]. These findings align with our results, suggesting that protective factors enhance resilience against negative perceptions of TS, which may be influenced by chance elements.

CONCLUSION

This study highlights the adverse experiences and resilience of Chinese patients with Tourette Syndrome (TS), offering valuable insights for parents, educators, and healthcare professionals. It identifies several factors contributing to resilience amidst the challenges faced by individuals with TS. However, the research is limited by its focus on Chinese patients, which restricts the generalizability of findings to other cultural contexts. Future research could explore cross-cultural comparisons between Chinese and non-Chinese populations, as well as investigate the experiences of Chinese families living in Western countries. Additionally, further studies should consider the perspectives of individuals with TS on resilience to inform educational interventions, which can help healthcare providers mitigate stress and improve the quality of life for patients with TS.

RELEVANCE TO CLINICAL PRACTICE

In addition to eliminating negative challenging factors, protective and supportive factors should be cultivated to increase adaptability for those with TS. From a policy perspective, the findings suggest that awareness of TS and its effects on QoL in society and clinical nursing practice should be increased.

STUDY IMPLICATIONS

The study underscores the importance of addressing both the challenging factors and supportive factors that impact the well-being of adults with Tourette Syndrome (TS). It highlights the need for healthcare professionals to focus not only on the clinical severity of TS but also on the psychosocial aspects, such as family support, social adaptation, and mental health challenges, which are often overlooked in clinical practice. The findings suggest that strengthening support systems and promoting positive coping mechanisms can significantly improve life satisfaction in individuals with TS. Culturally tailored interventions, considering the differences in perceptions and beliefs about TS across regions, are essential for effective care. These insights can inform policy and healthcare resource allocation, guiding the development of more holistic, individualized treatment strategies that address both the psychological and social needs of adults with TS.

LIMITATION

The experiences of people with TS vary by cultural, social, economic, and other conditions. The respondents in this study constituted only a small and potentially unrepresentative sample of Chinese people with TS. Since we found satisfaction with life did not correlate with GTS-QoL or self-assessment of TS severity in purposive sampling, more studies of mixed qualitative and quantitative research are warranted.

AUTHORS' CONTRIBUTIONS

It is hereby acknowledged that all authors have accepted responsibility for the manuscript's content and consented to its submission. They have meticulously reviewed all results and unanimously approved the final version of the manuscript.

LIST OF ABBREVIATIONS

GTS-QoL = Gilles de la Tourette Syndrome - Quality of Life

S-TS-I = Self-assessment of Severity of TS Symptom Index

SL-I = Self-assessment of Satisfaction with Life Index

TS = Tourette Syndrome

YGTSS = Yale Global Tic Severity Scale (YGTSS)

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

The Ethics Committee of Taipei Hospital, Ministry of Health and Welfare, New Taipei, Taiwan approved the study (TH-IRB-0022-0009).

HUMAN AND ANIMAL RIGHTS

All study procedures were performed in accordance with the ethical standards of the Ethics Committee of Taipei Hospital, Ministry of Health and Welfare, and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

CONSENT FOR PUBLICATION

Written informed consent was obtained from all participants of this study.

AVAILABILITY OF DATA AND MATERIALS

The data and supportive information are available within the article.

STANDARDS OF REPORTING

COREQ guidelines were followed.

FUNDING

None.

CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

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SUPPLEMENTARY MATERIAL

Supplementary material is available on the publisher's website along with the published article.

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