

Abstract

Objective: Individuals with Tourette Syndrome (TS) typically experience its onset in childhood, and the adverse experiences from that period can influence their mental health in adulthood. Despite this, the social struggles of adults with TS often go unrecognized in clinical nursing practice.

Methods: The primary objective of this research was to explore the impact of TS on quality of life and satisfaction, as well as to assess the severity of symptoms experienced by individuals. By using a combination of qualitative interviews and quantitative scales, the study provided a well-rounded understanding of how TS affects daily living, personal well-being, and the overall quality of life for those with moderate-to-severe symptoms.

Results: Our analysis revealed ten resilience factors, divided into two broad categories: risk and protective factors. The risk factors comprised a lack of familial support, difficulties in adjusting to societal norms, bullying from peers, friends, or educators, and negative self-perceptions regarding TS. In contrast, protective factors included familial, teacher, and peer support, positive perspectives on TS, professional interventions, personal aspirations, and effective coping mechanisms. Adults with TS who exhibited a greater number of protective factors than risk factors demonstrated higher levels of life satisfaction. The GTS-QoL showed a correlation with S-TS-I (TS severity) but not with SL-I (TS satisfaction). Additionally, cultural beliefs and perspectives on TS varied depending on geographic location.

Conclusion: The understanding, impact, and coping mechanisms of Chinese individuals with TS were found to be influenced by two main factors: risk and protective elements.

Keywords:

Traditional Chinese medicine;
Hepatocellular carcinoma;
Bibliometric analysis.

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A qualitative investigation of adverse experiences and resilience in Chinese adults with Tourette syndrome

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Introduction

Tourette Syndrome (TS) is a long-term neurological disorder where people have multiple motor tics and at least one vocal tic for over a year. Symptoms usually start between ages 5 and 8, with the most severe tics appearing around ages 10-12 [1]. Children with TS often face more bullying than their peers [2], which lowers their quality of life [3].

Even though TS starts in childhood, it continues to affect people into adulthood. The condition is found in 0.4% to 5.0% of children worldwide [4]. In the U.S., 0.4%-0.8% of children have TS [5], while in Taiwan, the prevalence is 0.56% [6]. Studies report a 0.4% prevalence among lower-middle-class children in Hong Kong [7] and a 2.46% rate of tic disorders in Mainland China [8].

TS is more common in boys. Among children aged 4-6, boys are four times more likely to have TS than girls [9]. The male-to-female risk ratio in Taiwan is 3.65 [10], while in Mainland China, it is 1.51 for tic disorders and 2.45 for TS [11].

In addition, TS is often linked to other mental health conditions, making it more complex. About 85.7% of people with TS have at least one psychiatric disorder, and 57.7% have two or more [12]. OCD and ADHD are found in 72.1% of cases, while about 30% of people with TS also experience mood, anxiety, or behavior disorders [12].

Materials and procedure

In this research, we utilized a mixed-methods approach, incorporating both qualitative data (interviews) and quantitative analysis (three quantitative scales). This design was chosen to offset the limitations of each method, expand the depth of the results, and provide a holistic perspective.

Ethical considerations

The Ethics Committee of Taipei Hospital, Ministry of Health and Welfare approved the study. 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.

Results

Our study included five participants: two from Taiwan, one from Hong Kong, and two from Mainland China. The sample comprised three men and two women. Four had comorbid OCD or ADHD, while one had only TS.

We identified ten key factors from the interviews, categorizing them as risk factors (adverse experiences) or protective factors (enhancing resilience). Risk factors included lack of family support, difficulty conforming to social norms, bullying, and negative views of TS. Protective factors involved support from family, teachers, and friends, positive attitudes toward TS, professional guidance, life goals, and coping strategies. summarizes these factors with representative quotes.

People with TS, particularly those exposed to childhood adversity, social disadvantage, or psychiatric conditions, are at higher risk of suicidal ideation. In our study, 63.2% of the reported experiencing suicidal thoughts or attempts due to childhood bullying and TS-related stigma. However, they highlighted that support from family, teachers, classmates, and friends serves as a protective factor against suicidal behaviour.

Discussion

Through the interviews, we identified two key factors influencing how Chinese individuals with TS understand and navigate their condition: risk factors and protective factors. Many interviewees described struggling with suicidal ideation and feeling less satisfied with their lives than those without TS. However, those who had protective factors—such as family and social support—reported feeling more optimistic, better equipped to handle TS-related challenges, and more resilient. This underscores the importance of protective factors in shaping well-being and highlights critical insights for healthcare providers, especially nurses, in managing TS among Chinese clients.

Resilience is built through the balance between risk and protective factors. It allows individuals to maintain emotional and psychological stability even in difficult circumstances. People with TS frequently encounter hardships due to their tics, comorbidities, and other psychological challenges. Among children and adolescents facing adversity, a close bond with caring parental figures is crucial for resilience. Research has shown that strong family cohesion can help reduce depressive symptoms, regardless of external stressors, demonstrating a compensatory effect. This finding holds true for Chinese children and adolescents with TS. Interviewees who expressed satisfaction with their lives tended to have strong family support, while those who lacked such support reported lower life satisfaction.

Conclusion

Our study highlights the challenges and resilience of Chinese individuals with TS, offering insights for parents, educators, and nursing professionals. Strengthening protective factors can help counteract the negative effects of risk factors, promoting resilience. Additionally, these findings may support cross-cultural comparisons of TS experiences between Chinese and non-Chinese populations or among Chinese families living in Western countries. Incorporating the perspectives of individuals with TS into educational interventions can help healthcare providers manage stress and improve the Quality of Life (QoL) for those affected.

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