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Living with tics: Nursing care of pediatric tourette syndrome



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ABSTRACT

Tourette syndrome (TS) is a neurodevelopmental movement characterized by abrupt, rapid, repetitive, and non-rhythmic tics. While TS is not life-threatening, such tics and comorbidities affect a children's physical and mental health and social interactions. Treatment is necessary when the children experience physical discomfort, functional dysfunction, and poor interpersonal interaction and mental health. Common management strategies for TS include psychological interventions and pharmacological treatment. Additionally, it is important to consider the individual needs of youths with TS and reassess the treatment outcomes and the need to receive continuous treatment regularly. This review summarizes the symptom management and nursing care measures for youths with TS. Understanding and listening to the healthcare problems of youths with TS can help providers develop healthcare interventions tailored to the youths' needs. Providing the youths with strategies to reduce the tics' interference with their learning outcomes and helping them develop strategies to cope with diverse interpersonal interactions at school are also important. Further, enhancing acceptance given by parents, teachers, and peers, as well as improving the general public's understanding of TS are important measures that promote the youths' social adjustment as well as their ability to coexist with TS.

Tourette syndrome (TS) is a neurodevelopmental movement disorder that onsets usually when a child is of school age. It is characterized by abrupt, quick, repetitive, and non-rhythmic motor and phonic tics [1,2]. The four diagnostic criteria for TS are: (1) The presence of both multiple motor tics and one or

more phonic tics, which do not necessarily occur concurrently; (2) the tics may wax and wane in frequency but have persisted for more than 1 year since first tic onset; (3) displaying tics before 18 years of age, and (4) having such impairments that are not caused by the use of a single substance

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or typical medical conditions [1]. One meta-analysis estimated that 0.52% of children between the age of 4 and 18 have TS [3]. The frequency, intensity, and complexity of tics are associated with a patient's surroundings. Although tics can be suppressed temporarily, they may rebound and lead to more frequent bouts of tics [4].

A scoping review highlighted that patients experience more frequent bouts of tics when they consume caffeinated foods or refined sugars. However, there is no evidence that taking supplements can help control tics [5]. 70% of parents of youths with TS reported that fatigue and major transitions exacerbate their children's tics [6]. In addition to tics, some children with TS also experience concomitant psychiatric comorbidities, such as attention-deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder/behaviors (OCD/B), learning difficulties, and depression. These conditions all affect the quality of life, self-esteem, academic performance, and social adjustment of youths with TS [7-9]. To date, the pathogenesis of TS remains unclear. It is suspected that TS is associated with excessively strong postsynaptic dopamine reactions [4]. TS reaches peak severity between 11 and 14 years of age, and 70%-80% of patients perceived that their tics decreased significantly in their late teens. However, tics may not be eliminated fully [10]. Although TS does not affect a patient's physical health significantly or threaten his/her life, tics that wax and wane interfere with a child's livelihood, family relationships, and peer interactions, as well as increase problems in social interactions [7,8,11,12].

Management of TS

Based upon parent-reported data, parents notice the presence of tics in their children typically at a mean age of 6.3 years, while they seek medical treatment for their children at a mean age of 7.1 years, and the mean age of TS diagnosis is 7.7 years [6]. These figures attest to parents' experiences of the TS diagnosis as a long and difficult process [13-15]. The Yale Global Tic Severity Scale (YGTSS) is among the common instruments used to evaluate the tic severity of patients with TS [16]. In addition to assessing the frequency, intensity, number, complexity, and interference of a patient's motor and phonic tics, the YGTSS also includes an overall impairment rating that assesses the patient's interpersonal, academic and occupational domains, with a higher score indicating a higher tics severity [16]. A systematic review pointed out that the YGTSS is currently the most comprehensive, reliable, and valid evaluation instrument, and is the only scale in which scores have cut-off values that indicate a patient's changes in clinically relevant exacerbations or treatment responses. However, the YGTSS requires a longer evaluation time and may not be suitable for preoccupied clinical professionals. Against this backdrop, experts recommend the use of more rapid scales in which not all dimensions of tic severity are necessarily evaluated, such as the TS-Clinical Global Impression and the Shapiro TS Severity Scale [17].

Regardless of the severity, when tics appear in children and youths, measures such as observations or watchful waiting can be taken temporarily in lieu of immediate treatment [18,19]. Treatment is necessary when the patient experiences

physical discomfort (pain or injury), difficulty in interpersonal interaction, poor mental health (depression or negative emotions), as well as functional impairment (poorer academic performance) triggered by tics [18]. Treatment methods for TS include pharmacological and non-pharmacological interventions. The former controls tics through antipsychotics such as pimozide and aripiprazole. It is necessary to monitor these drugs' side effects, such as motor impairment, hypersomnia, and endocrine dysfunction, concurrently [19]. The latter includes common measures such as psychoeducation, behavioral therapies, and exercise therapies. Psychoeducation provides youths with TS not only the mental support they need and improves their sleep quality and interpersonal interaction, but also enables their parents and teachers to understand TS and develop strategies to manage tics [19,20]. According to the clinical consensus attained in the latest version of the European clinical guidelines for TS, psychoeducation is recommended as an initial intervention in spite of the patient's tics severity. Further, if standalone psychoeducation is inadequate for the patient, habit reversal therapy (HRT) and comprehensive behavioral intervention for tics (CBIT) can be employed as first-line interventions in tics disorder management [21]. Other studies have demonstrated significant reductions in tics frequency through physical activity or exercise [22,23]. A systematic review pointed out that there is some empirical evidence on the effectiveness of physical exercise for reducing tics severity in short periods. Few studies also highlighted the feasibility of physical exercise for treating TS comorbidities such as anxiety. However, the effectiveness of physical exercise demonstrated in these studies were not derived from well-designed randomized controlled trials, which calls the need for rigorous and robust methodologies in the future [24]. Therefore, it is recommended strongly that healthcare providers consider the individual needs of youths with TS when they administer relevant treatment measures, as well as evaluate the patients' need to receive continuous treatment regularly [19].

Nursing care and symptom management of youths with TS

Understanding the care needs of youths with TS and their families

TS typically onsets when children are of school-age. Parents play an important role not only in helping their children manage their symptoms, but also must endure numerous care-related challenges and stress [15,25], such as the difficulty diagnosing TS [13—15], developing the ability to manage their children's tics and comorbidities, the lack of experience in educating youths with TS, and addressing their children's academic problems and peer conflicts in school [14,15,25]. In comparison with the parents of typical children, 40% of parents of youths with TS expressed that their children suffered from rejection on the part of their peers at school [26]. Many parents of youths with TS also experienced a lack of understanding of TS and social support on the part of the general public [14,15]. The main stressor that affects the interaction between youths with TS and their parents is child care

difficulty, which is correlated positively with tic severity. Providing more social support to these parents can help reduce their parenting stress [27]. Nonetheless, some youths with TS are susceptible to emotional outbursts that are difficult to control, which strains their relationships with their parents and siblings [14]. Parents of youths with TS who also suffer from ADHD or OCD perceived greater caregiver stress as well. This high level of stress concomitantly increases the parents' anxiety and depression [28]. In comparison with parents of children with asthma, parents of children with TS have a greater caregiver burden [29].

Parents expect healthcare providers to provide opportunities for them to learn caregiving techniques in response to TS's effects on their children and themselves [21,30]. Several studies have also shown that when parents seek assistance from, or communicate with, healthcare providers, they are often unable to receive desirable responses and care services, which leads to their perception that healthcare providers lack professionalism in TS-related knowledge and treatment [13-15,25,30]. A mixed-methods study on British youths with TS and their parents with respect to TS treatment revealed that the youths perceived that pharmacological and behavioral interventions have limited effectiveness. To them, eliminating and reducing tics, as well as managing the urge to tic, are desired outcomes of treatment, and they also expect healthcare providers to help them manage the emotional problems attributable to tics. Both the youths and their parents also perceived the importance of strengthening the control of tics and reducing anxiety-related symptoms [15]. Therefore, it is suggested that healthcare providers evaluate and understand the care-related needs and opinions of youths with TS and their parents first, and then provide patient education and instruction by using non-medical jargon to improve communication and ensure that the educational measures match the patients' needs more closely.

In a qualitative study, Taiwanese youths with TS perceived that pharmacological interventions only reduced their tics, but did not eliminate them. They also had low self-esteem because their tics hindered their interactions with their peers. Therefore, it is suggested that healthcare providers help youths with TS increase their knowledge about TS and its comorbidities, and strengthen their self-control of, and selfesteem in, their disease through self-assessments and records about the associations between their physical self, tics, and life situations (including events and interpersonal interactions) [7]. Several studies have noted that healthcare providers can help improve the abilities of youths with TS and their parents to recognize symptoms, discuss the coping strategies jointly, and develop interventions that actually support the parents in raising their children. Taken together, these measures enhance the parents' capacity and competence in giving care to children with TS [2,9,31].

Coping with and integrating into school life: academic performance and peer relationships

Previous studies have demonstrated that children and youths with TS often encounter a panoply of problems related to school life [7,11,32]. Tics, which wax and wane, have direct and indirect effects on a child's academic performance, and

severe tics can lead to fatigue and chronic pain [32]. Tic occurrence becomes more frequent when a child perceives a higher level of academic stress in the classroom [7,8]. Frequently occurring phonic and motor tics interrupt the flow of speech and conversation in youths with TS, as well as cause difficulties in reading and completing assignments [11,33]. Furthermore, the comorbidities of TS are among the factors that contribute to a child's unsatisfactory learning outcomes and academic performance. Compared to children with ADHD, children with both TS and ADHD experience more handwriting problems [34]. Certain school-related factors, such as fixed examination dates, the first day of school, and the need to keep quiet in a library also exacerbate tics [35]. In addition, youths with TS experience attention and stigma directed toward them by their peers in the classroom. Therefore, they invest considerable effort to suppress their tics, which consequently reduces their classroom attentiveness and academic performance [7,8,11,33]. According to a qualitative study, youths with TS not only endure skepticism and taunts from their tic-free peers in the classroom, but also experience the feeling of helplessness when they are unable to acquire assistance from their teachers. As a consequence, they find it extremely difficult to adapt to school life [8]. Compared with typical children, it is more challenging for youths with TS to cope with their emotional issues, poor attentiveness, and peer relationships [36]. These youths are also subjected to the mockery and mimicry of their tics by their tic-free peers, and thus develop a feeling of peer rejection, and choose to undergo social isolation as a way to avoid these peers [37]. To prevent their tic-free peers from viewing them as abnormal, youths with TS would suppress or conceal their tics purposely. Yet, they would always have the urge to express their tics, which results in feelings of physical discomfort and insecurity. Some youths with TS expressed that they have considered disclosing their diagnosis to their tic-free peers, but feared that they would be misunderstood or receive excessive concern, and therefore have to deal with the dilemma of either expressing or suppressing their tics

A majority of tic-free youths in the classroom would perceive that youths with TS are more aggressive and less welcoming than typical peers [39]. To them, youths with TS are emotionally negative and socially withdrawn, have poor interpersonal relationships, and are more likely to clash with their peers [40]. However, several studies have highlighted the importance of peers' friendliness and positivity toward youths with TS. One cross-sectional study indicated that 55% of tic-free peers expressed that they were willing to tolerate the inappropriate disease-related behaviors youths with TS display, 56% expressed that they were willing to befriend these youths, and 83% acknowledged that educating teachers and classmates about the symptoms and behavioral difficulties of TS is useful for them to help these youths manage TS-derived problems [41]. Peers are significant others who are willing to accept and support youths with TS, and are an important source of motivation for youths with TS to develop the courage to accept themselves [7]. Some studies have demonstrated that educating teachers and tic-free peers about TS can help them adopt a positive attitude when interacting with youths with TS [7,42]. Teachers educate

students about TS commonly through educational videos or films about the disease. Although this approach allows students to acquire an understanding of TS, it is suggested that teachers should encourage students to discuss the positive implications of the video/film contents to avoid misperceptions and negative opinions about TS [11].

Tics are indeed among the primary factors that affect the school life of children with TS. Teachers play a key role in helping tics-free peers accept youths with TS [7,9]. Although some teachers would offer assistance to youths with TS purposely to improve their academic performance, they seldom evaluate the effectiveness of these measures. For instance, they ask a child to leave the classroom with their tics become frequent. This action prompts the child to feel isolated and causes them to miss lessons, which affects their learning outcomes thereby [43]. Therefore, teachers or tutors must respect and accept the personalities of youths with TS. They must also be a good listener, and assess the feelings of these youths, as well as the situations they face and the severity of the tics and comorbidities' effects on their learning. Moreover, teachers and parents should discuss whether to disclose a child's TS diagnosis to their peers while respecting the child's consent and willingness [11,44]. Educating school teachers and staff about TS can help youths with TS manage their tics while learning, and also receive the mental and social support they need. The aforementioned measures are all salient management strategies that also enable teachers to maintain a positive attitude when they help youths with TS overcome their learning and interpersonal problems [8,19]. Some studies have highlighted several strategies to prevent tic symptoms from interrupting a patient's classroom learning, such as switching to other alternatives (typing or dictation) when frequent tics affect a child's handwriting skills, reducing homework load, as well as offering flexibility in submitting assignments. They can also discuss with youths with TS the need to provide a personal examination hall, or prolong or waive examinations' duration to help reduce stress. Providing a secure environment allows youths with TS to express their tic symptoms freely, and thus achieves stress relief [8,45]. In addition, teachers can discuss with these youths and their parents measures to prevent misunderstandings or punishments caused by frequent tics. At the same time, behavioral problems in children with TS should be managed appropriately to promote desirable learning outcomes at school [7,8,32].

Furthermore, it is extremely important for healthcare providers, teachers, and parents to learn about the characteristics of the psychosocial development of youths with TS. School-age children shift their focus from family life to school life gradually, and emphasize completing assignments and achieving good academic performance, as poor grades often reduce their self-esteem [46]. As youths with TS grow up, they shift their focus to peers in their teenage years, and develop their own autonomy and competence as well as strategies to help overcome TS's interference in their learning and interpersonal relationship [7,11]. In addition, parents' and teachers' understanding of TS is also important, as it affects their attitudes when educating their children/students about symptom management [31]. Therefore, parents and teachers must have a comprehensive understanding of TS and its characteristics

and should avoid using an authoritative attitude and demanding tic control or suppression. Instead, parents and teachers must respect and listen to the opinions of youths with TS, and trust them to be able to manage their interpersonal interactions and tic-derived problems, thereby facilitating effective communication [11,31].

Enhancing social adjustment and coexisting with TS

While tics can be suppressed temporarily, their unexpected nature and waxing and waning in daily life affect the social interactions of youths with TS adversely. A patient's uncommon or inappropriate tics, as well as the potential social stigma and pitifulness would make them feel abnormal [12,38,47-50]. Both Eastern and Western societies in general still misinterpret and ostracize those with TS. Tics are regarded as demonic possessions, which exacerbate the isolation and withdrawal of youths with TS in their social interactions [49,51]. In Taiwan, expressing tics are known as "dea-gau" which literally means that a child is purposely being mischievous like a monkey [51]. Based upon others' unfriendly responses, youths with TS become aware that most people do not accept their physical appearance. Thus, to conform to social expectations as a normal person on the exterior, they choose to suppress their tics when in public or when interacting with strangers, and thereby avoid drawing unnecessary attention to themselves [11,49,50]. Youths with TS perceive that the misperceptions of TS on the part of teachers, peers, or the general public result in stigmatization, social maladjustment, and discrimination [9]. Compared with their tic-free peers, youth with TS reported poorer social adjustment [39] and lower self-esteem [39,52]. It is inferred that these feelings experienced by the youths are associated with the mimicry of seemingly abnormal tics or taunts from their peers [7,11], as well as poorer interactions with their peers [39,52].

A cross-sectional study found that youths with TS with lower self-esteem have poorer social adjustment. Youths with TS with comorbidities also have significantly poorer selfreport than those without comorbidities. Therefore, comorbidities are a moderating variable between self-esteem and social adjustment. Compared to youths with TS with comorbidities, strengthening the self-esteem of those without comorbidities is an effective intervention that promotes their social adjustment [53]. Indeed, receiving the support of their parents and friends is key for youths with TS to develop good interpersonal relationships and better social adjustment [7,11,54]. It is suggested that healthcare providers, teachers, and school staff employ the social adjustment scale for adolescents with TS (SASATS) to evaluate the social interaction and self-adjustment status of youths with TS. The SASATS consists of for dimensions (relationship between self and TS, academic performance, family relationship, and peer interaction). Early screening and detection of social maladjustment among youths with TS can help provide further assistance or referral for treatment [55]. Previous studies have mentioned that children and youths worry that TS would become a barrier in their employment prospects [9,12,38] and romantic developments [7]. A qualitative study revealed that some adolescents perceived TS as an obstacle and source of suffering in their growth. Yet, a positive attitude is a stepping stone that allows them to become braver and more mature [11]. The acceptance and concern given by parents, teachers, and friends are motivating forces that help children and youths with TS accept and live with their illness, strengthen their personal advantage, and find success in life [2,7,9,11,51]. Healthcare providers can also provide relevant information to educate the general public about TS, thereby reducing the stigmatization of TS attributable to their ignorance or misunderstanding of tics. Furthermore, establishing a patient support network allows youths with TS and their family to receive better social support.

Summary

While TS is not life-threatening, tics and comorbidities affect a patient's physical and mental health, family relationships, school life, and social interactions. Common strategies to manage TS include psychological interventions and pharmacological treatment. Meanwhile, it is essential to consider the individualized needs of youths with TS and reassess the treatment outcomes regularly. Understanding and listening to the experiences and feelings of youths with TS can help healthcare providers develop health care interventions tailored to the youths' care needs. Providing the youths with strategies to reduce the interference of tics in their learning outcomes and discussing ways to develop strategies to cope with diverse interpersonal interactions at school are also important. Furthermore, enhancing the level of acceptance and concern given by parents, teachers, and peers, as well as providing more information about TS to the general public can help improve social acceptance of TS. All of these measures promote the social adjustment of youths as well as their ability to live with TS.

Conflicts of interest

No conflict of interest has been declared by the author.

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REFERENCES

- [1] American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Arlington, VA: American Psychiatric Association; 2013.
- [2] Leckman JF, King RA, Bloch MH. Clinical features of tourette syndrome and tic disorders. J Obsess-Compuls Rel 2014;3:372–9.
- [3] Scharf JM, Miller LL, Gauvin CA, Alabiso J, Mathews CA, Ben-Shlomo Y. Population prevalence of Tourette syndrome: a systematic review and meta-analysis. Mov Disord 2015;30:221–8.

- [4] Gloor FT, Walitza S. Tic disorders and tourette syndrome: current concepts of etiology and treatment in children and adolescents. Neuropediatrics 2016;47:84–96.
- [5] Ludlow AK, Rogers SL. Understanding the impact of diet and nutrition on symptoms of Tourette syndrome: a scoping review. J Child Health Care 2018;22:68–83.
- [6] Wolicki SB, Bitsko RH, Danielson ML, Holbrook JR, Zablotsky B, Walkup JT, et al. Children with tourette syndrome in the United States: parent-reported diagnosis, Co-occurring disorders, severity, and influence of activities on tics. J Dev Behav Pediatr 2019;40:407–14.
- [7] Lee MY, Mu PF, Wang WS, Wang HS. 'Living with tics': self-experience of adolescents with Tourette syndrome during peer interaction. J Clin Nurs 2016;25:463–71.
- [8] Wadman R, Glazebrook C, Beer C, Jackson GM. Difficulties experienced by young people with Tourette syndrome in secondary school: a mixed methods description of self, parent and staff perspectives. BMC Psychiatr 2016;16:14.
- [9] Eapen V, Cavanna AE, Robertson MM. Comorbidities, social impact, and quality of life in tourette syndrome. Front Psychiatr 2016;7:97.
- [10] Hassan N, Cavanna AE. The prognosis of Tourette syndrome: implications for clinical practice. Funct Neurol 2012;27:23–7.
- [11] Lee MY, Wang HS, Chen CJ, Lee MH. Social adjustment experiences of adolescents with Tourette syndrome. J Clin Nurs 2019;28:279—88.
- [12] Smith H, Fox JRE, Trayner P. The lived experiences of individuals with Tourette syndrome or tic disorders: a metasynthesis of qualitative studies. Br J Psychol 2015;106:609–34.
- [13] Rivera-Navarro J, Cubo E, Almazán J. The diagnosis of Tourette's Syndrome: communication and impact. Clin Child Psychol Psychiatr 2009;14:13—23.
- [14] O'Hare D, Eapen V, Grove R, Helmes E, McBain K, Reece J. Youth with Tourette syndrome: parental perceptions and experiences in the Australian context. Aust J Psychol 2017;69:48–57.
- [15] Cuenca J, Glazebrook C, Kendall T, Hedderly T, Heyman I, Jackson G, et al. Perceptions of treatment for tics among young people with Tourette syndrome and their parents: a mixed methods study. BMC Psychiatr 2015;15:46.
- [16] Leckman JF, Riddle MA, Hardin MT, Ort SI, Swartz KL, Stevenson J, et al. The Yale Global Tic Severity Scale: initial testing of a clinician-rated scale of tic severity. J Am Acad Child Psychiatr 1989;28:566–73.
- [17] Martino D, Pringsheim TM, Cavanna AE, Colosimo C, Hartmann A, Leckman JF, et al. Systematic review of severity scales and screening instruments for tics: critique and recommendations. Mov Disord 2017;32:467–73.
- [18] Roessner V, Plessen KJ, Rothenberger A, Ludolph AG, Rizzo R, Skov L, et al. European clinical guidelines for Tourette syndrome and other tic disorders. Part II: pharmacological treatment. Eur Child Adolesc Psychiatr 2011;20:173–96.
- [19] Pringsheim T, Okun MS, Müller-Vahl K, Martino D, Jankovic J, Cavanna AE, et al. Practice guideline recommendations summary: treatment of tics in people with Tourette syndrome and chronic tic disorders. Neurology 2019;92:896–906.
- [20] Verdellen C, van de Griendt J, Hartmann A, Murphy T. European clinical guidelines for Tourette syndrome and other tic disorders. Part III: behavioural and psychosocial interventions. Eur Child Adolesc Psychiatr 2011;20:197–207.
- [21] Andrén P, Jakubovski E, Murphy TL, Woitecki K, Tarnok Z, Zimmerman-Brenner S, et al. European clinical guidelines for Tourette syndrome and other tic disorders—version 2.0. Part II: psychological interventions. Eur Child Adolesc Psychiatr 2021:1—21.

- [22] Wang HS, Kuo MF, Stern JS. Possible role of repetitive practice of activities requiring reflexive responses in the treatment of Tourette's disorder. Chang Gung Med J 2011;34:650–3.
- [23] Nixon E, Glazebrook C, Hollis C, Jackson GM. Reduced tic symptomatology in Tourette syndrome after an acute bout of exercise: an observational study. Behav Modif 2014;38:235—63.
- [24] Reilly C, Grant M, Bennett S, Murphy T, Heyman I. Physical exercise in Tourette syndrome—a systematic review. Child Adol Ment H-Uk 2019;24:3—11.
- [25] Bitsko RH, Holbrook JR, Visser SN, Mink JW, Zinner SH, Ghandour RM, et al. A national profile of Tourette syndrome, 2011-2012. J Dev Behav Pediatr 2014;35:317–22.
- [26] Wei MH. The social adjustment, academic performance, and creativity of Taiwanese children with Tourette's syndrome. Psychol Rep 2011;108:791–8.
- [27] Lee MY, Chen YC, Wang HS, Chen DR. Parenting stress and related factors in parents of children with Tourette syndrome. J Nurs Res 2007;15:165–74.
- [28] Stewart SB, Greene DJ, Lessov-Schlaggar CN, Church JA, Schlaggar BL. Clinical correlates of parenting stress in children with Tourette syndrome and in typically developing children. J Pediatr 2015;166:1297–302.
- [29] Cooper C, Livingston G. Psychological morbidity and caregiver burden in parents of children with Tourette's disorder and psychiatric comorbidity. J Am Acad Child Psychiatr 2003;42:1370–5.
- [30] Ludlow AK, Brown R, Schulz J. A qualitative exploration of the daily experiences and challenges faced by parents and caregivers of children with Tourette's syndrome. J Health Psychol 2018;23:1790–9.
- [31] Evans GA, Wittkowski A, Butler H, Hedderly T, Bunton P. Parenting interventions for children with tic disorders: professionals' perspectives. J Child Fam Stud 2016;25:1594—604.
- [32] Claussen AH, Bitsko RH, Holbrook JR, Bloomfield J, Giordano K. Impact of tourette syndrome on school measures in a nationally representative sample. J Dev Behav Pediatr 2018;39:335–42.
- [33] Kurlan R, McDermott MP, Deeley C, Como PG, Brower C, Eapen S, et al. Prevalence of tics in schoolchildren and association with placement in special education. Neurology 2001;57:1383—8.
- [34] Ricketts EJ, Wolicki SB, Danielson ML, Rozenman M, McGuire JF, Piacentini J, et al. Academic, interpersonal, recreational, and family impairment in children with tourette syndrome and attention-deficit/hyperactivity disorder. Child Psychiatr Hum Dev 2022;53:3—15.
- [35] Silva RR, Munoz DM, Barickman J, Friedhoff AJ. Environmental factors and related fluctuation of symptoms in children and adolescents with Tourette's disorder. J Child Psychol Psyc 1995;36:305–12.
- [36] Hoekstra PJ, Dietrich A, Edwards MJ, Elamin I, Martino D. Environmental factors in Tourette syndrome. Neurosci Biobehav Rev 2013;37:1040–9.
- [37] Rindner EC. Living with Tourette's syndrome. J Psychosoc Nurs Ment Health Serv 2007;45:19—23.
- [38] Wadman R, Tischler V, Jackson GM. 'Everybody just thinks I'm weird': a qualitative exploration of the psychosocial experiences of adolescents with Tourette syndrome. Child Care Health Dev 2013;39:880—6.

- [39] Stokes A, Bawden HN, Backman JE, Dooley JM, Camfield PR. Peer problems in Tourette's disorder. Pediatrics 1991;87:936–42.
- [40] Carter AS, O'Donnell DA, Schultz RT, Scahill L, Leckman JF, Pauls DL. Social and emotional adjustment in children affected with Gilles de la Tourette's syndrome: associations with ADHD and family functioning. Attention Deficit Hyperactivity Disorder. J Child Psychol Psyc 2000;41:215–23.
- [41] Brook U, Boaz M. Attitude and knowledge of high school pupils towards adolescents with special needs (Tourette's syndrome). Indian J Pediatr 2006;73:1099–104.
- [42] Nussey C, Pistrang N, Murphy T. How does psychoeducation help? A review of the effects of providing information about Tourette syndrome and attention-deficit/hyperactivity disorder. Child Care Hlth Dev 2013;39:617–27.
- [43] Packer LE. Tic-related school problems: impact on functioning, accommodations, and interventions. Behav Modif 2005;29:876–99.
- [44] Nussey C, Pistrang N, Murphy T. Does it help to talk about tics? An evaluation of a classroom presentation about Tourette syndrome. Child Adolesc Ment Health 2014;19:31–8.
- [45] Tourette Association of America. Classroom strategies and techniques for students with Tourette syndrome. https:// tourette.org/resources/overview/tools-for-educators/ classroom-strategies-techniques/;2016 [accessed 1 September 2021].
- [46] Feldman RS. Development across the life span. 8th ed. USA: Pearson; 2017.
- [47] Holtz KD, Tessman GK. Evaluation of a peer-focused intervention to increase knowledge and foster positive attitudes toward children with Tourette syndrome. J Dev Phys Disabil 2007;19:531–42.
- [48] Edwards KR, Mendlowitz S, Jackson E, Champigny C, Specht M, Arnold P, et al. A qualitative exploration of the experiences of children and adolescents with Tourette syndrome. J Can Acad Child Ado 2017;26:39–44.
- [49] Malli MA, Forrester-Jones R, Murphy G. Stigma in youth with Tourette's syndrome: a systematic review and synthesis. Eur Child Adolesc Psychiatr 2016;25:127—39.
- [50] Malli MA, Forrester-Jones R. "I'm not being rude, I'd want somebody normal": adolescents' Perception of their Peers with Tourette's Syndrome: an Exploratory Study. J Dev Phys Disabil 2017;29:279–305.
- [51] Wang HS, Kuo MF. Tourette's syndrome in Taiwan: an epidemiological study of tic disorders in an elementary school at Taipei County. Brain Dev 2003;25:S29–31.
- [52] Bawden HN, Stokes A, Carol S, Carol S, Camfield PR, Salisbury S. Peer relationship problems in children with Tourette's disorder or diabetes mellitus. J Child Psychol Psyc 1998:39:663–8.
- [53] Lee MY, Wang HS, Lee TY. Psychosocial stress, self-esteem, and social adjustment: a moderated mediation analysis in Taiwanese adolescents with Tourette syndrome. J Pediatr Nurs 2021;59:55–62.
- [54] Altman G, Staley JD, Wener P. Children with Tourette disorder: a follow-up study in adulthood. J Nerv Ment Dis 2009;197:305–10.
- [55] Lee MY, Wang HS, Chen CJ. Development and validation of the social adjustment scale for adolescents with tourette syndrome in taiwan. J Pediatr Nurs 2020;51:e13–20.