

RESEARCH ARTICLE

# Filial Experiences and Challenges of Caregivers of the Individuals with Tourette Syndrome

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**Abstract:** Tourette Syndrome (TS) is a neurological condition that has physically and psychologically affected individuals afflicted with this condition. Their health situation has an impact on their families' lives. In this case study, we aimed to examine the various experiences of the family members of the individuals with TS. Informed by the postulations of Ramanathan (2010) and Rivera-Navarro et al. (2014), we interviewed parents and siblings of individuals diagnosed with TS. Through these interviews, our study revealed that family members share the struggles of individuals with TS in dealing with and managing their conditions. They also shared some of their perceptions about having a life of normalcy despite living with family members with TS. Furthermore, dealing with the realities of living with them with this kind of condition has opened up a greater understanding of their physiological makeup. Finally, parents expressed the need for various agencies to extend their support to groups like them in achieving their full potential as individuals.

**Keywords:** Tourette Syndrome, family experiences, health care, oral communication, caregiver experience

Atypical language learners are those individuals who are divergent from the normative language learning profile. Ullman and Pierport (2005) proposed that these learners may have concerns about their language development. Those who learned past critical periods as products of abuse, deafness, severe mental health problems, and inherited language disorders may be deemed atypical learners (Jafari, 2015). The critical period refers to the early years in which individuals are exposed to and learn a language, whether it is their first or second language (Friedmann & Rusou, 2015), thus supporting Lenneberg's (1967) assertion that when a child's brain maturation is affected by any condition, it may have implications for their linguistic abilities. In line with the group, Arciuli and Conway (2018) and Friedmann and Rusou (2015) argued that people with

developmental impairments often experience major to minor linguistic difficulties. These dysfluencies may also affect their ability to communicate and comprehend information effectively (Arciuli & Conway, 2018). Moreover, this condition may also impair their capacity to interact with others. As such, communication with others poses a challenge and great dependence on their caregivers is inevitable. Ramanathan (2010) also argued that the family, especially those related by blood, plays a significant role in the lives of their relatives with this condition because they perform various roles in their lives that may help improve their quality of life in almost all aspects. Because little is known about this condition, as cases may not be reported and recorded, stakeholders' support is still needed to address the needs of this population.

### ***Tourette Syndrome***

One of the groups under the atypical learners' category is individuals with Tourette Syndrome (TS), a neurodevelopmental condition characterized by the presence of tics (DSM-5; American Psychiatric Association, 2013). It is also termed Gilles de la Tourette Syndrome (GTS), after the French neuropsychiatrist Georges Albert Édouard Gilles de la Tourette (Lavoie & O'Connor, 2012). TS is defined by the presence of two or more simple or complex vocal or motor tics (DSM-5; American Psychiatric Association, 2013) and a year of daily tics, which is a crucial hallmark of TS (Isaacs & Riordan, 2020). Typically, TS is diagnosed during childhood or adolescence, and its severity peaks during early adolescence (DSM-5; American Psychiatric Association, 2013). As indicated in the meta-synthesis conducted by Smith et al. (2015), the global TS population is approximately 1%. Hence, studies involving this group may have a very small number of research participants. Further, it is a vulnerable group characterized as being very prone to negative experiences, anxious about the future, and encountering problems with interpersonal relationships (Smith et al., 2015). Moreover, Soós et al. (2022) categorized TS as a chronic condition that adversely affects the quality of life, particularly for individuals experiencing severe tics. This condition can have negative impacts on mental well-being, self-esteem, and physical health (Soós et al., 2022, p. 2). Therefore, it is evident that they experience struggles in various forms. Consequently, social, physical, and psychological support is crucial for individuals with TS, particularly among their family members.

According to Rivera-Navarro et al. (2014), individuals with TS experience various overwhelming effects of this condition in the physical, psychological, and social domains of their lives, which not only affect the individuals who have the condition but also their families or the people who are close to them. Himelstein (2006) also argued that the family is at the forefront of caring for their children with conditions such as TS, hoping to enhance their quality of life. This may be a lifetime engagement that may further impact different aspects of the family's lives. Additionally, Ramanathan (2010) posited that a phenomenon such as this is observed among the "sufferers," or those with this condition, and their loved ones. This notion suggests that people who "suffer" from medical or psychological conditions experience various sorts of

"ailments, disabilities, and disabling language skills" that make body parts appeal to "malfunction" Even though there is an attempt to perform "normal" (p. 2).

Consequently, the condition shapes the family's attitudes and views about it and even what can be deemed normal (Himelstein, 2006; Ramanathan, 2010), and this results in accommodating others through provision of extra care and understanding. Ramanathan (2010) reported that family members adjust to the mood and other extra needs. As reported by various studies involving caring for people with TS, emotions such as sadness, anxiety, and anger are commonly observed by those people who take care of those with specific conditions (e.g., Limonero et al., 2018; Travis & Juarez-Paz, 2020). For instance, Grbich et al. (2001) reported that caregivers often experience unmet needs as a result of sleep deprivation, reduced socialization, and self-neglect. Similarly, studies such as that of Limonero et al. (2018) have identified dominant emotions like emptiness, resentment, helplessness, anxiety, guilt, and uncertainty. These emotions are brought forth by their daily engagement with their loved ones who have this condition.

However, a collective understanding and acceptance of this condition pave the way for a more open dialogue between the person with the condition and their families (Ramanathan, 2010). Intentions for communication with people who have TS may affect how they deal with others. This requires adjusting their actions or behaviors to accommodate their loved one with TS.

The emerging familial practice seems to challenge Bronfenbrenner and Morris' (2007) bioecological systems theory. They contended that the sociocultural environment influences the parental practice in interacting with their offspring along with the children's behavior towards their parents. As the physiological, psychological, and emotional conditions of atypical individuals seem to deviate from the social and cultural perceptions of parenthood, the notion of authority may differ from the current sociological landscape. As a result, the current condition such as those with TS affect the attitudes, beliefs, and goals of their parents and other family members.

### ***Tourette Syndrome in the Philippines***

Existing literature in the Philippines reveals a lack of aggregated scholarly pursuits that describe the population. In the investigation of Yu et al. (2021), TS is described as a small percentage of the population

(0.9%; N=12) based on data from a known private hospital in Metro Manila. This suggests that TS is not a prevalent movement disorder in the country.

Moreover, Abendan (2018) examined the relationship between self-stigma and quality of life among individuals with TS, with a sample size of 12 participants. The qualitative findings showed the participants' views on alienation, discrimination, social disengagement, and the quality of life (physical, psychological, social, and environmental) of those afflicted with this condition.

By and large, it appears that there are very few studies that focus on the role of parents or caregivers who support their children with TS in their daily lives. Thus, this current study presents the various contexts and experiences of the family members caring for this vulnerable group. Hence, this investigation aims to answer the question, "What are the various experiences of Filipino caregivers in taking care of individuals with TS?" In particular, the study aims to answer the following questions: (a) What are the roles of caregivers in aiding individuals with TS, especially in the area of oral communication? and (b) What are their challenges in fulfilling their roles?

## Method

### *The Participants*

The research participants in this case study are the first-degree relatives, family members, or caregivers of individuals with TS. In particular, the study comprised five caregivers of those with TS. Caregivers are identified in this study as either the parents (Sullivan-Bolyai et al., 2003) or siblings (Pollack, 2002) of individuals with TS. Their children or siblings with TS are in different stages in terms of onset, severity, and co-occurring condition or comorbidity. The caregiver selection was adopted from the investigation of Mataix-Cols et al. (2015) with the following criteria:

1. is a registered member or has a relative who is a member of a local TS organization;
2. is a first-degree family member of the individual with TS, such as a parent, spouse, or sibling;
3. directly takes care of the individual with TS at the time the interview was conducted; and
4. lives with the individual with TS.

These participants were invited through a local

Tourette Syndrome (TS) organization that supports individuals with this condition. Their names have been anonymized to protect their identities. All caregivers reported that they are college graduates, and the majority of the participants mentioned that they belong to the lower socioeconomic strata. Most of the participants are predominantly from Luzon. As observed in the literature, case studies that involved individuals with TS had a range of one to five research informants. Also, very few responded to the research invitation, which is even evident in the earlier studies of Yu et al. (2021) and Abendan (2018), wherein less than 1% of the total population is identified with this condition. In the case of our investigation, the organization had around 20 caregivers were considered active in the Facebook groupchat. Six of them agreed to participate, but only five were interviewed and provided consent to publish the data. However, a short interview, the support group organization leader mentioned that very few among the individuals with TS in the Philippines joined the support group. This supports that participants in a study such as this are smaller in number.

Following the protocols set by the university research ethics committee for dissertations, we also sought the consent of the participants and informed them about their rights as participants. A local Tourette Syndrome support group in the Philippines contacted all participants. An announcement was posted in their group chat, and the participants volunteered to take part in the study. Each was interviewed through Zoom from November to December 2021. It must be noted that during this time, the Philippines was under stricter community quarantine protocols in response to the rapid spread of the COVID-19 virus. We gave Internet data loads and refreshments amounting to five hundred Philippine pesos each. In addition, we sought permission to report which part of the data and whether we observed accuracy in the ideas or feelings they shared during the interviews.

### *Data Collection and Analysis*

The interviews were conducted via Zoom, wherein each participant was interviewed and given open-ended questions. To ensure their anonymity, the participants were instructed to turn off their cameras and rename the visible Zoom names prior to the recording of the session. The questions were culled from the discussions of Ramanathan (2010) and Rivera-Navarro et al.

(2014), which delved into the experiences of family members in three areas: (a) healthcare practices provided to individuals with TS, (b) assistance in developing oral communication skills for individuals with TS, and (c) assistance and support received from non-family members. Follow-up questions were asked based on the responses given.

Using Rivera-Navarro et al.'s (2014) data analysis framework, the responses were transcribed, and the statements were coded manually. In terms of the codes, the recurring ideas or themes from the transcription were grouped until the major groups were created. In addition, another online meeting was arranged to confirm the themes and findings with the informants of our study. Also, during this meeting, we sought the permission of the informants to determine whether the themes could be included in the study. This collaborative approach helps ensure the trustworthiness and credibility of the research findings.

## Results and Discussion

Table 1 presents the profiles of the caregivers of the individuals with TS. Almost all of them are the parents of the individuals with TS, except for the one informant who is the sister of the individual with TS. All participants are from Luzon and are active in the online group for individuals with TS. In addition, the tic severity of their loved ones varies despite having the same tic variables.

### *Roles of the Caregivers in Aiding Their Offspring or Relatives With TS*

There are various roles of the caregivers (i.e., parents or siblings) of individuals with TS, one of which is to address the external factors that may trigger the tics. These tics affect the mood and behavior and the quality of their utterances when communicating. As presented in Table 2, the most common role of the

**Table 1**

*Caregivers' Profile*

Subject	Age	Relationship	Gender of the Individual with TS	Individual with TS' Tic Severity	Individual with TS' Tic variables	Age when the Individual with TS was formally diagnosed	Individuals with TS' Associated Condition	Individual with TS' Medication	Individual with TS' Reported Academic and Communication difficulties
Caregiver A	35	Father	M	Severe to Very Severe	Vocal and motor	8	Asthma	Medicated	None; no communication difficulties
Caregiver B	40	Mother	M	Moderate to Severe	Vocal and Motor	9	ADHD	Medicated	Learning difficulty; low scores; could not concentrate on performing academic-related tasks
Caregiver C	30	Sister	M	Mild to Moderate	Vocal and Motor	12	None	Medicated	Difficulty in critical thinking questions / Task
Caregiver D	55	Father	M	Very Mild to Mild	Vocal and Motor	11	Stroke of the Young (17) and Stomach Ulcer (17)	Used to be Medicated	None
Caregiver E	58	Mother	F	Very Mild to Mild	Vocal and Motor	7	ADHD OCD	Used to be Medicated	None

**Table 2***Caregivers' Roles in Improving the Oral Communication Skills of Individuals With TS*

<b>Roles</b>	<b>Caregiver C</b>	<b>Caregiver B</b>	<b>Caregiver A</b>	<b>Caregiver D</b>	<b>Caregiver E</b>
Helping in Controlling the External Factors that Cause the Tics	Encourage everyone in the household to work together.  Seek for non-family support (neighbors, school staff, faculty, etc.).  Massages and investigate foods that may have made the tics worse (processed food, soda, etc.).  Strengthen family ties.	Encourage everyone in the household to work together.  Massage him to make him feel better.  Observe the tics and what triggers them.  Provide gadgets to reduce the anxiety.	Change of environment from time to time (province to city; vice versa).  Provide activities to reduce anxiety.  Adjust the tutoring tasks or schedule depending on the child's mood.  Reminder to relax and breathe.	Gave space during social withdrawal moments due to severe tics.  Encourage the son to have outdoor activities.  Send to a school with a smaller and more "family-like" community.	Researched about TS.  Monitor the tics severity and the probable trigger.  Send to a Special Education institution during the onset of the condition.  Maintain a positive community environment.  Spread knowledge about TS.
Embracing life with TS	Seek assistance of an organization about tics.	Give certainty, encouragement, and support.	Give certainty, encouragement, and support.	Give certainty, encouragement, and support.	Give certainty, encouragement, and support.
Present a typical or "normal" day in the life	Get kids to play with their friends and play games online.	Encourage having a pet.		Encourage having a pet.	Permit diverse social experiences (drinking, partying, etc.).
Improve Interpersonal Skills	Act as a go-between for the child and the other person.  Nudge to get the job done.  Help with tasks related to school.	Act as a go-between for the child and the other person.  Encourage to finish the tasks / homework.	Act as a go-between for the child and the other person.	Act as a go-between for the child and the other person.  Tutor during the initial onset of the condition.	Expose to various literacy resources.

caregiver is to help reduce anxiety through different means, such as giving space and speaking words of encouragement. Based on the table, there are various roles that the caregivers perform, and it confirms Ramanathan's (2010) postulation that the roles are tied to the challenges and experiences of individuals with a specific condition. In the case of persons with TS, caregiver roles revolve around giving assistance in tic management to allow them to experience a "normal life."

One caregiver shared, "*Umuwi kami ng probinsya naglagay ako ng aso at maraming hayop tapos bumili rin ako ng Rubiks cube...*" [We went to the province, bought a dog and other animals, and I bought Rubiks cube) when he found out about his son's condition and learned that his son's tic might get worse because of the new environment due to anxiety in adjusting to the unfamiliar setting. Another mentioned, "*Ang adjustment po aming ang unang una ay iniwasan po aming yung mag trigger siya*" [Our adjustment primarily involves avoidance of what might trigger his tics].

Another role of the caregivers is to assist the individual with TS in accepting their current condition. Encouragement and improved family relationships allow individuals with TS to recognize the presence of tics and how they can manage and live with them. One caregiver shared, "*...sinasabi na lang po aming sa kanya na tingnan mo na lang ang paligid mo; hindi lang ikaw ang may problema mayroon pang mas worse pa sa atin. Yung condition mo gawin mong inspiration*" [We tell him to look around him to realize that he is not the only one who has a problem, and that there are people who experience worse situations than him]. Alampay (2014) reported that Filipino families center on aspiring for "smooth interpersonal relations" (SIP) (p. 107), which seeks the presence of harmony and "inclusiveness" (p. 107) in the relationships. This results in *pakikisama* (harmony within the group), allowing family members to get along. However, instead of teaching this value of *pakikisama* to the individuals with TS, which is a common practice among families, it is the parents who practice the value and teach this to the other family members without the said condition. This challenges the common notion that the value should be imbibed by all offspring in the household and applied to other people; hence, *pakikisama* is practiced within the family. However, it appears to be a divergent practice as the younger family members should demonstrate it to adjust to the

older members. Thus, we observe that the caregivers' attitudes are geared towards caring and managing the condition and not instilling values in their children with TS. As such, the younger family members attempt to do the same when their parents are not around. As a result, *pakikisama* is still bolstered by the caregivers.

Aside from that, the family's significant role is to provide a "normal life" to individuals with TS. Data revealed that this is done through exposing those with TS to activities and things that would allow them to recognize that they are like any other child or person who can do various activities. Hence, it gives them the confidence to deal with others without the fear of being judged or rejected. This challenges the concept of *hiya* [shame] that was reported by Alampay (2014). In her study, she argued that *hiya* is a value that puts a premium on behaving "properly and with dignity with respect to self and the family" (p. 108) so that family members will not bring shame to the family. It is noteworthy that in the case of the individuals with TS, their families redirected the notion of *hiya* by emphasizing that their condition does not bring shame to the family. Hence, instead of being mindful and prioritizing others, the families value their members more than others or outsiders. This challenges the Filipino values of being mindful and prioritizing others before the family.

Lastly, enriching oral communication skills is another role of the family. This is done through tutorials or coaching, in which they act as intermediaries or interpreters (middle person) in the conversations, expose their relatives with TS to diverse literacy materials, and interact with other people. We observed these dynamics during the task given to the adolescents with TS, who received assistance from their caregivers during the assessment. Likewise, caregivers also reported that when the teacher or other people do not seem to understand what their relative with TS is saying, they act as interpreters for the interlocutor. This practice aligns with Ramanathan's (2010) position that the loved ones of individuals with this particular condition developed the practice of intentionality. This practice of intentionality, in the context of the caregivers of persons with TS, is reflected through their words and actions that aim at alleviating the pain or improving the condition of their loved ones. In their case, the loved ones attempt to be the "middle person" between the relatives with TS and non-familial interlocutors to ensure successful communication and mitigate potential

negative experiences, such as frustration on the part of their loved ones. Moreover, this practice reinforces the Filipino values of *hiya* and *pakikisama*. In terms of *hiya*, family members endeavor to uphold the dignity of their loved ones with TS by facilitating effective conversations. Similarly, this aligns with the principle of *pakikisama*, as helping with communication serves as a means of accommodating the needs of both the family member with TS and the interlocutor.

The above-mentioned roles of the parents fulfill the basic responsibilities of Philippine parents, which are to protect, care for, and instill values for their children's welfare (Alampay, 2014). However, the last among the enumerated roles above—the middle-person role—seems to be an uncommon one, as this is not typically observed in the family dynamics of the household. It is expected, especially for late adolescent offspring, that they should display a sense of maturity and independence. Additionally, the findings confirm the position of Eapen and Črnčec (2009) that tics can lead to misinterpretation and miscommunication that result in family conflicts. It arises because people with TS have difficulty expressing themselves. Hence, assisting them may be beneficial for the group to be understood.

### ***The Challenges of the Caregivers in Fulfilling Their Roles***

There are various challenges that caregivers experience in taking care of individuals with TS. First, parents and siblings found certain miscommunications between them and the persons with TS, as frustration arises due to conflicting points of view. A caregiver narrated, "*Kinakausap namin siya na magpagaling na siya... Ang sinasabi nya ay, 'Mama pag hindi ako gumaling magpapakamatay na lang ako. Ayoko kayong nahihirapan.'*" [We, as a couple, tell him to get well, but our son tells us, "Mama, if I don't get healed, I will kill myself. I don't want you to suffer.]]

Another challenge is the notion of discipline, which is deemed a Filipino value of filial care. Usually, such discipline in a Filipino household employs corporal punishment, such as spanking, scolding, pinching, or ear pulling (Blair, 2014). However, this results in resistance or, worse, rebellion from those with TS and is interpreted as being given less love or care. One caregiver explained, "*...gusto ko naman lumaking mabuting bata ang anak ko...pero papaano nga po kung 'pag pinapagalitan ko sya doon siya nagkaka tics?'*" [I want my child to grow up becoming a good

person, but how can I ensure that if his tics come out whenever I reprimand him?] She also added, "*kinukuha niya yung kutsilyo sa kusina tuwing napapagalitan namin*" [He gets the knife from the kitchen and points it to us whenever we reprimand him]. Thus, this negative feeling may sometimes engender pain and contempt in both parties. Parental distress has been noted by studies (e.g., Rivera-Navarro et al., 2014; Matlakala et al., 2022) as a common psychosocial experience in the context of TS.

It is worth reporting that some caregivers we interviewed experienced self-blame at the onset of the diagnosis because they felt burdened that their past activities, food intake, and age during pregnancies could be a factor in why their children have TS. However, they overcame this phase as they continued learning more about TS. During the interview, one of them said:

*Bakit hinintay pang magkombulsyon bago isugod? Kaya ang lagi kong sinasabi kung hindi ako nagtrabaho hindi magkakaganito ang anak ko...Isa rin yan sa tinanong ko sa doctor kung iyong edad ko ba ang dahilan bakit sya nagkaganoon baka nakaapekto iyon. At palaging ang sagot ng doctor ay hindi. [Why did (my husband) wait for my child to have convulsion before rushing him to the hospital? That's why I tell myself that had I not been working then, my child would not end up like this...another cause I suspect was my age. So, I asked his doctor whether age could be a factor, but he would always say no.]*

### ***Community Support for Individuals With TS***

Despite having a support group like that of the schools, caregivers experience underwhelming assistance from the government despite its efforts to help them in many ways. First, marginalized assistance is observed in the limited benefits that can be obtained from health agencies as a result of the numerous documents being demanded. These documents, such as medical abstracts, updated test results, and current prescriptions from doctors, are deemed challenging, especially during the COVID-19 pandemic because of mobility restrictions. As a result, caregivers end up shouldering the entire cost. One explained, "*... meron po (subsidy ang government) pero hindi ko pa po nalalakad ngayon...nanghihingi po kami ng gamot nyan dito sa center o sa munisipyo.*

*Hindi ko lang po nalalakad kasi hinihingan ako ng (medical) abstract.*” [His medicine is subsidized by the Philippine government. We request the medicine from the health center or the local city government. The medical abstract is one requirement that we do not have currently].

Likewise, the challenges of remote neurological or psychological consultations were reported to be tremendously difficult during the stricter community quarantines in the country. Thus, the needed check-ups were delayed. One caregiver reported, “*Ngayon pong quarantine, ang hirap pong magpa schedule ng appointment sa doctor. Minsan kapag conflict kasi may pasok siya, nagpapa reschedule kami, so nauurong ng nauurong*” [It is more challenging to book a doctor’s appointment, and sometimes there is a conflict in schedule, so the supposed meeting gets rescheduled instead.]

Second, limitations on government facilities, such as Magnetic Resonance Imaging (MRI) and Electroencephalography (EEG), yielded slower capacity to obtain updated medical records needed to avail of the free or discounted medications. Thus, delayed documents may also result in delayed procurement of the needed medicines, especially for underprivileged families. A caregiver mentioned, “*Matagal po bago kami nakapagpa MRI at EEG kasi mahaba na po ng pila sa public hospital*” [It took us a long while before he finally underwent an MRI and EEG in a public hospital.]

Another challenge is the lack of education on TS in the country, which has resulted in a negative stigma toward this group. Despite the emergence of its exposure on social media, limited knowledge about the condition is still observed, which makes both caregivers and individuals with TS confront various challenges when in public places.

## Conclusion

Tourette Syndrome is a neurological condition where an individual suffers from uncontrollable tics. Although studies report that it may potentially wane during early adulthood, some individuals may still have TS even into adulthood. Thus, it may be a life-long condition that even their loved ones need to live with.

In line with this, various implications can be drawn from the experiences of the caregivers. First,

they play a vital role in aiding a person with TS in communicating with others by being middle persons. Thus, knowledge of performing this role is necessary, which may be obtained through government programs that give them the pedagogical tools they need. Second, strengthening the parent-teacher partnership in aiding individuals with TS may help both the parent and the person with TS. In relation to this, strengthening the school’s inclusive environment plays an important role in providing an environment that can accommodate students with this condition and encourage a culture that supports atypical learners. Third, strengthening the government’s healthcare facilities and programs is essential as it extends support to caregivers of the vulnerable group. Perhaps further expansion of the country’s inclusive education program should also give attention to individuals with TS through specialized education teachers who will be handling these atypical learners. Fourth, scholarly pursuits on understanding the experiences of the caregivers of those with vulnerable conditions unpack their strengths and challenges in a way that shows how the community can further support them and provide the assistance they need. Through this, emotional and psychosocial support can be extended to those who provide care for their loved ones. Ultimately, community involvement is essential in raising awareness and ensuring the welfare of individuals with TS.

## Declaration of Ownership

This report is our original work.

## Conflict of Interest

None.

## Ethical Clearance

This study was approved by our institution.

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