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# Parent-young person lived experience of sensory dysregulation in children with tic disorders: a qualitative study

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## ABSTRACT

**Purpose:** To understand the breadth of sensory dysregulation on participation in daily tasks for young people with tic disorders, as research identified that sensory dysregulation experiences are broader than the symptoms being assessed.

**Methods:** Eighteen semi-structured interviews were conducted with 16 families with children (5–16 years) with tic disorders. Interviews ranged from 45 to 120 min and were transcribed verbatim. Data collected from parents and young people were analysed and coded together. Thematic analysis using inductive and open coding methods was implemented using NVivo.

**Results:** The impact of sensory dysregulation on daily life may be understood through the higher-order theme: “sensory, emotions and tics; it’s a ticking time bomb”, and three subthemes: (1) we sacrifice and adapt to get daily activities done in the home, (2) my child’s experience of the community environment hinders participation, and (3) sensory preferences impact our entire family.

**Conclusion:** Sensory dysregulation experiences impact the entire family’s quality of life, yet patient-reported sensory measures do not adequately capture the impact on the family unit and breath of symptoms. A sensory-based measure for children with tics is needed to comprehensively assess sensory dysregulation sensitivities for this population, ensuring patients’ needs and effectiveness of therapy can be measured.

## ARTICLE HISTORY

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## KEYWORDS

Sensory dysregulation; tic disorders; qualitative study; lived experience; paediatric

## ► IMPLICATIONS FOR REHABILITATION

- This qualitative study provides health professionals with a greater understanding of the sensory dysregulation experiences of children and young people with tic disorders.
- This study highlights that the sensory dysregulation experiences of children and young people are broader than the symptoms assessed through standardised questionnaires.
- To comprehensively assess and treat sensory dysregulation in clients with tics, the impact on the family unit needs to be evaluated and understood.
- When comprehensively assessing sensory dysregulation, understanding the interplay of tics, sensory and emotional dysregulation aids in treatment planning.


## Introduction

Tic disorders, a neurodevelopmental disorder, are the most common movement disorder in childhood, affecting 1 in 100 children [1]. Tics are repetitive, stereotypical, rapid, non-rhythmic movements or vocalisations that negatively interrupt a child’s daily participation [2–4]. According to the Diagnostic and Statistical Manual of Mental Disorders 5<sup>th</sup> edition (DSM-V), when both vocal and motor tics have been experienced in a waxing and waning pattern for longer than one year, the condition is referred to as Tourette’s syndrome (TS) [4]. Co-existing neurodevelopmental and neuropsychiatric conditions are present in 80–90% of children

with tic disorders [1,5]. These include obsessive-compulsive disorders (OCD) (30–40%), attention deficit hyperactivity disorders (ADHD) (54–60%) and autism spectrum disorders (ASD) (5–15%) [1,3,6].

As reported in people with other neurodevelopmental disorders [7–12], children with tic disorders and comorbidities experience sensory dysregulation [6,13–22] when compared with typically developing children [23–25]. Sensory dysregulation is more prevalent in children with neurodevelopmental disorders than in typically developing children [26–32]. Sensory dysregulation has been extensively researched in children with ASD [1,30,33–42]. Children with ADHD were identified as experiencing increased sensory

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dysregulation symptoms [43–45] and 81% more likely in the presence of foetal alcohol syndrome [7]. Abnormal sensory dysregulation was also found to have a significant relationship with overall adaptive behaviour [46]. As was the case with children with ADHD, children with OCD were also reported to experience increased sensory dysregulation symptoms [31,47].

Yet, there is limited research into sensory dysregulation in children with tic disorders. Since the study by Jewers et al. [14], which investigated sensory dysregulation in children with TS and ADHD compared with children with only TS, there has been growing interest in the area of sensory dysregulation in both children [15,48–50] and adults [22,51,52] with tic disorders. Furthermore, there is a growing interest globally in research into sensory dysregulation in children with various neurodevelopmental disorders, with research occurring in Australia [32,53], Brazil [12], Canada [7,14,54], Iran [55], Israel [15,56,57], Taiwan [58], Turkey [59], the United Kingdom [50,60], and the United States of America [40,43,45,60,61]. With growing interest in the area of sensory dysregulation in children with tic disorders, a recent case series study in 2018 was the first article to report on misophonic experiences and associated clinical characteristics in young people with tic disorders [49]. Misophonia is the triggering of inappropriate or extreme emotional or psychological responses due to certain sounds. This study by Robinson et al. highlights misophonia could be an underestimated phenomenon for abrupt emotional dysregulation in children with tic disorders [49].

Convergent evidence from electrophysiological studies [62,63], magnetoencephalography [64], and neuroimaging [65,66] are suggestive of people with tic disorders and TS experiencing altered sensory–motor processing involved in voluntary movement control. Deficits in sensorimotor gating, resulting in problems filtering irrelevant sensory stimuli, have been reported in individuals with TS [13,63]. As a result of these sensorimotor abnormalities experienced by people with tic disorders, tic disorders should be recognised as a “sensorimotor” phenomenon rather than being understood to be pure movement disorder [1,6,15,19,62].

Several terms are used to describe these observed behaviours to sensory stimuli in children with neurodevelopmental disorders, including “sensory dysregulation”, “sensory processing”, and “atypical sensory reactivity” [15,34,62,67]. Here, we use the term “sensory dysregulation” [15,68,69].

Sensory dysregulation can result in functional impairment and impact children's participation and enjoyment of tasks due to their atypical reactions to sensory stimuli [70]. Difficulties associated with sensory dysregulation across various neurodevelopmental disorders have been categorised into five functional impairment areas: (i) decreased social skills and involvement in occupational performance areas; (ii) reduced frequency, duration, or complexity of adaptive responses; (iii) impaired self-confidence or self-esteem; (iv) poor family and daily life skills; and (v) impaired gross-motor, fine-motor and sensory-motor skill development [60]. Sensory dysregulation is associated with reduced enjoyment and participation in daily life, including school engagement [24,30,37–39] and increased parental stress [9,30,70,71].

Accordingly, the assessment and management of sensory dysregulation is an accepted part of comprehensive care for children with neurodevelopmental disorders [72]. Therapeutic approaches are commonly used to address sensory dysregulation in children with neurodevelopmental disorders, with most of these strategies having been developed for children with ASD [34,73,74]. Validated, sensitive, reliable, and responsive clinician-, teacher-, patient-, and proxy-reported outcome measures to assess treatment efficiency are necessary for clinical use in sensory dysregulation [75].

Our recent systematic review of a proxy-reported sensory-based measure for children with neurodevelopmental disorders found only one measure, the Participation and Sensory Environment Question Home Scale (PSEQ-H) [76,77], satisfied moderate content validity [78]. The PSEQ-H was the only proxy-reported sensory-based measure from 12 measures evaluated to have consulted with consumers as part of measurement development to ensure the measure was comprehensive, comprehensible and relevant [78]. Yet anecdotal reports from paediatric patients with tics and their parents described sensory dysregulation experiences not recorded by either the PSEQ-H or the other commonly used proxy-report sensory-based measures [19,78]. These reported sensory dysregulation experiences predominately relate to auditory sensitivities such as “people-made” noise, including cutlery scraping on crockery, chewing of food, or the “scratching” sounds of clothing [19,78]. A recent study with children with tic disorders reported similar observations relating to experiences of auditory sensitivity to the same sounds made by other people [49]. It is uncertain whether these tic-specific experiences are adequately captured in current patient or proxy-reported sensory dysregulation outcome measures [19,78].

Therefore, a qualitative study was undertaken to understand the lived experience of sensory dysregulation experiences and the impact these have on the daily lives of young people with tic disorders. This study aimed to understand the breadth of sensory dysregulation experiences and the effect on participation in daily tasks by exploring the lived experience of young people with tic disorders and their parents.

## Method

The study gained ethical approval through the Human Research Ethics Committee (2020/ETH00132) and Clinical Governance Committee (2020/STE00307) at the Sydney Children's Hospital Network, Sydney, Australia.

### Patient and public involvement

The study protocol, as well as the interview guide, was developed with consumer consultation. The principal investigator (NS) met with two adults diagnosed with TS and sensory dysregulation to understand their lived sensory experiences and the impacts of the sensory experiences on their daily lives. From the knowledge gained through consulting with consumers, clinical experience with working with children with tic disorders and literature review, aiding in developing the study protocol and interview questions. The researchers also conducted previous research into the prevalence of sensory symptoms in children with tic disorders and comorbidities and a systematic review of parent and child report measures of sensory-based measures [19,79]. The knowledge gained from these studies and in clinical practice supported the development of this study.

### Research design

Using thematic analysis, the researchers identified, analysed and reported themes within the data obtained from semi-structured interviews utilising pre-determined questions [80]. Key features from the extensive data sets were analysed and summarised using thematic analysis, permitting the perspectives of each study participant to be examined [80,81]. Although an advantage to thematic analysis is the flexibility of the approach, the researchers

conducted the study in a precise, consistent and exhaustive manner through recording, systematising and transparency of analysis to ensure the study's trustworthiness and the reported findings [81].

The pre-formulated interview questions explored participants' responses to their sensory dysregulation experiences and the impact on their daily lives and function (Supplementary Documents 1 and 2). The wording and sequence of questions were left open-ended to support broader discussion and were guided by participant responses. In addition, study participants were provided with two prompt pages that used pictures and simple words to support discussions about lived experiences of sensory dysregulation and the impact on the person's activities of daily living (Supplementary Documents 3 and 4). The semi-structured interviews were anticipated to be 30–60 min in duration. A demographic questionnaire was completed on the day of the interview.

The recruitment of study participants ceased once the research team agreed that data saturation had been achieved. The data saturation point was understood to be once the same recurrent themes were identified through subsequent interviews, and no new themes were identified by additional participants [82].

### Sampling and recruitment

Recruitment of study participants occurred through the Tic Clinic at a tertiary-level Children's Hospital in Sydney, Australia. The study recruited either i) parent(s) who had a child/young person with a confirmed tic disorder or ii) young people with a tic disorder and their parent(s). It was at the family's discretion if the young person with a tic disorder would engage in the interviews.

The inclusion criteria for young people with tics to be eligible to engage in the study include: (i) be between the ages of ten and sixteen years, (ii) have a confirmed diagnosis of a tic disorder by a paediatric neurologist, (iii) have known or suspected sensory dysregulation and (iv) if prescribed pharmacotherapy, be on a stable medication regime for a minimum of six weeks prior to the time of recruitment. Study participants were not excluded if they had confirmed comorbidities in addition to a tic disorder diagnosis. Furthermore, the young person needed to (vi) have conversational verbal skills to engage in the semi-structured interviews. Informed written consent was obtained from the young person and their legal guardian.

For parents or carers to participate in the study, they needed to be the carer of (i) a child or young person between the ages of five and sixteen years with a medically confirmed diagnosis of a tic disorder. Eligible participants were sent information about the study and invited to participate *via* mail. After receiving a signed consent form, a convenient date for the family was set for the interviews.

Of the 29 families invited to participate, 18 engaged in this study. Two families were excluded as additional medical information during the interview resulted in the study participants being ineligible. Two families were interviewed twice, as a separate parent interview, and then a parent and young person interview was conducted at the families' request. Therefore, data was collected through interactive means as the principal researcher conducted all 18 semi-structured interviews with the 16 families engaged in the study. Ten interviews were conducted with the young person with tics in the presence of a parent(s), and eight interviews were conducted with parents of children/young people with tic disorders without the child/young person present.

The interviews ranged between forty-five minutes to two hours in duration. The mean duration of the interviews was 72 min.

The demographic details of study participants are provided in Tables 1 and 2. All names are pseudonyms to maintain confidentiality.

### Data collection

Due to the Covid-19 pandemic at the time of this study, all interviews were conducted *via* telehealth using Zoom software© [83]. All interviews were recorded with written consent from study participants and transcribed verbatim. All interview transcripts were uploaded and coded using NVIVO 12 software [84]. All study participants were provided with pseudonyms to protect their privacy and identity. When the interview was conducted with the young person and parent present, the interviewer asked the young person the questions first so that they were not biased or guided by their parents' responses.

### Data analysis

The descriptive qualitative data was analysed to determine the common themes concerning the participants' experience of sensory dysregulation and their impact on their daily function. The researcher used an inductive analysis approach as this was the best design for the question asked [80]. The themes were also identified within the coded data transcripts and were data-driven [80]. The researchers analysed the themes for each study participant after the interview was conducted to understand the common themes emerging from the data and to allow for the analysis of new emerging themes. When no new themes were identified, it was agreed that data saturation had been reached for the study.

The researchers ensured the study's trustworthiness by being credible, transferable, dependable and confirmable [85] by implementing the six phases of thematic analysis, an iterative and reflective process, to analyse the data [80,81,86,87]. These phases were [1]: familiarising yourself with the data [2], generating initial codes [3], searching for themes [4], reviewing the themes [5], defining and naming the themes, and [6] producing the report [81].

Fortnightly meetings with the principal investigator (NS) and research supervisor (PB) were undertaken regarding information gained from semi-structured interviews and to discuss findings in assisting with peer debriefing. Frequent meetings with the research team were held to examine and define codes, aiding researcher triangulation. Through discussion and agreement from the research team, a coding framework, identifying codes and definitions of these codes, was developed. Copies of transcripts, journals, memos, email correspondence between the research team members, meeting agendas, and meeting minutes were stored to ensure an audit trail for the generation of the codes. Hierarchical coding was used to allow the researchers to analyse the texts at varying levels of specificity, with higher-order codes providing an overview and lower-order codes providing more specific and detailed distinctions between study participants [81, 86,87]. Research team members vetted themes and subthemes by testing for referential adequacy by referring back to the raw data and the study participants' quotes [81]. Team consensus on the themes and the naming of these themes was achieved following researcher triangulation, peer debriefing and team meetings. Documentation of the team meetings regarding the agreement of themes and the naming of themes was kept [81].

To ensure the validation and trustworthiness of the findings, the principal investigator met with another occupational therapist with experience in qualitative research to review the themes and peer debriefing [81]. Study participants were asked to answer ten

**Table 1.** Demographics of study participants, including parents and children and young people engaged in the study.

Demographic details of parents interviewed		
Characteristics	All parents interviewed (n=19)	Parents of young people interviewed (n=13)
Biological sex (female, male)	F=15, M=4	F=9, M=4
State:		
ACT/NSW/VIC	3 / 12 / 1	3 / 6 / 1
Level of income:*		
Most financially advantaged	7	5
Financially advantaged	1	0
Between advantaged and disadvantaged	6	5
Financially disadvantaged	0	0
Most financially disadvantaged	2	0
Marriage status of families:		
Married	11	7
Defacto relationship other than biological parent	2	1
Single	2	2
Employment status of parents interviewed		
Paid employment	14	11
Carer to child	5	2
Demographic details of children and young people		
Characteristics	All children/young people in study (n=16)	Young people interviewed (n=10)
Biological sex (female, male)	F=9, M=7	F=4, M=6
Age: mean age (years & month)	11, 5	12, 2
Range (years & months)	7, 4–15, 11	9, 2–15, 11
Primary diagnosis of tic disorder:		
Tourette's syndrome	14	9
Chronic vocal tic disorder	1	1
Chronic motor tic disorder	1	0
Average age of onset	4 years, 4 months (Range: 2–10 years)	4 years, 3 months (Range: 2–10 years)
Secondary diagnosis:*	16	10
Allergies	1	0
Anxiety**	12	7
Attention deficit disorders:	7	5
Inattentive subtype	6	5
Hyperactive subtype	1	0
Autism spectrum disorder (Level 1)	4	1
Dyspraxia	2	2
Eating disorder	1	0
Eczema/skin conditions	3	2
EDS	2	0
Emotional disorder	16	10
Insulin resistance	1	1
Mood disorder	4	2
Obsessive-compulsive disorder	5	4
Oppositional defiance disorder	2	1
PANS phenotype	1	0
Sleep disorders	3	1
Speech difficulties***	5	1
Taking prescription medication	13	9
Specialist medical care:		
Cardiology	1	0
Neurology	16	10
Psychiatry	2	1
Participating in therapy:	12	7
Dietician	2	0
Occupational therapy	9	5
Physiotherapy	1	0
Psychology	11	6
Speech therapy	5	1
Year of education: mean & range	Year 5 (3–10)	Year 6 (3–10)
Type of schooling:		
Mainstream without support	2	1
Mainstream with support****	12	9
Homeschooled	2	0
Handedness: right/left	15, 1	10, 0
Premonitory urge experienced (PU)	12	6
No PU experienced	2	2
Unsure if PU experienced	2	2
Have siblings	16	10
Siblings have a diagnosed NDD*****	9	6

ACT (Australian Capital Territory), NSW (New South Wales) and Vic (Victoria). The level of income is based on the study participants' post-code in relation to the information provided by the Census of Population and Housing: Socio-Economic Indexes for Areas (SEIFA), Australia, 2016.

\*As per Diagnostic and Statistical Manual 5 (DSM-5) [4] criteria for comorbidities.

\*\*Anxiety disorders include all forms of anxiety, such as generalised anxiety, social anxiety, separation anxiety etc.

\*\*\*Speech difficulties included stutter, articulation, pronunciation or social skills training.

\*\*\*\*School support includes the provision of additional time for classwork or exams, special accommodations such as writing exams in a different venue, ability to leave the classroom to tic, additional learning support officer involved, use of therapeutic strategies in the classroom etc.

\*\*\*\*\*NDD=Neurodevelopmental disorder.



questions as part of the member-checking process to ensure that the themes reflected the study participants' experiences and echoed their voices (Supplementary Documents 6 and 7). The questions ensured the findings relating to the themes were relevant, comprehensible and comprehensive and reflected the study participants' words and lived experiences [88,89].

Three study participants provided feedback relating to member checking. Gaining knowledge that other children with tic disorders reported similar sensory dysregulation experiences as their child or young person highlighted for these study participants that they were not isolated in their experiences. Through member checking, there was consensus on the comprehensiveness and relevance of all the themes. Regarding comprehensibility, members agreed with the wording used to describe all the themes except for the wording of the second theme by one study participant. This study participant, Karen (Interview PC011), explained that for them, her 13-year-old daughter, Keri's, perception or experience of the community environment hindered her participation, not the environment itself. Following this insight and knowledge, the wording of the second theme was corrected to reflect this feedback.

## Results: themes

One higher-order theme emerged: "sensory, emotions and tics; it's a ticking time bomb" was established, and three subthemes were identified. These subthemes were: (i) "we sacrifice and adapt to get daily activities done in the home"; (ii) "my child's experiences of the community environments hinder participation"; and (iii) "sensory preferences impact our entire family" (Figure 1; Table 3).

### Main theme: sensory, emotions and tics, it's a ticking time bomb

The families have described an interplay between sensory and emotional dysregulation that exacerbates the child/young persons' tics, resulting in emotional outbursts and reduced participation or engagement in tasks, reduced quality of life, and impacts affecting the entire family unit. Gretel, mother to 9-year-old Grace with TS, used the term 'ticking time bomb'. This term explained how, at any point, their child or young person's tics could be expressed as a result of their experiences of sensory experiences or emotional dysregulation. The 'explosion of tics' would result in further emotional dysregulation and thus further exacerbate the tics due to the impact of stress on increased tic expression. In 17 of the 18 interviews (94%) the impact of rage and emotional outburst by the child/young person with tics impacting on family members was identified.

This interplay was described by Gretel, mother to 9-year-old Grace with TS (Interview P007):

*"So, she's [daughter Grace] averse to heat. She hates the heat, and her tics go, um, like a hundred times worse in the summer. So does the rage. I think when she can't move that she gets more anxious, and then she'll tic more... Yeah. I think that's a big thing... Um. I honestly feel that if the sensory triggers weren't there, I think if they weren't so pronounced the tou, the Tourette's wouldn't be so bad. So, we see a huge increase in tics when she has to put clothes on. The whole neighbourhood hears us say F'ing C."*

Keri, 13 and 5-month-old with tics (Interview PC011), explained her experience:

*"Breathing. [the sound of other people breathing] I think is definitely a trigger. It makes me very uncomfortable, and then it like goes and turns into a tic."*

### Sub-theme 1: we sacrifice and adapt to get daily activities done in the home

Five families engaged in this study explained they lived their lives predictably and had become adept at identifying sensory triggers for their children. Parents and siblings avoid sensory stimuli, environments, activities, or events that may cause the child emotional distress resulting from sensory dysregulation. Parents also talked about adapting, accommodating and making sacrifices to ensure their child felt safe and comfortable to reduce sensory overload, emotional meltdowns, reduce tics and stress. Nine families stated that 'things have to be just' in their children's environment otherwise, this would lead to emotional outbursts.

Felicity, mother to 9-year-old and 2-month-old son Flinn (Interview P006): *"We learn to function. We're every day making the different meals and cutting off tags. It's just as soon as I buy his clothes now I know to have tags already off. And his dinner is always different to ours, as it has been for the last couple of years. So that's just part of our routine now. Very Stressful."*

Within the home environment, the different tasks were broken down into [1] dressing [2], mealtimes [3], hygiene and grooming and [4] sleep which were problematic due to various sensory stimuli. It was also identified that participation in activities was affected by temperature, such as the ability to do homework. Each of these tasks will be explored in detail, and additional quotes to support the findings are provided in Table 3.

### Dressing is a big challenge

Many aspects of clothing are known to be problematic from a sensory perspective, such as the texture or feel of the fabric ( $n=12$ ), the clothing tags ( $n=17$ ), seams in socks and wearing shoes ( $n=14$ ), wearing underwear and fabric stitching ( $n=17$ ). These same challenges were reported by the majority ( $n=15$ ) of the 16 families interviewed. In 17 of the 18 interviews, it was identified that parents assisted their children in wearing clothing by cutting out the tags or purchasing clothing with the tag details screen printed on the fabric instead. During 50% of the interviews, tight clothing was identified as problematic, and respondents mentioned purchasing clothing items that were much too large for their child, which overcame the issue of the clothing feeling restrictive. Thirteen families explained they had adapted the school uniform. In some cases, the children gained school permission to wear the sports uniform over the formal school uniform, as this was more tolerable. Ten children preferred to be naked than wear clothes.

Erin (mother to 10-year-old and 11-month-old Emma with TS) stated: (Interview P005): *"Um, but we've just learned to adapt to it, and we just buy. I only buy now what I know she'll like, or I'll let her pick it. Yeah, undies are a pain. Always have been. So we cut the tags off the undies, and from Best and Less, we buy these seam-free ones where the actual tag is like a stamped onto it, as opposed to having a, an actual tag."*

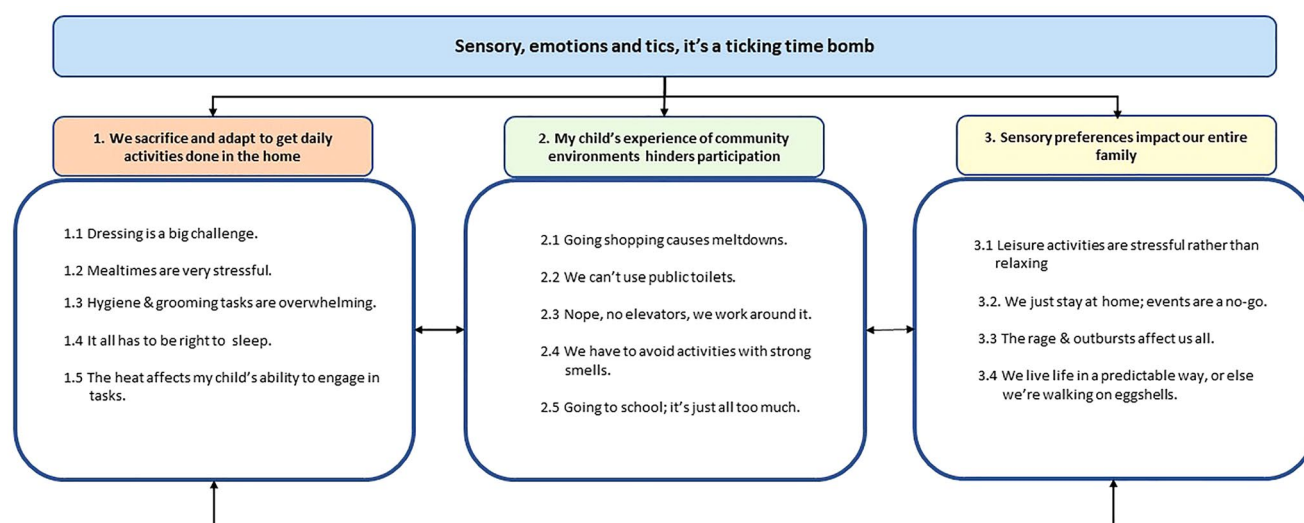
These sensory challenges to clothing are well documented in the literature and rated on the current sensory assessment measures [90–92]. This was further supported in this study, as in all 18 interviews, it was identified that getting children to wear clothing was a problem. The breadth of the sensory problem of dressing is broader than just problems relating to the feel of the clothing or fabric. Brian explained the impacts of his 10-and-a-half-year-old son, Brett, not being able to wear clothing (Interview PC002):

*"Use to make us late all the time because, you know, he just wouldn't find something that was comfortable, and it'd be an ordeal to get dressed. Yeah. Well, I took him to school in his undies once. It was that bad. [Laugh] Like, he just would not get dressed."*

Table 2. Details of each interview with each of the 16 study participants.

Interview	Interview format	Parent(s) (pseudonym)	Parent's biological sex	Second parent(s) (pseudonym)	Second parent's gender	Child (pseudonym)	Child's biological sex	Child present	Interview duration (min)	Primary diagnosis	Age of onset (years)	Age at interview (years: months)	Comorbidities	Medication
*P001 PC001	Parent only Parent & young person	Annie	F			Andrew	M	N Y	89 67	TS	5	9, 10	ADD & OCD traits	Clonidine
PC002	Parent & young person	Brian	M			Brett	M	Y	62	TS	3	10, 6	Dyspraxia, OCD traits	Catapres, Risperidone
PC003	Parent & young person	Carmen	F			Claire	F	Y	58	TS	5	13, 1	ADD, anxiety, dyspraxia	Concerta
PC004	Parent & young person	Debbie	F	David	M	Derek	M	Y	71	Chronic motor tic	2	9, 2	Anxiety	Fluoxetine; Quetiapine
P005	Parent only	Erin	F			Emma	F	N	78	TS	4	10, 11	Anxiety, ASD, mood disorder	Catapress
P006	Parent only	Felicity	F			Flinn	M	N	46	TS	3	9, 2	Anxiety	Risperidone, Guanfacine
P007	Parent only	Gretel	F			Grace	F	N	114	TS	8	11, 2	ADHD, anxiety, ASD, ODD	Aripiprazole, Cannabidiol, Fluoxetine
PC08	Parent & young person	Heather	F	Hamilton	M	Harry	M	Y	67	TS	5	13, 2	ASD, ADD, anxiety, ODD	Catapress, Lovan, Ritalin LA, Risperdal
P009 PC010	Parent only Parent & young person	Irma Heather	F	Hamilton	M	Inge Jesse	F M	N Y	52 116	TS TS	3 3	7, 4 13, 2	Anxiety, ASD, ADD, anxiety, OCD	NI Clonidine, Lovan, Ritalin LA Risperidone
*P011 PC011	Parent only Parent & young person	Karen	F			Keri	F	N Y	73 07	TS	10	13, 5	Anxiety, mood disorder	NIL
PC012	Parent & young person	Laura	F			Liam	M	Y	56	TS	3	10, 11	ADD, OCD traits	Atomoxetine
P013	Parent only	Maree	F			Megan	F	N	80	TS	3	14, 11	ADD, Anxiety, mood disorder, OCD	Clonidine, Sertraline
PC014	Parent & young person	Naomi	F			Natalie	F	Y	66	TS	4	15, 11	Anxiety, mood disorder	Abilify Lovan
P015 PC016	Parent only Parent & young person	Olga Penny	F F			Olivia Phoebe	F F	N Y	47 67	TS TS	6 3	9, 4 12, 6	OCD Anxiety.	Nil Fluoxetine

The interview is coded as either PC or P. PC identifies that both the parent and the child were present in the interview, and a code of P identifies only the parent was present. \* Two families were interviewed twice as the parents wanted to be interviewed in the absence of their child (P001 & P011) and then again with their child present (PC001 & PC011). One family had two children with a tic disorder, and both children participated in the study (PC080 & PC010). All study participants identified as being Australian in relation to their ethnicity, except the families of PC080 & PC010, who identified as European. All children/young people engaging in this study had a primary diagnosis of Tourette's syndrome (TS) except Derek, a 9-year-old who was diagnosed with a chronic motor tic disorder.



**Figure 1.** A diagram depicting the themes identified in this study. There is one higher-order theme: “sensory, emotions and tics, it’s a ticking time bomb” and three subthemes: (1) We sacrifice and adapt to get daily activities done in the home, (2) my child’s experience of community environments hinder participation and (3) sensory preferences impact our entire family.

To tolerate the continuous feeling of wearing clothing, families have adapted to having their children dress and undress multiple times throughout the day. Sixty-two percent of children can only tolerate clothing for a limited time, such as when in public or essential. Nine-year-old Derek (Interview PC004) explains his routine of putting on clothing when leaving the house, but the moment he has the opportunity, such as in the car or at home, he takes off his clothes again.

*“When my Nan comes over to pick us up, um, ... I wait for the last second to go to the car and then put them [clothes] on. And then when I’m in the car, I take them off and then put them on [to get out of the car] and then at my Nan’s house, I then take them off when I’m inside.”*

For nine-year-old Grace, being naked in public is preferred over the sensation of clothing on her body, as described by her mother, Gretel (Interview P007). Due to the difficulty tolerating the feeling of clothing on her skin, her preference for being naked makes it impossible for her mother to have people come to the home to visit.

*“Even if that means being naked in front of a crowd of people. Um, that’s, that’s a big thing. Cause after we leave the beach, I can’t go and get milk or anything. We have to come straight home with a naked Grace in the backseat. Um, and what it means is that we’re restricted to the home, and she doesn’t wear clothes. So, people can’t come in.”*

The inability to tolerate the feeling of clothing outweighs the need to wear appropriate clothing. During the interviews, eight children explained that they would rather be cold than wear clothing. It was not that they did not feel the cold, but rather the intolerance of the fabric surpassed the need to be warm in cold weather. Annie, mother to 9-year-old Andrew (Interview P001), explained:

*“He [Reference to son Andrew] really doesn’t like wearing clothes. He likes to walk around in his underwear, and he would do that year-round if we didn’t insist that he put something more on in the colder weather. Um, and in the colder weather even, he will only wear short sleeves [Pause], including to school. He wears the summer uniform year-round. [Laughing] He will have a shower or bath and then put [his] underpants back on until he has to go out or somebody comes to the door. There’ll be a mad rush.”*

When purchasing clothing, 12 families mentioned that buying clothing for their child with sensory sensitivities was a struggle.

It was identified that money was wasted on clothing items children would not wear. The solution was only to buy clothing items chosen by the children. It has to be appreciated that taking children with sensory sensitivities to shopping centres to find clothing items of their preference comes with its challenges. Seven families identified that the sensory overload from shopping centres causes meltdown. This will be further addressed in theme 2.

Brian, father to 10-year-old Brett (Interview PC002), explained: *“So, this is the big one. You can’t, can’t buy clothes for him and say, here you go, you have to take him to the shop, and he has to try it on. He’s got to feel the material. Then he will decide to buy it or if he wants it, and then we’ll buy it. But if he turns around and says, I don’t like the feel of it, even though it fits right, there’s no point buying it because he won’t wear it.”*

Although parents make financial and time sacrifices to ensure they can provide clothing their children can tolerate, it is evident that parents still feel shame at how their children are presented in public. The feeling of guilt is attributed to the concern that others may think they are not adequately providing for their children when they are not appropriately clothed in public. However, in reality, their children are wearing the clothing they can tolerate, even if this means wearing old, worn-out clothes that no longer fit, clothing not suited to the appropriate weather or occasion, or scantily clothed with possibly no shoes, socks and so forth.

Gretel, mother to 9-year-old Grace with TS (Interview P007) stated: *“So on a carer’s pension when you buy clothes for your kid, but then when they won’t, you’ve got to spend more money. And not only that, while you’re waiting to find more money to spend and try and find clothes that they will actually wear, that’s a really tough thing. You can’t go anywhere... And that’s really, really hard because I sacrifice a lot to give her really comfortable shoes. It’s winter. And I just said, okay, my child is out at respite care with no shoes and no jumper. And everyone probably thinks I’m horrible and her t-shirts are disgusting.”*

### **Mealtimes are very stressful**

Mealtimes as a family is a very stressful activity, resulting in nine families reporting that they eat meals separately to accommodate their child’s sensory preferences. Families reported feelings of loss and being “unconventional and different to other families,” resulting in needing “a different parenting approach to other families.” This is reflected in the quotes by the following families:



Table 3. Quotes from parents and young people to provide evidence of themes and subthemes.

Study participant & interview details	Quote
Theme 1: We sacrifice and adapt to get daily activities done in the home	
1.1 Dressing is a big challenge.	
David (Father), PC004	<i>So, when he, when he goes to bed, he'll, he'll put pyjamas on, but when he's ready to go to sleep, he has to take all these clothes off, and he's much more comfortable that way... So, what's happened a few times is he'll be, he gets agitated, and then the clothes become more of an issue. Um, and things go downhill quite rapidly.</i>
Brian (Father), PC002	<i>Look, he will. He will. More often than not, honestly, go nude... Oh yeah. So, he went through a stage where he wouldn't wear anything to bed, and we were fine. You know, he's in bed, he's under the cover or whatever, but. But I think that is this is part of his condition that we can say he doesn't like. Definitely, that's a big, big thing. And it's always been a big thing since he was little.</i>
Gretel (Mother), P007	<i>That's a problem. Most of the time, T-shirts just need to be cotton. Um, but yeah, nothing on the inside and no tags. So yeah, seams, tags, mesh, yeah. Anything touching the skin. ...she won't wear underwear. Cause it's tight.</i>
Liam (10 year-11 month old with TS), PC012	<i>But like, like socks, some socks just hurt.</i>
Harry (13 years and two months old with TS), PC008	<i>I hate tags.</i>
Phoebe (13 years and two months old with TS), PC016	<i>'I don't like the tags because some tags are really sharp and kind of cut my legs and I don't like the feel of the tags rubbing against my back.</i>
Jesse (13 years and two months old with TS), PC010	<i>Um, if I've just had my nails clipped, socks are complete goddamn hell. (The seam) It's that rubbing against it.</i>
Carmen (Mother), PC003	<i>And, you know, she carries on about tags all the time... Yeah, we cut them out.</i>
Brian (Father), PC002	<i>So, this is the big one. Yeah, he's [son Brett], ah, the seams in his clothes, like, you buy him a nice pair of expensive tracksuit pants, and it's got that stitching on the seams on the inside. Won't wear it. You buy the cheap two-dollar fleecy ones, loves it. The stitching across the toes, yeah, [is] a big problem for him. Yeah. And your tags on your shirt.</i>
Erin (Mother), P005	<i>She does have a pair [jeans], but we have to wear, you know, opaque tights underneath that are really silky. Yeah. So, she, if she has to wear jeans, she will wear tights underneath. So, she doesn't feel it. Um, all her clothing is a couple of sizes bigger.</i>
Carmen (Mother), PC003	<i>Finding underpants at one stage was a real challenge. So, we found a particular type, and we have had those for about four years.</i>
David (Father), PC004	<i>...he was stuck on the one pair of undies, and I found some... So, he had about six pairs of them that he's worn for about the last three or four years. And it got to a point where they were just a piece of Holy rag,</i>
Felicity (Mother), P006	<i>Very hard. Very hard. Certain shirts, like I brought him a shirt the other day that I thought he'd loved because it was Minecraft. And he's obsessed with Minecraft, but because it had a pattern through it that wasn't in the shirt, it was actually built into it, so the stitching or it had lines across it that you could feel he refused to wear it... It's a big issue at the moment.</i>
Gretel (Mother), P007	<i>She, she will wear fluffy clothes. If I buy normal pants or jumpers, she won't wear them. She'll just go naked. Which is something else she enjoys.... I bought her a pair of Nikes, and she won't wear them.</i>
Heather (Mother), PC010	<i>Um, it takes a lot to get him a pair of shoes, and even then, you know, we have bought shoes, brought them home, and he just never wears them.</i>
Laura (Mother), PC012	<i>We just gave in, you know, the options, and he had to try them on like we just couldn't buy them off the rack. He tried them on, and he picked the ones that [he] felt that he liked the best, but no, we don't, we don't actually shop for clothes very much, yeah.</i>
Carmen (Mother), PC003	<i>I think the fabric annoys her; we have to find the right one.</i>
Claire (13 years and one month old with TS), PC003	<i>I don't like certain fabrics.</i>
David (Father), PC004	<i>So, school clothes are harder than others.</i>
Irma (Mother), P009	<i>She [Inga] always wears a long-sleeve seamless, um, shirt underneath her winter uniform 'cause her winter uniform is quite heavy, and it has quite a lot of seams and things like that and pleats and stuff like that and pleats really bother her.</i>
Carmen (Mother), PC003	<i>Um, at her old school, she would never wear the skirt or the stockings. She would wear just pants, um, and sometimes socks were an issue.</i>
Heather (Mother), PC010	<i>Yeah. So, he wears his tracky dax [track suite pants] to school even if it's not sports day, and they let him.</i>
Felicity (Mother), P006	<i>So Flinn wears plain white polo shirts from Best and Less now because when he feels this stitching of the school emblem, he refuses to wear it.</i>
Andrew (9 years, and ten months old with TS), PC001	<i>Hot. I feel like really hot. After my school day, after we walk home, I really want to take off my, um, my shoes. And then it feels really good because I've had them on for like five hours. Um, so in wintertime, I will just wear shorts and a t-shirt.</i>
1.2 Mealtimes are very stressful	
David (Father), PC004	<i>It was pretty stressful for you [talking to son Derek] at dinner time, usually wasn't it because, um, you know, we'd, we'd try and always offer something different for him to try.</i>
Karen (Mother), PC011	<i>... and we can't have a family meal together anymore. She eats in her room most nights...</i>
Laura (Mother), PC012	<i>And I would obviously try not, you know, eat around him or eat like I was chewing gum next to him the other day, and I realised that's a silly thing to do. So, you know, you just get it built into you that there are certain things that you just try and avoid.</i>
Liam (10 year-11-month-old with TS), PC012	<i>When I hear this happens rarely, but like when I'm eating breakfast or something when somebody bites on the metal (Reference to cutlery). It makes this really; really bad noise, and I just don't like it at all</i>
Phoebe (13 years and two months old with TS), PC016	<i>I hate cutlery scrapping on plates.</i>
Andrew (9 years, and ten months old with TS) PC001	<i>Oh, I hate it when like two utensils touch and they scarp.</i>

(Continued)

Table 3. Continued.

Study participant & interview details	Quote
Karen (Mother), P011	...but the thing that's impacting for the most at the moment is the misophonia... Um, well, uh, pretty much most interactions my daughter has with her dad, Ken, her um she will yell, or you know have a tic response. Particularly if it's around mealtimes. Um... That's the worst uh um [Pause] yeah, whenever they are chewing, or Ken is breathing at the moment, um, with the pandemic and the lockdown, it's been particularly challenging for Keri because she can't get away [laugh] and Ken's working from home, and so she has um been asking for Ken to sleep on the couch... um yeah, it tends to be more loud noises and the swallowing, chewing um and breathing...Oh, uh [Pause] not so much. We've all become so conscious of it that [Laughs] we just try not to swallow; we try to breathe shallowly. [Laughs] It's just ridiculous.
Debbie (Mother), PC004	We tend to, um, we tend to structure Derek's dinner time a little bit differently. So, Derek will have, um, uh, different portions through like throughout the night. Um, and it just keeps him happier. So, he might have a bowl of, um, he likes raw carrots. So, we just chop up like raw carrot, and he'll eat that. Um, and he eats a lot slower, and then I'll make him a corn on the cob, and he'll have that. And then he'll either have, um, like cheese and bikkies or he'll have toast or something like that. So, it's all staged, it's not all on one plate, and it's, um, just calmer.
David (Father), PC004	It's just toast, corn and carrots every night. (Reference to all their son Derek will eat).
Penny (Mother), PC016	Um, she is not a very good food eater. She [Pause] she doesn't like to try foods. She doesn't like a lot of foods. Um, I think we are a very plain eater.
Phoebe (13 years and two months old with TS), PC016	Um, if I see something I don't like, I sometimes try it, but sometimes I like it because of the taste and sometimes because I don't like the sort of taste, it's more the taste... Like the fat on meat makes me feel ill. I don't know why I don't like food, because there is a lot of food in the house. But some foods I don't like, so I don't bother eating it.
1.3 Hygiene & grooming tasks are overwhelming	
Hamilton (Father), PC010	Yeah, the sensory stuff in the mornings is just insane. (Reference to the morning grooming tasks)
Felicity (Mother), P006	Yes. That is a struggle to the point where we say a, um, the one barber, and he's really, really good with Flinn. I think he has tics himself. So, he understands what it is, but so he takes his time with Flinn, and he talks to him and tells him it's alright, but just the build-up of getting his hair cut is a struggle.
David (Father), PC004	Yeah, so he's, um, his nails, he, he won't. If we say, can we cut your nails? No, no, no. Um, and if we do it while he's asleep, he wakes up the next morning, and he knows instantly that they've been cut, and his disposition is somewhat, hmm, unpleasant, you might say.
1.4 It all has to be right to sleep	
David (Father), PC004	So, when he, when he goes to bed, he'll, he'll put pyjamas on, but when he's ready to go to sleep, he has to take all these clothes off, and he's much more comfortable that way.
Erin (Mother), P005	He'll only still sleep in like a t-shirt, but we've just got to put extra layers on the bed. So, she wants to be a warm but not restricted.
Phoebe (13 years and two months old with TS), PC016	That's because the sensory thing because sleeping, I like; um, the sound of rain really helps me sleep. If it is not raining, I put on a rain sound, like music. Yeah, and that helps me.
Keri (13 years and five months old with TS), PC011	Like if I am too hot, um, it really does, like also, um, in my room at night it gets quite stuffy, and that really makes me very anxious. I am not very good at coping with lots of heat.
1.5 The heat affects ability to engage in tasks	
Maree (Mother), P013	Um when. The year that she was, um, diagnosed, in year six, yeah, I definitely did see in summer because that was around the time, um, that she definitely was quite heightened.
Phoebe (13 years and two months old with TS), PC016	Um, I think heat affects my tiredness because I use all my energy to not be hot.
Gretel (Mother), P007	Um. Cooler temperature. We see, like I see, a 50% improvement in everything when it's cooler. My dad came over a month or two ago, and he said, oh, you know, huge improvement in Grace. They're trying to give me hope and everything. And I just said summer's over. You know, he tried to tell me everything like he's preaching, you know, but no, it's just, you remove heat from the equation, and she's so much better.
Theme 2: My child's perception of community environments hinders participation	
2.1 Going shopping causes meltdowns	
Hamilton (Father), PC010	I think part of the problem, I think, is that when we go shopping, you just want to get out of the shops, you get to a certain point you've just got to leave and then it doesn't matter.
Heather (Mother), PC010	There will be lots of reasons that he doesn't want to be there. It's either too peopley. It's too loud. You know, like you go into some shops or you walk past them, and music is blaring and stuff like that.
Hamilton (Father), PC010	Also, with noise or just movement in shopping centres he, you can see him start to build up sometimes and then he will have a meltdown and then it takes a while for him to settle down as his biochemistry settles down.
Erin (Mother), P005	Almost every time we're at the big shopping centres, whether it's right at the beginning or halfway through. She was just grabbing me and squeezing me. She says it's cause there's too many people. Um, and so we'll walk for a little while hugging each other, and she'll go, it's time to go... sometimes she just gets overwhelmed...It could be anytime during that trip. She'll just feel this like she's overwhelmed. Too many people, too much going on, and she'll just walk with both arms around my waist, and I'll sort of put one arm around her and just go out for a little while until she overcomes it, or we just leave because she's had enough...Yeah. And the only times I'd ever seen it or, um, the shopping centre, like in a Westfields or something like that, she's really, closed in spaces, lots of shops, lots of noise, lots of people bumping her. Yeah, it's too much.
Carmen (Mother), PC003	I think definitely bigger crowds of, with a mix of people, um, so like going to a place or an event, not necessarily going to the shops, but going to um, like a school assembly or [Pause] um, a party at someone's house or to somewhere that she's not comfortable with or she doesn't know or it's a place she doesn't know as well.

(Continued)

Table 3. Continued.

Study participant & interview details	Quote
Maree (Mother), P013	<i>Yeah, all those sorts of um things, anything, yeah, like loud noises, I suppose and lots of people. Like, sometimes when we are out and about, there is lots of um, like a crowd, she yeah doesn't particularly like that sort of stuff.</i>
Naomi (Mother), PC014	<i>She doesn't do well in big crowds. But somewhere like the Sydney Royal Easter Show or the shops at Christmas time, she doesn't do very well with that.</i>
2.2 We can't use public toilets	
Annie (Mother), P001	<i>from the time he could talk, one of the first things he didn't like was the sound of a hair dryer in a public toilet cause he would say, 'Don't use the hand dryer'.</i>
Carmen (Mother), PC003	<i>but she used to be absolutely petrified of like hand dryers in public toilets.</i>
Karen (Mother), P001	<i>Yeah, that, yeah, she is really scared of those. [Reference to hand dryer in public toilets]. She actually hates those.</i>
Hamilton (Father), PC008	<i>The other thing that really annoys you centrally is, is, um, um, hand dryers the air, hand dryers. They drive you absolutely nuts. They drive me insane.</i>
Harry (13 years and two months old with TS), PC008	<i>He puts his hands over his ears, and he screams and has to get out. (Heather – Mother PC008): The Dyson ones in particular. (Hamilton): Yeah, those ones are really shrill.</i>
2.3 Nope, no elevators, we work around it	
Natalie (15 years and eleven months old with TS), PC014	<i>I don't like escalators. I don't like heights in general.</i>
Karen (Mother), P011	<i>Yeah, and she lifts; she is really terrified of lifts as well. [Laughs]... she doesn't like the sensation, I think.</i>
Keri (13 years and five months old with TS), PC011	<i>I really don't enjoy heights. I kind of I'm afraid of elevators and things like that.</i>
2.4 We have to avoid activities with strong smells	
Maree (Mother), P013	<i>Yeah, I think I do believe she is, um, pretty sensitive; she can smell something like I have no idea what you are talking about [Laughs]. I can't smell anything.</i>
2.5 I don't want to go to school; it's just all too much.	
Heather (Mother), PC008	<i>So, he could never be in the hall. Because of like the noise in the assembly</i>
Natalie (15 years and eleven months old with TS), PC014	<i>Um, my school is very loud. So, I don't find school assemblies overly bad because I can tic there. But sensory wise it does get a bit over-stimulating sometimes.</i>
Keri (13 years and five months old with TS), PC011	<i>Sometimes if there is like a lot of um noise in the classroom, it can bother me.</i>
Irma (Mother), P009	<i>The playground, the school playground, she finds the playground really tough.</i>
Maree (Mother), P013	<i>Um, well, the school, her school, um, were doing assembly, so yes, that was a bit of a difficult spot. So and also at school too, year seven and year eight, they were doing like woodwork and all that sort of stuff and the noise of the machinery in there she would um, she would just scream because it was just yeah irritating her.</i>
Carmen (Mother), PC003	<i>But she used to like I remember. She didn't like finger painting</i>
Heather (Mother), PC010	<i>He wouldn't even let you, you know, put his hand in the plaster or anything like that. Jesse wouldn't let us do it. He just screamed and screamed and wouldn't let us do it.</i>
Theme 3: My child's perception of community environments hinders participation	
3.1 Leisure activities are stressful rather than relaxing	
Gretel (Mother), P007	<i>Vacuum cleaners are generally fine, but the TV can't be up too loud. I can't put the radio in the car loud... We have this. Um. Yeah [Pause] she's, even in the home, it's a thing... It's more just the loud noises. Yeah. Like music or TV or the radio.</i>
Penny (Mother), PC016	<i>Um, what about the movies, watching TV? That's an issue.</i>
Maree (Mother), 013	<i>Um yeah, I think the volume on the TV.</i>
3.2 Car trips are challenging	
Gretel (Mother), P007	<i>Um, like, even if the TV is up a little bit too loud, she will actually come along and turn it down.</i>
Felicity (Mother), P006	<i>can't put the radio in the car loud</i>
Debbie (Mother), PC004	<i>(Laura – Mother PC012): We have a bit of a problem in the car with the sounds because they eat there in close proximity of one another. It's like if we have the music on in the car too loud for him. What about the car seat? He doesn't like the car seat. (David – Father-PC004): So, I've got just the normal fabric car seats in my car. And, um, and he was having an issue with that. And then I put some seat covers on, and that lasted for a day or two. And then he didn't like those.</i>
3.3 We just stay at home; events are a no-go	
Carmen (Mother), PC003	<i>[Pause] I don't know. Um. I think definitely bigger crowds of, with a mix of people, um, so like going to a place or an event, not necessarily going to the shops, but going to um, like a school assembly or [Pause] um, a party at someone's house or to somewhere that she's not comfortable with or she doesn't know or it's a place she doesn't know as well. Discos were always horrible at school. it's too much or fireworks and stuff like that.</i>
Felicity (Mother), P006	<i>She doesn't do well in big crowds. But somewhere like the Sydney Royal Easter Show or the shops at Christmas time, she doesn't do very well with that, nor do I, for that matter.</i>
Naomi (Mother), PC014	
3.4 The rage & outbursts, we're walking on eggshells	
David (Father), PC004	<i>if devices get taken away from him and said no, no, he can't have them. Um, he does get really angry really quick and, uh, gets quite violent at times as well.</i>
Felicity (Mother), P006	<i>so when he gets angry or very emotional, it's not in with his tics, it's just. It could be the slightest thing. Like I say no to him. And then we have baby gates around our house cause we have the baby, and he'll slam the baby gates to the point where it breaks off the, it comes loose off the wall, or he goes in his room and destroys his bedroom to the point where I've got to go in and clean up everything around and all.</i>

(Continued)

Table 3. Continued.

Study participant & interview details	Quote
Inga (Mother), P009	<i>Um, sometimes it can be regulation where she will just come home and burst out into tears, and we're not sure what's going on, and that can happen all week..., but a lot of the time, we miss the early signs, or by the time we notice somethings up it's almost to its kind of already too far gone almost. Absolutely, yes, she much harder than a three-year-old emotionally [laughing] but, um, which sounds horrible, but it just is.</i>
Heather (Mother), PC010	<i>Well, he was having rages from a really, really young age.</i>
Laura (Mother), PC012	<i>I think it's, I think you just, um, he just doesn't have the controls in that anger department, or it's a, you know, he doesn't know when to put the brakes on, and he can't put the brakes on and in certain situations he's got to let it out, and usually, that's at home with us, which is good because otherwise, it could be at school. Um, which would be worse.</i>
Penny (Mother), PC016	<i>Emotions can get quite wild, but um, yeah, I don't know whether that's. I guess I am assuming it's the age bracket, really. Um, but yeah, I guess yes, she can get angry pretty quickly. Yeah, but I don't know. [Laughs].</i>
Phoebe (12 years and six months old with TS), PC016	<i>Um, if I am trying to keep my anger down, I sometimes do it too, like, push the pain away. The pain from the anger, like I am trying to put my anger away.</i>
Natalie (15 years and eleven months old with TS), PC014	<i>Yeah, until something goes wrong, and then I have a little hissy fit. I used to I used to have really severe rage attacks... I, literally anything. The smallest little argument. Dad and I used to have a really not great relationship. Um, I yeah, it was to the point where I. Him and I actually went and seen my psychologist, Neil, um, to try and fix things because our relationship was not was not what it is today and what it needed to be. You know I was screaming at him most days. You know I have told him that I have hated him. I have told him that I want to never talk to him again, and I hate the fact that I have done that.</i>
Naomi (Mother), PC014	<i>But yeah, it could have been anything that was a trigger. Anything you know, anything minor from you know someone put their plate in the wrong spot to you know someone looked at her the wrong way, and they were pretty significant meltdowns. For no apparent reason so. Yeah, sometimes it is hormonal, whatever it is, but yeah. Like there is no warning, and we just sort of sit there and go, oh well, here we go.</i>

Maree, mother to 14 years and 11-month-old Megan (Interview P013), reflected: *"We have now gotten to the point where, and I know it's probably a really bad setting, but none of us sort of really eat together anymore because it's just too, too stressful."*

Food texture, taste, and smell are known sensory issues relating to food sensitivities and often result in families having to cook separate meals. In 17 interviews (94%), families identified their child tolerated a limited range of foods. Two families engaged a dietician to assist with their concerns relating to their child's nutritional intake. In addition to these sensory challenges around meal times and food, a broader sensory issue relating to food and meal times was identified. In 61% of the interviews, families identified that the sounds relating to eating were problematic, resulting in stressful mealtimes and eating together as a family impossible. These include i) the sound of other people chewing food or swallowing, ii) slurping a drink, or iii) the sounds of cutlery scraping on plates.

Keri (13 and 5-month-old with tics) (Interview PC011) explained: *"Anyone chewing sounds. Ah, sometimes it stops us from having family meals."*

Sensitivities relating to food caused seven families to be unable to eat outside of the home environment, such as at restaurants or parties, due to the sensory input from the environment and the lack of acceptable food options for the child.

Felicity, mother to 9-year and 2-month-old Flinn (Interview P006), explained: *"Yes, so we've given up on going out to family restaurants. If me and my partner do want to go to a restaurant, it's just us two now because taking Flinn is just, but taking Flinn off to a restaurant, it's just a struggle."*

### **Hygiene and grooming tasks are overwhelming**

Six families reported that the morning and evening self-care and grooming activities cause their children distress and are emotionally overwhelming due to the sensory input experienced. These

activities included but were not limited to bathing, washing hair, brushing teeth, and cutting their nails and toenails. Due to the distress and time these self-care tasks take to complete, families are frequently late for work and other activities. Seven parents explained that they support their children in completing daily routine tasks by providing particular products to try and reduce the sensory issues their children experience.

Karen, mother to Keri (13-year and five-month-old with TS) (Interview P011): *"Actually, Keri finds just the whole package really stressful. And overwhelming, the whole the getting ready, all the steps, um, needed um, so as a whole it is quite stressful for Keri and feeling stressed and agitated and oh I got to get there on time, that is a big thing."*

For some families, challenges around self-care activities relate not just to the child partaking in the task but also to the child's sensory experience of family members participating in self-care activities. Irma, mother to 7-year and 4-month-old Inga with TS, (Interview P009), expressed the difficulty she and her husband, Ian, have with using deodorant, as Inga struggles with the smell of them applying deodorant. The lengths the family goes to accommodate Inga's needs were outlined.

*"So even Ian's [father], Ian's deodorant. He can only put it on outside. [Laughing] Because when he puts it on inside, that's all she [Inga] can smell for half the day, and she complains about it the whole day. So [Laughing]... Even mine smells. He's tried a fair few different kinds, so it's not like he hasn't tried different kinds, she just doesn't like it, and I use a natural one."*

Through these interviews, it was highlighted that for young girls who have reached puberty, the feeling of menstrual products is a problem, to the extent of impeding leaving the house or attending school.

Karen, mother to 13-year and five-month-old daughter with TS, (Interview P011): *"But now she is actually, [she] just got her period in the past couple of months, and so that is really, really challenging, she [Keri]*



*can't stand the feeling of that. Yeah, I have tried so many things, and we find we have gotten onto a couple of products, but yeah, she's like so happy that it's lockdown [reference to COVID-19 lockdown] because she has got her period again."*

### ***It all has to be right to sleep***

Several aspects concerning the sensory environment have to be controlled by parents to enable their children to feel comfortable and assist them in sleeping due to their child's sensory needs and sensory dysregulation. Six families explained this included the feeling of the bedding, ensuring the fabric does not make a rubbing sound (such as when the material of the sheets rubs together), and the type of clothing or lack of clothing the child needs to wear.

Gretel, mother to 9-year-old Grace with TS (Interview P007): *"Yes. Um, she didn't want me putting flannelette sheets on in winter because she likes the sheer cotton feeling. Um, but because she sleeps naked and only with one doona and I had to buy that doona in a hundred percent cotton and a certain type. And she makes me shake the, I have to shake the doona and make sure the quilt is distributed evenly every night, before bed. Mmm. And yeah, the sheets, she doesn't, she doesn't like me changing them very much. If the sheets change, everything is a problem. Anything that touches her skin is a problem. She doesn't have a top sheet because of that, so she just has a bottom sheet, and she has like, um, a light blanket and then a heavier blanket."*

In seven interviews, parents aided their children in sleeping by providing a sensory-supportive environment. This includes offering soothing sounds such as the sound of rain, ensuring the room temperature is comfortable, and the weight from the bedding is the right feel.

Karen, mother to 13-year and five-month-old daughter Keri (Interview P001): *"She just gets too hot, all the time, like she is always hot and, um, can't cope with it, it just feels so stuffy and um, just she doesn't sleep with very much on at all because she is just feeling hot all of the time. And um, and has to have a fan blowing on her all summer and often ice packs. Um yeah. Our bedroom is fairly close to Keri's bedroom, and she, even though she actually sleeps to a rain soundtrack to block any noise, and I am sure that she cannot hear Ken [reference to Keri's father] breathing through that, but she feels that she can, and so then she gets agitated and can't sleep, and so poor Ken has been on the couch for a few months now."*

### ***The heat affects my child's ability to engage in tasks***

The environmental temperature was not only identified as causing the child sensory dysregulation discomfort but also impacted the ability of the child to participate in tasks, and three families identified heat exacerbated tic expression. One parent reported scheduling their child's tasks during the day to accommodate the weather, thus ensuring that the tasks may be completed in the cooler parts of the day. Gretel, mother to 9-year-old Grace with TS (Interview P007), explained the observations in Grace's functioning when it is a hot day:

*"Um, when it's hot, yes. It changes how our things are done. Um, she's [Grace] home-schooled. So. We have to try and do her schoolwork before she overheats and then just let it go for the afternoon. Um, everybody walks on eggshells. It's basically how can we manage not to piss off Grace but still get her to learn things like basic chores, some schoolwork, [and] attend appointments. It's, it's hard."*

## ***Theme 2: my child's experience of the community environment hinders their participation***

### ***Going shopping causes meltdowns***

Seven families identified that crowded places that are noisy and loud and embody multi-sensory experiences are challenging for

children with sensory dysregulation. Such locations include shopping centres, parties, and social events. Due to children's emotional distress at being in these environments, parents explained that they frequently make accommodations by shopping online or avoiding events altogether. Not all shopping can be conducted online, especially when buying clothing for their child, as they need to feel the fabric to ensure that it meets their tactile needs, or else the clothing will not be worn. Gretel, mother to 9-year-old Grace, relayed their experiences (Interview P007):

*"And then the shopping and stuff too. That's off the wall, [laughs], you know. Um, yeah, that's hard. We have to go shopping sometimes, I can't do everything online, but the sensory stuff with that, it's not sensory seeking. It's more avoidance. So, she is constantly overwhelmed by loud noises as well. She's very loud herself. Um, and just being in the proximity of people. But when we went to our tiny little shop, she couldn't, she went in once and came out, and she just beat the crap out of me."*

### ***We can't use public toilets***

Community outings need to be planned around their child's toileting needs, as for eleven families in this study, their children are unable to access public toilets. Public toilets pose a problem due to the sounds made from the toilet flushing, the loud noise from the hand dryers and the smells ( $n=11$ ) and the smell ( $n=2$ ).

Felicity (Mother P006): *"He [Flinn] refuses to use public toilets... He just says they smell bad."*

Penny, mother to 12-and-a-half-year-old Phoebe (Interview PC016): *"I think noise has been a big thing for Phoebe from the beginning. She would block her ears when you flush the toilet and run away so she can try, so she can try, and block both ears whilst she presses the button." Phoebe (12-and-a-half-year old with TS) (Interview PC016): "Because it's always very loud. Um, like, I can't really be that far away when I flush the toilet. Although I do it a lot, it gives me a fright when I do it. Because of the noise level. Um, the yelling. Um, I feel a little bit freaked out about stuff. Yeah. I know, but it keeps scaring me."*

### ***Nope, no elevators, we work around it***

Escalators and lifts in community settings pose a problem to some children and young people because they fear heights and dislike the feeling of being on a moving surface, and this experience was reported in 6 interviews. It is appreciated that parents accommodate their children's needs around using escalators and lifts in various ways, such as [1] using the stairs [2], choosing different shopping centres without lifts or escalators [3], parking on the same floor as the shop they want to access in a multistorey shopping centre or [4] supporting their children with strategies to manage to travel on the escalator or lift. Maree (Interview P013) explains that she uses the escalator while her daughter Megan (14 years and 11 months) uses the stairs to accommodate her daughter's dislike of escalators.

*"Yes, definitely escalators. She would go to the stairs over an escalator if there was a choice next to each other. [Laughs] Because she does that at Sydney Central Station, she will go up the stairs. I'm just like, I'm going up the escalator."*

### ***We have to avoid activities with strong smells***

Smells that children find overwhelming or offensive result in children ceasing to partake in activities or be in particular environments (identified during 4 interviews). For instance, Keri (13-year and five-month-old with TS) (Interview PC011), a young person engaged in this study, refuses to attend appointments with her



treating Ear, Nose and Throat Specialist due to the smell of his breath. Irma explains how accommodating her 7-year and four-month-old daughter with TS, Inga's sensitivities to smells in the environment, have alternated and impacted their lives significantly (Interview P009).

*"If we outside and there's smoke or something like that, she gets quite upset with that, so smells do impact her, yes. So I will quite often avoid that area because I know how upset she gets, and then we trapped in a car, and it can be quite, um, hard for her, she gets, she, it doesn't work. Well, most of the time, we will move because I know that it just escalates. So, if we don't do something about it, it can just get worse, and she can get more uncomfortable and then, um, her anxiety can grow. I know it has definitely come up in our lives a lot. So, we have to alter our lives, yes."*

### ***I don't want to go to school; it's just all too much***

There are multiple facets to the school environment being recognised as a very challenging place for children ( $n=13$ ) with sensory dysregulation. Some of these factors were classrooms and the playground being identified as too loud, the tactile element to certain activities, such as arts and crafts or sensory play, and this being offensive to children sensitive to getting their hands dirty and extra-curricular activities such as school discos being overwhelming. Attending school assemblies is a difficult environment for many of our study participants from a sensory and tic perspective. These difficulties relate to the loud and echoing environment, the expectation that children need to remain seated and still, the close proximity to other people in their space and having to suppress tics or being concerned that peers will notice their tics. As a result, parents explained that getting their children to attend school was difficult. In two cases, parents home-schooled their children so they could provide an environment to support their child's learning and sensory preferences.

Heather, mother to 13-year-old Jesse (Interview PC010): *"It used to be hard to get him to go to school."*

Annie, mother to 9-year-old Andrew, explained (Interview P001): *"School assemblies are difficult for him. Generally, I would say the classroom is his least favourite place, although he really loves this teacher. But even with all those support strategies in place, he still finds the classroom difficult."*

### ***Theme 3: sensory problems impact our child and family***

Even though it is the child or young person who experiences sensory dysregulation, the interviews highlighted the functional impact and toll that affects every aspect of the entire family's function, daily activity and quality of life. In 17 interviews, families explained that social events were a "no go" due to the crowds, loud noises and other sensory input. Karen, mother to 13-year-and five-month-old Keri (Interview PC011), provided insights into how their entire family's lives are impacted by Keri's challenges with the sensory input from her environment:

*"It's horrible. I look at photos of how we were two and a half years ago, and I can't believe it's the same family [laugh]. [Sigh]. Like, uh, it's just awful, we can't go camping, we can't do that anymore. You know going in cars are really difficult, it's just awful, and we can't have a family meal together anymore. ... it just got worse, and I think now that has become, um and over time, it's just become morphed into Ken's [father] eating and chewing and breathing and my swallowing sometimes. [Laughs]. And if I accidentally click my nails when I am when I'm driving the car. [Laughs]. And Ken's sleeping on the couch. We can't have a meal. So, it was a bit confusing. I don't quite understand what that means, and it's like, oh my God, our family is breaking up. We've all become so conscious of it that [Laughs] we just try not to swallow. We try to breathe shallowly. [Laughs] It's just ridiculous."*

### ***Leisure activities are stressful rather than relaxing***

During nine interviews, families identified that things have to be just right in the environment for everyone to be able to relax. Four families explained that the television or radio volume is frequently a trigger for a child with sensory sensitivities to loud noises. As a result, the volume will be turned down, the show may be switched off, or an argument may ensue between the child and other family members. What was planned as a relaxing time for the family to spend meaningful time together inevitably becomes a stressful and disruptive event.

Karen, mother to 13 and 5-month-old Keri (Interview PC011): *"Every Friday night, we'd have a family movie night, and um, we just noticed every time she [Keri] would just get really agitated then start yelling at her brother, who is two years older than her."*

Families also mentioned that they noticed their child's tics worsen when watching television. As previously highlighted, a link between sensory stimulus and tic expression is apparent.

Penny, mother to twelve and a half-year-old Phoebe (Interview PC016): *"So, I don't know whether it is the noise or the flash of the TV, I don't know what it is. But, ever since we have noticed this, uh, since the age of seven, well, when we first started with you guys as well, that was, um, definitely the biggest thing we noticed was in front of the TV, the tics got ten times worse. So, um yeah, whether it's the noise or the lights, I am not sure. So. Yeah."*

Erin (mother to 10-year-old and 11-month-old Emma with TS) (Interview P005): *"It's so strange, the neck tic [reference to daughter Emma's tics] is just once every, so often at night time and when she's tired and when she's home or watching TV, and she's quite relaxed, that's when you'll get seven or eight in a row."*

### ***Car trips are challenging***

Travelling by car ( $n=7$ ) or public transport ( $n=2$ ) is challenging due to factors such as the sounds from other passengers breathing, the car radio, the proximity of passengers to the child/young person, and the feel of the seatbelt or car seats being offensive. The inability to travel in a car or use public transport impacts not only functional activities such as attending school, medical appointments or community activities but also being able to go on holiday. Families try to work around the sensory issues their children experience in these settings by using headphones, not having the radio or music playing, avoiding long car trips, and using private vehicles instead of public transport. Karen, mother to 13-year-and five-month-old Keri (Interview P011), highlighted that the family are unable to go on holiday as their daughter is too distressed by travelling in a car or on public transport due to the sounds made by other people around her, including people breathing.

*"You know going in cars are really difficult, ... um we can't go on family holidays uh she has to um, car trips are really difficult um she has to have headphones on... Um the car would be very challenging [due to the sound of people breathing]. Um, but uh, she found the travel on public transport overwhelming and couldn't cope with the crowded carriages."*

Brian, father to 10-and-a-half-year-old Brett (Interview PC002), explained: *"But I think constant sound also in the car. Like, if we crank up the music, the other son and me love it, whereas Brett's, like, blocked ears, too loud. Got to turn it down."*

### ***We just stay at home; events are a no-go***

In 17 interviews, families reported that their children with sensory dysregulation felt most comfortable and preferred to stay home. This resulted in families not being able to engage in community activities the same way other families would.

Maree, mother to 14 years and 11-month daughter Megan (Interview P013) explained: *"I suppose it has just been our norm, um, like because nowadays she just, yeah, won't really go anywhere. She just wants to be at home."*

Families experienced social isolation as not only could they not engage in community events or activities, but hosting friends and family at their homes was not even possible.

Karen (Interview P011): *"Loud noises, um, are an issue. She [Keri] has always been really like [that] all of her life actually, just very worried about all fireworks... We can't go out to see friends as much anymore or have friends over."*

When going to a music concert, Brian (Interview PC002) mentioned that his son 10-and-a-half-year-old Brett became upset as the environment was too loud:

*"Concerts, yeah. He doesn't like loud music, let's say we went to the U2 concert last year and it was a bit of a struggle with him. He got upset. I think it was a bit too much, we. We weren't right in the middle of it. We're sort of in the stadium towards the back."*

A discussion between Harry (13-year-and-two-month-old with TS,) and his father, Hamilton, during interview PC008, provided insight into how parents are aware of and protect their children from the triggering sensory stimuli in the community environment:

Harry (13-year-and-two-month-old with TS): *"When it's too loud. It's a small space, and the sound waves echo through... Well, I don't avoid."*  
Hamilton (Father): *"Yeah, well, you sort of do. I've got to protect you from them. You run away. You put your hands over your ears."*

### **The rage & outbursts, we're walking on eggshells**

Emotional outbursts by children and young people were described in 17 interviews (94%) by parents when either a sensory trigger or a build-up of sensory input was experienced. Derek (9 years old with chronic motor tics) and his father, David (Interview PC004), explained that as the day progressed, Derek became overwhelmed by the various sensory experiences involved in his daily routine, causing emotional dysregulation and resulting in family arguments.

David: *"When you have a bad day, is it like all different things that are, like one thing might annoy you and then another one annoys you more, and it sort of builds up, and then everything explodes over the top. Derek: "Yeah. Cause, like, the other day, um, my clothes, I didn't like my clothes, and then, I had an argument with my dad, mom, brother, and nan."*

Collectively, families voiced the emotional outbursts experienced by their children 78 times during these interviews, which impacts participation in activities, quality of life, family togetherness, and relationships. Gretel, mother to 9-year-old Grace with TS (Interview P007), details the impact Grace's emotional outbursts have on their family and the lengths she goes to support Grace to stay calm:

*"It's hard because I restructure everything. Everything to make things less stressful for her because if she's not stressed, I'm not stressed. But when Grace is stressed, the iPad gets thrown at me. Holes get put in walls. The baby gets hurt. I get hurt. Then she thinks she's the worst person in the world and hates herself. And it's just a cycle, and it's horrible. So, yeah, I do very much change everything."*

Besides the sensory triggers, parents described their sensory-sensitive children to anger very quickly, and emotional dysregulation was very common. Multiple parents reported that their children became physically violent when angered. Brett, a 10-and-a-half-year-old with TS (Interview PC002), described his challenges with emotional dysregulation:

Brett: *"Yes. Yes, I get angry easily, yeah. Yeah. Yes. Controlling my emotions is very hard. And it does get a bit tricky doing that."*

Families reported that even though their child's sensory preferences caused sensory dysregulation, impacting the quality of life and function, it was actually the behaviours resulting from emotional dysregulation rather than sensory dysregulation that was most challenging.

Gretel, mother to 9-year-old Grace with TS, (Interview P007): *"Um, everybody walks on eggshells. It's basically how can we manage not to piss off Grace but still get her to learn things like basic chores, some schoolwork, [and] attend appointments? It's, it's hard. It's like she has this internal engine that is just going, going, going, going, and it only has one gear, well, maybe one or two gears, but not enough to slow down by yourself sort of thing. Once she, once she revs up, she can't get back down, and that's actually, that's, that's a major thing. So, when you try and take that away (iPad), people get injured. The anger and the rage is so big and horrible that I don't get to see the other sides of her as much as I'd like to. That's really hard."*

Laura, mother to 11-year-old and two months son, Liam (Interview PC012), explains the impact Liam's anger has on the family unit and on his brother too:

*"He just gets really angry. I mean really angry. Like people wouldn't believe me how angry he can get, he gets really angry... its starts a lot of the time it starts with frustration. And it could last maybe, you know, half an hour... That we can get into these spirals where we, you know, we've just go and lie down or do something until we can bring ourselves back to where you can actually function. So that, that's probably has a massive impact on our, on our lives. Well, the family unit. I mean, he's got a younger brother who tends to, you know, bear the brunt of it. It's just not a nice environment. Like when we are all yelling at one another, and um, you know where you worry that you know his head is going to come off because he's so angry."*

## **Discussion**

The interplay between sensory dysregulation, emotional dysregulation and tic expression ought to be considered. In a case series of twelve children with tic disorders, the researchers hypothesised that sensory sensitivity to sound (misophonia) caused abrupt emotional dysregulation in individuals with tic disorders and should be considered part of a comprehensive clinical assessment [49]. Furthermore, children with tic disorders and comorbidities have been identified to experience sensory and emotional dysregulation [15, 19]. Tic expression is significantly related to stress and emotional dysregulation by various emotional states [93–95]. It is suggested that treatment focusing on the mediating role of emotion dysregulation may contribute to developing improved therapies for children with tic disorders [94]. As there was a common interplay between sensory and emotional dysregulation and tic expression expressed by our study participants in these interviews, consideration of all these factors through the assessment and treatment process to ensure a holistic and comprehensive understanding of the patient's needs and condition.

Families explained the complexity of managing the child/young person's sensory needs, in addition to dealing with tics, emotional dysregulation, and neurodevelopmental and neuropsychiatric comorbidities. The impact of sensory dysregulation on function, participation and quality of life resulting from the child experiencing sensory dysregulation affects the entire family, not just the child or young person. In many cases, the child's sensory needs are accommodated by the parents, who provide an environment that facilitates the child's or young person's sensory needs and preferences, ensuring harmony in the home. We completed 18 interviews, and overwhelmingly, all families reported

the impact of sensory dysregulation on all aspects of their child and young person's life and the quality of lives of the entire family.

The impact on the family ranged from being unable to eat meals together to being unable to listen to the radio in the car or watch television without upsetting their child with auditory sensitivities. The noises made by family members, such as chewing and swallowing sounds, scraping of cutlery on plates, breathing noises and clicking of fingernails, cause disharmony in the family and impact the family togetherness. In addition, the effects of temperature on the child's ability to engage in tasks, the difficulty with tolerating the feeling of seatbelts and car seats, and the inability to travel in a car. Hence family holidays are impossible or very difficult, due to the difficulty travelling together.

It was also explained that when watching television, children and young people's tics increased and therefore, as stated in theme three, "leisure activities are stressful rather than relaxing". The increase in tics when watching television could be accounted for various reasons: the child's fatigue level at the end of the day, the sensory overload from the television, the emotional response to the content they are watching and the impact this may have on the child's tic expression, the child is cognitively not engaged in an activity and hence tics seem worse when children are bored, the child may feel comfortable around their parents and not wish to suppress their tics as a few explanations.

The findings highlight that parents have learnt to understand their child's sensory needs. They adapt the environment and the tasks so their children can successfully complete tasks. Not all environments can be adapted, so some families have made sacrifices impacting their quality of life to meet their children's or young persons' needs.

A qualitative study by DeGace (2004) found that families with children with severe ASD may experience difficulty engaging in daily activities that hold positive meaning for them due to sensory needs and rigid routines [96]. Intervention for sensory dysregulation focuses on supporting the child rather than facilitating the occupations and needs of the entire family unit [96]. As the family unit provides a valuable source of learning and development for a child with neurodevelopmental disorders, it is prudent that, as clinicians, we support the family in expanding and enhancing these opportunities for their children [96].

Parents voiced that addressing their child's emotional dysregulation in therapy was paramount, over and above the challenges of sensory dysregulation. This need to address emotional dysregulation over and above the sensory dysregulation experiences may be because families have learnt to be insightful regarding their children's sensory preferences and how to accommodate them. Study participants also mentioned an interplay between sensory dysregulation, emotional dysregulation and tic expression. Research on the prevalence of sensory dysregulation and tics [15, 19] is emerging, and the effects of emotional dysregulation and tics, such as factors such as stress, anxiety, excitement and fatigue, exacerbate tics is well documented [97]. Yet the interplay between sensory and emotional dysregulation and tics is to be further understood.

In addition, the researchers acknowledge that 80–90% of children with tics experience other neurodevelopmental or neuropsychiatric disorders [1, 3, 6]. All the study participants experienced at least one other comorbidity in addition to a confirmed tic disorder (Level 1ASD:  $n=4$ , OCD:  $n=5$ , ADHD:  $n=7$  and anxiety:  $n=12$ ). Even though all study participants ( $n=16$ ) experienced sensory dysregulation, these experiences could be at least partly influenced by another comorbidity such as ASD (need for sameness, restricted eating), OCD (need for things to be same, just right), and anxiety (how sensory issues trigger emotional dysregulation) [4]. But this is a 'reality' of children with

neurodevelopmental disorders, who rarely have a single disorder but often have multiple comorbidities. All the study participants were diagnosed with a tic disorder ( $n=16$ ), and all reported experiencing sensory dysregulation, which impacted function regardless of the presence of various neurodevelopmental comorbidities. Thus, sensory dysregulation in children with tic disorders was not restricted to children with any specific comorbidity, i.e., ASD or OCD.

Therefore, as clinicians and researchers, it is valuable to understand and measure the breadth of sensory dysregulation experiences children with tic disorders experience to ensure a comprehensive assessment of the issues. This is to aid in determining the severity of the impact on function, assist with formulating treatment planning and measure treatment outcomes. The impact of sensory dysregulation experiences on the family unit as part of the assessment should be considered to ensure that therapy focuses not only on improving the function of the child, but the entire family unit. Quantifying the strategies used by families needs to be captured as these provide valuable data on how best to support children and provide an understanding of the implications these accommodations have on the quality of life for the entire family unit [96].

### Limitations of the study

Although inductive analysis was the predominant approach to data analysis, it is understood that researchers could not free themselves of their theoretical and epistemological commitments [80]. The researchers had prior theoretical knowledge and experience in paediatric tic disorders, having conducted previous quantitative research studies [19,78,79] and worked clinically in this field. Steps were taken to overcome this bias, which included researcher triangulation, peer debriefing, themes and subthemes being vetted by team members, and member checking to ensure that the research themes were trustworthy and credible. In addition, should the Yale Global Tic Severity Scale have been used, the severity of the study participants' tics would have been reported. With this said, tic is present in a wax and waning pattern; therefore, it may not be a true reference for the level of impairment. To understand the severity of symptoms, a list of prescribed medication for each study participant has been provided in Table 2.

We also acknowledge that having both the young person and parent present in the interview may have created a bias in the data obtained. Still, we had to ensure that the young person felt comfortable with the process of being interviewed. Thus, they were offered the opportunity to be interviewed in the presence of their parents, and all young people interviewed chose this format to their interview. Two parents requested to be interviewed in addition to the young person and parent interview so additional information could be provided that they did not feel comfortable discussing in front of their young person.

### Future research

As the current proxy-report sensory-base measures focus only on rating the sensory dysregulation of the child [78], there is a need for the development of a new measure that comprehensively assesses the breadth of sensory dysregulation experienced by children with tic disorders and comorbidities as identified through these lived experiences [89, 98–100]. In addition, the measure needs to allow for the impact of sensory dysregulation on the family unit and an understanding of the interplay of sensory, emotional dysregulation and tic symptoms. This would not only



aid in approved assessment and treatment planning but also allow for rating the effectiveness of treatment through the clinical utility of comprehensive, comprehensible and relevant sensory-based assessment measure for children with tic disorders and comorbidity.

In addition, future research needs to focus on whether the sensory experiences of children with tic disorder differ from those experienced by children or young people with other neurodevelopmental conditions. Due to the premonitory urge experienced before the tic, this does question whether interoception and sensory experiences are involved in tic expression and if the tic expression impacts the child or young person's sensory experiences.

## Conclusion

Children with tics and their families experience impacts on their participation in daily tasks due to sensory dysregulation that often remains unmeasured and a resultant lack of treatment options due, in part, to the hidden nature and lack of awareness of these issues. Families have reported incredible resourcefulness in adapting to the challenges. Still, a holistic response is needed to manage the impact on function resulting from these sensory dysregulation experiences. A comprehensive evaluation of the effects of sensory dysregulation in children with tic disorders needs to consider a broader list of experiences than is currently being assessed in current practice. The assessment needs to provide insight and measurement of the accommodation and adaptations made by the family and the impact of sensory dysfunction on the entire family unit. A comprehensive, comprehensible, relevant sensory-based measure is required to effectively assess and treat children and young people with tic disorders.

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## Authors' contributions

All authors have read and agreed to the manuscript being submitted for publication, and contributors have been acknowledged. All authors contributed to the conception and organisation of the research project. Nicolette Soler interviewed the study participants, transcribed the transcripts verbatim and completed the initial coding in Nvivo. All authors read the transcripts and were involved in the establishment of codes, themes and sub-themes. Nicolette Soler and Adj. Associate Professor Paula Bray were involved in member checking. The writing of the first draft was completed by Nicolette Soler and Adj. Associate Professor Paula Bray, and all authors provided critical revision. All authors had access to the study data.

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