

Behind the Smile: Unpacking Behavioural Challenges and Parental Responses in Children with Down Syndrome—A Mixed-Methods Study in Sri Lanka

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Abstract

Background

Down syndrome (DS) is the most common chromosomal disorder, with 25–33% of individuals exhibiting clinically significant behavioural concerns. Despite the established impact on child outcomes and family functioning, research on behavioural difficulties and parental management strategies in Sri Lanka is lacking. This study aimed to describe the prevalence and profile of behavioural challenges in children with Down syndrome and explore caregiver management strategies.

Methods

A mixed-methods design was employed. The quantitative component used the Child Behaviour Checklist (CBCL) to assess behavioural difficulties in 71 children (38 preschool-aged, 33 school-aged) attending the Down Syndrome Clinic at Lady Ridgeway Hospital for Children, Colombo. The qualitative component comprised semi-structured interviews with 30 primary caregivers, analysed using thematic analysis.

Results

Quantitative findings revealed a high prevalence of behavioural difficulties. Externalising problems affected 76.3% of children in both age groups, while internalising problems affected 63.1%. Aggressive behaviour was the most prevalent syndrome scale, affecting 73.6% of preschoolers and 66.6% of school-age children. Attention problems increased with age, from 42.1% to 57.5%. Despite high prevalence, clinically significant scores were rare, with only one child scoring in the clinically significant range. Qualitative analysis revealed six themes: the nature of challenging behaviours; near-unique reliance on ignoring; unsupported parents with intuitive skill without formal knowledge; lack of proactive strategies; challenges from family and formal support; and the silent struggle of acknowledged and unacknowledged needs.

Conclusions

This first comprehensive examination of behavioural difficulties and parental strategies in Sri Lankan children with Down syndrome reveals a high prevalence of subclinical behavioural challenges alongside parents' limited behavioural toolkit—predominantly relying on ignoring as a sole strategy. Findings highlight the urgent need for structured, culturally appropriate parent training programmes, routine behavioural screening, family-inclusive interventions, proactive assessment of parental needs, and a shift from reactive to proactive management approaches. These findings underscore the importance of systematic, family-centred care to improve outcomes for children with Down syndrome and their families in Sri Lanka.

Background

Down syndrome (DS) or Trisomy 21 stands as the most common chromosomal disorder worldwide, with a prevalence around 1 in 700 live births. It is caused by an extra copy of chromosome 21, which leads to the overexpression of a series of genes and, in turn, causing a wide range of physical, cognitive, and developmental issues (1). The neurodevelopmental profile of DS exhibits considerable individual variation, thus challenging the notion of a single "DS profile" but highlighting a complex range of cognitive abilities, adaptive functioning, and behavioural challenges (2). Currently research has shown 25-33% of individuals with DS will have clinically significant behavioural concerns – with co-morbid neurodevelopmental conditions like autism spectrum disorder, ADHD/ADD, or anxiety (3).

The increasing knowledge on significant variability in behaviour in Down syndrome—some having greater sociability and empathy, others difficulty with executive function, language development, and maladaptive behaviours—highlights the necessity for developmental-behavioural assessments to identify each child's unique behavioural profile, instead of focusing only on the chromosomal diagnosis (2,3). Despite this, behavioural challenges are often ignored or dismissed simply as a consequence of the associated intellectual disability, a phenomenon referred to as diagnostic overshadowing. This highlights even further the need for multi-faceted, specialist assessment frameworks that incorporate assessments of behavioural functioning alongside assessments of the cognitive and physical health throughout the lifespan. (1,3).

The high prevalence of clinically significant behavioural concerns in children with Down syndrome, coupled with the complex interplay between executive function deficits and challenging behaviours, underscores the critical need to understand how parents currently manage these difficulties. Prior research has demonstrated that child behavioural challenges are significantly associated with both positive and negative parental feelings about parenting, with behavioural difficulties fully mediating the relationship between a child's executive function and caregiver well-being. This suggests that the way parents respond to and manage challenging behaviours may have profound implications not only for child outcomes but also for family functioning and parental mental health. (4)

Despite the established impact of behavioural challenges in children with Down syndrome, a critical gap remains in the scientific literature regarding how these behaviours are understood, assessed, and managed in specific cultural and geographical contexts. While international research has developed and evaluated evidence-based behavioural interventions for children with neurodevelopmental disorders, the translation and applicability of these approaches to diverse populations remain underexplored (5).

In Sri Lanka, the scarcity of research on behavioural problems in children with Down syndrome is particularly striking. To date, no published studies have systematically examined the prevalence, nature, or correlates of behavioural difficulties specifically in Sri Lankan children with Down syndrome. Similarly, there is a notable absence of research investigating how Sri Lankan parents and caregivers manage behavioural challenges in their children with Down syndrome—what strategies they employ, what gaps exist in their knowledge and practice, and what formal or informal support they access. Existing Sri

Lankan literature has primarily focused on medical care protocols, the experiences of siblings, or educational provisions for children with Down syndrome, with minimal attention to behavioural phenotypes or parental management strategies (6).

This knowledge gap is concerning as without foundational research documenting the current landscape of behavioural challenges and their management in this population, the development of culturally appropriate, evidence-based interventions remains impeded, and healthcare providers lack the contextual knowledge necessary to offer practical, relevant guidance to families.

Therefore this study aimed to describe the prevalence and profile of behavioural challenges in preschool- and school-aged children with Down syndrome using the Child Behavior Checklist and explore the behaviour management strategies and their gaps currently used by caregivers.

Methods

Study Design

This study employed a mixed-method design with both quantitative and qualitative components to comprehensively examine behaviour management strategies used by parents of children with Down syndrome. The mixed-method approach allowed for triangulation of findings, with the quantitative component identifying the prevalence and nature of behavioural difficulties, and the qualitative component exploring the depth and context of parents' experiences, strategies, and support needs.

Study Setting

The study was conducted at the Down Syndrome Clinic in the Professorial Paediatric Unit of Lady Ridgeway Hospital for Children, Colombo, Sri Lanka.

Study Population and Participants

Inclusion Criteria

- Children diagnosed with Down syndrome clinically or genetically
- Age range: 1.5 to 18 years

Sample Size and Sampling Method

A total of 71 children with Down syndrome attending the Professorial Paediatric Unit during the study period were enrolled. This represented all eligible children who met the inclusion criteria. With this sample size, and assuming an expected behavioural problem prevalence of 30% (7) based on previous literature, the study provides a precision (margin of error) of approximately $\pm 10.7\%$ at the 95% confidence level.

A consecutive sampling method was employed in this study. All children with Down syndrome who met the predefined inclusion criteria and attended the Down Syndrome Clinic at the Professorial Paediatric Unit, Lady Ridgeway Hospital for Children, during the study period were invited to participate. Recruitment was conducted on days when the research team was available at the clinic.

Out of the 71 primary caregivers participated in the quantitative component of the study 30 participants who deemed to have behavioural concerns were selected for the qualitative component of the study. The participants were predominantly mothers, with a small number of fathers included. Children's ages ranged from 1.5 to 18 years, representing a broad developmental spectrum and corresponding to the validated age ranges of the Child Behaviour Checklist (CBCL) instruments used in the quantitative component.

Quantitative Component

Tool: Child Behaviour Checklist (CBCL)

The **Child Behaviour Checklist (CBCL)** was used to systematically identify and categorise behavioural difficulties in children with Down syndrome. The CBCL is a validated, standardised instrument widely used in clinical and research settings to assess behavioural and emotional problems in children and adolescents.

Age-Appropriate Versions

Given the age range of the study population (1.5 to 18 years), two versions of the CBCL were utilised to ensure age-appropriate and standardised behavioural assessments:

- CBCL/1.5–5 - Preschool version assessing behavioural and emotional problems in young children
- CBCL/6–18 - School-age version assessing behavioural and emotional problems in older children and adolescents

Both versions are validated instruments with established reliability and validity. The use of age-appropriate versions ensured that behavioural assessments were developmentally sensitive and standardised across the entire sample.

Data Collection and Categorisation

The CBCL was administered to primary caregivers during clinic visits. Responses were scored and categorised according to the CBCL standardised scoring protocols.

Qualitative Component

Data Collection: Semi-Structured Interviews

A qualitative research design employing **semi-structured interviews** was used to explore the experiences, strategies, and perspectives of parents regarding behaviour management. This approach allowed for in-depth exploration of parental experiences and the contextual factors influencing their behaviour management approaches (Braun & Clarke, 2006).

Interview Guide

Data were collected using a semi-structured interview guide developed specifically for this study. The guide covered the following sections:

1. Introduction and Context
2. Strategies Used to Manage Behaviour
3. Sources of Behaviour Management Knowledge
4. Cultural, Family, and Social Influences
5. Challenges and Support Needs
6. Reflections

Data Analysis

Quantitative Data Analysis

Quantitative data from the CBCL were analysed using descriptive statistics. Behaviours were categorised according to CBCL syndrome scales, internalising and externalising composite scores. This categorisation allowed for:

Qualitative Data Analysis

Qualitative data from the semi-structured interviews were analysed using thematic analysis following the six-phase framework described by Braun and Clarke (8).

The analysis process included:

Phase 1: Familiarisation

Phase 2: Generating Initial Codes

Phase 3: Searching for Themes

Phase 4: Reviewing Themes

Phase 5: Defining and Naming Themes

Phase 6: Producing the Report

Six overarching themes emerged from the analysis, which form the structure of the qualitative findings:

1. The Nature of Challenging Behaviours
2. The Near-Unique Reliance on Ignoring
3. The Unsupported Parent: Intuitive Skill Without Formal Knowledge
4. The Lack of Proactive Strategies
5. Challenges from Family and Formal Support
6. The Silent Struggle: Acknowledged and Unacknowledged Needs

Ethical Considerations

This study will adhere to the ethical standards mentioned in the Declaration of Helsinki, as well as Sri Lanka's national requirements for research involving human participants. Prior to participation, all caregivers will submit informed written consent, and information sheets will be provided in their preferred language (Sinhala, Tamil, or English). Participation will be fully voluntary, and caregivers can withdraw at any time without affecting the child's ongoing clinical care.

To maintain anonymity, all participant data will be anonymized and securely stored, with access restricted to the study team. No identifiable information will be released. For components involving video or observational data, explicit consent will be obtained, and recordings will be utilized purely for research analysis before being deleted in compliance with ethical data management principles. All data will be stored within computers of the research team and will be destroyed after data analysis. Any AI-assisted analysis will be performed on anonymized data alone, guaranteeing that no personal identifiers are handled through external platforms.

Participants face limited risks, which are mostly connected to time and emotional distress when discussing behavioural difficulties. Interviews will be conducted respectfully. If any clinical issues arise during the trial, families will be referred to appropriate care.

Recruitment Process

Participants will be recruited independently of the treating clinicians. A designated research assistant or an independent team member not involved in clinical care will approach eligible families after their consultation or during follow-up visits. Participation will be entirely voluntary, and caregivers will be informed that their decision to participate or decline will not affect the child's care in any way.

Results

Quantitative Data

The quantitative component of this study utilised the Child Behaviour Checklist (CBCL) to systematically assess the prevalence and types of behavioural difficulties in children with Down syndrome attending the Professorial Paediatric Unit at Lady Ridgeway Hospital for Children. A total of **71 children** were assessed using age-appropriate versions of the CBCL: **38 children** using the preschool version (CBCL/1.5–5) and **33 children** using the school-age version (CBCL/6–18). Data are presented as frequencies and percentages, with scores categorised as clinically borderline or clinically significant according to standardised CBCL scoring protocols.

Preschool Version (CBCL/1.5–5): n = 38

Syndrome Scales

The preschool version of the CBCL assesses eight syndrome scales. The most prevalent behavioural difficulties observed are shown in Table 1:

Table 1
Most Prevalent Behavioural difficulties reported in Preschool age group

Syndrome Scale	n	Percentage	Clinically Borderline	Clinically Significant
Aggressive Behaviour	28	73.6%	0	0
Anxious/Depressed	16	42.1%	0	0
Attention Problem	16	42.1%	1	0
Somatic Complains	14	36.8%	1	0
Emotionally Reactive	10	26.3%	1	0
Withdrawn	7	18.4%	1	0
Sleep Problems	6	15.7%	0	0

Aggressive Behaviour was the most frequently reported concern among preschool-aged children, affecting 73.6% (n = 28) of the sample. This was followed by Anxious/Depressed and Attention Problem, each affecting 42.1% (n = 16) of children. Somatic Complains were reported in 36.8% (n = 14) of children. Lower prevalence rates were observed for Emotionally Reactive (26.3%, n = 10), Withdrawn (18.4%, n = 7), and Sleep Problems (15.7%, n = 6).

Clinically borderline scores were rare across all syndrome scales, with only 1 child each scoring in the borderline range for Attention Problem, Somatic Complains, Emotionally Reactive, and Withdrawn. No clinically significant scores were recorded on any syndrome scale in the preschool version.

Composite Scales

The CBCL/1.5–5 also provides composite scores for internalising and externalising problems, which are shown in Table 2:

Table 2
Internalising and Externalising Behaviours of Preschool age group

Composite Scale	n	Percentage	Clinically Borderline	Clinically Significant
Internalizing	24	63.1%	1	0
Externalizing	29	76.3%	1	0

The behavioural profile of preschool-aged children in this sample is illustrated in Fig. 1. Externalising Problems were present in 76.3% (n = 29) of preschool-aged children, representing the most common composite problem domain. Internalising Problems were present in 63.1% (n = 24) of children. One child each scored in the clinically borderline range for both internalising and externalising problems, with no clinically significant scores recorded.

School-Age Version (CBCL/6–18): n = 33

Syndrome Scales

The school-age version of the CBCL assesses eight syndrome scales, providing a comprehensive profile of behavioural and emotional difficulties in children aged 6 to 18 years as shown in Table 3:

Table 3
Most Prevalent Behavioural difficulties reported in Preschool age group

Syndrome Scale	n	Percentage	Clinically Borderline	Clinically Significant
Aggressive Behaviour	22	66.6%	2	0
Attention Problem	19	57.5%	1	0
Social Problems	14	42.4%	0	0
Rule Breaking Behaviour	12	36.3%	1	0
Anxious/Depressed	11	33.3%	0	0
Withdrawn/Depressed	8	24.2%	1	0
Thought Problem	7	21.2%	1	0
Somatic Complaints	4	12.1%	0	0

As with the preschool version, Aggressive Behaviour was the most frequently reported concern among school-age children, affecting 66.6% (n = 22) of the sample. Attention Problem was the second most common, affecting 57.5% (n = 19) of children. Social Problems were reported in 42.4% (n = 14) of children, followed by Rule Breaking Behaviour in 36.3% (n = 12). Anxious/Depressed was present in

33.3% (n = 11) of children. Lower prevalence rates were observed for Withdrawn/Depressed (24.2%, n = 8), Thought Problems (21.2%, n = 7), and Somatic Complains (12.1%, n = 4).

Clinically borderline scores were observed across several scales: Aggressive Behaviour (n = 2), Attention Problem (n = 1), Rule Breaking Behaviour (n = 1), Withdrawn/Depressed (n = 1), and Thought Problem (n = 1). No clinically significant scores were recorded on any syndrome scale in the school-age version.

Composite Scales

The CBCL/6–18 provides composite scores for internalising and externalising problems, which are shown in Table 4:

Table 2 Internalising and Externalising Behaviours of School age group				
Composite Scale	n	Percentage	Clinically Borderline	Clinically Significant
Internalizing	15	63.1%	1	0
Externalizing	23	76.3%	2	1

The behavioural profile of school-aged children in this sample is illustrated in Fig. 2. Externalising Problems were present in 76.3% (n = 23) of school-age children, mirroring the pattern observed in the preschool sample. Internalising Problems were present in 63.1% (n = 15) of children. Clinically borderline scores were observed for Internalizing (n = 1) and Externalizing (n = 2). Notably, one child scored in the clinically significant range for Externalizing Problems, representing the only clinically significant composite score recorded across the entire sample.

Qualitative Data

The thematic analysis revealed 6 key themes that characterise the experiences of parents in managing the behaviour of their children with Down syndrome. These themes are presented below.

Theme 1: The Nature of Challenging Behaviours

Across all interviews, parents described a range of challenging behaviours that formed the primary focus of their management efforts. The most commonly reported challenging behaviour was aggression, which manifested primarily as temper tantrums and were described across multiple interviews. Parents reported that children would roll on the floor/shout/cry loudly and become physically aggressive when their demands were not met or when they were refused on their desired items such as toys, mobile phones, or food. Attention-seeking behaviour was also common, with children frequently shouting/crying/engaging in disruptive actions to gain attention or to express displeasure when attention was diverted elsewhere. Additionally, hyperactivity was a frequently reported, with parents describing their children as "hyperactive," "explores everything," "goes around exploring," and being in constant motion.

Theme 2: The Near-Unique Reliance on Ignoring

This theme outlines the overwhelming reliance on "planned ignoring" as the primary behaviour management strategy often at the expense of other evidence-based techniques. Across the interviews, "ignoring" emerged as the most frequently reported strategy for managing challenging behaviours. Almost all the parents reported using ignoring to address behaviours such as shouting, tantrums, and attention-seeking behaviours. This strategy appeared to be learned through trial and error often after other approaches (such as giving attention) were found to exacerbate the behaviour. Parents frequently described the sequence of events in behavioural terms, articulating a clear understanding of the cause-and-effect relationship between their response and the child's behaviour. However, their toolkit remained remarkably limited to ignoring.

Theme 3: The Unsupported Parent: Intuitive Skill Without Formal Knowledge

Parents demonstrate a natural ability to apply behavioural principles and adapt through trial and error. However, this skill remains untapped by formal healthcare systems, with parents receiving minimal structured guidance. Despite the absence of formal training in behaviour management, parents exhibited a remarkable intuitive understanding of behavioural principles. This intuitive skill was developed through practical experience, observation, and experimentation rather than formal education. They demonstrated the ability to learn from experience, as illustrated by the mother who initially responded to head-banging by providing attention (which exacerbated the behaviour) and subsequently discovered that ignoring was more effective. This learning process reflects an inherent understanding of extinction principles.

Theme 4: The Lack of Proactive Strategies

The data strongly suggest a reactive pattern of behaviour management: parents respond to behaviours after they occur, with a near-absence of proactive, preventative measures such as structured routines, visual aids, or environmental modifications. This meant that parents were perpetually responding to behaviours rather than preventing them. This was also evident in the way parents described their management approach—almost exclusively in terms of responding to specific behavioural incidents rather than creating environments that reduce the likelihood of such incidents occurring. This pattern likely contributes to parental stress and fatigue, as parents are constantly responding to the behaviours rather than implementing systems that promote positive behaviour.

Theme 5: Challenges from Family and Formal Support

This theme outlines the key finding that parents' efforts are often undermined by inconsistent responses from other family members especially grandparents, who may reinforce problematic behaviours. The involvement of extended family members, particularly grandparents, emerged as a significant factor influencing behaviour management effectiveness. While grandparents often provided valuable practical support, their approach to managing the child's behaviour frequently differed from that of the primary caregiver, creating inconsistency that undermined the parent's efforts. This inconsistency took several

forms: grandparents giving in to the child's demands when the parent had refused, providing attention to behaviours that the parent was trying to ignore, and using different disciplinary approaches. Such inconsistent responses likely reinforce challenging behaviours, as children learn that persistence may eventually be rewarded by a grandparent, even if the parent initially refused.

Other than that the role of formal support was also problematic. While some parents had received advice from clinic doctors or other professionals, this guidance was often described as impractical or unhelpful in their day-to-day lives. This suggests a disconnect between clinical recommendations and the realities of home management, highlighting the need for more practical, contextually appropriate advice.

Theme 6: The Silent Struggle: Acknowledged and Unacknowledged Needs

While some parents explicitly express a need for "parent training" or "advice," many simultaneously deny facing any particular challenges. This "silent struggle" may indicate a high level of normalisation of stress, a coping mechanism, or a difficulty in articulating the burden of caregiving. One of the most nuanced findings of this study is the apparent paradox between parents' expressed needs and their denial of current difficulties. Many parents explicitly requested "parent training," "advice" or "strategies" indicating a recognition of their knowledge gap and a desire for support. However, when asked directly about the difficulties they face or the support they are missing, the same parents often responded with a simple "No." This "silent struggle" is concerning because it suggests that parents may be experiencing significant stress and unmet needs that they are unable or unwilling to express, potentially leading to burnout and negative outcomes for both parents and children.

Discussion

This mixed-methods study examined the behavioural difficulties and behaviour management strategies among children with Down syndrome attending the Professorial Paediatric Unit at Lady Ridgeway Hospital for Children. The quantitative component, utilising the Child Behaviour Checklist (CBCL), assessed the prevalence and types of behavioural difficulties in 71 children (38 preschool-aged and 33 school-aged). The qualitative component, comprising semi-structured interviews with 30 primary caregivers, explored the strategies parents employ to manage challenging behaviours, their sources of knowledge, and their support needs. The integration of both methodologies provides a comprehensive understanding of the behavioural landscape and parental experiences in this population.

The quantitative findings reveal a strikingly high prevalence of behavioural difficulties among children with Down syndrome in this sample. Externalising Problems were the most common, affecting 76.3% of children in both preschool and school-age groups. This finding is consistent with previous research documenting elevated rates of externalising behaviours in children with Down syndrome, including aggression, attention problems, and disruptive behaviours (9, 10). This is also consistent with local study of behavioural problem of 4-6y where it showed externalizing behaviours were more common in 4–6 year age group (11).

However, a notable contrast emerges when examining the age-related patterns in the literature. Previous studies have suggested that while externalising behaviours are common in early childhood, internalising problems—such as anxiety, depression, and social withdrawal—tend to become more prominent as children with Down syndrome reach puberty and adolescence. In this study, internalising problems were present in a substantial proportion of children (63.1% in both age groups), but externalising problems remained the more prevalent domain across both preschool and school-age groups, with no increase in internalising problems observed in the older age group. This contrasting finding may be explained by the composition of the school-age sample, which included more children who were pre-pubertal rather than in late adolescence. This highlights the importance of considering pubertal and developmental stages when interpreting behavioural profiles and planning interventions for children with Down syndrome.

Aggressive Behaviour emerged as the single most prevalent syndrome scale, affecting 73.6% of preschoolers and 66.6% of school-age children. This high prevalence aligns with the qualitative findings, where parents most frequently described challenging behaviours including temper tantrums, shouting, rolling on the floor, and physical aggression when children were denied access to desired items or when attention was diverted. This finding is consistent with literature which reported high rates of unsocialized disturbances of conduct (37.5%) and identified significant behavioral problems in 55% of children with Down syndrome compared to 12.5% in control groups (12).

Attention Problems were the second most common concern, affecting 42.1% of preschoolers and increasing substantially to 57.5% of school-age children. The qualitative findings provide complementary insights into attention-related challenges. Parents frequently described children as "hyperactive," "needs attention," "explores everything," and "goes around exploring." These descriptions suggest that attention difficulties manifest not only as inattention but also as hyperactivity and overactivity, which may be particularly challenging for parents to manage. The high prevalence of attention problems in this sample is consistent with studies reporting elevated rates of Attention-Deficit/Hyperactivity Disorder (ADHD) symptoms in children with Down syndrome (13, 14).

Internalising Problems affected 63.1% of children in both age groups, representing a substantial proportion of the sample when considering subclinical symptomatology. The most common internalising symptoms were Anxious/Depressed (42.1% in preschoolers, 33.3% in school-age children) and Somatic Complaints (36.8% in preschoolers, 12.1% in school-age children). The qualitative data also captured some internalising difficulties, with parents describing children who were "withdrawn," "silent," or who "talks to himself," suggesting that internalising features were observable even if not clinically prominent.

Unlike local studies conducted in the Kandy district among 7–11 year-olds and among institutionalised school-aged children, which reported clinical or borderline internalising problem rates of 6.6–12.1%, the present study found minimal prevalence at these clinically significant thresholds. This discrepancy may be attributed to several factors. First, the present sample comprised predominantly community-dwelling children from families with relatively stable caregiving environments, whereas the comparative local studies included institutionalised populations who are known to experience higher rates of internalising

disorders due to early adversity and attachment disruptions. Second, the Kandy district study focused on older school-aged children (7–11 years), a developmental period when internalising symptoms such as anxiety and depression tend to increase in prevalence, particularly with growing academic and social pressures. In contrast, our sample included a substantial proportion of preschoolers, for whom internalising problems often manifest differently—and may be less readily identified by parents—compared to the more observable externalising behaviours that predominated in our findings. This high subclinical internalising rate nevertheless signals a vulnerability that, without intervention, could progress to clinical significance, particularly during the transition to middle childhood—a critical period supported by developmental research linking early anxiety to later depressive disorders (15).

One of the most striking findings of this study was the overwhelming reliance on "planned ignoring" as the primary behaviour management strategy, with nearly all parents reporting its use to address behaviours such as shouting, tantrums, and attention-seeking actions. While ignoring is a recognised behavioural technique, its near-exclusive use, at the expense of other evidence-based strategies such as positive reinforcement, token systems, and teaching replacement behaviours, represents a significant gap in parental behavioural toolkits. This pattern is consistent with prior Sri Lankan research found that Sri Lankan parents predominantly employ authoritarian and reactive disciplinary approaches, with limited awareness of positive reinforcement principles (16). Similarly, another study reported that Sri Lankan parents demonstrated low awareness of proactive behaviour management strategies, often resorting to reactive techniques in the absence of accessible parenting programmes (15).

Despite the absence of formal training, parents in this study demonstrated remarkable intuitive understanding of behavioural principles. This finding resonates with research from other Asian contexts, where parents often develop practical strategies through experience and community knowledge rather than professional guidance. Studies from Sri Lanka examining caregivers of children with dyslexia have similarly found that parents can identify that "something was wrong" with their child but lack the formal knowledge to effectively address the difficulties (18).

The "unsupported parent" theme is particularly salient in the Sri Lankan context, where research has documented significant gaps in support services for children with developmental disabilities and their families. A study exploring challenges faced by parents of children in inclusive education units in Sri Lanka found that parents face inadequate resources, poor communication with educators, and limited access to essential support services and therapies (19). Similarly, research on caregivers of children with dyslexia in Sri Lanka revealed that parents feel emotionally pressured, helpless, and stressed, receiving insufficient support from both education and health sectors due to multiple complexities including inadequate knowledge and skills, unavailability of resources, and inaccessibility to services (20).

The Qualitative data strongly suggested a reactive pattern of behaviour management: parents respond to behaviours after they occur, with a near-absence of proactive, preventative measures such as structured routines, visual aids, or environmental modifications. This reactive pattern is consistent with prior research in local contexts which documented that Sri Lankan parenting is predominantly incident-driven,

with limited use of structured routines or environmental modifications, a pattern he attributed to cultural expectations of child obedience and limited parental knowledge of behavioural principles (16). Similarly, another study identified a gap in Sri Lankan parents' awareness of antecedent-based strategies, noting that the absence of accessible parenting education perpetuates reactive approaches (17).

The involvement of extended family members, particularly grandparents, emerged as a significant factor influencing behaviour management effectiveness. While grandparents often provided valuable practical support, their approach to managing the child's behaviour frequently differed from that of the primary caregiver, creating inconsistency that undermined the parent's efforts. Another study identified intergenerational conflict in parenting approaches as a common challenge in Sri Lankan families, noting that grandparents often hold more traditional, permissive views and may undermine parental authority by giving in to children's demands (16).

While some parents explicitly requested parent training or advice, many others simultaneously rejected the notion that they faced any substantial challenges. This apparent contradiction—the "silent struggle"—may stem from an internalisation of ongoing stress, serve as a defence mechanism, or reflect difficulty in expressing the true weight of their caregiving responsibilities. This apparent contradiction is consistent with prior Sri Lankan research found that parents of children with neurodevelopmental disorders, including Down syndrome, employed coping mechanisms such as developing routines, facing "one day at a time," and avoidance (20).

Conclusion

This mixed-methods study provides the first comprehensive examination of behavioural difficulties and parental management strategies in children with Down syndrome in Sri Lanka. The quantitative findings reveal a strikingly high prevalence of behavioural challenges, with externalising problems affecting over three-quarters of children (76.3%) and internalising problems affecting nearly two-thirds (63.1%) across both preschool and school-age groups. Aggressive behaviour emerged as the single most prevalent concern, affecting 73.6% of preschoolers and 66.6% of school-age children, while attention problems showed a notable increase with age, rising from 42.1% in preschoolers to 57.5% in school-age children. Despite this high prevalence, clinically significant scores were rare, suggesting that while behavioural difficulties are highly prevalent in this population, they often remain subclinical yet still substantially impact family functioning.

The qualitative findings elucidate the significant gaps in parental knowledge and support systems. Parents demonstrated remarkable intuitive understanding of behavioural principles, yet their management toolkit remained overwhelmingly limited to a single strategy—planned ignoring—with a notable absence of proactive strategies such as structured routines, visual aids, or positive reinforcement. This reactive pattern of management was compounded by inconsistent family support, particularly from grandparents who often inadvertently reinforced challenging behaviours, and formal healthcare advice that parents frequently perceived as impractical or unhelpful. The "silent struggle"

phenomenon—where parents simultaneously expressed a need for training while denying current difficulties—highlights the normalisation of chronic stress and the critical need for proactive, routine assessment of parental well-being and support needs.

Strengths & Limitations

This study has several strengths, including its mixed-methods design, which integrated standardised behavioural assessment using the Child Behaviour Checklist with in-depth qualitative exploration of parental experiences, providing a comprehensive understanding of behavioural challenges and management strategies in Sri Lankan children with Down syndrome. The use of age-appropriate CBCL versions and consecutive sampling further enhanced the validity and representativeness of the findings. However, several limitations must be acknowledged. The study was conducted at a single tertiary care centre, which may limit generalizability to children who do not access specialist services. The relatively small sample size ($n = 71$ quantitative, $n = 30$ qualitative) restricts statistical power and the precision of estimates, with a margin of error of $\pm 10.7\%$. Reliance on parental report for both quantitative and qualitative data may introduce recall and social desirability bias. Additionally, recruitment occurred only on days when researchers were available, which may have introduced minor availability bias, and the cross-sectional design precludes examination of developmental trajectories. The qualitative sample was predominantly mothers, limiting exploration of fathers' perspectives, and the study did not systematically collect data on socioeconomic status or parental education. Despite these limitations, this study provides foundational evidence to inform culturally appropriate interventions and guide future research in Sri Lanka and similar resource-limited settings.

Declarations

Ethics approval and consent to participate

Ethical approval for the study was taken from the Ethics Review Committee of Faculty of Medicine, University of Colombo, Sri Lanka. Written informed consent was obtained from the parents or legal guardians of any participant under the age of 16 years, prior to data collection. Parents/caregivers were provided with detailed information about the study purpose, procedures, potential risks and benefits, and their right to withdraw at any time without affecting their child's care. Confidentiality was maintained throughout the study, with all data anonymised and stored securely.

Consent for publication

Not applicable. This manuscript does not contain any individual person's data in identifiable form, including individual details, images, or videos. All data presented are aggregated or anonymised, and individual participants cannot be identified from the information provided. Participants were informed during the consent process that anonymised data would be used for publication purposes.

Availability of data and materials

The datasets generated and/or analysed during the current study are not publicly available due to ethical restrictions and the need to protect participant confidentiality. However, anonymised quantitative data may be available from the corresponding author upon reasonable request, subject to approval from the Ethics Review Committee of Lady Ridgeway Hospital for Children.

Competing interests

The authors declare that they have no competing interests. The study was conducted independently, without any commercial, financial, or other relationships that could be construed as a potential conflict of interest.

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Authors' contributions

MBN conceptualised and designed the study, supervised data collection, performed the qualitative analysis, and drafted the manuscript. RD and SW contributed to study design, supervised the data collection, and critically revised the manuscript for important intellectual content. KK performed the quantitative and qualitative data collection. All authors read and approved the final manuscript and agree to be accountable for all aspects of the work.

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Figures

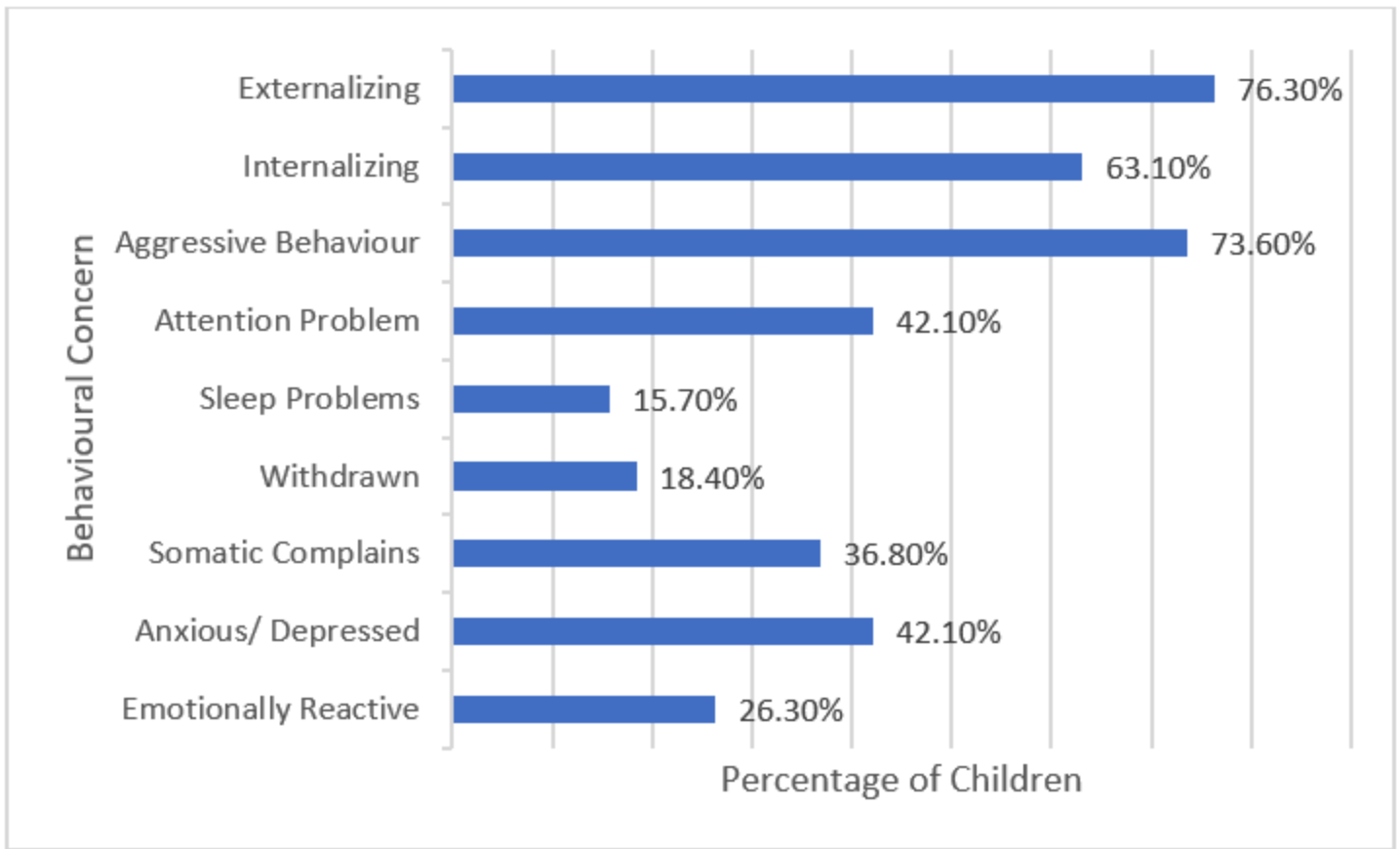


Figure 1

Behavioural Patterns in Preschool-Aged Children with Down Syndrome (CBCL/1.5–5; n=38)

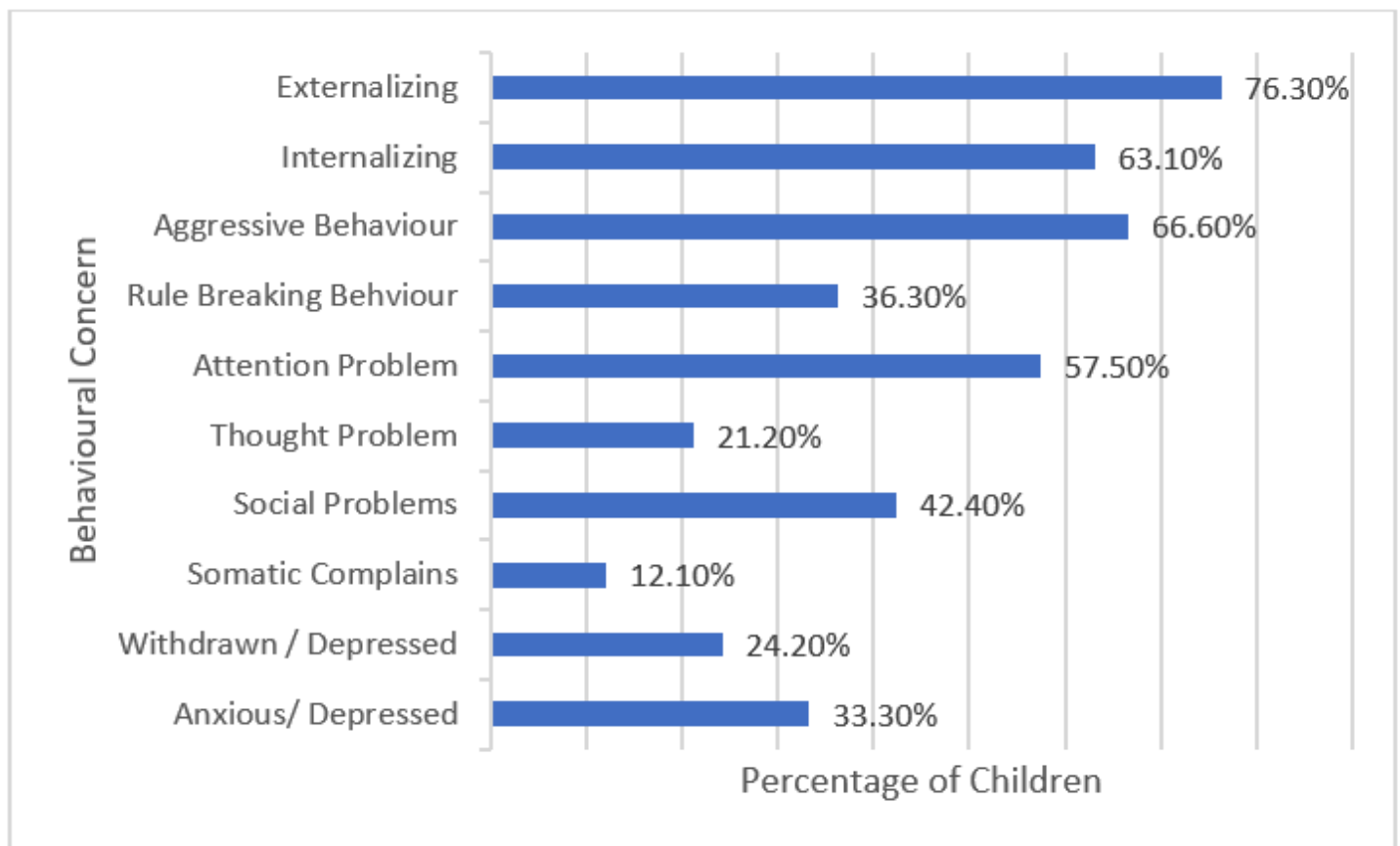


Figure 2

Behavioural Patterns in School-Aged Children with Down Syndrome (CBCL/6-18; n=33)