

The Experience of Children with Sensory Over-Responsivity

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Abstract

Sensory processing and integration challenges affect as many as 5%-16% of children in the United States. These individuals present with differing types of symptom presentation, and differing disruptions in the organization and processing of sensory experiences (STAR Institute for Sensory Processing, 2020). While not officially a diagnosis in the DSM V, the behaviors defined and categorized by occupational therapists describe difficulties in one or more of the sensory systems in the body that are not functioning properly.

Keywords: Behavioral Dysregulation; Behaviors; Children; Response

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Introduction

Sensory over-responsivity (SOR) is one of the most common types of sensory processing and integration disorders [1,2]. Children with SOR experience typical sensations in daily life more intensely and for longer duration than their neurotypical peers [3-5]. SOR is described as a heightened response to ordinary, non-threatening stimuli. Individuals experience adverse, negative responses that often have behavioral manifestations such as prolonged, explosive outbursts, crying, aggressive behaviors, and withdrawal [5].

Studies show that children with SOR show high activation of the sympathetic nervous system (SNS), which is reflective of a fight, or flight reaction to sensory experiences [6,7]. While a link to the sympathetic nervous system has been proposed there isn't much known about the variability in expression and/or severity of expression, for example, how often SOR episodes occur, how long they last, and what range of behavioral reactions are observed. Oftentimes, these neurologically driven SOR episodes are described by observers as 'meltdowns' but what is not known is how children describe their felt experience of sensory overwhelm.

The term "meltdown" is used colloquially by parents of children with sensory over responsively to describe a cluster of emotions

and behaviours. This study sought to address a gap in the literature by exploring the lived experience of parents and children during such episodes. An association between SOR and trauma has been suggested in the literature. While this co-occurrence has not been well studied, there appears to be evidence lending support to the possible coexistence of SOR and trauma [8,9]. Thus, the nature of this relationship and its impact on the parent, child, and parent children relationship requires further exploration. Importantly, empirical data from the perspective of the parent and the child can help to differentiate behavioral clusters associated with emotional reactivity to sensory events that may be uncomfortable for a child to experience, versus those same behavioral and emotional clusters that suggest a traumatic reaction/experience.

Disruptions in sensory processing that cause reactivity characteristic of children with SOR can have a negatively impact relationships, quality of life, and the child's capacity to engage in meaningful activities of daily living throughout each developmental stage. This can be stressful for both the child and the caregivers [1,4,5,10]. SOR can impair participation in play, social emotional learning, self-care, academics, and can negatively affect relationships with family members and peers [2]. Children and their parents can develop chronically strained relationships due to the emotional repercussions [11]. Research shows that

parents of children with SOR feel their child’s symptoms limit the family’s activities even more than parents of children with Autism or ADHD [8].

SOR episodes not only take a toll on the child, but also on the parent. Research indicates elevated stress rates among caregivers of highly stressed populations, resulting in accelerated biological aging, immune dysfunction, and higher rates of depression [2,12,13]. Studies also indicate that the chronically dysregulated physical and emotional responses in children with SOR have a systemic impact on the family [14]. Findings further suggest that parenting stress is both an antecedent and consequence of child behaviour problems, while child behavioral problems are also an antecedent and consequence of parental stress [15].

When symptoms of SOR interfere with the quality of relationships within a family and with participation in activities of daily life, families may seek treatment from Pediatric occupational therapists. This is often a child-centered approach that involves individualized child treatment and includes parent education and strategies for carryover at home. While occupational therapist best practice interventions involve participation of the caregiver/parent in the therapeutic process, a parent may need supplemental support to implement specific tools that best help their child when they are experiencing a SOR episode. It is clear from anecdotal descriptions that occupational therapy that involves both the child and the parent, is different from the mental health or parenting coaching support that parents might need when their child is experiencing emotional and behavioral dysregulation due to a SOR episode. Currently, occupational therapists offer strategies to ensure carryover at home of skills learned in treatment, however, parents may need additional tools that ensure emotional safety, promote secure relational attachment, and assure physical safety of everyone in the household.

Due to the negative impact of SOR episodes on both child and caregiver, this descriptive, exploratory study sought to investigate the experience of children and parents as well as the interrelationship between the child and the caregiver when sensory dysregulation occurs. The chronically stressful impact that SOR has on the child and on the entire family warrants research into the lived experience of SOR children: their personal descriptions of sensory overwhelm, and the lived experience of their parents. Additionally, little is known about the frequency of these occurrences and the range of behaviors children display. Lastly, learning how parents respond to their child during a SOR episode, can inform professionals about as to the unique needs of families who have children with SOR, and the specialized support strategies that they could benefit from. Given the potential association between SOR and trauma, it is important for professionals to be informed by first-hand accounts from the child and the parent about their experience. Little is written that describes the child’s experience or the parent’s ability to intervene on behalf of their child.

Thus, the current study sought to explore the experience of parents and children with SOR. The specific research questions were:

Do parents report that their child with SOR experiences sensory reactions that result in an outburst or ‘meltdown’? How often does this occur, how long does it last and what is the range of behaviors they display? This information will contribute to our understanding of the range of variability in frequency and behavioral reactivity of children’s SOR episodes.

Do parents ask their child how a SOR episode feels-Knowing how children feel during SOR episodes might provide insight into what the child is experiencing and inform how to intervene.

Do children with SOR experience pain during a SOR episode and if so, how do they describe this experience.

Knowing if child experiences of pain can inform the language and perspective of families and professionals in understanding and formulating treatment plans for an individual’s SOR reactions.

What strategies do parents use to support their child during a SOR event and do parents feel confident in their ability to support their child during a SOR event.

Recognition of the needs of parents will allow therapists to better target interventions to support the entire family.

Obtaining this data is essential to better understanding the experience of both the child and parent during SOR episodes and is the first step in determining parent intervention strategies that build confidence in the caregiver and that strengthen the relationship between the caregiver and child.

Method

This was a descriptive, exploratory study that utilized a survey research method to collect data. All data were de-identified. The study was reviewed by the Institutional Review Board (IRB) of Rocky Mountain University of Health Professions and was determined to be exempt by this IRB.

Participants

Acute Thirty six parents responded anonymously to a Sensory/SOR Event Questionnaire emailed to all members of the organization Sensory Kids in San Francisco (n=110). Parents self-selected to take the survey if they identified with having a child with SOR. Demographic data showed the majority (n=29, 80.6%) of respondents were parents of children between the ages of 5 to 13 (Table 1). The only inclusion criteria were being a parent of a child with SOR. No identifying information was collected from the survey respondents.

Table 1 Demographics

Age (years)	n	Percent of Sample
02-Apr	2	5.6
05-Jul	11	30.6
08-Oct	8	22.2
Nov-13	10	27.8
14-16	2	5.6
17-18	3	8.3

Instrumentation and measures

The Sensory/SOR Event Questionnaire were developed by the first author of this study. Questions were based on the professional experience of the first author as a mental health therapist with 15 years of experience supporting parents of children with SOR. The survey consisted of seven multiple choice questions that related to their child’s reactions during a SOR episode. Additionally, there was one open ended question that required parents to fill out a narrative description of their child’s ‘yes’ response to the question “Does it hurt?” The last two questions focused on parent strategies used to manage their child’s behavior and the degree of confidence felt about their ability to support their child emotionally during a sensory event.

Procedure

A questionnaire was sent via email to a convenience sample of parents who were members of an organization called Sensory Kids in San Francisco. Completing the questionnaire implied consent. Participants completed an online survey via the online tool Survey Monkey. No personal identifying information was collected.

Data analysis

Data were analyzed using Excel. Graphs and percentages were calculated to gain an understanding of the parent’s perceptions in response to the questions. Qualitative data was obtained from the open-ended questions to better understand the lived experience of children with SOR.

Results

Results from 36 respondents showed an overwhelming majority (n=32, 88.9%) reported that their child experiences an extreme SOR event (Table 2). Answers to questions regarding the lived experience of a sensory episode included frequency, duration, and behavior. The majority of parents reported a daily or multiple weekly SOR experience (n=23, 63.8%). Events were described as lasting 10 min-60 min in 61.1% of the sample (n=22). The most frequently described behaviors during these episodes include screaming (70.6), aggressive attacks toward parent (67.7%) crying (58.8%) or throwing things (58.8%).

Table 2 Responses to survey questions

Survey Question	n	Percent of Sample
Does your sensory child experience SOR meltdowns?		
Yes	32	88.9
No	4	11.1
How often does your child experience meltdowns?		
Several times a day	2	5.6
On a daily basis	7	19.4
A few times a week	16	44.4
A few times a month or less	11	30.6

How long does a sensory meltdown usually last for your child?		
≤ 10 minutes	11	30.6
10 min-20 min	14	38.9
30 min-60 min	8	22.2
≥ 60 minutes	3	8.3

Just over half (n=18, 51.4%) of parents surveyed had asked their child what that experience feels like (Table 3). Of those parents who asked, 11 children (31.4%) reported ‘yes’ to ‘does it hurt?’ during a SOR episode. Those children who could respond to the question ‘does it hurt?’ offered descriptions such as: “it feels like knives are stabbing my bones”, ‘my whole body hurts’, ‘it’s killing me”, “it’s painful”, “I’m so scared”, “it’s completely overwhelming.”

Table 3 Responses to survey question: During a meltdown does your child (check all that apply)

Response	n	Percent of Sample
Scream	24	70.6
Cry	20	58.8
Drop to the floor	14	41.2
Aggressive attack	23	67.7
(hitting, biting, kicking crashing into you)		
Throws things	20	58.8
Attack a younger sibling	8	23.5
Attacks an older sibling	2	5.9
Attacks a pet	2	5.9
Hurts themselves	5	14.7
(scratching, hitting, biting, pulling hair)		
Runs away	16	47.1
Loses the ability to speak	14	41.2

Qualitative data was obtained from parent responses to the question “How did your child respond when you asked “What does a sensory episode feel like?” The most extreme descriptions from children reported by parents included: “it feels like knives are stabbing my bones”, ‘my whole body hurts’, “I’m so scared”. “You’re killing me.” A full description from the last child’s report included him saying: “It’s painful, not physically, but it’s just too much. Don’t touch me, but don’t leave me because it’s just too much. I’m so scared. There’s so much pressure that I have to go onto the ground (Table 4). If you come over to comfort me, it’s killing me. I’m already down on the ground and now you’re killing me.”

Table 4 Response to survey questions

Survey Question	n	Percent of Sample
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Have you ever asked your child what that SOR event feels like?		
Yes	18	51.4
No	17	48.6
If you have asked your child "does it hurt," how have they answered?		
Yes	11	31.4
No	3	8.6
They do not remember	4	11.4
Did not ask their child	17	48.6

Other children indicated sensory specific reactions that included: "Smells are too strong", "Sounds are too loud", "It hurts my ears", "Textures are too rough", "It's completely overwhelming", "I hate the feeling", "It's too loud." one parent described anger as a result of the experience of a sensory episode in the following description, "He describes feeling like too many things are happening in his head and body at once and it makes him mad."

Lastly, several parents reported descriptions that some children do not remember the experience of a SOR episode when asked [16]. Such responses include "he can't recall the details", "he is unable to describe the experience", "he shuts down instead of explodes", "he's minimally verbal and can't remember".

The majority of parents reported feeling frustrated that their efforts don't seem to help (n=24, 66.7%) or confused about how to help (n=23, 63.6%). Parents also reported feeling hopeless about their efforts to help (n=14, 38.9%) and angry at their child (n=16, 44.4%). A minority (n=11, 30.6%) of parents reported feeling confident responding to their child during a SOR episode (Table 5).

Table 5 Response to survey question: How confident do you feel parenting your child during a sensory melt down?

Response	n	Percent of Sample
1. I feel hopeless about my efforts to help.	14	38.9
2. I often feel angry at my child when they have a (SOR) meltdown.	16	44.4
3. I feel frustrated that my efforts don't seem to help very much.	24	66.7
4. I have no idea if I'm helping or hurting.	13	36.1
5. I'm confused about how to help, but I keep trying.	23	63.9
6. I feel confident that I have a good strategy, and that I am helping my child feel safe. We feel hopeful that things are improving.	11	30.6

Note: Parents were instructed to check all statements that apply.		
14.7	14.7	14.7

Most common strategy that parents use is to 'stay with their child' (86.1%) followed by giving them proprioceptive input (58.8%), a gentle hold to keep everyone safe' (58.3%) or 'naming their feelings' (55.6%) (Table 6).

Table 6 Response to survey question: During your child's sensory meltdown, what have you tried? (Check all that apply)

Response	n	Percent of Sample
Stay with my child	31	86.1
Gentle hold to keep everyone safe	21	58.3
Give them a time out	7	19.4
Give consequences (i.e., withdraw a privilege)	7	19.4
Yell	11	30.6
Spank	-	-
Countdown 5, 4, 3, 2, 1	8	22.2
Name their feelings	20	55.6
Give them oral chewies or gum	9	25
Give them proprioceptive input	21	58.3
Other	13	36.1

Discussion

This descriptive, exploratory study captured the lived experience of parents and children with SOR and their families. Although more than half of parents reported having a child with an extreme reaction, up to 48% did not report these episodes. For children who have an extreme reaction these episodes are frequent and can last for up to an hour.

The range of behaviors described suggests that not every child experiences SOR in the same way. There are different sensations and different levels of intensity for different individuals. While only a few parents reported that their child experienced a SOR episode several times a day, many more parents reported the frequency as several times a week. Variances in duration were also observed, with eleven parents reporting their child's extreme reactions lasting up to an hour or longer and 11 parents reporting the duration as 10 minutes or less. These results describe a spectrum of experiences, suggesting that while one child may have a mild experience of sensory SOR, lesser in severity, duration, and frequency, another child may experience a SOR episode of greater intensity, longer duration, and higher frequency [17].

Commonalities in behavior during such episodes included

expressions of high distress and fight/flight responses, such as aggression or running away from a parent. These responses imply fear based reactivity with some parents also reporting their child losing the ability to speak. Additionally, some of the parent reports of their children's descriptions suggest an inability to remember or talk about the SOR experience. One possibility is that the experience is so overwhelming that they experience what the literature called sympathetic shutdown or a freeze response of the sympathetic nervous system [18]. These responses may reflect extreme fear or trauma that renders the child nonverbal.

The responses captured in this study suggest that SOR has a spectrum of responsiveness. Survey results indicated that 11% of this sample did not have children who experienced SOR episodes. Within the group who did experience a SOR episode, close to a third experienced such episodes less than once a month and indicated that the episodes lasted for less than 10 minutes. This finding speaks to the dimensionality of sensory over-responsivity. While this study focused particularly on those individuals with severe reactions, secondarily it suggests that intensity of reactivity may need to be studied separately. The literature hypothesizes that some children with less severe SOR symptoms may struggle with impairment in family life [19] as well as challenges in socialization and other activities of daily living even though they may not experience the extreme reactions reported by some parents in this study [2,11]. Additionally, existing scales to measure sensory symptoms may benefit from modifications to allow the inclusion of severity ratings. Future study is needed to determine the degree to which lower intensity reactivity interferes with daily life, and how those findings compare to disruptions in social-emotional learning, activities of daily living, and 'joy of living' for children with more intense, longer duration, and more frequent SOR episodes.

Although only approximately half of the parent respondents asked their child what a SOR episode feels like this question elicited rich first-person accounts from children with SOR of those who responded, the majority reported painful experiences by saying 'yes' to the question 'Does it hurt?'. While many of the parents surveyed did not report their child experiencing pain during a SOR episode, there was a large percentage who did not ask their child what these episodes feel like. It is possible that this number would have been greater had more parents asked their child how these episodes feel to them. This finding contributes to the growing body of literature describing a relationship between SOR and pain [19,20].

Recent physiological evidence shows that children and adults with SOR have abnormal pain perception [20]. Sensory testing reveals altered pain processing along with enhanced and lingering pain sensation [4]. Pain hypersensitivity in SOR suggests involvement of the central nervous system (CNS) as an underlying mechanism. In light of findings in this study, it is important for parents and professionals to recognize that the experience of pain is involuntary, due to altered underlying mechanisms and informs behavioral responses to sensation. Given that SOR and pain have shared underlying central mechanisms, it is hypothesized that sensory stimuli and pain have a bidirectional influence/impact

producing the type of behavioral reactions described in this study including physical, emotional, and psychological overwhelm, panic, and fight/flight responses and potential trauma [17]. Over time, these repeated experiences of SOR likely strengthen neural pathways that produce the resulting reactivity and may also influence the way that others respond to the SOR child [21]. More research is needed examining the link among SOR, pain and trauma, as well as parent perceptions and interventions.

This study contributes knowledge to our understanding of how SOR episodes shape the experience of daily life challenges for these individuals, which can impact outcomes in such areas as social interaction, sense of agency, capacity for self-regulation and self-control, and self-esteem. These chronic, body initiated sensory assaults likely inform the documented correlation between SOR and the development of chronic anxiety and depressive disorders in adulthood [22].

Results of the first-person accounts from children with SOR suggest that the term 'meltdown' is not the most appropriate term to describe episodes of extreme SOR. When used in reference to children in sensory crisis, the term 'meltdown,' can be misinterpreted as pejorative, or dismissive of children experiencing panic secondary to sensory overwhelm and loss of neurological control, and as such, minimize complexities that parents face in raising a child with SOR. Importantly, when children talk about their experiences as 'hurting' (or causing pain) they use words that convey violent imagery such as stabbing knives, killing experiences, and of feeling completely overwhelmed and exhausted during and after. These descriptors imply an experience of trauma; the child feels trapped in a frightening experience that overwhelms the capacity to think, and can result in either motoric discharge, such as acts of aggression against self or others, or social and emotional withdrawal [23-25]. Knowing about experiences of pain can inform the language and perspective of families and professionals in understanding an individual's SOR reactions. Behaviors of children seen as aggressive or defiant could be reframed as behaviors of children who are overwhelmed and frightened in response to an experience of pain. Caregivers can then respond with strategies that prioritize reestablishing the child's sense of safety within his/her body and within the child-caregiver relationship, while simultaneously managing both child and caregiver safety needs and behavioral reactivity.

Such a shift in understanding could warrant that the terminology used be more consistent with the feelings and sensations that a child with SOR experiences, rather than an onlooker's descriptor of a child in crisis. We suggest that the word assault may be a more accurate and appropriate way to describe a SOR episode rather than the word meltdown, which is frequently used in the literature. Thus, this study introduces the term sensory assault to describe the disproportionate response to sensory stimuli for a child with SOR. This term is more consistent with the literature linking physiological, neurologically driven adverse sensory experiences that activate autonomic nervous system fight, flight, or freeze response [18,24].

Pain during a SOR episode has potential to be experienced as traumatic for some children. The pain, fear, and panic associated

with a SOR episode engage the interoceptive system that and may overwhelm other capacities of the nervous system, impairing the person's ability to think, relate or be in control. This sensory assault experience produces a response that overrides the individual's ability to utilize mobilization strategies or social engagement strategies for the purpose of coping [23,24]. Additionally, the experience of chronic sensory episodes throughout childhood may have long term psychological effects into adulthood, as research suggests [8,16]. Further research considering the link between sensory episodes and trauma is warranted.

Parents play a crucial role as first responders to a child who is experiencing a sensory episode or sensory assault. Survey findings indicate that parents struggle to co-regulate their child during a SOR episode. Parents reported feeling confused, frustrated, angry, and eventually hopeless about caring for a child with SOR. This suggests that parents require greater knowledge regarding the cause of sensory driven behaviors, as well as the strategies and tools needed to help their child during a SOR episode. Importantly, these findings also suggest that parents themselves need more emotional and mental health support to ensure that their efforts are helping their SOR child [26]. Although caregivers shared a range of responses about strategies, they use to support their child during a sensory assault; only one third were confident about the tools they were using. Caregivers also differed in the specific strategies used during a sensory episode. The most reported strategy was to stay with their child for the duration of the experience. A little over half of parents said they held their child gently, named their feelings or provided proprioceptive input. Very few indicated that they would give their child a time out or negative consequences and none reported spanking their child.

Though exploratory and preliminary in nature, this study has important practical and theoretical implications, with respect to the parent experience, the child experience and the parent and child relationship. Secure attachment formation is the primary goal of parenting, and the foundation for regulated emotions and behaviors. Thus, it is not surprising that the literature suggests that sensory processing deficits can disrupt the attachment relationship between parent and child. Studies found that the over-responsivity subtype not only negatively impacts attachment [27,28] but is also associated with attachment anxiety and distress [29]. Additionally, sensory deficits are reported to be correlated with higher rates of parental stress [10]. Safe emotional connections between parent/caregiver and child during a sensory crisis are crucial for the establishment of secure parent child attachment [30-32]. These findings underscore the critical need for appropriate services for parents of children with SOR, and must include strategies and tools to employ when their child's is suffering a sensory episode/assault.

Clearly parents also play a critical role in the treatment process of children with SOR. Occupational therapists and mental health professionals need to collaborate to provide the knowledge and the tools that parents can implement when a child is experiencing a sensory episode/assault. An appropriate parenting approach will be one that prioritizes relational, psychological and physical

safety as the foundation upon which children's behaviors are understood and responded to. More support is needed for parents to better understand what their child is experiencing, how to individualize strategies used to care for the child during a sensory assault, and importantly, that acknowledge and attend to parents' feelings of anger, confusion, frustration, and hopelessness about raising a child with SOR. An emphasis on relationship and safety characterizes many of these newly developed programs [33]. Attention towards parenting can address the need, identified in this study, to expand efforts to reduce parent/child stress and support parent/child attachment. Future research should focus on the effectiveness of different strategies that parents use to help their child during sensory assaults as well as to gain a better understanding of each unique child's experience. Parents themselves need ongoing emotional support towards the work of parenting a SOR child, as well as intelligent parenting strategies to implement during a child's sensory assault in order to remain emotionally regulated, resilient, and confident about parenting their SOR child.

Conclusion

This descriptive, exploratory study captured the lived experience of parents and children with SOR. Parents did not feel confident about strategies they use with their child during a sensory assault; they feel frustrated confused, angry, and hopeless. While more than 50% of parents reported having a child with an extreme SOR reaction, this study also found a spectrum of responsiveness. Many of the children who reportedly experienced a SOR episode also reported feeling pain. Thus, the term 'sensory assault' is offered as an alternative to 'meltdown' or 'episode' as better capturing the potentially traumatic experience of these children. Talking to children with SOR about their lived experience may offer more insight into how to best understand and support secure attachment in the parent child relationship and physical safety. Clearly more research is necessary to explore the elements that determine effective parenting of a child with SOR. Most importantly, further understanding of these phenomena has the potential to positively impact the lives of children with SOR and their caregivers.

Study Limitations

The current study had several limitations. Participants were a small convenience sample coming from one online parent group in northern California and thus may not be representative of all parents of children with SOR. Parents self-identified as having a child with SOR in order to participate in the study. Therefore, researchers cannot confirm that every parent in the study had a child with SOR. This study focused on parent responses and did not directly question children with SOR. Additionally, this survey did not explore why parents did not ask their child what a SOR episode feels like. Due to the nature of the survey and the data collection procedure that was used, we could not calculate # of parents using multiple strategies. The study also did not define "confidence" when parents were asked if they felt confident in the strategies they used. Furthermore, we were unable to determine if parent sense of confidence was associated with the

frequency, duration, and intensity of their child's SOR episodes. That is, did parents of children who had longer, more frequent, and more intense episodes have less confidence than parents of children whose episodes were less frequent and shorter in duration? Lastly, there are several disadvantages to self-reporting including the potential for response bias, social desirability bias, and admittance of private and/or potentially embarrassing details.

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Conflict of Interest

The authors have no relevant financial or non-financial interests to disclose. All authors declare that they have no affiliations with or involvement in any organization or entity with any financial interest or non-financial interest in the subject matter or materials discussed in this manuscript.

Contributions

The first author was responsible for the study conception and design. All authors contributed to material preparation, data collection and analysis. Each author reviewed all versions of the manuscript, read and approved the final manuscript.

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