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The Lived Experience of Meltdowns for Autistic Adults

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Abstract:

Autistic meltdowns have been explored from the perspectives of parents, but there is a paucity of research on the experience of meltdowns from the autistic perspective. Little is known about how adults experience these events. In this descriptive phenomenological study, we conducted online interviews with 32 autistic adults on the experience of having a meltdown. Data were analyzed using Colaizzi's 7-step method. Six themes emerged from data that captured the essence of meltdowns, including: *feeling overwhelmed* by informational, sensory, social, or emotional stressors; *experiencing extreme emotions* such as anger, sadness, and fear; *losing logic*, including challenges with thinking and memory; *grasping for self-control*, in which participants felt out of touch with themselves; *finding a release* for emotions, often described as an "explosion" of external behaviors or self-harm; and *minimizing social, emotional, or physical harm* by avoiding triggers or self-isolating when possible. Findings highlight the painful and distressing internalized experience of meltdowns beyond behavioral characteristics. Participants shared examples of internal meltdowns, in which external characteristics of meltdowns were camouflaged. Participants also suggested that meltdowns may serve a functional role in regulating emotions and making one's voice heard. Meltdowns are diverse experiences that hold different meaning to different people.

Lay abstract:

There is not a lot known about what it feels like for autistic people to have a meltdown. Past research has focused on what meltdowns are like for parents and what meltdowns look like from the outside without understanding what it is like for the person having the meltdown.

We asked 32 autistic adults about what it is like for them to have a meltdown. We asked them to tell us about their thoughts and feelings about having a meltdown. Then, we looked for themes in their responses that summarized the meltdown experience.

Our findings showed that meltdowns hold different meaning to different people. During a meltdown, we found that most autistics described feeling overwhelmed by information, senses, and social and emotional stress. They often felt extreme emotions such as anger, sadness, and fear and had trouble with thinking and memory during the meltdown. Participants described trying to stay in control of themselves, often feeling like they were not themselves during meltdowns. They described the meltdown as a way letting go of or releasing the extreme emotions they felt. Participants tried to stay away from things or people that might trigger a meltdown or tried to make sure they were alone if they felt a meltdown may be coming as a way of avoiding harm – including harm to their bodies, their emotions, and their relationships. These findings offer an important look into what it is like for autistic adults to have meltdowns from their own point of view.

Keywords: autism, challenging behavior, meltdown, qualitative, tantrum

The “autistic meltdown” is a well-known phenomenon often mentioned in literature on autism and in discourse in online autistic spaces. Several organizations that include autistic voices have defined these events using language about feeling “overwhelmed” and “losing control.” For example, the Autistic Press (2021) explains:

Meltdowns happen when autistic people get overwhelmed by our senses. We may get overwhelmed by things that don’t bother you, like the noise of an air conditioner. That can make us lose control of our body. We can’t control if or when we have a meltdown. (p. 14)

Similarly, the National Autistic Society (2020) defines meltdowns as:

an intense response to an overwhelming situation. It happens when someone becomes completely overwhelmed by their current situation and temporarily loses control of their behavior. This loss of control can be expressed verbally (eg shouting, screaming, crying), physically (eg kicking, lashing out, biting) or in both ways. (para. 2)

Both of these organizations stress the importance of giving the person space, treating them with respect, and trying to make the environment safe for the person, for example by reducing environmental stressors. They emphasize that autistic meltdowns differ from temper tantrums and should never be treated as “bad” or “naughty” behavior.

Still, meltdowns are consistently labeled as “disruptive,” “challenging,” or “problem” behaviors in autism literature (O’Nions et al., 2018; Ryan, 2010; Stewart et al., 2017; Tarver et al., 2021), and many continue to use the terms “tantrum” and “meltdown” interchangeably (Kinneer et al., 2016; Lecavalier et al., 2014; Maskey et al., 2013; O’Nions et al., 2018; Silva & Schalock, 2012). Meltdowns are a common concern reported by parents of autistic children,

often contributing to parental stress (Maskey et al., 2013; Silva & Schalock, 2012) and stigma (Kinnear et al., 2016; Montaque et al., 2018; Ryan, 2010; Stewart et al., 2017). Maskey et al. (2013) found that “temper tantrums” associated with autism were the third most frequently occurring “behavior problem” reported by parents in a survey study of 863 autistic children.

Typical characteristics of autistic meltdowns identified in previous literature include crying (Beauchamp-Châtel et al., 2019), screaming (Beauchamp-Châtel et al., 2019; Ryan, 2010), verbal or non-verbal requests (Beauchamp-Châtel et al., 2019), and self-harm behaviors such as head banging (Ryan, 2010; Stewart et al., 2017). Parents have reported that their children’s meltdowns are often triggered by overwhelming situations such as lights, loud or unusual noises, changes in routine, and being exposed to new experiences (Rubenstein et al., 2015; Ryan, 2010), though many report that precipitating factors are often unknown (Rubenstein et al., 2015; Tarver et al., 2021). Meltdowns have also been associated with anxiety (Cervantes et al., 2013; Lecavalier et al., 2014; Rzepecka et al., 2011) and emotional stimuli (Milner et al., 2019). Meltdowns have been identified as an area of concern for parents of children with diverse autistic characteristics and verbal communication skills (Mayes et al., 2017), including parents of autistics who speak few or no words (Tarver et al., 2021) as well as parents of autistics who are considered “gifted students” (Rubenstein et al., 2015).

While meltdowns have been explored extensively through the lens of parents, no studies to date examine firsthand accounts of what it is like to experience a meltdown from the autistic perspective. In addition, studies exploring meltdowns are limited to those that occur in childhood, and there is a dearth of evidence on how these events are experienced in adulthood. Exploring the lived experience of meltdowns can provide insight into how meltdowns are felt and perceived internally, beyond externalized behaviors associated with these events observed by

others. Recognizing autistic people as experts of their own experiences can provide a critical perspective to understanding the meaning of meltdowns for autistic individuals, which is absent from current literature. As a beginning exploration into the autistic experience of meltdowns, the purpose of our study was to describe the lived experience of having a meltdown for autistic adults.

Methods

Design

Descriptive phenomenology is an inductive approach used to explore and describe the essence of a phenomenon as it is perceived by those living it. Rooted in the philosophy of Edmund Husserl, descriptive phenomenology calls on researchers to step back from their own presuppositions and “natural attitude,” often taken for granted by the researcher as objective fact, and instead open their minds to seeing the world through a new lens (Husserl, 1970). This is accomplished through epoché, or “bracketing” and suspending previous assumptions about the phenomenon, and then through reduction, or opening oneself to the world without presuppositions to see the phenomenon for what it truly is. Husserl’s philosophy also emphasizes intentionality, meaning that a phenomenon can only be fully understood by calling to consciousness the feelings, perceptions, judgments, and memories that accompany an experience rather than relying solely on sensory details. In this way, truth is in the eye of the beholder. In this study, we used Colaizzi’s (1978) method of descriptive phenomenology to describe the experience of meltdowns as they are consciously experienced by those who live them.

Sample

Individuals were eligible to participate if they identified as autistic, were 18 years or older, and had experienced a meltdown as an adult. We opted to include individuals who were self-diagnosed in light of growing evidence that many autistics reach adulthood before they are diagnosed and formal diagnosis can be difficult to obtain in adulthood (Lai & Baron-Cohen, 2015; Lewis, 2017). The sample consisted of 32 autistic individuals from seven countries, primarily the United States ($n = 18$), United Kingdom ($n = 4$), and Canada ($n = 4$). Table 1 includes demographic and background information. Specific data on socioeconomic status were not recorded.

Table 1

Demographic characteristics of sample (N = 32)*

| | <i>n</i> | % |
|--------------------------------------|----------|------|
| Age | | |
| Mean: 33.4 years | | |
| Range: 18-66 years | | |
| Gender | | |
| Female | 17 | 26.7 |
| Male | 4 | 56.7 |
| Gender Fluid/Gender Queer/Non-Binary | 5 | 16.6 |
| Sexual Orientation | | |

| | | |
|-----------------------------------|----|------|
| Heterosexual or straight | 15 | 50.0 |
| Gay or lesbian | 6 | 20.0 |
| Bisexual | 1 | 3.3 |
| Asexual | 5 | 16.7 |
| Other | 3 | 10.0 |
| Diagnosis | | |
| Formally diagnosed | 21 | 70.0 |
| Self-diagnosed | 9 | 30.0 |
| Highest Level of Education | | |
| High school graduate | 6 | 20.0 |
| Some college | 7 | 23.3 |
| College graduate | 8 | 26.7 |
| Some post graduate work | 3 | 10.0 |
| Post graduate degree | 6 | 20.0 |
| Employment Status | | |
| Employed, full time | 10 | 33.3 |
| Employed, part time | 4 | 13.3 |

| | | |
|---|----|------|
| Student | 3 | 10 |
| Homemaker | 2 | 6.7 |
| Retired | 2 | 6.7 |
| Unable to work/disabled | 6 | 20.0 |
| Unemployed | 3 | 10.0 |
| Race | | |
| White | 27 | 90.0 |
| Black | 2 | 6.7 |
| Asian/Pacific Islander | 1 | 3.3 |
| Ethnicity | | |
| Hispanic or Latino | 1 | 3.3 |
| Not Hispanic or Latino | 29 | 96.7 |
| Level of Assistance Needed with Activities of Daily Living | | |
| No assistance needed | 10 | 33.3 |
| Minimal assistance needed | 8 | 26.7 |
| Some assistance needed | 7 | 23.3 |
| A great amount of assistance needed | 5 | 16.7 |

** Missing demographic data for 2 participants*

Procedure

After obtaining approval from an Institutional Review Board, participants were recruited via social media and online forums related to autism. Recruitment posts contained the title of the study, a brief description of study procedures, and a link to the study website. Data were collected via asynchronous online interviews using LimeSurvey, a secure survey platform. Online consent was obtained prior to interviews. We chose to conduct interviews in writing via online surveys rather than traditional interviews based on the reported communication preferences of autistic individuals (Gillespie-Lynch et al., 2014). This approach allowed participants to take their time in responding to questions without the added social pressures of real-time communication. Individuals who were interested in the study were directed to the study website, which included an information sheet, two screening questions to self-report that inclusion criteria were met, and initial interview questions.

In initial interview questions, we asked participants to respond to the following statement: “Please try to recall the experience of having a ‘meltdown.’ Please share any thoughts, feelings, and overall reflections about your experience in as much detail as possible.” Participants were also asked to describe their experiences with “shutdowns,” which are not reported here. We asked demographic questions such as their age and gender as well as background information, such as how often they experience meltdowns and a description of the level of assistance they need with activities in their daily lives. Participants were notified that they could stop participation at any time and were encouraged to stop participation and seek support if they became distressed. We provided a list of support organizations at the start and end of the survey. Participants were not compensated for their participation in this study.

After reading initial responses, we created individualized surveys for each participant containing any clarifying and probing questions and emailed these unique survey links to each participant for follow-up. For example, we asked participants questions such as: “In your previous response, you described what a meltdown *looks* like for you. Can you tell us more about what a meltdown *feels* like for you? For example, what is going through your mind during a meltdown?,” and, “You mentioned that during a meltdown you may ‘start to be violent.’ Can you tell us more about this?” Follow-up surveys were sent to 24 participants, with 14 participants responding (58% response rate). Of those, 10 participants were sent an additional follow-up survey and 9 responded (90% response rate). We repeated this process until we reached saturation, i.e., when responses became redundant and no new themes emerged from the data.

We used Colaizzi’s (1978) method for data analysis. We extracted all significant statements related to the experience of meltdowns from participants’ written interviews, and formulated meanings for each significant statement. We organized formulated meanings into clusters to identify themes within the dataset and incorporated these into an exhaustive description of the phenomenon of interest. Finally, we shared our findings with participants to validate findings. Eight participants provided feedback on our interpretation of findings and shared statements such as, “This is exactly how I feel,” and “This is 100% accurate. Thank you.” There was no other community involvement in the reported study.

Trustworthiness & Positionality

Lincoln & Guba’s (1985) criteria were used to establish trustworthiness. Credibility was established through triangulation of analysts and member checking. Findings were independently analyzed by the first and second authors and then discussed together to explore alternative ways of viewing the data. Transferability was enhanced through thick description of findings through

rich quotes to provide context and bring data to life. A Masters-prepared nurse with training in qualitative research reviewed an audit trail of findings to establish dependability and confirmability. Both authors maintained a reflexive journal to bracket preconceptions, assumptions, and biases and to establish confirmability. Authors attempted to remain open to understanding the meaning of these experiences for those living the phenomenon.

As part of this reflexivity, the authors wish to disclose our own positionality as it relates to this research. Our thinking is informed by our background as nurses. Our initial understandings of autism were shaped by training in the medical model of disability, in which autism was identified as a problem of the individual, with “symptoms” that are to be “treated” or otherwise minimized. Over the last 5+ years, we have engaged in a re-learning process as we have become familiar with the Neurodiversity Movement and the social model of disability. We now recognize autism as an important variant in human diversity that, like any neurotype, comes with individual strengths and challenges. We recognize that our environment is structured to privilege those with so-called “neurotypical” neurotypes while marginalizing those who are neurodivergent, which frequently results in disability. We have attempted to bracket our own worldviews here to reflect the perspectives of our participants as presented to us, though we recognize our interpretations are inevitably shaped by our own underlying biases and assumptions, our privilege, and our surrounding culture of systemic ableism, racism, sexism, classism, and heterosexism.

Results

Participants reported varying frequencies of experiencing meltdowns, ranging from every few hours to once a year, and three participants reported that they could not identify a frequency because they experience meltdowns only in specific circumstances (e.g. “only when public

speaking”). Most participants shared that it was difficult to capture frequency, for example sharing, “They happen once a month, sometimes less. I can have 3 meltdowns in a week and then nothing for 6 months,” and another, “Every few hours but maybe get an extreme one (to the point of it being so bad I consider suicide) every 2-3 days.” Many shared that frequency varied based on their circumstances, for example, “It depends on how I am with my mental health and what I am doing,” and, “It varies. If I’m exhausted, the probability increases significantly.” In general, of those who identified a timeframe, 18.5% ($n = 5$) participants reported experiencing more than 2 meltdowns per week; 37% ($n = 10$) experienced 1-2 per month; 22.2% ($n = 6$) experienced 4-6 per year; and 22.2% ($n = 6$) experienced 1-2 per year.

Six themes captured the essence of the experience of having a meltdown for participants, including: feeling overwhelmed, experiencing extreme emotions, losing logic, grasping for control, finding a release, and minimizing harm. Themes are explored in depth in the following sections.

“I am crushed by the overload”: Feeling overwhelmed

Most participants described a sense of feeling “overwhelmed” by information, sensory stimuli, social situations, changes in a plan or routine, their emotions, or other stresses leading up to a meltdown. Examples of situations that led to meltdowns included being at a busy tourist attraction, experiencing poor customer service, feeling let down by a partner or friend, and having a deep philosophical discussion in a class. Many described scenes where stressors were compiled, such as when they felt overwhelmed by sensory stimuli and their coping strategies brought on unwanted social attention that added to their stress. For example, one participant described trying to meditate after becoming overwhelmed in a grocery store, which prompted strangers to approach him to ask if he was okay, ultimately leading to a meltdown. He shared, “If

people would just leave me alone I could have calmed myself and been OK but no, people assume you want/need help.”

Some shared that it can be difficult to detect why they were overwhelmed. For example, one wrote, “Meltdowns are generally linked to feeling overwhelmed but can be difficult to decipher why, whether it’s emotional, physical (due to hypersensitivity of various senses or touch being triggering due to trauma), social or just anxiety.” Several participants shared that they experienced different “types” of meltdowns in different circumstances, often based on what they felt had “triggered” them to feel overwhelmed (e.g. social triggers vs. sensory triggers vs. emotional triggers).

Participants described feeling overwhelmed as a trigger to the meltdown itself, but also as a predominant feeling throughout and after the experience. For example, one simply shared, “Meltdowns are overwhelm.” Another shared that during a meltdown, “It was as though I was crushed by the sensory/informational overload that I had tried so hard to keep under control.” One more wrote that even after the meltdown had stopped, “The sense of being pressured, closed in, and overwhelmed lasted most of that day.”

“I can feel my emotions at full force”: Experiencing extreme emotions

Participants described feeling “uncontrollable anger,” “frustration,” “sadness,” and “fear,” throughout a meltdown. Many shared that they did not know how to process the intensity of their emotions during these events:

For me, a meltdown is tied heavily to my emotional state. I am rarely aware of my own emotions – and I typically feel as though I am not experiencing emotion at all. During a

meltdown it is as though I can suddenly feel emotion at full force, and it is such a strong, negative state of emotions that I will often lash out despite my best interest.

Another shared, “There’s too much emotions, too much sadness, too much anger inside.”

Some participants also described intense feelings of “guilt,” “shame,” “pain” and “self-hate” during meltdowns. One shared:

It is like a bubble of very strong emotions. The “I am worthless” and other negative thoughts make total sense in that state, but not so much outside it. The everyday world feels less “present”; there is a strong feeling of total aloneness.

Participants equated their emotions to physical pain, sharing, “It’s like a loop of pain and I don’t know how to stop it. It’s like bleeding and no one to help.” Another described, “I felt like I was going to die.”

“I lose the ability to think clearly”: Losing logic

Participants shared that they felt that their thinking and memory were affected during meltdowns. One shared, “It feels like my brain can’t process a sudden change,” and another, “I lose the ability to think clearly. My head feels foggy and muddled... My mind goes blank.”

Several talked about “losing control” of their thinking. One shared, “I lose control of my mind. If I try to be calm, I simply can’t.”

Some participants also shared feeling a different sense of logic during meltdowns. One participant explained, “There is a set of other assumptions and ‘logic,’ different from my everyday logic, that become ‘reasonable’ to me when the meltdown is going on.” One referred to logic being overrun with “mental spam” and shared, “Meltdowns are like a spammy pop-up that

refuses to close and keeps making noise whenever you try to interact with it.” Several described that they act “irrationally” in the moment, but are not able to recognize this until after the meltdown has passed.

Others described feeling “paranoid” and “delusional” and are unable to process others’ intentions. One participant shared:

I will verge on delusional, genuinely believing that the people surrounding me are “out to get me” if they so much as challenge my behavior. The intensity of the emotion makes it difficult for me to not only control my impulses but also rationalize people’s behavior.

Another shared a story about experiencing a meltdown while shopping: “Conversations and other noise seemed magnified and distinct. Peoples’ movements seemed threatening like claustrophobia. I really was very bewildered and couldn’t quit crying. Luckily a friend was there who stepped in and guided me out of the store.”

Several participants shared that they did not remember what happened during meltdowns. For example, some used phrases such as, “According to my partner, I...” or “Apparently, I...” or, “All I remember was....” when describing their behavior. When asked about these memories, participants reported, “It’s hard to recall what happens during a meltdown,” and “I’m not quite sure of how to describe these events because I hardly remember them.” One shared, “I am aware of my surroundings and what’s in my way to where I need to get to feel safe. I never remember what I say. Until I feel safe. Then it all comes back.”

“I feel not in touch with myself”: Grasping for Self-Control

Many participants shared that they did not feel like themselves during meltdowns. One shared, “I feel not in touch with myself,” and another said, “The meltdown becomes my reality;

it becomes how I feel ‘me.’” Participants described acting in ways that were not in line with their typical behavior. For example:

Something cracked inside me and I lost all control of myself and who I was. Normally I am fairly unassuming and quiet, in a meltdown I explode into uncontrollable bursts of emotion and action. In a meltdown, I feel completely out-of-control and inhuman in the moment.

Participants shared that they became “very primal and animalistic” in the ways that they responded to their surroundings. One described, “I become a completely different persona full of rage and anger, when in this state I have been compared to the Incredible Hulk from Marvel.” This change in persona often left participants feeling that they had lost control of themselves. Participants shared, “It makes me feel lost, like I’m no longer in control of my own little world,” and, “Meltdowns make me feel out of control of myself.”

That said, some participants shared that they had learned to maintain a sense of control to protect themselves from potentially unsafe situations. One participant shared:

It feels very important to me that your wording be inclusive of autistics whose brains have adapted in ways that do not let meltdowns show in public, for survival. If clinicians are only looking for people who “lose control” -- using the common meaning of that phrase -- I think they will miss some people who could be having serious problems.

This participant described that she had learned to control her external reactions to meltdowns in public, and instead often internalized her experiences, resulting in negative self-talk and self-injury.

“I explode”: Finding a release

Many participants shared that they “erupted” or “exploded” in their outward behaviors during meltdowns. Participants described a range of reactions such as “crying,” “screaming,” “hitting,” “kicking,” “throwing,” “breaking objects,” and more. One shared, “I have dropped to the floor in the middle of the street, ran from supermarkets and into the road, and self-injured to the point of leaving marks.” Several described becoming “aggressive” and “violent.”

Most participants shared that this outward expression served as a “release” for the intensity of the emotions they were experiencing. One participant described, “Meltdown to me is volatile. It’s about getting my emotions out.” Another said, “You’re basically venting all the rage and frustration externally.” One more explained, “The emotions build up and rage in my arms or legs. I expel it by throwing things on the ground or kicking objects.”

Others shared this this was the only way that they knew how to communicate their message in that moment: “I don’t know any other way to get my point across or be heard.” Another shared that he would “attack with verbal ferocity” during meltdowns, describing, “I viewed these meltdowns as a fight against evil and ignorance where language would be used to win or dominate while spewing out ‘reality’ that they needed to hear and accept.”

For some participants, they found this emotional “release” through self-injury. One explained that self-injury was a way of taking back control: “Sometimes I hurt myself with the first object I find (lighter, pen, screwdriver... a wall... or my nails). Hurting myself is being in control. Sadly, it helps.” Another shared, “I would often end up doing ‘minor’ self-injury to avoid doing anything worse. That seemed to stop the feelings.” Several others described head banging or “hitting my head on a wall or floor.” One more described:

I feel massive depression, ranging from crying a lot to suicidal thoughts. Other times, I end up just hitting an inanimate object, such as walls or doors, because I NEED to release. I have permanent soft tissue damage in my left hand where I HAD to hit a wall to get over my meltdown.

One participant described redirecting her behaviors in a way that she believed would not cause significant harm:

When this happens, my head is clear enough to recognize that the discharge should be directed as to not hurt myself or others. I have been known to slap walls (I don't want to hurt my knuckles) and to kick furniture (I turn my foot to the side to avoiding breaking toes).

“I'm trying to stay safe in the world”: Minimizing Harm

Many participants described their attempts to avoid, manage, and control meltdowns as a way of minimizing social, physical, or emotional harm. For instance, many participants described wanting to “isolate” themselves when a meltdown began to avoid saying or doing something that might damage a relationship, as well as to avoid social triggers that exacerbated their feeling of being overwhelmed.

Some explained that they were able to detect when a meltdown was coming and either avoid the triggers to prevent the meltdown altogether, or to go to a place that was “private” and “safe.” For example, one shared:

I avoid meltdowns by leaving the situation, but this is not always possible. I know a meltdown is coming on when I'm stimming excessively. Then I feel terrifically angry and

start screaming and crying. I usually retreat to my room where I can do this in private.

Since I have learned what triggers me, meltdowns are far more rare for me now.

Others mentioned that they “only do it in front of people I’m close to.” One shared that she is more likely to have a meltdown when she is at home “because I’m more comfortable, so I don’t bother trying to restrain myself as much.”

Many described having more autonomy in adulthood than that had in childhood, which led to fewer meltdowns as an adult. One participant wrote, “I think as an adult, having the agency to back out of most situations keeps meltdowns to a minimum.” For others, they described learning to manage the expressive aspects of the meltdown, but still described an internalized experience. For example, one participant explained:

As an adult the consequences are generally worse, so it’s almost easier to just internalize things. Children act out, children have temper tantrums. [Autism] is often seen as a "child's disorder." If I were to have a meltdown at 12, people would be bothered but it might not affect their opinion of me permanently. At 21, I'm expected to "act like an adult," and acting in such a bizarre way really affects how people see me in a negative way.

Others talked about “camouflaging” their external reactions as a matter of safety:

I am trying to stay safe in the world, camouflage my inner feelings which I guess I feel unsafe showing at that point. I am just really really strongly working to focus on “acting normal.” Camouflaging is a survival skill for me.

For others, meltdowns remained unpredictable. Participants said, “Almost always unexpected. A lot of times I don’t even know why they happen,” and, “I have had no warning

that this is about to happen.” These individuals who could not detect and retreat during meltdowns described a fear of the experience:

I can't detect them. It's really violent. In the process and in the way it starts. I feel helpless. I write these lines with a certain amount of anxiety. That's how much I'm afraid of meltdowns. I have hope one day I can improve and detect them. I think meltdowns are the most difficult aspects of my autism.

Discussion

Overall, participants emphasized that the meltdown experience is diverse, and the specific characteristics of a meltdown are often unique to the set of circumstances an individual is experiencing at a given time. Previous studies on parents' perspectives on meltdowns have focused on external behaviors that occur during a meltdown (Beauchamp-Châtel et al., 2019; Montaque et al., 2018; Ryan, 2010), and our findings yielded similar behavioral characteristics for most participants. However, our study adds an important understanding of the underlying thoughts and feelings that lead to and accompany meltdowns for those living these experiences. Most participants described meltdowns as distressing, scary, confusing, and intensely painful events. Many shared that they felt emotionally, physically, and socially unsafe during meltdowns.

Participants who were able to identify and avoid triggers were often able to minimize the frequency of and harm caused by meltdowns. Some participants learned to manage meltdown behaviors through “camouflaging” or “masking,” often as a protective mechanism to avoid stigma, discrimination, or other harm. Participants described a need to “hide” meltdowns more in adulthood, particularly given the greater social cost of meltdowns for adults compared to

children. These findings parallel previous qualitative research exploring parent experiences, in which parents described stigma and other social costs related to their children's meltdowns. In a thematic analysis of interviews with 46 parents of autistic children about their experiences with meltdowns, Ryan (2010) found that the most significant problems parents faced in public places were the unpredictability of their children's behaviors and how others reacted to those behaviors. Participants described restricting their outings based on their children's needs, such as reduced sensory stimuli, while still trying to maintain a "normal life" for themselves and their children. Montaque et al. (2018) conducted an interpretative phenomenological analysis of interviews with six parents of autistic children about their experience of meltdowns. Participants shared that the triggers and progression of meltdowns were unpredictable, often leaving them feeling helpless. Participants lived in a state of constant vigilance as they tried to control external factors to avoid a meltdown event and reported a sense of condemnation, from both themselves and from others, in response to their children's behaviors.

Our findings are also consistent with previous literature that shows associations between meltdowns and self-harm. Prior studies include examples of children throwing their bodies into windows, kicking walls, head banging, and acquiring unexplained bruises (Stewart et al., 2017). Parents in a study by O'Nions et al. (2018) described the need to prioritize safety, at times by physical restraining their children to "prevent dangerous or destructive behavior or elopement" (p.1281). For some participants in our study, meltdowns were associated with specific thought-patterns or behaviors that might place the individual in a harmful situation during a meltdown, such as individuals who report becoming unaware of their surroundings or unable to rationalize others' behaviors. In some cases, participants described carrying out behaviors that they believed would cause only minimal self-harm as a means of avoiding behaviors that they believed would

cause more self-harm. Clinicians should be mindful that some individuals may not consider themselves at-risk for self-injurious behavior and may not experience negative self-worth outside of these isolated events but may still experience risk. Assisting autistic individuals in identifying emotions and strategizing other forms of release, such as hitting a pillow or punching bag instead of hitting a wall, may be helpful in minimizing harm.

Still, even when participants were able to “hide” meltdowns and prevent externalized behaviors that may cause harm, they shared that they were not able to eliminate the harm of the internalized experience, only the outward expression of the experience to others. Individuals who described an internalized experience frequently described negative self-worth and self-harm. These findings suggest that an individual may experience a meltdown as an internal event that is invisible to the outside observer. Thus, beyond maintaining physical safety, our findings suggest that it is critical to prioritize management of the distressing triggers and emotions associated with the meltdown, not just the behaviors used to express that internal experience.

In addition, our findings add an alternative to the traditional view of meltdowns as “problem behavior” that has dominated prior work on meltdowns. Instead, it is important to recognize that these experiences hold different meaning to different individuals. For example, while most participants described meltdowns as upsetting, some described them as a sign of being able to freely express themselves when they were in a comfortable and safe environment. Some participants shared that they were more likely to experience meltdowns at home, alone or with close loved ones, or in other situations where they did not feel the need to “mask” their autistic traits. While some behaviors may be deemed “problematic” or “challenging” by parents, clinicians, or researchers, it is important to avoid placing meaning on these experiences beyond those shared by the individual experiencing them.

Participants in this study also shared experiences in which meltdowns served a purpose as a coping mechanism when faced with overwhelming triggers. Meltdowns were used to release emotions, manage dysregulation, and make one's voice heard. Other studies have also suggested a possible functional purpose of meltdowns. For example, Beauchamp-Châtel et al. (2019) identified that autistic children more frequently made demands during "tantrums" and that their parents gave them what they were asking for more frequently compared to a non-autistic comparison group, leading researchers to conclude that meltdowns may serve a role in communication for autistic children. In addition, while Milner et al. (2019) identified meltdowns as a "negative aspect" of autism, one participant in this study also shared that meltdowns are "kind of cathartic to me sometimes," indicating a potential purpose of these events as an emotional release. These findings mirror prior research on other behaviors to manage dysregulation, such as stimming behaviors, which autistic adults commonly feel compelled to hide or "mask" due to social pressures (Charlton et al., 2021; Kapp et al., 2019).

Limitations

This study was limited in its singular approach to data collection. While we selected a communication style frequently endorsed by autistics (Gillespie-Lynch et al., 2014), participants were limited to those with physical, financial, and cognitive access to a computer and written forms of communication. Future studies should explore use of multimodal methods such as interviews, focus groups, and surveys in combination to capture the unique communication styles and preferences of this population. We were also unable to detect nonverbal cues such as silence, body language, and tone through this approach. Furthermore, this sample was lacking in racial and ethnic diversity, which limits transferability of findings. We also did not collect information about other co-occurring conditions that may have impacted the meltdown experience, such as

post-traumatic stress or attention-deficit/hyperactivity conditions, or about communication ability. In addition to exploring these additional factors, future research should explore firsthand accounts of autistic children who experience meltdowns to understand how these events evolve across the lifespan and whether these events are experienced differently in childhood than in adulthood.

Conclusion

This study captured the experience of meltdowns for autistic adults. Autistic meltdowns are often experienced as distressing and painful events. They are diverse in their internal and external characteristics, and they hold different meaning for different people. While the behavioral characteristics of meltdowns have been highlighted in the past, our study sheds light on the emotional and cognitive characteristics of meltdowns that have not been previously explored. Importantly, participants in this study also shared that the internal experience of a meltdown can exist outside of the external expression of a meltdown. Participants shed light on possible functional roles of meltdowns, such as releasing and regulating emotions or ensuring that they are being heard.

Our findings indicate that working to eliminate behavioral responses during meltdowns without addressing underlying emotions may lead to internalization, trauma, and harm. Clinicians should aim to support autistics to manage aspects of meltdowns that they find distressing and build on individual strengths to regulate emotions in ways that are comfortable and acceptable to the autistic person. Our findings add a unique perspective in understanding these phenomena from the voices of those living this experience.

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