

Clinical Child Psychology and Psychiatry

“It feels like something difficult is coming back to haunt me”: An exploration of ‘meltdowns’ associated with Autistic Spectrum Disorder from a parental perspective.

Journal:	<i>Clinical Child Psychology and Psychiatry</i>
Manuscript ID	CCPP-17-0053
Manuscript Type:	Original Manuscript
Keywords:	autism, meltdowns, attachment, parents, qualitative research
Abstract:	<p>The research explored the experience and understandings expressed by parents of children with autism concerning ‘meltdowns’, which are commonly described as distressing, escalating episodes of conflicts. Semi-structured interviews were conducted with six parents of children with a diagnosis of autism regarding their experience of ‘meltdowns’. Parents were asked to track the process of the meltdowns as well as to describe their experiences. Three over-arching themes emerged which encapsulated their experience: Circularity of Meltdowns, Parents’ Adverse Childhood Experiences with Corrective Scripts, and Condemnation. The findings suggested that the meltdowns were perceived as having an escalating and predictable process, that parents anticipated meltdowns with anxiety, experienced feeling of helplessness and felt condemned by others. Importantly, it also appeared that parents’ responses were influenced by their own childhood experiences of parenting and that they attempted to ‘correct’ these to be better parents. A model of the metdowns is suggested along with a discussion of clinical implications for early intervention with families.</p>

SCHOLARONE™
Manuscripts

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

“It feels like something difficult is coming back to haunt me”: An exploration
of ‘meltdowns’ associated with Autistic Spectrum Disorder from a parental
perspective.

For Peer Review

For submission to Clinical Child Psychology and Psychiatry

Keywords: Autism Families Meltdowns Qualitative Research Attachment

Abstract

The research explored the experience and understandings expressed by parents of children with autism concerning 'meltdowns', which are commonly described as distressing, escalating episodes of conflicts. Semi-structured interviews were conducted with six parents of children with a diagnosis of autism regarding their experience of 'meltdowns'. Parents were asked to track the process of the meltdowns as well as to describe their experiences. Three over-arching themes emerged which encapsulated their experience: Circularity of Meltdowns, Parents' Adverse Childhood Experiences with Corrective Scripts, and Condemnation. The findings suggested that the meltdowns were perceived as having an escalating and predictable process, that parents anticipated meltdowns with anxiety, experienced feeling of helplessness and felt condemned by others. Importantly, it also appeared that parents' responses were influenced by their own childhood experiences of parenting and that they attempted to 'correct' these to be better parents. A model of the metdowns is suggested along with a discussion of clinical implications for early intervention with families.

1
2
3 Autism Spectrum Disorder (ASD) refers to a neurodevelopmental disorder (DSM (5),
4
5 APA 2013,) involving two main impairments: difficulties in socio-communicative
6
7 interactions and restricted and repetitive patterns of behaviours. It is regarded as a
8
9 spectrum condition with wide ranging individual presentations. However,
10
11 homogeneous traits and patterns are apparent in individuals at the upper end of the
12
13 spectrum (Kamp-Becker et al., 2010). In this research, the focus will be on parents of
14
15 children with 'High Functioning Autism'.
16
17
18
19

20 21 **Parental Stress and 'Meltdowns'**

22
23 Parenting stress is consistently reported as being higher in families of a child with
24
25 ASD, than families of children with other conditions (Mugno, Ruta, D'Arrigo, &
26
27 Mazzone, 2007). Elevated levels of stress in these families may be a consequence
28
29 of the difficulties in parenting a child with ASD (Estes et al., 2014). There are many
30
31 detrimental outcomes of parenting stress within this group, ranging from physical
32
33 burnout (Weiss, 2002) to mental health issues, such as affect or anxiety disorders
34
35 (Benson & Karlof, 2009).
36
37

38
39 Behavioural problems associated with ASD are often referred to as
40
41 'meltdowns', which are intense explosions of difficult behaviours which resemble
42
43 'tantrums' in younger children, but are more intense, protracted and potentially
44
45 physically and emotionally dangerous to both the child and parents (Mazefsky, 2012).
46
47 Parents explain these problems in various ways. Some understand them as related
48
49 to the egocentric nature of ASD traits, explaining that their child's difficult behaviour
50
51 governs and controls their life choices to meet the child's demands (Myers,
52
53 Mackintosh, & Goin-Kochel, 2009). Although the meltdowns can be seen to cause
54
55 stress for the parents, arguably it is a more complex process than simple cause-
56
57
58
59
60

1
2
3 effect (Hastings et al., 2005). A transactional process may emerge where parental
4
5 stress and distress interact with and possibly exacerbate the child's difficult
6
7 behaviours (Baker et al., 2003). Over time this reciprocal pattern is prone to
8
9 escalation and leads to characteristic sequences of highly emotional interactions
10
11 between parents and child (Neece, Green, & Baker, 2012).
12
13

14 Meltdowns share similarities with temper tantrums, but differ with regards to
15
16 antecedent, function and presentation, as they do not have a set agenda dependent
17
18 on another individual and can be uncontrollable (Lipsky, 2011). Reports suggest that
19
20 94% of individuals with ASD exhibit a minimum of one challenging behaviour
21
22 (Matson, Wilkins, & Macken, 2008). The typical behaviours, such as kicking,
23
24 screaming, destruction of property and withdrawing are disruptive and destructive for
25
26 the individual with ASD and intervening persons, particularly caregivers (Larson,
27
28 2006). It has been proposed that meltdown experiences are a circular process,
29
30 which implies that behaviours of parent and child are perpetuating (Colvin &
31
32 Sheehan, 2012).
33
34
35

36 Research from a behavioural perspective suggests that meltdowns can be
37
38 understood in terms of a sequence of predisposing, precipitating and perpetuating
39
40 factors (Mazefsky & Handen, 2011). Predisposing factors include an increased
41
42 sensitivity to sensory stimulation, difficulties in understanding social relationships and
43
44 anxiety (Lipsky, 2011). Precipitating events can be frustration of needs and criticism
45
46 from parents (Matson et al 2008), which are perpetuated by anger from the parents
47
48 due to the behaviours and passivity in intervention (Baker et al., 2003). Parents are
49
50 required to be mindful of their child's and others' safety due to the display of
51
52 meltdowns, especially when out in public (Ryan, 2010). However, there is relatively
53
54
55
56
57
58
59
60

1
2
3 little qualitative research, which explores the experience of meltdowns from a
4
5 caregiver's perspective.
6

7 Stigma is generally attached to an ASD child's difficult behaviours, particularly
8
9 in public settings (Gill & Liamputtong, 2011). Parents describe feeling misunderstood
10
11 by onlookers, who they see as making negative judgements regarding their
12
13 parenting, which leads to embarrassment, anxiety and a desire to remain secluded
14
15 (Fleischmann, 2004). Research findings suggest that parents of children with ASD
16
17 are less likely to attend public events, even compared to parents of children with
18
19 conduct disorders, who exhibit similar behaviours (Lee, Harrington, Louie, &
20
21 Newschaffer, 2008). Qualitative accounts from mothers of children with ASD indicate
22
23 that they feel a persistent, subjective feeling of stigmatisation from other individuals
24
25 and organisations (Gill & Liamputtong, 2011).
26
27
28

29 Interestingly, when the influence of behaviour problems on parenting stress is
30
31 accounted for, the child's developmental delays and other difficulties do not
32
33 contribute to other additional variance in stress experienced by parents (Baker,
34
35 Blacher, Crnic, & Edelbrock, 2002). This indicates that the outcome of stress may be
36
37 the direct result of a parent's experience of the child's problem behaviour. However,
38
39 similar behavioural difficulties associated with other disorders are not predictive of
40
41 the same level of stress experienced by ASD parents (Lee et al., 2008). Therefore,
42
43 perhaps the *parent's* role in the transactional model (Baker et al., 2003) may belie
44
45 the crucial differentiation that contributes to the pronounced disparity in stress, rather
46
47 than the child's behaviour itself.
48
49
50
51
52
53
54
55
56
57
58
59
60

The Relationship between Meltdowns and a Parent's Adverse Developmental History

Parent's intervention in their child's maladaptive behaviour requires a parenting stance, which varies between individuals, depending on parenting style and the child (Osborne, McHugh, Saunders, & Reed, 2008). A number of environmental and biological factors can influence parenting style, and one of the most influential contributors is an individual's past experience of being parented (Lomanowska, Boivin, Hertzman, & Fleming, in press). If mothers report positive experiences of being parented, this predicts later positive traits, such as warmth and stimulating maternal behaviour towards their own child. Conversely, if a mother's early parented experiences comprise adversity; this has been associated with later difficulties parenting in the next generation (Moehler, Biringen, & Poustka, 2007). This intergenerational transmission of parenting style outlines that a negative or positive past will influence present parenting behaviours (Belsky et al., 2005).

The medium for translation of past adversity and inconsistent care experiences to the present may be due to an insecure attachment relationship during childhood (Sitko, Bentall, Shevlin, & Sellwood, 2014). Where parents of children with autism have insecure attachment models, this has been shown to negatively affect their relational skills with respect to their child (Seskin et al., 2010). Roberts, Lyall, Rich-Edwards, Ascherio and Weisskopf (2013) also identified past childhood abuse and adversity in parents raising a child with ASD. The researchers furthered this, by suggesting that there is an intergenerational causal process, which links mother's negative childhood experiences and increased risk for ASD in the next generation.

Overall, it may be inferred that within this parent group, insecure attachment models and experience of trauma is likely to impact on managing and understanding their child's difficult behaviour. A transactional approach may provide a systemic

1
2
3 explanation for these interacting factors (Baker et al., 2003) within the family unit and
4
5 wider social systems (Kinnear et al., 2015). Assessment of the overall psychological
6
7 functioning of the family unit raising a child with ASD requires consideration of the
8
9 reciprocal nature of these processes (Hastings et al., 2005) and implicates the
10
11 influence of societal factors, such as stigmatisation, in the outcome.
12
13

14 15 16 **Rationale and Aims of the Present Study**

17
18 Meltdowns may be an inevitable accompaniment of an ASD diagnosis (Attwood,
19
20 Evans, & Lesko, 2014). Research has investigated the nature of these behaviours
21
22 for the individual with ASD (Colvin & Sheehan, 2012), but has neglected how parents
23
24 experience meltdowns (Bedrossian, 2015). Furthermore, based on literature which
25
26 reports childhood adversity among these parents (Roberts et al., 2013; Seskin et al.,
27
28 2010) this research also aimed to explore the influence of parent's developmental
29
30 history on meltdowns and the interventions parent's employ.
31
32

33
34 The two specific aims of the research were to explore:

- 35
36 a. Parents' accounts of meltdowns and how they try to manage their child's
37
38 difficult behaviours.
39
40 a) Their understanding of the influence of their own developmental histories on
41
42 their parenting strategies
43
44
45
46

47 48 **Method**

49
50 Semi-structured interviews were carried out with parents. Interpretative
51
52 Phenomenological Analysis (IPA) was used to guide the interviews and analysis to
53
54 capture the experience of 'meltdowns' of six parents. IPA was chosen to move
55
56
57
58
59
60

beyond participant's descriptions, by actively engaging in interpreting their experiences, including their attempts to make sense of their world.

A semi-structured interview schedule was used to guide the format of the session, comprising three broad areas: Understanding of ASD, Nature of Meltdowns and Developmental History. Questions were formulated based on the aims of the research, facilitated by past evidence in the area. Other queries emerged from the interview, which were unique, based on the participant's responses, and a reflection of their personal lived experience.

Participants

Full approval for the study was gained from the relevant University Ethics Committee in line with British Psychological Society research ethics guidelines. The parents engaging in the study were part of a support network for families with a child with autism. A detailed information sheet for the study was produced and parents signed a consent form to participate and to allow their data to be used for publication.

Six participants were recruited as a purposive sample, having a child who had received a diagnosis from a multi-disciplinary team of ASD and who would be considered 'High-Functioning' (See Table 1).

Table 1. Participant information (pseudonyms used)

	Age	Background	Family composition	Diagnoses
Jenny	31	White British University student	Married, 3 children (8,3 and 1), all live at home	Eldest child (8) ASD diagnosis
Pru	47	White British Tutor	Co-habiting, one child	Child (9) ASD
Florence	46	White British Volunteer ASD	Married, one child	Child (12) ASD
Trish	37	White British	Married, 2 children; 20 (left home) and 18	Child 18 ASD at home
Peter	49	White British Manager	Married to Trish. As above	As above
Nancy	40	White British	Cohabiting, 2 children (8, 6)	Child (6) on ASD assessment pathway

Analysis

All interviews were transcribed verbatim, in accordance with IPA transcription template guidelines. Transcripts were first anonymised and then descriptively coded. Preliminary codes were then re-analysed to cluster them into preliminary themes. This interpretative analysis was repeated and resulted in the eventual emergence of subordinate themes. Finally, these were examined across the six transcripts to develop the superordinate themes. As part of the internal validity enhancement procedure, an independent analysis of one of the transcripts was carried out by the investigator (RD), which produced a good agreement and high qualitative inter-rater agreement in terms of similar themes being derived

Findings

Three superordinate themes emerged in the analysis; *Living in Dread: Anxiety and fear of escalating patterns*, *Parents Attempting to Correct for Negative Childhood Experiences and Condemnation from the Self and Others*. The quotes offered represent general themes shared by the participants.

Living in Dread: Anxiety and fear of escalating patterns

The meltdowns took many forms, but were commonly experienced as a complex, recurring process, with many facets and contributions from both the parent and the child. They were widely experienced as unpredictable in what triggered them and in how they would progress and possibly escalate out of control. Overall this theme captures the experience of unpredictability, helplessness, anticipatory high anxiety and dread of the recurrence of the meltdowns:

1
2
3
4
5 *he has very fixed ideas with what he wants and if something isn't exactly how he*
6
7 *wants it he can have huge meltdowns just the slightest thing like the internet going*
8
9 *off for a couple of minutes can produce [...] huge you know violent outbursts (Pru)*
10
11

12
13
14 Parents appeared to have a view of their child as having fixed and rigid
15
16 psychological states and hence searched for explanations that were not related to
17
18 the child's mental states or possibly relational factors. Instead the focus was on
19
20 external factors:
21
22

23
24
25 *my parents had come round sort of unexpectedly which was okay but my daughter*
26
27 *doesn't really like people turning up unexpectedly [...]..... she didn't realise until we*
28
29 *got out of the car that we weren't at this place that's five minutes away so then that*
30
31 *was another thing cos [...] we weren't where she thought she was going [...] then*
32
33 *she said there were too many people and we were also walking along the river and*
34
35 *the river was suddenly too loud (Nancy)*
36
37
38
39

40
41 This suggests that parents are making sense of their child by focusing on general
42
43 factors related to an ASD diagnosis rather than specific mental states which could
44
45 offer an understanding specific to their child. Viewing their child in such a general
46
47 way involved trying to foresee, control or avoid external triggers. Remaining in this
48
49 state of constant vigilance was described as exhausting and frustrating.
50

51
52 The parents' accounts suggested that they frequently felt a need to oversee
53
54 all their child's behaviour and activities, which results in constant anxiety and
55
56 hypervigilance. These feelings indicate a starting point for the circular nature of a
57
58
59
60

1
2
3 meltdown situation, rather than the child's display of difficult behaviour, or even the
4
5 preceding events:
6
7

8
9
10 *Yeah it's huge [the anxiety] it's there all the time you know erm (.) and [...] it's very*
11
12 *difficult because sometimes you just want to desperately avoid meltdowns but at the*
13
14 *same time it isn't always good to do everything to avoid them because [...] you'd*
15
16 *make the world an artificial place for them where they get everything they want so*
17
18 *they don't have a meltdown (Pru)*
19

20
21
22
23 A strong thread in this theme was a sense that the parents felt helpless, as they
24
25 could not influence their child's emotions and actions. They also described how this
26
27 in turn resulted in ineffective intervention, such as attempts to stifle, suppress or
28
29 pacify the meltdown:
30
31

32
33
34 *when my son would have a meltdown you'd have to get his father stomping around*
35
36 *and saying 'I can't cope with this' [...] but it just makes it worse (Pru)*
37
38

39
40 The parents also appeared to consider that their own negative feelings could
41
42 become counterproductive to the intervention, resulting in a battle between the
43
44 parent and the child:
45
46

47
48
49 *if I manage to hold it [frustration] in but I think there have been times when [...] I do*
50
51 *tend to have to physically manhandle her (Nancy)*
52
53
54
55
56
57
58
59
60

1
2
3 The accounts also indicated that there were significant emotional consequences for
4
5 the parents. They described that their child eventually returns to calm, but the
6
7 parents are left with negative feelings of being 'emotionally drained':
8
9

10
11 *[after a meltdown I feel] tired drained frustrated annoyed erm because everything*
12
13 *just seems to have just gone back to normal often you know there's no residual*
14
15
16 *(Peter)*
17
18

19
20 This emotional state for the parents was also seen as necessitating their continued
21
22 hyper-vigilance in attempting to anticipate and prevent the possibility of the next
23
24 meltdown:
25
26

27
28
29 *because he needs constant supervision one of us is always on duty and so we can't*
30
31 *just relax (Pru)*
32
33

34
35
36 Thus the 'end' of a meltdown was also seen as the possible starting point for
37
38 anticipating the next meltdown. Meltdowns were, therefore, experienced as
39
40 controlling and pervasive throughout family life:
41
42

43
44
45 *we're all trying to work round my daughter all of the time (Nancy)*
46
47 *it's not healthy erm for me not healthy for him it's exhausting and it interferes with*
48
49 *everything else [...] (Florence)*
50
51

52
53
54 However, the picture was not all negative and parents also described positive factors
55
56 following a meltdown, including empathy from the child or affection seeking
57
58
59
60

1
2
3 behaviours. Parents describe taking solace in these moments, but not enough to
4
5 combat the anxiety in anticipation of further meltdowns. This perpetuating process
6
7 contextualises the meltdowns within the family system (Kinnear et al., 2015), and
8
9 may indicate the maintenance of the child's behaviours by the parent's emotions.
10
11

12 13 14 **Parents Attempting to Correct for Negative Childhood Experiences**

15
16 Parents expressed a variety of adverse childhood experiences, with disclosures
17
18 including death of a key caregiver, inconsistent care, controlling parented style and
19
20 domestic violence. Running through their accounts was also a theme of wanting to
21
22 do things better for their children. The negative experiences were described as
23
24 frightening and dangerous:
25
26

27
28
29 *My father was a very violent man to my mum over a long period (Peter)*

30
31 *I was severely emotionally abused as a child [...] and I was screamed and screamed*
32
33 *at for years on end and thrown out of home at a very young age (Pru)*
34
35
36

37
38
39 Aside from the danger, the parents also described a lack of clarity and structure in
40
41 their experience of being parented:
42
43

44
45 *as children they [parents] didn't really discipline us I don't think (Jenny)*
46
47
48

49
50 The parents felt that these experiences had damaging consequences for the
51
52 resulting attachment relationship with their child. Though not overtly seen to be
53
54 connected to the causes of meltdowns, the parents indicated that these early
55
56 experiences left them vulnerable:
57
58
59
60

1
2
3
4
5 *the reason I suffer from stress and anxiety is because my mother was schizophrenic*
6
7 *and I was severely emotionally abused (Pru)*
8
9

10
11 The parents also described that their childhood experiences gave a confusing model
12 of parenting, for example experiencing role reversals and being relied upon for
13 support:
14
15
16
17

18
19
20
21 *I was a latch key by the age of nine by the time I was ten I was quite sufficient in self-*
22 *care cooking cleaning whatever (Trish)*
23
24
25
26

27 Participants experienced violent, degrading acts inflicted upon them as children. The
28 majority of preceding events are not recalled in great detail, but feelings associated
29 with this, are held onto throughout adult life. These experiences are reflected on with
30 resentment, bitterness and confusion, especially when messages are conflicting and
31 contradictory:
32
33
34
35
36
37
38
39

40
41 *I can remember was being shut in the cold cupboard for what felt like a lifetime (Trish)*
42
43
44

45 The accounts suggested that parents felt that their attachment relationship to their
46 own child was influenced negatively by these experiences and that they transferred
47 aspects of these experiences in seeing their child as persecuting them:
48
49
50
51

52
53
54 *I was quite resentful for a while toward him (her child) it's like 'why are you doing this'*
55 *(Florence)*
56
57
58
59
60

1
2
3 *I remember thinking 'ohh just stop [...] I'm thinking why don't you (her child) just not*
4
5 *do it' (Jenny)*
6
7

8
9
10 Running through this theme was a thread of the parents wanting to do things better
11 with their own children. Some described wanting to do the opposite of their
12 experience of being parented:
13
14

15
16
17
18 *Every decision I've made I've always asked myself 'what would my mum do' answer*
19 *it and then do the opposite that's been my philosophy (Trish)*
20
21 *I've always had this in my mind that what my mother did has to stop here it can't*
22 *continue into the next generation (Florence)*
23
24
25
26
27

28
29 However, their accounts also indicated attempts to apply positive aspects (replicative
30 scripts) from their childhoods in relation to their parenting:
31
32
33

34
35
36 *from my childhood I've tried to take the nice stuff and keep that and [...] be different*
37 *where I feel (.) where I can [...] I can see that my parents weren't necessarily going*
38 *about it the right way (Peter)*
39
40
41
42
43

44
45 To overcome their negative childhood experiences the parents described searching
46 for ways to gain competence as parents, for example searching for information to
47 advise parents on management of meltdowns:
48
49
50

51
52
53
54 *I was desperate not to be like that [own parent] and that I was going to be a fantastic*
55 *parent and I got all these parenting booksI was gunna do it right and I was gunna*
56
57
58
59
60

1
2
3 *be a constant predictable parent ... and I was really confident that with proper*
4 *parenting my child would turn out alright and that I could provide what was never*
5 *provided for me (Pru)*
6
7
8
9

10
11
12 It appeared that responses to the meltdowns were influenced by attempts at
13 correcting their script by pursuing knowledge in parenting and ASD. Sometimes
14 parents described employing passive responses to meltdowns so as not to resemble
15 their parents and prevent replication of adverse childhood experiences. In these
16 accounts parents also sometimes indicated a merging of the impact of their own
17 childhood experiences with what they had been taught to do in, for example,
18 parenting classes:
19
20
21
22
23
24
25
26

27
28
29 *meltdowns (.) are distressing for the child they're exhausting you know he needed*
30 *reassuring and loving and cuddling and not punishment erm but he also needed to*
31 *understand the process [...] so there was no way I was gunna (.) reinforce that*
32 *behaviour (Florence)*
33
34
35
36
37
38

39
40 This appeared to lead to contradictory feelings for the parents, in that they perceived
41 that they could not be both an expert in meltdown management as well as being the
42 loving parent they desired to be. Hence, the mediation of meltdowns became
43 entangled with a wish to provide love and security. The parents described how,
44 despite their best efforts, some negative factors that they experienced were
45 transmitted through the generations:
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 *it's quite complex [my childhood] and not very nice and actually has absolutely no*
4 *bearing on what I do with my son well I say that (.) maybe the certain amount of*
5 *controlling element carries over because I'm trying to control what happens to him*
6 *but I'm not I'm trying to equip him that's the difference I'm very aware that [...] I don't*
7 *wanna do what she did to me (Florence)*
8
9
10
11
12
13
14
15

16 Florence illustrates the dilemmas here in seeing her parenting as both not related to
17 her childhood, but acknowledging that at times she replicates aspects of her
18 experience.
19
20
21
22

23 For Pru, her beliefs that her child's meltdowns are a link to her difficult
24 childhood directly influences how she intervenes. The prompting of negative
25 memories during meltdowns influences her attempts to suppress and stifle, rather
26 than actively problem-solve. This is an attempt to repress the memories that
27 accompany the onset of meltdown behaviours:
28
29
30
31
32
33
34
35

36 *when my son starts screaming it triggers those feelings of stress that I had when my*
37 *mother used to scream [...] and there's behaviours that he does that erm (.) that that*
38 *kind of bring it all back it sort of like triggering which is why I think that I find it*
39 *particularly stressful [...] there you know there's a link between the past and the*
40 *present (Pru)*
41
42
43
44
45
46
47
48

49 This association captures the unwanted and terrifying nature of meltdowns in her life,
50 which brings with it a host of negative issues from the past. The meltdowns may
51 challenge a parent's own insecure attachment style and pressures to correct their
52 script. This is summarised again by Pru,
53
54
55
56
57
58
59
60

1
2
3
4
5 *it feels like something difficult is coming back to haunt me [...] it's not just about the*
6 *meltdowns it's about a whole load of other things as well that you know tend to get*
7 *stressed a lot and [...] anything to do with er (.) confrontation or criticism or things*
8 *tends to stress me which [...] because of erm issues that I'd had in the past so*
9 *having a son that's very oppositional and confrontational [...] that's quite difficult (Pru)*
10
11
12
13
14
15
16
17

18
19 Overall, this theme encompassed parents' acknowledgement of association
20 between meltdowns and their past, and despite the difficulty of executing correction,
21 they persevere with their active attempt to correct this script, and remain resilient in
22 their meltdown management approach.
23
24
25
26
27
28
29

30 **Condemnation from Self and Others**

31
32 The theme of condemnation emerged from parents' experience of judgement from
33 others and themselves. It featured their feelings of responsibility for the meltdowns
34 and condemnation and criticism by others. More broadly the parents even
35 condemned themselves for having passed on 'faulty' genes to their child. Reports of
36 disapproval and censure from strangers and family members, especially when out in
37 public were frequent and clearly painful:
38
39
40
41
42
43
44
45
46

47 *so my daughter went into full meltdown in a shoe shop I was out with my mum and I*
48 *was like 'we're going home' I got up picked her up lifted her out we went in a taxi and*
49 *got home and when I went got home my mum went absolutely crazy at me for*
50 *ruining her shopping trip (Jenny)*
51
52
53
54
55
56
57
58
59
60

1
2
3 Sometimes censure from others is silent, but often, strangers vocalise their criticisms,
4
5 and even take action on the child's meltdowns:
6
7

8
9
10 *people don't actually say anything but I get a feeling that people just think that we're*
11
12 *hopeless parents (Nancy)*
13

14
15
16 Participants recall being upset by these events and as a result, their intervention in
17
18 the meltdown was not reflective and considered, but emotionally driven to prevent
19
20 the negative consequences anticipated from public meltdowns.
21
22

23
24
25 *it does change the way I intervene cos I would just do anything I can to get out of the*
26
27 *situation (.) even if it's just taking my daughter away so that nobody else know she's*
28
29 *having the meltdown (Nancy)*
30
31

32
33
34 These experiences appeared to engender a sense of isolation for the families and a
35
36 belief that withdrawing was the only solution:
37
38

39
40
41 *We can't meet up with other families cos he won't he doesn't get on with the children*
42
43 *and (.) erm (.) and most of your friends a lot of them the people that you think are*
44
45 *your friends will stop contacting you because they don't want your child being with*
46
47 *their child and er (.) so it's socially very isolating (Pru)*
48
49

50
51
52 This further reinforced any negative feelings and beliefs associated with blaming the
53
54 self. These negative judgements appeared to place parents in a dilemma of feeling a
55
56 need to be seen to be able to control and manage meltdowns, to receive acceptance
57
58
59
60

1
2
3 from others, but feeling anxious and helpless regarding their ability to do so. In
4
5 addition, this seems to conflict with their corrective scripts around not wanting to be
6
7 controlling. However, parents also described some support from others who were
8
9 educated in ASD:
10

11
12
13
14 *meeting other parents in the same boat and stuff is really helping [...] and just having*
15
16 *things explained a different way you just get more and more detail (Nancy)*
17

18
19
20 Although positive, these exceptions appeared to fuel a sense of 'us' and 'them',
21
22 people who understand and those who do not. A second layer of this theme
23
24 consisted of criticism from the inside, including a sense of failure as parents, but an
25
26 even deeper sense of responsibility for passing on 'faulty genes':
27
28

29
30
31
32 *I think it [ASD] probably comes from my mother's side (Trish)*
33

34 *My family the only member I could possibly put it [ASD] down to would be my brother*
35
36 *(Peter)*
37

38
39
40 Within this frame parents appeared to engage in self-confirming re-appraisal of their
41
42 family and started to retrospectively reflect on ASD traits within other family
43
44 members. Pru's self-blame reflects beliefs that she personally has transmitted her
45
46 child's diagnosis. She saw her mother's schizophrenia and her child's ASD as
47
48 genetically overlapping.
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 *there you know there's a link between the past and the present erm but obviously the*
4 *two conditions are related they're genetically related conditions (.) so sort of that*
5 *knowledge that I've kind of passed something on is quite difficult (Pru)*
6
7
8
9

10
11
12 Overall their acceptance of blame appeared to shape their attempts to make sense
13 of meltdowns, in that they attributed the child's difficult behaviour to their parenting
14 faults. Their accounts in turn indicated that they were mindful of wanting to provide
15 better experiences, but felt defeated by the meltdowns:
16
17
18
19

20
21
22
23 *back then I kept thinking what if it is cos I'm weak what if it i- what if it is me (Jenny)*
24 *my role was I had to stand back and watch this happen while the therapist and*
25 *everybody else dealt with my son and I never felt so inept (Florence)*
26
27
28
29

30
31
32 Engaging in self-blame for the child's condition and behaviour appeared to engender
33 a sense of hopelessness. Condemnation from the self and other, acted to perpetuate
34 the predisposed anxiety from childhood, and contributed to the initial stage of the
35 circular process of meltdowns. Accepting their biased beliefs of responsibility also
36 appeared to lead to delays in seeking help, as participants believed meltdowns
37 reflected poor parenting:
38
39
40
41
42
43
44

45
46
47 *I just got to the point where I was just like I can't do this but again I don't know why*
48 *now I d- didn't ask for any extra help I think it's probably because I was erm probably*
49 *pride really because I worked at the nursery [...] (laughs) thinking back on it- and*
50 *embarrassment as well it's both (Jenny)*
51
52
53
54
55
56
57
58
59
60

1
2
3 Parents, therefore, indicated that they were often reluctant to seek advice due to
4
5 pride, their beliefs about autism and dissatisfaction with their own parenting ability.
6
7

8 9 **Discussion**

10 The aim of the research was to explore parents' experience of meltdowns and how
11
12 they regarded their own developmental history as related to their experience of
13
14 meltdowns.
15
16

17
18 Three super-ordinate themes emerged in parents' accounts of meltdowns:
19
20 *Living in Dread: Anxiety and fear of escalating patterns, Attempting to Correct for*
21
22 *Negative Childhood Experiences and Condemnation from the Self and Others.*
23
24 Surprisingly most of the parents described extremely negative, even harrowing
25
26 childhood experiences in their own families. This appeared to fuel a vulnerability and
27
28 self-doubt about their own parenting. We do not know what proportions of parents of
29
30 a child with autism have had such severely difficult childhood experiences. However,
31
32 the literature (Roberts, et al., 2013) and our current work with families suggests that
33
34 many of these parents do report extremely difficult family experiences and a wish to
35
36 provide better experiences for their children.
37
38
39

40 The parents' attempts to 'correct' their own experiences seemed to be
41
42 challenged by their lack of a positive working model and by a sense of condemnation
43
44 from self and others. Their accounts indicated that meltdowns are not simply
45
46 triggered by external, concrete factors, but occur as a circular process shaped by the
47
48 parents' underlying thoughts, feelings and anxieties. Their reports indicated that
49
50 these feelings might also maintain the process of meltdowns and their negative
51
52 consequences. Although a somewhat adaptive response to assist preparation for a
53
54
55
56
57
58
59
60

1
2
3 difficult scenario, the anxiety in anticipation of a meltdown appears to be pervasive
4
5 and dictatorial in parents' lives (Schaaf et al., 2011).
6

7
8 Meltdowns were not seen as isolated events, but as aggravated by issues
9
10 specific to a parent's adverse childhood and anxiety related to their developmental
11
12 insecure attachment relationship. This seems to promote and contribute to the
13
14 experience of hypervigilance in anticipation of the next meltdown, and may provide
15
16 an explanation for the increased levels of stress within this parent group (Rivard,
17
18 Terroux, Parent-Boursier, & Mercier, 2014). The significance of the proposed circular
19
20 model (See Figure 1) is an indication of a process, which does not have an end point,
21
22 as associated predisposing factors are constantly perpetuated. This process may
23
24 require therapeutic mediation to break the cycle. These findings develop
25
26 understanding of the nature of ASD meltdowns from the parent's perspective, as
27
28 being affected by the negative consequences of the child's behaviour (Silva &
29
30 Schalock, 2012), but also influencing the child's behaviour (Baker et al., 2003).
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Figure 1: A proposed model of the circular process of meltdowns

Emotional mirroring

Parent's physiological responses to child's emotional state (mirror neurones)

Implicit memories from childhood: hurt, upset, 'not good enough'

CHILD – angry, 'don't want to do this'

PARENT – asks, insists, ...flight, freeze

My own parenting experience is not a helpful guide

Experience of condemnation

Professional advice and books are confusing/contradictory (do not reinforce behaviour; show love)

Combined effect of arousal, confusion, and self-doubt

Feel inadequate, fight-flight triggered, cycle repeats

The majority of research has focused on the experience of stress involved in raising a child with ASD (Baker et al., 2003; Davis & Carter, 2008), but the findings of this research allude to anxiety and hypervigilance regarding meltdowns and difficult behaviour preceding the onset of stress. The findings also question the cause-effect notion of parental stress as an outcome of the child's meltdowns, emphasising the reciprocal nature of the process. However, this research did not explore mediators of

1
2
3 the anxiety, such as self-efficacy, or detail the positive factors following a meltdown.
4
5 Future research into these factors could be vital in guiding intervention.
6

7
8 The main findings of this research indicate that anxiety experienced by these
9
10 parents is influenced by difficult childhood experiences and insecure attachment,
11
12 manifesting in anticipation of their child's meltdowns. Most frequently this featured an
13
14 attachment orientation involving dismissing feelings and attempting to avoid
15
16 emotional conflicts and confrontations. These findings supplement research, which
17
18 highlights the negative impact of insecure attachment and consequent internal
19
20 working models in relating to a child with ASD (Seskin et al., 2010). The disclosure of
21
22 a variety of adverse childhood experiences by all participants is consistent with past
23
24 research (Roberts et al., 2013), and may identify this population group as being at
25
26 risk of having a child with ASD. Along with Roberts et al. we call for more research in
27
28 this area.
29
30

31
32 In addition, the parents' responses to meltdowns appear to be related to self-
33
34 inflicted pressure and desire to correct negative scripts and provide positive,
35
36 structured experiences, which they feel they were denied in their own childhood.
37
38 Meltdowns challenge the execution of this corrective script and create self-doubt
39
40 about parenting competency. Such doubts and reflection on negative memories
41
42 make positive responses difficult (May, 2005). Intervention may need to focus on
43
44 amending parenting behaviours, where this is not available or is ineffective; over-
45
46 correction could result in parents being passive and helpless.
47
48

49
50 The findings indicate that parents condemn themselves for causing ASD,
51
52 which suggests the need for professionals and clinicians to discuss aetiology at the
53
54 diagnosis stage, to discourage parents from engaging in self-blame (Harrington,
55
56 Patrick, Edwards, & Brand, 2006). The child's difficult behaviour was found to elicit
57
58
59
60

1
2
3 judgement and condemnation from family members and strangers, adding to parents'
4 anxiety, (Kinnear et al., 2015) and highlighting the influence of societal judgement on
5 meltdowns and parents' interventions. This emphasises the difficulties for parents in
6 maintaining informal support, which often dissolves after a diagnosis (Woodgate,
7 Ateah, & Secco, 2008) and the lack of therapeutic input despite the potential benefits
8 for parents (Keen, Couzens, Muspratt, & Rodger, 2010).
9

10
11 In conclusion, our findings suggest that meltdowns are shaped by a complex
12 interplay of factors. Parents and professionals may find it more tolerable to attribute
13 young people's behaviour to concrete factors like heat, noise, busyness and pain
14 rather than thoughts or feelings. The lived experience of these young people can be
15 very hard to understand and tolerate and our study suggests that parents are very
16 vulnerable to feeling blamed. This makes it all the harder for them to be able to
17 reflect on the meltdowns in terms of relational processes. All of the parents in our
18 study had tried very hard to overcome their own difficult childhood attachment
19 experiences in their own families. They need their efforts to develop corrective
20 scripts to be acknowledged to help them to be able to reflect on their role in the
21 meltdown processes. Our study indicates that the alternative is to risk seeing the
22 children predominantly through a diagnostic label, rather like robots or just sets of
23 behaviours and the meaning of their experience is missed. Importantly this can result
24 in a form of mirroring of the children's preference for concrete, predictable
25 experiences and avoidance of feeling.
26

27
28 A further eight families seen in a clinical family therapy context provided
29 corroborating background data in that this interview was employed to explore their
30 experience of meltdowns. This supported the findings of this study and also
31 suggested that the format of this interview has useful clinical applications. All of the
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

families reported that an exploration of the circular process maintaining meltdowns was helpful in assisting them to develop alternative coping strategies.

Word count 6971

References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)*. Washington, DC: American Psychiatric Publishing.
- Attwood, T., Evans, C., & Lesko, A. (Eds.). (2014). *An Aspie's Guide to Living with Meltdowns: Been There. Done That. Try This!*. London, UK: Jessica Kingsley Publishers
- Baker, B. L., Blacher, J., Crnic, K. A., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three-year-old children with and without developmental delays. *American Journal on Mental Retardation*, *107*, 433-444.
- Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: Behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research*, *47*, 217–230
- Bedrossian, L. (2015). Understand autism meltdowns and share strategies to minimize, manage occurrences. *Disability Compliance for Higher Education*, *20*, 6-6.
- Benson, P. R., & Karlof, K. L. (2009). Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal of autism and developmental disorders*, *39*, 350-362.

- 1
2
3 Byng-Hall, J. (1985). The family script: A useful bridge between theory and practice. *Journal*
4
5 *of Family Therapy*, 7, 301-305
6
- 7 Byng-Hall, J. (1986). Family scripts: A concept which can bridge child psychotherapy and
8
9 family therapy thinking. *Journal of Child Psychotherapy*, 12, 3-13.
10
- 11 Colvin, G., & Sheehan, M. R. (2012). *Managing the cycle of meltdowns for students with*
12
13 *autism spectrum disorder*. Thousand Oaks, CA: Corwin Press.
14
- 15
16 Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with
17
18 autism spectrum disorders: Associations with child characteristics. *Journal of autism*
19
20 *and developmental disorders*, 38, 1278-1291.
21
- 22
23 Estes, A., Vismara, L., Mercado, C., Fitzpatrick, A., Elder, L., Greenon, J., ... & Rogers, S.
24
25 (2014). The impact of parent-delivered intervention on parents of very young children
26
27 with autism. *Journal of autism and developmental disorders*, 44, 353-365
28
- 29
30 Fleischmann, A. (2004). Narratives published on the internet by parents of children with
31
32 autism: What do they reveal and why is it important. *Focus on Autism and Other*
33
34 *Developmental Disabilities*, 19, 35-43.
35
- 36
37 Gill, J., & Liamputtong, P. (2011). Being the mother of a child with Asperger's syndrome:
38
39 women's experiences of stigma. *Health care for women international*, 32, 708-722.
40
- 41
42 Hastings, R. P., Kovshoff, H., Ward, N. J., Degli Espinosa, F., Brown, T., & Remington, B.
43
44 (2005). Systems analysis of stress and positive perceptions in mothers and fathers
45
46 of pre-school children with autism. *Journal of autism and developmental*
47
48 *disorders*, 35, 635-644.
49
- 50
51 Kamp-Becker, I., Smidt, J., Ghahreman, M., Heinzl-Gutenbrunner, M., Becker, K., &
52
53 Remschmidt, H. (2010). Categorical and dimensional structure of autism spectrum
54
55 disorders: The nosologic validity of Asperger syndrome. *Journal of autism and*
56
57 *developmental disorders*, 40, 921-929.
58
59
60

- 1
2
3 Keen, D., Couzens, D., Muspratt, S., & Rodger, S. (2010). The effects of a parent-focused
4 intervention for children with a recent diagnosis of autism spectrum disorder on
5 parenting stress and competence. *Research in Autism Spectrum Disorders*, 4, 229-
6 241.
7
8
9
10
11 KingKing, M., & Bearman, P. (2009). Diagnostic change and the increased prevalence of
12 autism. *International journal of epidemiology*, 38, 1224-1234.
13
14
15
16 Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2015). Understanding the
17 Experience of Stigma for Parents of Children with Autism Spectrum Disorder and the
18 Role Stigma Plays in Families' Lives. *Journal of autism and developmental disorders*,
19 3, 1-12.
20
21
22
23
24
25 Larson, E. (2006). Caregiving and autism: How does children's propensity for routinization
26 influence participation in family activities?. *OTJR: Occupation, participation and*
27 *health*, 26, 69-79
28
29
30
31
32 Lee, L. C., Harrington, R. A., Louie, B. B., & Newschaffer, C. J. (2008). Children with autism:
33 Quality of life and parental concerns. *Journal of autism and developmental*
34 *disorders*, 38, 1147-1160.
35
36
37
38
39 Lipsky, D. (2011). *From anxiety to meltdown: How individuals on the autism spectrum deal*
40 *with anxiety, experience meltdowns, manifest tantrums, and how you can intervene*
41 *effectively*. London, UK: Jessica Kingsley Publishers.
42
43
44
45 Lomanowska, A. M., Boivin, M., Hertzman, C., & Fleming, A. S. (in press). Parenting begets
46 parenting: A neurobiological perspective on early adversity and the transmission of
47 parenting styles across generations. *Neuroscience*.
48
49
50
51
52 Mackintosh, V. H., Myers, B. J., & Goin-Kochel, R. P. (2005). Sources of information and
53 support used by parents of children with autism spectrum disorders. *Journal on*
54 *Developmental Disabilities*, 12, 41-51.
55
56
57
58
59
60

- 1
2
3 Mak, W., & Kwok, Y. (2010). Internalization of stigma for parents of children with autism
4 spectrum disorder in Hong Kong. *Social Science & Medicine*, 70, 2045–2051.
- 5
6
7 Matson, J. L., & Kozlowski, A. M. (2011). The increasing prevalence of autism spectrum
8 disorders. *Research in Autism Spectrum Disorders*, 5, 418-425.
- 9
10
11 Matson, J. L., Wilkins, J., & Macken, J. (2008). The relationship of challenging behaviors to
12 severity and symptoms of autism spectrum disorders. *Journal of Mental Health*
13 *Research in Intellectual Disabilities*, 2, 29-44.
- 14
15
16 May, J. C. (2005). Family attachment narrative therapy: Healing the experience of early
17 childhood maltreatment. *Journal of marital and family therapy*, 31, 221-237.
- 18
19
20
21
22
23 Mazefsky, C. A. (2012). Managing problem emotions and behaviors in children with ASD: an
24 assessment-driven three-step approach. *SIG 1 Perspectives on Language Learning*
25 *and Education*, 19, 38-47.
- 26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
- Mazefsky, C. A., & Handen, B. L. (2011). Addressing Behavioral and Emotional Challenges
in School-Age Children and Adolescents with ASD. *Autism spectrum disorder*, 253.
- Moehler, E., Biringen, Z., & Poustka, L. (2007) Emotional availability in a sample of mothers
with a history of abuse. *American Journal of Orthopsychiatry* 77, 624–628
- Mugno, D., Ruta, L., D'Arrigo, V. G., & Mazzone, L. (2007). Impairment of quality of life in
parents of children and adolescents with pervasive developmental disorder. *Health*
and quality of life outcomes, 5, 1.
- Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). “My greatest joy and my
greatest heart ache:” Parents’ own words on how having a child in the autism
spectrum has affected their lives and their families’ lives. *Research in Autism*
Spectrum Disorders, 3, 670-684.

- 1
2
3 Neece, C. L., Green, S. A., & Baker, B. L. (2012). Parenting stress and child behavior
4 problems: A transactional relationship across time. *American Journal on Intellectual*
5 *and Developmental Disabilities, 117*, 48-66.
6
7
8
9
10 Newschaffer, C. J., Croen, L. A., Daniels, J., Giarelli, E., Grether, J. K., Levy, S. E., ... &
11 Windham, G. C. (2007). The epidemiology of autism spectrum disorders*. *Annual*
12 *Review of Public Health, 28*, 235-258.
13
14
15
16 Osborne, L. A., McHugh, L., Saunders, J., & Reed, P. (2008). The effect of parenting
17 behaviors on subsequent child behavior problems in autistic spectrum
18 conditions. *Research in Autism Spectrum Disorders, 2*(2), 249-263.
19
20
21
22
23 Read, J., & Bentall, R. P. (2012). Negative childhood experiences and mental health:
24 theoretical, clinical and primary prevention implications. *The British Journal of*
25 *Psychiatry, 200*, 89-91.
26
27
28
29
30 Rivard, M., Terroux, A., Parent-Boursier, C., & Mercier, C. (2014). Determinants of stress in
31 parents of children with autism spectrum disorders. *Journal of autism and*
32 *developmental disorders, 44*, 1609-1620.
33
34
35
36 Roberts, A. L., Lyall, K., Rich-Edwards, J. W., Ascherio, A., & Weisskopf, M. G. (2013).
37 Association of maternal exposure to childhood abuse with elevated risk for autism in
38 offspring. *JAMA psychiatry, 70*, 508-515
39
40
41
42
43 Ryan, S. (2010). 'Meltdowns', surveillance and managing emotions; going out with children
44 with autism. *Health & place, 16*, 868-875.
45
46
47
48 Schaaf, R. C., Toth-Cohen, S., Johnson, S. L., Outten, G., & Benevides, T. W. (2011). The
49 everyday routines of families of children with autism: Examining the impact of
50 sensory processing difficulties on the family. *Autism, 15*, 373 – 389.
51
52
53
54 Seskin, L., Feliciano, E., Tippy, G., Yedloutschnig, R., Sossin, K. M., & Yasik, A. (2010).
55 Attachment and autism: Parental attachment representations and relational
56
57
58
59
60

1
2
3 behaviors in the parent-child dyad. *Journal of abnormal child psychology*, 38, 949-
4
5 960.

6
7 Silva, L. M., & Schalock, M. (2012). Autism parenting stress index: Initial psychometric
8
9 evidence. *Journal of Autism and Developmental Disorders*, 42, 566-574.

10
11 Sitko, K., Bentall, R. P., Shevlin, M., & Sellwood, W. (2014). Associations between specific
12
13 psychotic symptoms and specific childhood adversities are mediated by attachment
14
15 styles: an analysis of the National Comorbidity Survey. *Psychiatry research*, 217,
16
17 202-20
18
19

20
21 The National Autistic Society. (2016). Statistics: How many people have autism spectrum
22
23 disorders? Retrieved from The National Autistic Society:
24
25 <http://www.autism.org.uk/about-autism/myths-facts-and-statistics>
26

27
28 Weiss, M. J. (2002). Hardiness and social support as predictors of stress in mothers of
29
30 typical children, children with autism, and children with mental retardation. *Autism*, 6,
31
32 115-130.

33
34 Wing, L. (2005). Reflections on opening Pandora's box. *Journal of Autism and*
35
36 *Developmental Disorders*, 35, 197-203

37
38 Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience
39
40 of parents who have a child with autism. *Qualitative Health Research*, 18, 1075-1083.
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60