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## Mothers' perspectives of co-occurring fatigue in children with autism spectrum disorders

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### ABSTRACT

**Background:** Fatigue seems deeply associated with Autism Spectrum Disorders (ASD) as reflected by the preferred terms 'autistic fatigue' and 'autistic burnout'. In ASD there is also a greater prevalence of sensory and cognitive demands, and medical conditions where persistent fatigue can be a symptom. This may contribute to some of the debilitating levels of fatigue evidenced, impacting on children with ASD and families.

**Objective:** As parents caring for a child with ASD experience high levels of stress this study aimed to provide a deeper understanding of the lived experiences of parenting a child with ASD with co-occurring fatigue.

**Design:** An interpretative phenomenological analysis was used to analyse semi-structured interviews from six mothers of children with ASD aged 4–19 who also had severe levels of co-occurring fatigue.

**Results:** Four superordinate themes were generated: The experience of fatigue; Making sense of their child's fatigue; Managing fatigue; Accepting needs and limitations. Mothers developed understanding of their child's fatigue, guiding their child to self-regulate. As mismanagement increased meltdowns and emotional outbursts, managing fatigue was perceived to be a key aspect of living with the phenomenon.

**Conclusion:** The findings reflect the impact of extreme fatigue on a child with ASD and families, supporting recent recommendations which state managing energy levels and reducing stressors is essential to prevent burnout in those with ASD and co-occurring fatigue. Better understanding, recognition and diagnosis would support parents, as would greater flexibility in schools to help children with ASD to better manage the demands of the school day.



### ARTICLE HISTORY

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Autism spectrum disorder;  
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Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder varying in severity. It is characterised by persistent deficits in social communication and interaction and restricted, repetitive patterns of behaviour, interests or activities [1]. The interplay between the severity and chronicity of ASD, comorbid mental health issues and often a lack of access to services, makes meeting the needs of individuals with ASD both challenging and stressful [2,3].

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Better contextual understanding of the complexities involved in caring for a child with ASD could help to support parents, because compared to parenting a typically developing child, parents of children with ASD have greater disturbance in their own sleep patterns [4] and higher fatigue levels [5]. Further, mothers of a child with ASD experience higher levels of anxiety and depression [6], spend more time providing childcare and doing chores, and less time in leisure activities [7], and have reduced perceived parenting efficacy and satisfaction [5]. Understanding the significance of maternal fatigue on their well-being has been highlighted as an important area for consideration in families of children with an ASD [8], in addition to improved interventions for families affected by ASD both in the short and long term [7]. This could be achieved through better recognition of the co-occurring issues, such as fatigue in children with ASD, which parents may manage when caring for their child.

Indeed, typical ASD behaviours include difficulties with social relationships and poor social interaction impeding learning [9], and the presence of sensory and cognitive factors in ASD may trigger mental fatigue after, or during, prolonged cognitive activity [10]. Compared to neurotypical peers this may increase stress, anxiety, depression and exhaustion for those with ASD [11]. Fatigue in ASD may also arise from suppressing stereotypical behaviours, known as masking or camouflaging [11,12]; and deficits in processing social experiences [13,14].

Fatigue can also make demands aversive, exacerbating challenging behaviours in those with ASD and a low IQ, increasing negative reinforcement [15]. For those with ASD, regardless of IQ levels, this potentially contributes to an unwillingness to face future demands and stressors. This context, where parents strive to meet their child's needs, may account for higher stress levels for parents caring for a child with ASD [16]. Further, as a lifelong disorder, for those living with ASD managing the culmination of everyday life, social situations and sensory demands, can result in extreme exhaustion. Adults with ASD have labelled this, autistic fatigue [17].

A potentially longer term output, autistic burnout [17,18], was articulately defined by one adult with ASD as being 'a state of physical and mental fatigue, heightened stress, and diminished capacity to manage life skills, sensory input, and/or social interactions, which comes from years of being severely overtaxed by the strain of trying to live up to demands that are out of sync with our needs' [18, p. 137]. It conjures a sense of extreme chronic fatigue brought out from years of unrecognised and/or unmet needs. Clinical observations suggest symptom overlaps between chronic fatigue syndrome (CFS) and neurodevelopmental conditions [19]. Specifically, studies looking individually at ASD and CFS populations highlight overlaps with fatigue, brain fog, cognitive impairments, increased pain and tenderness, impaired emotional contact and increased sensitivity to sound, light, and odour [20]. Nevertheless, recent explorations have ruled out a direct link between ASD and CFS. For example, in the absence of a known medical explanation for fatigue, those with CFS do not have autistic traits [20], tend to be females diagnosed at a later age. Also in younger people diagnosed with CFS, there tends to be an even gender balance [21].

Furthermore, there is an added burden for parents managing the various physical health conditions associated with ASD, such as gastrointestinal problems [22] including abdominal pain, constipation, and diarrhoea [23]. Such conditions, when chronic, may impact health and energy levels. Managing the explained and unexplained health

complexities of a child with ASD may be another reason for the higher levels of stress in mothers caring for a child with ASD compared to mothers caring for children with other disabilities [24]. Indeed, parents of children with ASD additionally manage increased aggression and tantrums [25,26], and more challenging behaviour when their children are fatigued [27]. For children with ASD and additional health needs, given the communication issues within ASD [1], parents take a central role in observing and managing their child's complex health needs. Mothers are often thrust into advocating for their child [28,29] fighting to ensure their child is not misrepresented and is given opportunities to succeed [30]. Yet healthcare professionals' lack of understanding often makes this an exhausting process for parents [31].

To summarise, literature in this area is only just starting to identify differences with CFS as well as a range of contributors to fatigue in ASD, impacting children and their parents. Better understandings are needed for the complexities and co-occurring issues observed in this population [8]. Qualitative research has the scope to provide a more nuanced understanding of lived experience, through case-to-case transfer generalisation [32]. Thus, the current study aimed to explore experiences of parenting a child with ASD and co-occurring fatigue to provide a deeper and direct understanding of lived experiences of fatigue in a child with ASD, including management issues and impacts on the child and family.

## Method

As this study aimed to explore the lived experiences of mothers caring for a child with ASD and co-occurring fatigue, interpretative phenomenological analysis (IPA) was used due to its idiographic approach and ecological validity [33]. IPA is a phenomenological and social constructionist approach which is informed by hermeneutics. It enables the exploration of rich and detailed experiences through semi-structured interviews [33]. Utilising quality criteria throughout [32,34], the interview schedule was developed and refined by the research team through consultation with those with lived experience of caring for a child with ASD and co-occurring fatigue. Questions included:

- (1) Can you describe when you first noticed your child's fatigue and what this looked like?
- (2) When your child is fatigued what impact does this have on him/her?
- (3) Can you tell me how your child's fatigue impacts you and your family?
- (4) What makes your child's fatigue better or worse?
- (5) What relationship do you think there is between fatigue and your child's ASD?
- (6) Has there ever been any investigations into your child's fatigue?

A pilot interview was conducted by the second author to become familiar with the questions and potential areas of exploration.

## Participants

As only mothers responded, a purposive homogenous sample of six biological mothers were recruited via advertisements posted on the Facebook pages of a local support group for caregivers of children with ASD and, also, on the second author's page. All responders met the inclusion criteria of having a child with a diagnosis of ASD who

experienced co-occurring fatigue; demographic information was collected (Table 1) and all were interviewed in their homes by the second author. Interviews lasted 44–66 min.

### **Ethical considerations**

Approval was granted by the institution's Ethics Committee (protocol number: LMS/PGT/UH/03762). Confidentiality was ensured throughout the study and written consent obtained from participants who were made aware of the recordings, how their data would be saved, stored, and deleted on transcription and used in a publication. Participants were informed they could withdraw at any time. Following the interview, participants were given the opportunity to share further information, thanked for their time and given a debrief sheet which included contact details for additional support. Audio recordings were made, interviews transcribed verbatim by the second author, pseudonyms applied, and recordings deleted after transcription; data were only seen by the research team.

### **Data analysis**

IPA was used to allow rich details to emerge, and to understand and interpret participants' subjective experience [33]. Before analysis, each transcript was read multiple times by the second author to provide familiarity with accounts. Initial reflections were noted alongside emerging themes. Themes were organised into named clusters and all relevant quotes across the transcripts were checked against the transcript to ensure a true representation of the participants' words. To ensure credibility [32,34,35], inter-rater reliability checks were conducted between first and second authors on the emerging themes, interpretations, and convergent and divergent themes. Credibility was further ensured through triangulation, which included consultations between clinicians and those with lived experiences who corroborated the final themes and provided feedback on the paper. The research team included a researcher experienced in neurodevelopmental conditions, a clinician with relevant lived experiences, and a research student. Thus, reflexivity was used to examine and acknowledge potential interviewer and researcher bias and

**Table 1.** Participant information.

Participant pseudonym	Marital status	Number of children	Age of ASD child	Age of ASD diagnosis*	Gender of child	Other Diagnoses*
Alice	Married	2	8	4	Female	n/a
Beth	Living with partner	3	4	4	Female	n/a
Cassie	Married	2	10	8	Female	ADHD; Auditory processing disorder; Hypermobility
Debra	Married	1	15	9	Male	Hypermobility; General anxiety disorder; Dyspraxia; ADHD
Ella	Married	4	19	5	Male	Chronic fatigue syndrome; Dyslexia; Dyspraxia
Faye	Married	1	15	5	Female	Depression**, dyspraxia and hypermobility

\*Diagnosed by a healthcare professional.

\*\*Unofficially, although a psychiatrist prescribed fluoxetine.

included the use of reflective notes and supervision [34]. Themes and supporting quotes were reviewed by all authors and refined into four superordinate themes and their subordinate themes (Table 2).

## Results

The final themes highlighted the overwhelming experience of fatigue mothers’ children experienced on a daily basis, and the impact this had on their child, themselves and their families.

The inevitability of their child’s fatigue, and absence of solutions from health care professionals seemed to result in mothers’ having to accept its presence and adapt accordingly. Indeed, mothers’ main concern was on their child’s development and wellbeing, rather than their own, producing child-focussed nurturing responses even in the absence of understanding from others, or the recognition of underlying reasons for the fatigue.

### *The experience of fatigue*

This theme explored the impact of their child’s fatigue and the ways in which it was experienced by the mothers and their children.

### *The impact of social demands and sensory sensitivities on fatigue*

All mothers described how stimulation and over-processing of sensory stimuli within the environment seemed to contribute to mental fatigue in their children. For example, Beth stated:

I think her brain is going a mile a minute every single day. You know? Think of what it’s like to be an autistic person with the sights and the smells and the sounds. There’s so much more to process. We just filter it in like every day, neurotypical people, doesn’t bother us at all. You know? We’re probably more tired from the fact we have been on our feet all day and you know? It is what it is. But I think she has so much more to ... think of.

In recognising the difficulties her child faced compared to the ease a ‘neurotypical’ person had in managing sensations, Beth’s account seemed filled with empathy, inviting the interviewer to empathically consider this hardship too when she stated, ‘you know’.

**Table 2.** Superordinate and subordinate themes.

Superordinate theme	Subordinate themes
The Experience of Fatigue	The impact of social demands and sensory sensitivities on fatigue The need for quiet time and shutdown The inevitability of a meltdown when pushed too far
Making Sense of Their Child’s Fatigue	Making sense, trying to understand Enabling their child to recognise and regulate needs
Managing Fatigue	Understanding and management can improve fatigue Misunderstanding and Mismanagement exacerbates fatigue
Accepting needs and limitations	The impact of fatigue on the family Limiting life to manage it better Accepting the enduring need to rest

The use of the phrase ‘a mile a minute’ highlighted vast and rapid amounts of processing Beth believed was occurring in her child. It seemed Beth almost felt a sense of defeat about her child’s fatigue along with her acceptance of it when she said, ‘it is what it is’.

Additionally, all mothers discussed the contribution of social situations to fatigue as illustrated by Faye: ‘... she talks about her social battery and she says that her social battery is four hours with people she likes and less for others’. The phrase ‘social battery’ evoked a sense of energy; interactions which tired her daughter out seeming to depend more on the person, and perhaps, the demands they placed upon her.

### *The need for quiet time and shutdown*

All mothers explained that their child’s fatigue improved from downtime. For example, Alice labelled this ‘quiet time’:

... it depends how tired she is. So if she’s really tired she will be collapsed with a book. Or ... asking for quiet time, which is what we call when they can go on the iPad ... if she’s exhausted I will give her longer quiet time

The sheer weight of the fatigue was conveyed in the terms ‘collapsed’ and ‘exhausted’. Other mothers, such as Debra and Beth, discussed downtime as a ‘need’ rather than a want, to aid cognitive processing and reenergise: ‘... we call it downloading, he’s downloaded the bits of the day ...’ (Debra); ‘... it’s like she needs time to process everything and I think once she’s processed it her energy levels do go back up’ (Beth). Beyond the need for downtime was a fatigued state Beth described as ‘shutdown’:

... she will just kind of ... just in the middle of the day, she will kind of, fall asleep, but it’s more like shutdown ... there’s no kind of like ‘oh lets snuggle up’ you know, ‘I know I’m going to sleep’, like it’s a conscious thought, it is literally like shutdown, ‘I need to process’ ... it’s just shocking, the way she falls asleep, the fact that it literally is like someone has pressed a button and she’s just gone, it’s a different kind of tiredness, you know? It’s a different kind of, a more intense kind of fatigue I think.

Terms such as ‘shocking’, ‘literally’ and beyond ‘conscious thought’ highlighted a physiologically inevitable need for rest, to be had whatever the costs. Debra described a similar experience in her son: ‘... he can’t function properly when he’s exhausted, he can’t function properly. He can get tearful ... and ... stroppy, argue, but he can’t function, when he’s exhausted, literally, he cannot function’. The repetitive statement of ‘can’t function’ emphasised her son’s exhaustion and, if forced to be present when fatigued, how his mood and behaviour were significantly impacted. It seemed demands in this heightened fatigue state were overwhelming, and all mothers described their child as needing to sleep at such times, almost like a recovery process.

### *The inevitability of a meltdown when pushed too far*

All mothers were aware tiredness could trigger ‘meltdowns’ in their children, for example, Alice stated:

... the meltdowns only happen now when she is very tired and we’ve pushed her, or circumstances have pushed her too far. So on holiday we often have meltdowns to start with. Or pre-holiday, or at the beginning of term or ... it’s always at peaks of anxiety.

It seemed the key to the trigger, particularly during ‘peaks of anxiety’, was being ‘pushed ... too far’ signifying the strain demands placed upon her daughter, particularly during times where she perceived she had minimal control. Mothers described pressure pot scenarios with metaphors conjuring an explosive quality when ‘social’ or ‘sensory’ demands piled on the ‘pressure’ for their child, for example, Faye explained:

All through the day little things happen which are like shaking the bottle ... so she’s under more and more and more pressure, whether it’s sensory pressure or social pressure or whatever ... and so by the time she gets home, you know it only takes the slightest thing for the lid to come off and it all to go \*tskkk\*

The inevitability of the mounting pressure exploding was let out at home, perhaps where it was safer for their child to let go; the onomatopoeia, ‘\*tskkk\*’, vocally symbolising their child’s extreme release into meltdown. Perhaps it was also inevitable that fatigue in their child induced releases into meltdowns which impacted family time as described by Faye when having to leave social events:

... if we didn’t then we were at risk of her becoming initially very rude and snappy, and if we didn’t leave at that point or we started to take too long saying our goodbyes that would turn into a full-on shouting, embarrassing meltdown

### ***Making sense of their child’s fatigue***

This theme explores mothers’ attempts to gain an understanding of their child’s fatigue, whilst simultaneously attempting to increase their child’s understanding. Fatigue was rarely acknowledged by healthcare professionals as a symptom worth further exploration and so mothers often had to seek their own explanations.

### ***Making sense, trying to understand***

Most mothers described how their child’s fatigue presented itself differently at different stages, contributing to different understandings at different times. For example, Alice stated: ‘... when she was ... younger and she was tired it led to much more dramatic challenging behaviour ... Now she tends to withdraw when she’s fatigued. So she will just disappear and spend time on her own.’ One could sense the impact of fatigue through the terms ‘dramatic’ and ‘challenging’; when her child was able to respond to her fatigue by ‘withdraw(ing)’, the impact seemed less challenging. Similarly, Faye stated: ‘I’ve learned over the years not to take it personally because I know it’s about ... she needs to get her needs met’.

Ella had previously approached medical professionals about her son’s fatigue, resulting in a formal diagnosis of CFS:

... they sent us away, nothing was ever done, so I don’t, I’m not convinced he’s got chronic fatigue as such, he’s just fatigued ... Yeah, I just, I just think it was a label ... so I’m not convinced ...

Yet, Ella lacked trust in the CFS diagnosis, repeating twice ‘I’m not convinced’ perhaps sensing there might be an underlying undiscovered reason beyond medical explanations that ‘it was because of his dyspraxia’. Furthermore, once an explanation of CFS was



provided, there was no further advice, seeming to further contribute to her mistrust in the diagnosis. As with the other mothers, she sought her own explanations.

### *Enabling their child to recognise and regulate needs*

It seemed mothers own understanding enabled them to assist their child in recognising and understanding their feelings and needs. For example, Beth stated:

I think once you start giving her the little choices and the little routines, at first we do them with her, so we encourage her, we be up there with her and we encourage her “oh you need to chill” you know? And then ... I guess ... she'll think “ ... ah I like how I felt when I did that, so I'll do that again”.

Encouragement seemed crucial in taking steps towards recognising the need to ‘chill’, to understand what needed to happen to feel better. The slow pace seemed important in enabling this burgeoning awareness in their child to develop. Likewise, Debra described the process of enabling her son to self-manage: ‘ ... really we've enabled him to ... gradually turn it over.’

Although the awareness grew, the gradual pace sometimes meant the behaviour remained, as Alice stated: ‘She's definitely aware now if she is reactive and angry and aggressive. She's more aware. It doesn't mean she can stop herself.’

### *Managing fatigue*

This theme explores how mothers managed their child's fatigue, and how the effects were worsened with mismanagement.

### *Understanding and management can improve fatigue*

All mothers described their child's use of self-soothing sensory stimuli to manage fatigue; either in terms of reducing stimuli or changing the scene. For example, Cassie stated:

You know what, it's her thumb sucking, and that's her comfort, and she reaches a point where she's worn herself out, and when she starts sucking her thumb and stroking her hair, you know that's the end of it, she will fall asleep, because you see her eyes go as soon as she puts her thumb in her mouth.

Cassie's child seemed to need comfort, perhaps to manage the discomfort of her fatigue, and the need for sleep which she achieved through self-soothing sensory behaviours; the finality and, perhaps, inevitability of this experience was evoked when Cassie stated: ‘that's the end of it’. For Beth, recharging her daughter's energy levels through sensory stimulation seemed helpful:

Sometimes we will pick her up and take her outside, change of scenery ... you know it's a sensory thing, the smells, the sight, the sounds, sometimes can just \*whoop\*, bring her back’.

It almost seemed as though this was like a defibrillator which brought her back to life, evocatively denoted by the onomatopoeia, ‘\*whoop\*’.

Sometimes environmental management was crucial in managing fatigue, and sleep was important, with all mothers noting their child needed lots of sleep throughout their lives to help manage fatigue. Further, whilst all children went or had gone to

mainstream school, Ella decided to send her child to a special needs secondary school due to its more flexible approach to his fatigue:

So I suppose having the responsibility and independence helped ... and that seemed to be the turning point for the fatigue not having such a big impact on his schooling, because he can do that, he can take himself away.

By describing this decision as 'the turning point', there was a sense that the school's allowance of personal autonomy to self-regulate enabled proper management, and this was a key factor in managing his fatigue.

Similarly, Alice moved her child to a mainstream school which more flexibly supported individualised needs: '... the school are uber-supportive but the school were very clear, we moved her in reception because she was so miserable where she was ...'. Whilst not directly stated, there seemed to be a profound impact from appropriate management of fatigue lifting Alice's daughter's mood dramatically out of misery. The school's support seemed crucial, and flexibility enabled Faye's daughter to manage her fatigue levels:

... she has three hours a week where she can go to the library to listen to music, if she's got homework she can do it, she can read or she can do whatever, and, she just started that the last few weeks of term, and that did seem to help, yeah and she really likes it, she really, really likes that, so she's looking forward to having that downtime.

### *Misunderstanding and mismanagement exacerbates fatigue*

All mothers specifically spoke of the influence anxiety had on their child's fatigue levels, perhaps due to the inability to manage it. For example, for Debra's son, a key stressor exacerbating fatigue seemed to be anxiety in the transition to secondary school: '... the overwhelming thing for the fatigue I would say is the anxiety, and he actually as he got older, when he started secondary school, we had a very difficult period'.

It seemed managing fatigue within inflexible school structures was often difficult, almost making mismanagement inevitable, as Faye stated:

... what I said to school is if there is somewhere she could go ... so that she can be letting little bits of gas out all throughout the day ... maybe leave each lesson five minutes earlier or go to the library of whatever ... then maybe she wouldn't need quite so much ... time to recover when she got home. But that was very difficult for them to manage.

For Ella almost impossible decisions had to be made between school attendance and her son's wellbeing:

... he would end up having a day off where I literally just couldn't get him out the bed because he was so tired. So he'd end up having a day off perhaps once a week maybe, so sickness at school went quite high so then it was a juggling act of whether we make him do the full week but bring him home early every day, or do we ... make him do the full week and then make him have days off sick.

The intensity of managing a normal school week and its impact on her son's fatigue evoked a sense that she was caught between a rock and a hard place. Indeed, Ella described her decision-making as 'a juggling act', making decisions against her better

judgement with wider expectations around school attendance driving decisions, yet resulting in mismanagement.

### ***Accepting needs and limitations***

This theme explored mothers' journeys of discovery and their movement towards acceptance of their child's fatigue.

#### ***The impact of fatigue on the family***

All mothers recognised the impact of their child's fatigue. For Cassie, the limitations fatigue imposed seemed to make it hard to accept, trying to keep up with outings, or managing when sleep occurred.

Mostly, try to stop her from sleeping, so, unless it, if it's a weekend and it is still quite early in the morning, so if its nine-o clock in the morning, I will encourage her then to sleep because that will help her get through the day. If she gets like that at one o'clock in the afternoon, I say it's time to go out, so ... \*laughs\*

Alice and Beth's relationships were both impacted by their child's sleep issues and limitations this brought, with Beth stating:

[we] don't get any time for us because by the time she falls asleep, well we're going to fall asleep too. Because we have to stay awake cos if she, she can get into thing ... it does put a strain, it does.

Putting their child's needs first, implicated a child-focussed nurturing approach despite the strains this seemed to create. Likewise, Beth seemed to put her daughter's wellbeing at the heart of her concerns. Beth went on to explain the emotional toll this had on her:

... it is a mixture between stress and heartache, you feel guilty for putting her in these situations and you feel bad like eurgh ... if they're going through a bad patch, it can seem like, you know, this must be a rubbish life, you're always crying, you're always tired, you're always sad.

The repetition of 'you're always' emphasised the constant struggle and hardship she faced through having to put her daughter in situations that overwhelmed and drained her, resulting in her own maternal experiences of 'stress', 'heartache' and 'guilt', highlighting the complex impact it had on her. It seemed in this context, realistic solutions were needed.

#### ***Limiting life to manage it better***

With the seeming inevitability of their child's fatigue, solutions were required, and all mothers highlighted how they had to limit theirs' and their child's life to better manage their child's fatigue. For example, Alice stated:

Whoooo family events! Yeah anything ... anything involving lots of people, we're really wary of. And, we ... try if possible to limit how many people come to the house at any one time. So we'll only have one family, or maybe two to visit. At any one time. And we'll keep it to a reasonably short period ... and if possible try and keep it to children that we know she can cope with.

Alice seemed to emphasise the extremity of the impact her child's fatigue had on daily familial life, with her emphatic opening statement, and repeated emphasis on 'anything ... involving lots of people' being met with trepidation. Thus, social interactions, even with family, had to be limited to manageable levels including the intensity and length of interactions; indeed, this seemed important for her daughter to 'cope', perhaps implying this was a way of minimising the risk of triggering a meltdown. Pacing and limiting activities seemed important as Ella stated: 'Yeah so on holiday we would have one day doing things and one day not. Because otherwise he wouldn't be able to handle it.' The acceptance of limiting life seemed crucial for the whole family, as Alice went on to say: 'Yes. We've learnt to our cost actually it's really not worth it... and it is, it is getting marginally easier'. The use of the word 'marginally' suggested the benefits of limiting life were still sometimes small, given the pervasiveness and inevitability of her child's fatigue.

### *Accepting the enduring need to rest*

All mothers spoke of the recognition that their child's needs differed to others, accepting the importance of adapting to their child's need to rest. For example, Beth stated:

It's not something that causes us massive, massive issues, but it is something that is not really within the norm. It's just a factor of her being autistic. We've always factored in, dealt with it, you know?

Whilst Beth repeated that there were no 'massive issues', this seemed because she had recognised her child was outside of 'the norm' implicating she had had no choice but to accept and factor in her daughter's ASD and fatigue. One wonders what it might have been like if she or others had not recognised her daughter's needs and managed the fatigue in an unhelpful way.

That this was their 'normal' was a term similarly utilised by Ella, Cassie, and Faye; as Ella repeatedly stated: '... it's hard to analyse it, because it's normal for us, it's our normal family life, and because that's all you know you can't think how it's different to anyone else's.' Ella's inability to analyse this, gave the sense that her child's fatigue was central to her core, internally driven and inevitable, giving this an enduring quality which could only really be managed through acceptance.

For Faye, an 'ideal' world offered a real solution, which was inaccessible in a mainstream school: '... I wish, what would be ideal I think is if there was somewhere at school she could go and sleep in the middle of the day.' That her wishful thinking was unattainable seemed to leave the listener sensing a profound sorrow.

## **Discussion**

Currently there is little formal recognition within the literature surrounding the experiences and characteristics of co-occurring fatigue in children with ASD and its impact on the child and family. Using a qualitative methodology which enables case-to-case transferability [32], this was the first study to address mothers' experiences of their child's fatigue providing acknowledgement of the importance of identifying and understanding underlying causes for fatigue in ASD, whilst also enabling individualised and flexible management of it for the wellbeing and development of their child. Mothers

talked about their child's excessive tiredness, intense day time fatigue and sleepiness overriding their child's ability to function, which needed careful management; such tiredness is more unusual compared to the general population [36]. In line with previous research, sensory sensitivities and sensory overload seemed to contribute to excessive cognitive processing, triggering or exacerbating their child's fatigue [10,13,37]. Mothers also perceived social demands as an influential factor for their child; perhaps understandable given strategies to cope with social situations take excessive mental effort for individuals with ASD [38], as does developing social understanding and self-awareness [39].

Adults with ASD prefer the terms autistic fatigue and autistic burnout [17], conceptualising a connection between the characteristics of ASD and fatigue. This differentiates it from other forms of fatigue seen in the general population where a diagnosis of CFS is made in the absence of a medical explanation [20]. Only one child in this study was diagnosed with CFS, yet their mother did not believe this provided an accurate explanation. Their child also had other neurodevelopmental disorders, including dyspraxia. Thus, labelling may not always be appropriate [40], particularly if it results in misunderstanding and mismanagement as has been noted in adults with autistic burnout [18]. Co-occurring issues were prevalent in this sample and, in addition to this one child being diagnosed with dyspraxia, half of the children were diagnosed with hypermobility. There are heightened levels of fatigue in adults with developmental coordination disorders [41] and hypermobility can trigger discomfort and pains in joints and muscles [42]. Hypermobility can also result in chronic pain and headaches [42], making it difficult for children to manage when they are expected to sit still and concentrate during the school day.

### ***Fatigue and shutdown***

The phrase 'burnout' was not used by mothers in the sample who instead used the phrase 'fatigue'. It is possible mothers adopted the terminology used throughout recruitment and interviews, or their children had not reached the level of burnout, as identified in adults with ASD [18]. The phrase 'shutdown' was used spontaneously by one mother to describe the extreme impact of fatigue she observed in her child rather than referring to the symptoms itself.

The phenomenon of shutdown has been described as an autonomic nervous system response to stressful circumstances [17]. It has been recognised as a complex response to ASD related stressors, such as sensory overload, or stressors specific to the individual [43]. The term autistic shutdown is used when someone removes themselves from the world partially or completely and can mean people stop communicating verbally, take themselves out of the situation or curl up or stay in bed [43,44]. Whilst this level was not evident in mothers' accounts of their children, it remains a potential longer-term outcome if overload and fatigue are mismanaged. For example, whilst there are other warning signs, shutdown has been highlighted as a potential early warning sign of ASD related catatonia [43,44]. Thus, when shutdown becomes prolonged or frequent it is imperative this is appropriately recognised and managed [43,44].

This may be particularly important as children's developmental steps towards independence involve attendance at nurseries and schools. In the current study, five out of six children went to mainstream schools. Whilst mothers stated the need for downtime was generally accommodated, this was not always consistent. Some mothers had to move

their child and find a more suitable placement. Mothers believed their child's anxiety was due to the sensory and social pressure of external environments. It has been noted that when social demands and sensory sensitivities cannot be controlled at school, it can induce shutdown [17]. Thus, for children with ASD and fatigue, minimising stimulation when fatigued seems crucial given the impact burnout can have in adults with ASD [18], and the impact this has on families.

### ***Managing fatigue: clinical implications and recommendations***

Given the early onset of difficulties in ASD which include deficits in sharing thoughts and feelings [1], social and emotional communication difficulties will also impact experiences such as fatigue, potentially hindering recognition, investigation and management. All mothers in the study recognised their child was impacted by fatigue, many from babyhood, and this in turn impacted family life. When fully recognised by others it was managed well; however, mothers believed it was often inadequately recognised or misunderstood where management in wider environments was often lacking.

Mothers in this study highlighted a sense-making process of their child's experiences identifying sensory stimuli, general stimulation, social interaction and demands as factors that exacerbated fatigue. Through this recognition process, they then taught their child to make sense of it too which seemed to enable some of the children to learn to self-manage or regulate stimuli and fatigue, with positive impacts on mothers and their families. Research does suggest that those with ASD are capable of successful self-management [45,46]. Behavioural issues are more likely to occur when both fatigue and demands are present in children with ASD [15]. As such, mothers acknowledged that when their child's fatigue reached a certain level, a meltdown seemed inevitable if the environment was not managed and stimulation reduced. This negatively impacted the mothers as well.

ASD-specific approaches which recognise sensory sensitive children and the importance of managing environmental contexts can provide the support required for children with ASD and fatigue. For example, to manage environmental stressors, a psycho-ecological approach to manage shutdown [43] is important as well as promoting an ASD favourable environment [17]. Both approaches aim to reduce stressors and sensory demands by matching environments to the needs of the individual, which could encompass managing fatigue.

To help carers manage burnout, fatigue, and shutdown in individuals with ASD, recent recommendations focus on reducing stimulation so energy levels can recover. This includes time off school, reducing the expectations of others, and removing high stress activities for children [17,44]. Further, recognising and managing energy levels through 'energy accounting' could be beneficial [47]. Moreover, generic recommendations enabling rest and naps in the school routine to improve learning outcomes could also benefit all children attending schools [48]; and the 'spoon theory' provides a helpful account of living life within the limits afforded by a chronic health condition [49], an analogy which could be used by those with ASD and co-occurring fatigue to articulate their personal experience and needs to others. Due to the idiosyncrasies of ASD presentations [50], individualised and flexible management seems crucial.

Whilst mothers acknowledged accepting their child's differences was a gradual learning process, acknowledging the impact of fatigue seemed essential, alongside finding ways to better manage it for the wellbeing of their child and themselves. Further, because mothers had to limit their lives to make life work better for their child and family, this potential isolation surrounded by misunderstanding could further isolate them [51]. It could easily be misconstrued that mothers were limiting opportunities for their child. It seems important to reframe this by recognising their dedication in facilitating their child's participation in life at a manageable level in line with their child's needs, in addition to developing social support which meets the specific needs of mothers of children with ASD [51].

Given that information sourced from professionals assists in the emotional adjustment, acceptance and management of a child's illness [52], it seems crucial that further research is conducted such that professionals become better informed about the assessment and diagnosis of fatigue in ASD and underlying reasons for it, and the supportive role families have in recognising and managing its impact.

### ***Strengths and limitations***

Although the sample size was appropriate for IPA [33] it is still a small number which limits generalisability. Further, whilst steps were taken to minimise researcher bias, there is always a possibility that this influenced the data collection and analysis. However, qualitative research does not aim to be generalisable, instead it provides meaning to rich and detailed data collected from participants [33], and case-to-case transfer generalisation [32]. Indeed, qualitative research in ASD has been recommended to enrich understanding about presentations and its impact across settings [53].

This study provides an understanding into the lived experience of mothers of children with ASD and co-occurring fatigue. As far as the authors are aware, this is the first study to address these issues. Future research should aim to explore this phenomenon from the perspective of male primary caregivers and in school settings given their presence in children's lives. Exploring the use of self-management techniques to equip children with the skills to manage their fatigue as they get older could have longer-term benefits. Further, given the co-occurring issues of the children in this sample, exploration of potential biological, neurological and medical reasons for fatigue may be useful to better recognise, manage and minimise the potential of more detrimental longer-term outcomes for those with ASD and co-occurring fatigue.

### ***Conclusion***

This study supports recent recommendations which state managing energy levels and reducing stressors is essential to prevent burnout in those with ASD and co-occurring fatigue. Mothers stated that fatigue impacted their child and their family in a range of ways. Due to lack of acknowledgement from some professionals, mothers developed their own understanding of the phenomenon, which helped them guide their child to better understand their own needs. Additionally, due to the idiosyncrasies of ASD, individualised diagnoses of underlying conditions and flexible, consistent implementation of strategies which support its management seems crucial for the wellbeing of young people with ASD and their families.

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## Disclosure statement

No potential conflict of interest was reported by the author(s).

## Ethics approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was approved by the Health, Science, Engineering & Technology ECDA, University of Hertfordshire (No. LMS/PGT/UH/03762).

## Data availability statement

Authors can confirm that all relevant data are included in the article and/or its supplementary information files.

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## References

- [1] American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Arlington (VA): American Psychiatric Publishing; 2013.
- [2] Bonis S. Stress and parents of children with autism: a review of literature. *Issues Ment Health Nurs.* 2016;37(3):153–163. doi:10.3109/01612840.2015.1116030.
- [3] Vohra R, Madhavan S, Sambamoorthi U, et al. Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. *Autism.* 2014;18(7):815–826. doi:10.1177/1362361313512902.
- [4] Varma P, Conduit R, Junge M, et al. A systematic review of sleep associations in parents and children. *J Child Fam Stud.* 2021; doi:10.1007/s10826-021-02002-5
- [5] Giallo R, Wood CE, Jellett R, et al. Fatigue, wellbeing and parental self-efficacy in mothers of children with an autism spectrum disorder. *Autism.* 2013;17(4):465–480. doi:10.1177/1362361311416830.
- [6] Megreya AM, Al-Attayah AA, Moustafa AA, et al. Cognitive emotion regulation strategies, anxiety, and depression in mothers of children with or without neurodevelopmental disorders. *Res Autism Spectr Disord.* 2020;76. doi:10.1016/j.rasd.2020.101600.
- [7] Smith LE, Hong J, Seltzer MM, et al. Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *J Autism Dev Disord.* 2010;40:167–178. doi:10.1007/s10803-009-0844-y.
- [8] Seymour M, Wood C, Giallo R, et al. Fatigue, stress and coping in mothers of children with an autism spectrum disorder. *J Autism Dev Disord.* 2013;43:1547–1554. doi:10.1007/s10803-012-1701-y.
- [9] Keen D, Webster A, Ridley G. How well are children with autism spectrum disorder doing academically at school? An overview of the literature. *Autism.* 2016;20(3):276–294.
- [10] Boksem MA, Tops M. Mental fatigue: costs and benefits. *Brain res rev.* 2008;59(1):125–139.
- [11] Hull L, Petrides KV, Allison C, et al. “Putting on my best normal”: social camouflaging in adults with autism spectrum conditions. *J Autism dev Disord.* 2017;47(8):2519–2534.
- [12] Lai MC, Lombardo MV, Ruigrok AN, et al. Quantifying and exploring camouflaging in men and women with autism. *Autism.* 2017;21(6):690–702.
- [13] Robertson CE, Baron-Cohen S. Sensory perception in autism. *Nat Rev Neurosci.* 2017;18(11):671–684.
- [14] Leader G, Flynn C, O'Rourke N, et al. Comorbid psychopathology, challenging behavior, sensory issues, adaptive behavior and quality of life in children and adolescents with autism spectrum disorder. *Dev Neurorehabil.* 2021;24(6):397–407.
- [15] Smith CE, Carr EG, Moskowitz LJ. Fatigue as a biological setting event for severe problem behavior in autism spectrum disorder. *Res Autism Spectr Disord.* 2016;23:131–144.
- [16] Pottie CG, Ingram V. Daily stress, coping, and well-being in parents of children with autism: a multilevel modeling approach. *J Fam Psychol.* 2008;22(6):855–864.
- [17] National Autistic Society. Autistic fatigue and burnout. <https://www.autism.org.uk/advice-and-guidance/topics/mental-health/autistic-fatigue/professionals>; 2021a, downloaded 20th April 2021.
- [18] Raymaker DM, Teo AR, Steckler A, et al. “Having all of your internal resources exhausted beyond measure and being left with no clean-up crew”: defining autistic burnout. *Autism Adulthood.* 2020;2(2):132–143. doi:10.1089/aut.2019.0079.
- [19] Rogers DC, Dittner AJ, Rimes KA, et al. Fatigue in an adult attention deficit hyperactivity disorder population: A transdiagnostic approach. *Brit J Clin Psychol.* 2017;56:33–52.
- [20] Bileviciute-Ljungar I, Maroti M, Bejerot S. Patients with chronic fatigue syndrome do not score higher on the autism-spectrum quotient than healthy controls: comparison with autism spectrum disorder. *Scand J Psychol.* 2018;59:428–432. doi:10.1111/sjop.12451.
- [21] Collin M, Nuevo R, van de Putte EM, et al. Chronic fatigue syndrome (CFS) or myalgic encephalomyelitis (ME) is different in children compared to in adults: a study of UK and Dutch clinical cohorts. *BMJ Open.* 2015;5. doi:10.1136/bmjopen-2015-008830.

- [22] Mannion A, Leader G. Comorbidity in autism spectrum disorder: A literature review. *Res Autism Spectr Disord.* 2013;7:1595–1616.
- [23] Coury DL, Ashwood P, Fasano A, et al. Gastrointestinal conditions in children with autism spectrum disorder: developing a research agenda. *Pediatrics.* 2012;130:160–168.
- [24] Hemati Alamdarloo G, Majidi F. Stress in mothers of children with neurodevelopmental disorders, *Advances in Autism,* 2021. doi:10.1108/AIA-12-2020-0073
- [25] Koegel LKE, Koegel RL, Dunlap GE. *Positive behavioral support: including people with difficult behavior in the community.* Baltimore: Paul H Brookes Publishing; 1996.
- [26] Jang J, Dixon DR, Tarbox J, et al. Symptom severity and challenging behavior in children with ASD. *Res Autism Spectr Disord.* 2011;5(3):1028–1032.
- [27] Adams HL, Matson JL, Jang J. The relationship between sleep problems and challenging behavior among children and adolescents with autism spectrum disorder. *Res Autism Spectr Disord.* 2014;8(9):1024–1030.
- [28] Boshoff K, Gibbs D, Phillips RL, et al. Parents' voices: "our process of advocating for our child with autism." A meta-synthesis of parents' perspectives. *Child Care Hlth Dev.* 2018;44:147–160.
- [29] Rausch J. Advocacy, intervention, and coping: a qualitative study of high functioning autism from a mother's point of view. *J Ethnographic Qual Res,* 2021. Available from: [https://collected.jcu.edu/fac\\_bib\\_2021/13](https://collected.jcu.edu/fac_bib_2021/13).
- [30] Ryan S, Cole KR. From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum. *J Appl Res Intellect.* 2009;22:43–53. doi:10.1111/j.1468-3148.2008.00438.x.
- [31] Strunk JA, Pickler R, McCain NL, et al. Managing the health care needs of adolescents with autism spectrum disorder: the parents' experience. *Fam Syst Health.* 2014;32(3):328–337.
- [32] Treharne GJ, Riggs DW. Ensuring quality in qualitative research. In: P Rohleder, A Lyons, editor. *Qualitative research in clinical and health psychology,* 1st ed. London: Red Globe Press; 2015. p. 57–73.
- [33] Smith JA, Flower P, Larkin M. *Interpretative phenomenological analysis: theory, method and research.* London: Sage; 2009.
- [34] O'Brien BC, Harris IB, Beckman TJ, et al. Standards for reporting qualitative research. *Acad Med.* 2014;89(9):1245–1251.
- [35] Nizza IE, Farr J, Smith JA. Achieving excellence in interpretative phenomenological analysis (IPA): four markers of high quality, *Qual Res Psychol,* 2021. doi:10.1080/14780887.2020.1854404
- [36] Baker E, Richdale A, Short M, et al. An investigation of sleep patterns in adolescents with high-functioning autism spectrum disorder compared with typically developing adolescents. *Dev Neurorehabil.* 2013;16(3):155–165.
- [37] Harrison J, Hare DJ. Brief report: assessment of sensory abnormalities in people with autistic spectrum disorders. *J Autism dev Disord.* 2004;34(6):727–730.
- [38] Griffith GM, Totsika V, Nash S, et al. 'I just don't fit anywhere': support experiences and future support needs of individuals with Asperger syndrome in middle adulthood. *Autism.* 2012;16(5):532–546.
- [39] Müller E, Schuler A, Yates GB. Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. *Autism.* 2008;12(2):173–190.
- [40] Bedson J, McCarney R, Croft P. Labelling chronic illness in primary care: a good or a bad thing? *Br J Gen Pract.* 2004;54(509):932–938.
- [41] Thomas M, Christopher G. Fatigue in developmental coordination disorder: an exploratory study in adults. *Fatigue: Biomed Health Behav.* 2018;6(1):41–51. doi:10.1080/21641846.2018.1419564.
- [42] Baeza-Velasco C, Cohen D, Hamonet C, et al. Autism, joint hypermobility-related disorders and pain. *Front Psychiatr.* 2018;9:656, doi:10.3389/fpsyt.2018.00656.
- [43] Shah A. *Catatonia, shutdown and breakdown in autism: a psycho-ecological approach.* London: Jessica Kingsley Publishers; 2019.
- [44] National Autistic Society. *Catatonia.* Available from: <https://www.autism.org.uk/advice-and-guidance/topics/mental-health/catatonia>, 2021b; downloaded 20th April 2021.

- [45] Koegel LK, Koegel RL, Hurley C, et al. Improving social skills and disruptive behavior in children with autism through self-management. *J Appl Behav Anal.* 1992;25(2):341–353.
- [46] Lee SH, Simpson RL, Shogren KA. Effects and implications of self-management for students with autism: A meta-analysis. *Focus Autism Dev Dis.* 2007;22(1):2–13.
- [47] Attwood T. Working with individuals on the spectrum. In: Bédard R, Hecker L, editor. *A spectrum of solutions for clients with autism: treatment for adolescents and adults*. 1st ed. London: Routledge; 2020. doi:10.4324/9780429299391
- [48] Ribeiro S, Stickgold R. Sleep and school education. *Trends Neurosci Educ.* 2014;3(1):18–23. doi:10.1016/j.tine.2014.02.004.
- [49] Miserandino C. The spoon theory; 2003. Available from: <https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/>.
- [50] Donnellan AM, Hill DA, Leary MR. Rethinking autism: implications of sensory and movement differences for understanding and support. *Front Int Neurosci.* 2013;6:1–11. doi:10.3389/fnint.2012.00124.
- [51] Alon R. Social support and post-crisis growth among mothers of children with autism spectrum disorder and mothers of children with down syndrome. *Res dev Disabil.* 2019;90:22–30.
- [52] Pain H. Coping with a child with disabilities from the parents' perspective: the function of information. *Child Care, Hlth Dev.* 2001;25(4):299–313.
- [53] Adams D, Young K, Keen D. Anxiety in children with autism at school: a systematic review. *Rev J Autism Dev Disord.* 2019;6:274–288. doi:10.1007/s40489-019-00172-z.