



“It Was Such a Different Experience”: a Qualitative Study of Parental Perinatal Experiences When Having a Subsequent Child After Having a Child Diagnosed with Autism

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Abstract

Objectives Children who have an older sibling diagnosed with autism have an increased likelihood of being diagnosed with autism or developing broader developmental difficulties. This study explored perinatal experiences of parents of a child diagnosed with autism, spanning pre-conception until the subsequent child’s early developmental period.

Methods Qualitative interviews were conducted with ten parents of a child diagnosed with autism, and ten parents of a child with no neurodevelopmental diagnosis, each of whom had gone on to have a subsequent child. Thematic analysis occurred concurrently with data collection and involved comparisons between the two samples.

Results Four themes were identified in relation to the perinatal period of a subsequent child following the autism diagnosis of an older child. These were parental experiences of “apprehension”, “adjustment”, and “adaptation”, underpinned by the “importance of support”. Many experiences of parenting were similar between the two groups, with comparison between the groups identifying the role of autism in an increased focus, concern, and hypervigilance to their child’s development.

Conclusions Having a child diagnosed with autism intensifies some of the common experiences of parenting and infancy. The challenges identified by parents throughout the experience of parenting an infant after having a child diagnosed with autism indicate that the development of supports could help empower families in this situation going forwards.

Keywords Autism · Development · Infancy · Parent experience · Qualitative

Autism spectrum disorder (hereafter autism) is a neurodevelopmental condition diagnosed based on the presence of social communication and interaction difficulties, and restricted and repetitive behaviours (American Psychiatric Association, 2013). Currently, the mean age of diagnosis of autism is typically between 3 and 4 years, with a recent review indicating a mean age of 43 months (van’t Hof et al., 2021), and with reliable diagnoses possible from the second year of life

(Guthrie et al., 2013; Johnson et al., 2007). The challenges that behaviours associated with autism can present, and their influence on general child development and daily functioning, can result in varied impacts on caregivers and families (Gau et al., 2012), as can the time-intensive demands on parents to support therapy attendance and implementation (Hastings & Johnson, 2001; Sawyer et al., 2010). As such, having a child diagnosed with autism has been found to impact parents in both the short and long term, including: parental stress and well-being; family functioning; financial stress; and planning for subsequent children (Davis & Carter, 2008; Hastings & Johnson, 2001; Navot et al., 2016).

Qualitative studies have examined the lived experience of parents of caring for an autistic child, revealing themes of this lived experience from early development through to post-diagnosis including: the centrality of autism in the family’s life and routines (DeGrace, 2004; Myers et al., 2009; Woodgate et al., 2008); parental isolation (Myers et al., 2009; Woodgate et al., 2008); insufficient support and the challenges of navigating the systems (Nicholas et al., 2016;

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Woodgate et al., 2008); and the re-configuring of their understanding of parenting (Nicholas et al., 2016). A meta-synthesis of qualitative research in this area identified six themes across studies of parents experience of parenting a child with autism: pre-diagnosis, diagnosis, family life adjustment, navigating the system, parental empowerment, and moving forward (Depape & Lindsay, 2015).

However, as has previously been highlighted (Brian et al., 2018), this field of work is developing, and many aspects of the experience have yet to be explored in the literature. With children being diagnosed from as early as 30 months of age (van't Hof et al., 2021), for many families the diagnostic process—or a preceding period of parental queries or concerns—often coincides with decisions around having further children (Tessema et al., 2021). Previous examinations in this field have found that the parental experience of having a child diagnosed with autism affects family planning in multiple ways. For parents who have had a child diagnosed with autism, the most prevalent perceived cause for autism was genetic factors, and for many parents this played a significant role in their family planning decisions (Selkirk et al., 2009). Further qualitative research in this field has found that whilst individual cognitive factors—such as parental cognitive flexibility—impact family planning decisions, ongoing challenges managing life after the diagnosis were also important in making decisions to not have, or to delay having further children (Navot et al., 2016).

Around 20% of infants who have an older sibling diagnosed with autism are later diagnosed with autism themselves (Ozonoff et al., 2011), and a further 20–30% develop broader developmental difficulties (Messinger et al., 2013). However, unlike single-gene inheritance disorders, such as fragile-X syndrome, or cystic fibrosis, whilst the genetic elevated likelihood of having a subsequent child with autism is known, no prenatal test or parental genetic testing can further inform this. Additionally, there is no test in early infancy to diagnose autism and provide parents in these early developmental stages of any certainty around whether or not their child is likely to be autistic and provide direction in what supports may be needed. However, early diagnosis and early intervention are hypothesised to improve long-term outcomes (Johnson et al., 2007; Rutter, 2006). Parents of children diagnosed with autism have indicated a high awareness of the message around the importance of early intervention but have also indicated that this results in both promise and pressure (Edwards et al., 2017).

Whilst research has explored how the diagnosis of a child with autism has short- and long-term impacts on multiple aspects of families lives, for those parents who do go on to have further children, research has yet to explore how their experience of having had a child diagnosed with autism impacts their experience of parenting a subsequent child. In

particular, it is unknown how this situation impacts parents' perinatal experiences when having subsequent children. Given the expected uncertainty of parents—knowing of the elevated likelihood of subsequent children having autism, and the importance of early intervention—we might expect this period of parenting to be impacted.

It is of additional responsibility as researchers to better understand the parental lived experience of this time period, as this sibling cohort—of younger siblings of children diagnosed with autism—has been, and continues to be, the focus of a great deal of prospective research. This includes research on early interventions, often implemented by their parents. It is thus of key importance for clinicians and in particular researchers in this space, to better understand the lived experience of parents—how having had a child diagnosed with autism before having another child impacts their experience of parenting, and thus how this may impact on the implementation of interventions, and the wellbeing of parents and families. Therefore, this qualitative study aimed to explore the lived experience of pregnancy and parenting of a subsequent child after having had a child diagnosed with autism.

Methods

Participants

Two groups of participants were sought for this study. Inclusion criteria for the first (focal) group were parents who had a child diagnosed with autism before the pregnancy of a subsequent child, and that the younger child was under 6 years old. This age restriction was employed to increase the chance that parents would be able to accurately recall aspects of pregnancy and the first 6 months of their child's life. Inclusion criteria for the second (comparison) group were parents who had two or more children, with the youngest child under 6 years old, where none of their children had a diagnosis of a neurodevelopmental condition. Exclusion criteria for both groups were non-English speaking parents (with a level of conversational fluency required), parents who lived further than 1-h commute from Perth, Western Australia, to enable in-person interviews, or participants under 18 years old. The aim was to recruit mothers and fathers; however, only mothers volunteered to participate. A convenience sample of ten participants in each group ($n = 20$) was recruited through social media, directly contacting parenting groups, and through a database of previous research participants. Participant recruitment was reviewed throughout the data collection and initial data analysis phases. Recruitment ceased when no new preliminary themes were identified, with the ensuing sample size then sufficient to meet the study aim.

All participants were from two parent households, with two or three children in each family. For the focal group, diagnostic information was collected for older siblings with an autism diagnosis, as well as for any other siblings where relevant. Varied diagnostic presentations (with different severity levels across domains of communication and restricted and repetitive behaviours, and with or without language impairment) and ages of diagnosis (23 months–8 years) were reported and are summarised in Table 1 along with information on family structure and sibling details. For the comparison group, family structure is reported. Families had 2 or 3 children, with 40% of focal families having two children, and 80% of the comparison families having 2 children. For the focal group, 70% of the

focal children (discussed in the interview) were male and their mean age was 3.5 years ($SD=2.6$), and for the comparison group, 40% of the focal children were male and their mean age was 3.3 years ($SD=1.8$).

Procedures

A phenomenological approach (Braun & Clarke, 2006; Creswell et al., 2007) with in-depth interviews was used to obtain a comprehensive understanding of how having had a child diagnosed with autism impacted parents' experiences of pregnancy and parenting a subsequent child. The first author (DC) led this study as part of her doctoral research. At the time she was a clinical

Table 1 Demographic data, family structure, and diagnostic information for participants

	Focal group		Control group	
	Mean (SD)	n (%)	Mean (SD)	n (%)
Characteristics of the family				
Number of children				
2		4 (40%)		8 (80%)
3		6 (60%)		2 (20%)
Characteristics of focal child				
Sex				
Male		7 (70%)		4 (40%)
Female		3 (30%)		6 (60%)
Age	3.5 (2.6)		3.3 (1.8)	
Characteristics of sibling(s)				
Sex				
Male		10 (62.5%)		6 (50%)
Female		6 (37.5%)		6 (50%)
Age (years)	7.5 (2.4)		6.7 (2.4)	
Diagnosis				
ASD (level 2) (DSM-5)	5 (31.1%)			
ASD (level 3) (DSM-5)	1 (6.2%)			
ASD (level not specified)	3 (18.8%)			
Autistic disorder (DSM-IV)	4 (18.8%)			
Language impairment (DSM-5)	2 (25.0%)			
GDD	1 (6.2%)			
ASD queried	2 (12.5%)			12 (100%)
Nil	2 (12.5%)			
Age of ASD diagnosis	3.9 (1.9)		N/A	

DSM Diagnostic and Statistical Manual: (American Psychiatric Association, 2000, 2013), *GDD* Global Developmental Delay

^aUnder DSM-5 a diagnosis of Autism Spectrum Disorder (ASD) is given, with level 1 indicating “Requiring support”, level 2 indicating “Requiring substantial support”, and level 3 “Requiring very substantial support”. Similarly, a diagnosis of language impairment is or is not given for children diagnosed under DSM-5 (these levels and specifiers were not present in DSM-IV diagnoses)

^bAll siblings are same age (i.e., the twin) or older than the focal child in both groups

^cAll families had one child diagnosed with autism before the pregnancy of the focal child. Diagnostic information for all siblings from families is presented here, including additional siblings

psychologist trainee, having previously worked closely with parents and families of children diagnosed with autism in the Perth community in research (primarily conducting clinical assessments) and service roles. The first author (DC) engaged in the data analysis process under mentorship from the senior author (KE), who has experience with numerous qualitative studies, including doctoral research looking at parental experience broadly and postdoctoral research exploring the perspectives of autistic individuals and their caregivers. The other authors (AW and MM) provided feedback throughout to contextualise the research study within the clinical and research landscape where they have extensive experience.

An initial intake screening phone call was utilised to confirm study eligibility and provide study information. The first author (DC) provided interested participants with an information sheet and obtained written consent prior to conducting each interview. Before the commencement of interviews, the intake survey was conducted to collect family demographic information. The primary form of data collection involved in-depth interviews using an interview guide to ensure questioning was consistent within and between the two groups. The interview guide was created in collaboration with two senior autism researchers and a child health nurse, and included a minimal number of broad, data-generating questions as recommended for phenomenological studies (Brod et al., 2009; van Manen, 2016). The initial question asked of parents was as follows: “Could you tell me about your experience of the pregnancy, birth, and early development of X”? Temporal probes were then used to follow up and guide the interview, prompting for different time periods, and content probes were used

to prompt for different elements of the experience, such as concerns, difficulties, or supports (see Fig. 1). Open-ended probes were used to facilitate parents’ telling of their stories. The interview guide was piloted with two parents, and their feedback was used to amend prompts to ensure they encompassed a wide breadth of experiences.

Interviews took place face-to-face in a quiet, private location of the participants’ choosing, either at their own home or in clinical rooms. Mean interview time for the focal group was 66 min (ranging from 47 to 102 min) and 46 min for the comparison group (ranging from 35–81 min). Field notes describing the context and interviewer reflections were made by the first author (A1) within the day following the interview. Interviews were audio recorded with the participant’s consent and were transcribed verbatim by the first author using Microsoft Word. Transcriptions were imported into NVivo software (QSR International, 2018) to assist in storing and managing the analysis.

Data Analyses

Interview transcripts were thematically analysed by the first and senior authors to explore the experiences of parents through the following four steps (Braun & Clarke, 2006; Creswell et al., 2007). First, the focal and comparison group transcripts were reviewed in their entirety by the first and senior authors to ensure they were familiar with the entire breadth of parental experiences, allowing them to attain a depth of understanding for the analysis (Braun & Clarke, 2006; Englander, 2012). Second, the first author inductively coded the focal and comparison group transcripts, through repeated reading of the text, identifying excerpts that were reflective of the experience, and assigning codes that reflected these broader themes or meaning

Fig. 1 Interview guide

Initial question:

“Could you tell me about your experience of the pregnancy, birth, and early development of X”?

Temporal probes:

- Tell me about when you found out you were pregnant.
- Tell me about during the pregnancy.
- Tell me about around the time of the birth.
- Tell me about the first few weeks after the birth.
- Tell me about the first 6 months.

Content probes:

- Were there any particular concerns that you had around this time?
- Was there anything around this period of time that you felt made your situation more difficult?
- Was there anything around this period of time that you felt made your situation easier?
- Were there any supports that you felt you did benefit from at this time?
- Was there any information or supports that you felt you would have benefited from at this time?
- With the care of your child in this period, what do you think worked well and is there anything you would you do differently?
- What would be your advice to other parents in the same situation?

units (Braun & Clarke, 2006; Creswell et al., 2007). Third, the first and senior authors met on several occasions to review the focal group codes and develop a thematic structure through arranging and re-arranging similar codes together for continuous comparison to form preliminary themes and sub-themes (Braun & Clarke, 2006). Preliminary themes and sub-themes for the focal group were re-evaluated by the first author as new data became available, and the transcripts were reviewed repeatedly for significant statements in an attempt to find meaning and understanding through themes (Braun & Clarke, 2006). During this phase, codes from the comparison group were compared to the thematic structure established for the focal group to determine if these experiences were unique to the focal group or common across both groups. No additional themes were identified for the comparison group during the inductive coding process undertaken by the first author. Discussion between all authors continued throughout this final phase until a final thematic structure, consisting of four themes and nine sub-themes, was confirmed.

Reflexivity was addressed throughout the data analysis process to ensure the findings were not the result of pre-conceived ideas by the authors. The first author (DC) kept a field journal as a strategy to reflect on the lens through which she was thinking about and interpreting the data collected and on the analysis of this data (Krefting, 1991). This reflection, alongside collaborative discussions throughout the study between the authors, assisted in identifying the expectations and viewpoints of the authors at all stages of the study, such as to be intentional throughout data collection to not provide leading questions or posit assumptions in interviewing participants, or in interpreting the data (Olmos-Vega et al., 2022). Dense descriptions and numerous participant quotations were utilised throughout to ensure the findings reflected the experiences portrayed by the parents (Krefting, 1991). As multiple quotes from

different parents reflected each theme, priority was given to select quotes from the breadth of parents to ensure all participants’ voices were represented.

Results

The analysis of the experiences of parents who have a child diagnosed with autism and have gone on to have a subsequent child resulted in four main themes (Fig. 2). The first three themes, “**apprehension**”, “**adjustment**”, and “**adaptation**”, refer to separate phases that the parents moved between. The final theme, “**importance of support**”, underpinned the other three themes, in particular parents’ description of transitioning between the three phases. In reporting the findings, we provide a description of participants, the thematic framework and the themes. Each theme comprises several sub-themes. For each theme, we provide: (a) a description of each sub-theme; (b) illustrative quotes that describe the sub-theme in the words of participants; and (c) a summary of the similarities and/or differences between the focal and comparison groups. A summary table of the themes and sub-themes with example quotes is provided in Table 2.

Apprehension

Uncertainty — “No One’s Got a Crystal Ball”

A common expression of apprehension amongst parents was experiencing uncertainty around what to expect. For parents, some of the uncertainty around parenting of subsequent children was experienced during the family planning stages. A common experience amongst parents was investigating the likelihood of having another child on the autism spectrum: “definitely when I found out that I was having her [second child], that thought entered my mind straight away”. Parents

Fig. 2 The experience of pregnancy and parenting an infant after having a child diagnosed with autism: An organising framework

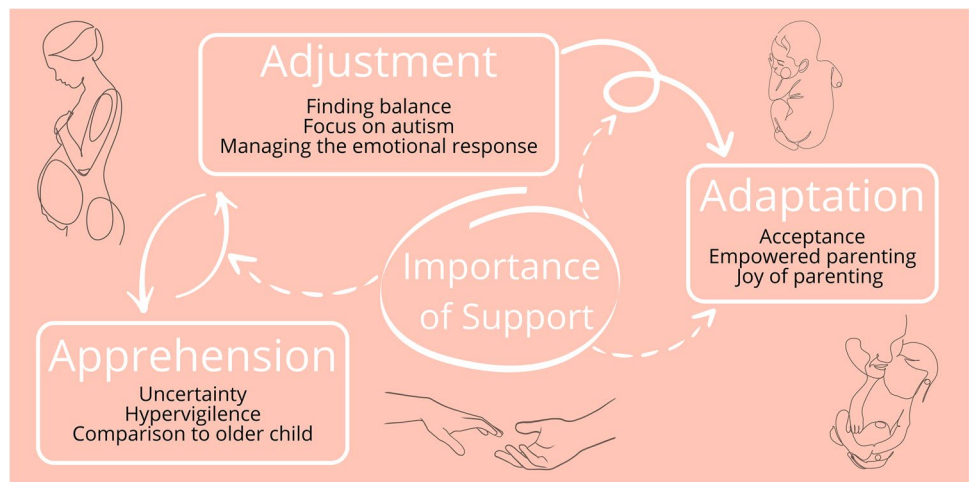


Table 2 Summary table with example quotes to illustrate themes

Apprehension	
Uncertainty	<p><i>"After we had (child-diagnosed)...we were initially going to try to start again...try to conceive after he turned one. After a couple of months, that's when I started seeing changes and differences and that, so we just kind of held off...and then we held off a little bit more."</i></p> <p><i>"So there's a gap because we weren't going to have another one, and it was purely based on, yeah, the whole fear of having another child with autism because we weren't sure if we'd be able to cope."</i></p>
Hypervigilance	<p><i>"She's a...brand new baby and you're already looking for signs."</i></p> <p><i>"I'm really...paying more attention...because I'm aware of it now...how important those things are, they're all indicators...is he hitting milestones, is he not hitting them, what can I do to help him hit them, those are the things that go through my mind"</i></p>
Comparison to older child	<p><i>"You're always comparing...from...about three months, four months, I knew (youngest child) was completely different."</i></p> <p><i>"We had definitely flagged by the time he was two months old that, yeah, something wasn't quite right again. So there was no eye contact ever, he was very quiet, sleepy. He was very much the picture of my first child all over again."</i></p>
Adjustment	
Finding balance	<p><i>"I...still had the other two and everything that comes with having two little children, you know, at school and doing swimming lessons and things like that. I was working part-time as well. And [we had] always been very conscious of trying to split our time between the children... So, yeah, just busy."</i></p> <p><i>"Everything is given and done very equally, very fairly. I'm very, very conscious that...you've now got another little person and you're now spreading yourself in three parts, not just two, but...very conscious of trying to spend a little bit of time with each of them."</i></p>
Focus on autism	<p><i>"We were doing three to four sessions at home and then going to speech [therapy] weekly...You've got all that extra stuff going on in your head and you're trying to...still trying to make time...for the baby."</i></p> <p><i>"I still kind of feel that the bottom line is that our whole house now is about autism and that's how we parent... We pick and choose where we go, when we go, how long we go for and (youngest child)'s a part of that. She's a part of our routines, the way we do things, the way we communicate, how we speak openly about things...part of the sensory things and stuff that we do because she's part of our family...she's grown up in that world."</i></p>
Managing the emotional response	<p><i>"I feel guilty in many ways because (third child)'s life has been compromised. I remember sitting for hours and hours and doing numbers and alphabet and all these things with (first and second children), but with (third child)...a lot of parents say, you know, if they have three or four children, that the third child, they don't really get that one-on-one time anyway, but I do still feel guilty...her life has been really affected by having to focus on autism and early intervention. It's really good but I also feel guilt."</i></p> <p><i>"Because of my fears, it was just really hard...because of the exhaustion that I was feeling through being pregnant and having (older children). And then not wanting her to have autism because of knowing the journey that I had ahead of me, of how involved it is with early intervention and knowing the energy that I needed. And having had a child before and knowing what it was like recovering from caesarean and breast-feeding and getting up during the night and all of those things. I kind of knew what was ahead of me. So, I was trying not to be negative, I was being realistic but...yeah, frightened."</i></p>
Adaptation	
Acceptance	<p><i>"But with this one, it'd be like, God, there goes our DNA again, you know...that's it and that's our family."</i></p> <p><i>"And I remember going for the scan...and, of course, it was another boy... (first child's name) had a paediatrician appointment a week or two after that and I remember saying to the paediatrician, "We found out it's another boy," and I remember him actually giving me all these percentages of, you know, well, 'the chances are.' And I said, "Yep, you don't need to explain all that to me...it doesn't really matter because we've already thought about all that, you know?""</i></p>
Empowered parenting	<p><i>"How we feel about autism and the [parenting] skillset that we have is good. We're in a good place now."</i></p> <p><i>"We can do this, you know, we're a strong unit together. So if we do have to go through it [another child diagnosed with autism] again we can do it."</i></p>
Joy of parenting	<p><i>"I feel like (third child)'s actually brought out a lot of positive stuff out of (second child-diagnosed) ...Families are great. The kids are beautiful."</i></p> <p><i>"When we have a good day, it's the best day in the world."</i></p>
Importance of supports	<p><i>"I didn't get the help when I really needed it."</i></p> <p><i>"Then I started to meet parents that became a new community, like-minded mothers that became my outlet, my mental health improved because I was with people who understood."</i></p>

sought information from medical professionals, other parents, and online sources, resulting in different outcomes and responses. Some parents recalled being told of the increased likelihood of having another autistic child, for example: “the likelihood of having another child with autism was actually really quite high...[this] was quite confronting”. Others felt that the increased likelihood was not elevated such that it was concerning to them: “the odds were pretty good... statistically speaking... so that put my mind at ease”. The remaining parents found information “conflicting”, leading to ambiguity in the decision-making process. For some, finding out the sex of their baby during pregnancy prompted reflection on the possible challenges: “obviously knowing that it was more common in boys...I would say that’s probably the first thing that entered my mind”. Uncertainty often led to “a gap” between children due to pausing their family planning. Multiple parents reported that the process of identifying developmental concerns and the diagnostic process meant that they “[weren’t] even thinking about [having another child]”. Parents felt they “wouldn’t have been able to deal with it” yet due to “fear of having another child with autism”. This additional time helped parents to feel “ready to have another one”. Two parents did not experience uncertainty, as they were unaware of the increased likelihood of having another autistic child; hence, their experiences were not impacted. As one parent articulated: “if I’d been told...more information about it...there probably would have been more age difference between them”. The theme of uncertainty was endorsed by some of the comparison group parents; however, the nature of the uncertainty was different. Parents of typically developing children primarily reflected on the uncertainty of how they would balance another child around the commitments of work and their older child(ren) as a factor in deciding the timing of having subsequent children.

Hypervigilance—“You’re Constantly Looking”

Another expression of the apprehension described by parents was through hypervigilance. Many parents described hypervigilant responses throughout pregnancy and the first 6 months of life as they attempted to manage this uncertainty. The first response was increased attention and ascribed meaning to infant development to ensure the “presence of concerning developmental signs” was identified early, because “I don’t want to be in the position again where my poor first child got no therapy for four years”. Parents described a constant internal dialogue during daily activities, where they questioned if their infant “should be” behaving in specific ways. For some parents this was deliberate, for example “I’m paying more attention to ...”, “I’m really looking at ...” and “I was quite paranoid about all of that stuff... not blasé about anything in terms of developmental”. This

resulted in worry for some parents, for example: “If I could have gotten help for the newborn I would have. That’s how worried I was”. For others this attention was less deliberate, for example: “I don’t know if you’re looking for it, but I think you’re obviously more aware of it”. This vigilance to monitoring development sometimes involved consulting clinicians (for example, “everything that can be asked got asked”) and extensive research that “consumes you”. This higher level of vigilance compared to their older child was explained with “Even though you always paid attention to [developmental behaviours], they have more meaning now” and “I’m aware of ...how important those things are”. For some parents, their second response was to augment their child’s opportunities or environment to support development. This was described as putting in a “more concerted effort” during pregnancy and the early developmental period, such as “reading...medical reports”, “food and diet” and doing “my own therapy at home” using knowledge from older children to boost language learning. This theme of hypervigilance was not described by the comparison group.

Comparison to Older Child—“You Don’t Want to Compare, but You Do”

Apprehension also presented through the comparisons that parents made, intentionally and incidentally, with their elder child as “it’s just your reference point”. Parents expressed that the experience of parenting between their children was “definitely different”, with parenting their younger child “like an experience I’d never experienced... a completely different feeling”. Differences and similarities between children were noted by parents, with parents reporting they “often” or “always” felt like they are comparing. Comparisons of differences in attention, facial expressions, and eye contact were noted by parents, for example, noting that “Yeah oh my god it was like the attention, the attention, it’s like she’s actually looking in my eyes. Whereas (autistic child) never ever did that...all those differences there were mind blowing really”. Noting differences in development were described as “a relief”, with differences interpreted as reassurance that development was “on track”: “I just turned to my husband and said, ‘We don’t have problems with this one’”. The differences for parents made the experience of parenting between their children very different, where “it really was [like] having a baby for the first time”. The experience of comparison was difficult for some parents when there were similarities to their autistic child, for example: “it was still panic, because, you know you’re looking at every move ... you’re looking at all these things that would remind you of (autistic child)” and “we had definitely flagged by the time he was two months old that something wasn’t quite right again. There was no eye contact ever...he was very much the picture of my first child all over again”. This theme

of comparison to older children was described differently by the comparison group, with parents generally not reporting concern or ascribing meaning to differences between children. For example, describing differences in developmental milestones as “kids do things differently and that’s okay”, and “you can’t compare them, because they’re just different personalities”.

Adjustment

Finding Balance—“It Was Hard to Try and Manage It All at Once”

One of the core themes of adjustment reported by parents was around the challenges of balancing the demands of their parenting role, both between children as well as amongst other roles and responsibilities. For many this involved the challenges in balancing time and energy to ensure that “the logistics of having multiple children” were achieved—sometimes impacting on parental stress and wellbeing. Many parents discussed their attempts to meet all their children’s needs equitably, taking time to ensure that “everything is given and done very equally, very fairly. I’m very, very conscious of that” and “they’d both have their needs and I really had to... just figure out how I could meet them both”. A challenge was that support was not always sufficient: “if I need something done, it needs to be me” and “being time poor was...the biggest thing...there was no time”. Coping strategies for time scarcity included humour and considering alternative perspectives, as one mother said, “I’ve always joked about my second and third child—‘I’m not neglectful, I’m building resilience’”.

Another challenge to achieving balance was influenced by the focus on managing the needs of an autistic child alongside a newborn. The challenges of balancing the needs of a developing infant were described to be complicated, as “the focus of caring for the newborn is secondary to maintaining support of autism”, with some parents articulating the challenge of balancing time and attention between their children, for example: “because (autistic child) had this disability he required more attention than what (subsequent child) does...and so (subsequent child) missed out a fair bit”. Parents described that their autistic children “were my main aim, not my newborn baby” and that “the siblings get forgotten about”. One parent summarised this dynamic with: “the bottom line is that our whole house now is about autism and that’s how we parent”. Parents who felt this had not been a primary challenge still noted the impact: “we were probably lucky that our first child was the one with autism because everything was about her...and we had the time and we didn’t have to feel guilty about [older] kids not getting attention”. The theme of finding balance was also experienced by all parents in the comparison group, who discussed

the challenges of balancing their time between commitments and between children, for example: “when [our second child] came into the fold, you felt like, am I giving enough attention to the baby because I’m giving a lot of attention to the three-year-old... I guess we were consciously trying to work out how do you negotiate time”. This theme was experienced differently, however, with the challenge of achieving balance mainly focussed on how to split time between children, without the complicating factor of a focus on autism.

Managing the Emotional Response—“It Was Just Really Hard”

Parents’ experience of adjusting involved the process of managing the emotional response to their situation. For many this involved a back and forth between proactively adjusting, focussing on the present and experiencing anxiety or guilt. This experience varied considerably between parents, as did the extent of the emotional experience that was recounted. Common emotional responses reported included feeling anxious, “stressed”, “nervous”, “panic”, “guilt”, “shame”, and/or “fear.” For some the uncertainty of the situation and “trying to juggle all the demands” made them feel “very, very overwhelmed” and as if they were “a wreck”. For some parents the situation also evoked a sense of “mummy guilt”, either because they felt “I’m failing...to do everything” for their children or because of the potential role their genetics had played: “the parental guilt is kind of huge...I’ve done this to you...I wouldn’t swap him for the world and I love him to pieces but I wish I could make life easier for him and I can’t”. For many parents, the process of adjusting involved learning how to cope with these challenging emotional experiences, and just “crossing the bridge, just getting over all the problems one at a time and not worry[ing] about everything”. For the comparison group, the adjustment process likewise evoked emotional responses, with feelings described of being stressed and overwhelmed in attempting to balance time, with parents “not feeling like you ever win at ‘mumming’” and feeling that the challenges of this meant that “there’s an enormous amount of guilt associated with parenthood”. These emotional responses, whilst present, overall appeared to be of a lesser intensity and were reported less frequently for the comparison group.

Adaptation

Acceptance—“That’s How We Contribute to the World”

One of the core themes of the parental experience was a sense of acceptance of everything that came with parenting their children, including the uncertainty. For some, this occurred during the family planning stages, feeling

that “at the end of the day they’re all kids, they’re all special and unique in their own way ... we didn’t want to [not] have more kids because we were scared about having another child on the spectrum”. For some parents this acceptance of uncertainty occurred during pregnancy or in early development, with parents learning to “try not to worry and stress about...what might happen, because whatever will happen will happen”. Another strategy was focusing on the positives of having an autistic child, such as “I’m not saying it was easy, but I’ve accepted it...and I just don’t need people feeling sorry for me... We have a beautiful child who’s doing really well” and so “it wouldn’t have worried me if I had another child with autism” because “I wouldn’t fear it... it’s what’s made our lives really amazing and really special and why we’re so close”. This theme was not described by the comparison group.

Empowered Parenting—“We Can Do This”

A core theme related to acceptance and moving forward was parents’ increased confidence in their parenting abilities, leading to a sense of empowered parenting. For some parents this confidence came from having already experienced pregnancy and parenting, feeling that “you have an instinct with your second child, you’re not a new mum”, and in particular their awareness of their own growth and abilities as parents, including in how to parent an autistic child. Parents felt that they “know more now...so if we do have to go through it again” they would feel prepared. Parents felt that they had benefited from their experience in parenting their elder child, both in their knowledge of parenting as well as their awareness of the systems and supports that were available should they be required. This sense of empowerment meant parents were more confident in how they would handle any possibilities. For example, when considering early development, they felt “that’s the difference this time round...I’m not stressed if he’s not doing something...I have information on how to help him get to that stage... Everything we’ve learnt with (autistic child)...has equipped us with knowledge”, and “how we feel about autism and the skillset that we have is good. We’re in a good place now”. This theme was described by the comparison group, with parents reflecting that the experience of having had a first child had prepared them and made them more confident about having a second, although without the focus on autism. As one mother said, “I kind of felt like I had gained enough experience through having a first to know what to expect with the second”, with parents “not questioning” how they parent as much with a second (or third) child.

Joy of Parenting—“He’s the Sunshine of Our Lives”

The last element of acceptance was descriptions of the joy of parenting their subsequent child. Mothers explained that it was joyful to spend one-to-one time with their subsequent child with “it was nice to just do stuff with [my infant] and it was just him and I” and “I had ... time exclusive with [my infant], so that was awesome”. This feeling of joy became stronger as their child’s personality started to emerge, for example: “he’s completed our family...and [his older sister] adores him and he adores her”. This theme was similarly described by the comparison group.

Importance of Supports

A pervading theme discussed by all parents was how key having a “supportive network in place” was in enabling them to cope with a subsequent child. The importance of support was highlighted throughout the different stages of the experience, with parents relying on support throughout as an integral element in supporting adjustment and adaptation. Parents explained that the positive role of support impacted decisions from family planning: “I probably wouldn’t have had another child if I didn’t have family around”, to helping them cope when they “needed a break”. As one parent summarised “just get as much as you can around you to help you...that’s what got me through”. The type of supports varied, with family, in particular grandparents, being relied upon for practical support, such as babysitting their younger child when taking their autistic child to therapy as “it was sometimes hard enough just taking him, let alone taking another baby as well”. For many parents the support of other parents, in particular other parents of autistic children, was integral to wellbeing, with parents finding that “like-minded mothers...became my outlet, my mental health improved because I was with people who understood”. Parents also discussed the difficulties of not “get[ting] the help when I really needed it” when the load of managing was difficult and “it’s always been me carrying all of that”. Some parents reported finding that practical support was required but not available: “All I needed was another pair of hands. I have no practical support, and I’ve looked for practical support and I couldn’t get any”. Parents also identified other supports that would have been beneficial but were not available, including: “I think psychological support could have been really, really helpful during the pregnancy [and] afterwards” and “mental support at that time was so difficult for me”. This theme was described by the comparison group, similarly highlighting the reliance on family and other parents, but without the discussion of the additional difficulties of managing therapy.

Discussion

The findings from this study describe that having another child, when you have had a child diagnosed with autism, is a unique and multi-layered experience. We compared the themes identified from the focal group to a comparison group of parents, to better understand which elements of the experience were unique. Across the two groups, we were also able to identify similarities in the experience of parenting. Both groups reported the uncertainty that surrounds the unknowns throughout pregnancy and how the addition of a child creates change. They also both described the challenges in adjusting throughout this change—learning how to manage both physically and emotionally the new demands of another child, and balance these with existing demands. This experience of the demands of caring for later born children altering parents' interactions and capacity with first-borns mirrors previous research on parenting (e.g., Belsky et al., 1984; Dunn & Kendrick, 1980; Kreppner, 1988). Both groups also described the empowerment and confidence that can come from knowing how to support and advocate for their children, through the experience gained from parenting their first child, as well as the joy of children and what they add to their lives.

Whilst many experiences of parenting were similar between the two groups, the comparison between the groups identified the role of autism in an increased focus, concern, and hypervigilance to their child's development. Having a child diagnosed with autism appears to intensify some of the common experiences of parenting throughout the process of pregnancy and the accompanying anticipation and uncertainty; the process of adjusting and finding balance with the addition of a new child; and the process of moving forwards and managing uncertainty and challenges as a parent. The findings of the current study lend support to broader research in the field of parenting experiences of parents of a child diagnosed with autism (Depape & Lindsay, 2015; Hoogsteen & Woodgate, 2013; Navot et al., 2016; Nicholas et al., 2016; Woodgate et al., 2008), as well as work in the field of parenting experiences of parents of children with chronic health conditions (Ray, 2002; Rempel & Harrison, 2007), and genetic disorders such as Down Syndrome (Steffensen et al., 2022).

For parents of children on the autism spectrum, prior qualitative studies have identified similar themes that articulate the difficulties experienced by parents. A meta-synthesis of parents' experience of caring for an autistic child indicated overall themes related to diagnosis, but further identified core themes of family life adjustment, parental empowerment, and moving forward (Depape & Lindsay, 2015)—similar to the theme of adjustment and the sub-theme of “finding balance” identified in this study, as well as the overall theme of adaptation and the subthemes of “acceptance” and “empowered

parenting”. Likewise, the themes of the challenges of balancing demands, as well as the parental approach of supporting their autistic children through vigilant styles of parenting in order to be doing all they can, have previously been identified (Woodgate et al., 2008). The report of supports and services being required, but often insufficient to meet the needs, has also previously been documented for parents of autistic children (Nicholas et al., 2016; Woodgate et al., 2008). These similarities highlight that which was also identified by the difference between the focus group and comparison group in this study: that the experience of having a child diagnosed with autism is influential in parents' experience of parenting, including with subsequent children.

When examining broader research, studies exploring parents of children with chronic health conditions have identified some similar themes to those found in the current study. Themes of “parenting plus” and “extraordinary parenting” have been previously identified—described as the additional demands of parents and the additional expectations parents place upon themselves in the context of providing additional support and monitoring for their child in the context of additional needs and uncertainty (Ray, 2002; Rempel & Harrison, 2007), with parallels to the “uncertainty” and “vigilant parenting” identified in this study. Similarly, themes around parents sense of a need to be present and focussed, similar to the “finding balance” theme identified here, have been identified in qualitative research examining parents of children with Down Syndrome (Steffensen et al., 2022). Recognising the parallels between the experiences of parents of children with chronic conditions or genetic disorders and parents of autistic children lends reinforcement for applying similar standards of care to support parents regardless of the unique nature of the child's condition. The findings of the current study extend prior research by identifying the ongoing impact of this experience for parents when parenting subsequent children.

Limitations and Future Research

Limitations of this research include the restriction of parental experiences reported coming from mothers, despite actively recruiting for fathers as well. Whilst the preference for this study was to explore the parental experience more broadly, despite follow-up with those fathers that did express an interest, participation did not eventuate, restricting our study to that of the maternal experience. Research has previously highlighted the difficulty in recruiting fathers to participate in paediatric research more broadly (Macfadyen et al., 2011). Further research in this space is needed to better understand the reasons why fathers are less likely to participate in research, in order to better address these issues such that research into parental

experiences can more wholly reflect the lived experience of families.

Further, parents interviewed here were only a subgroup of parents with children on the autism spectrum. This research specifically recruited for parents who had had a child diagnosed with autism and went on to have another child. This precluded parents who have not had subsequent children after having a child receive a diagnosis of autism, as well as parents who have had subsequent children before receiving a diagnosis for an older child. However, given the similarity in the essence of the themes to those of parents with an autistic child more broadly, we might expect these similar experiences for parents with different family situations. Future research could employ broader inclusion criteria to further establish this.

In recruitment we attempted to sample broadly amongst parents; however, with a small sample ($n = 20$) the demographic breadth is likely not representative of the broader Australian population. More targeted explorations of this experience for families with more diverse ethnic backgrounds, as well as families from lower socio-economic family backgrounds, would be important to expand the scope of understanding from the current sample. Further targeted or incentivised recruitment to families to participate in research may assist in this. The current study focussed on families with an autistic child, in comparison to families with a child with no diagnosis or concern of a neurodevelopmental disorder. We do not know from the current sample the impact of having other physical or developmental conditions and how this would impact the parenting experience of having a subsequent child. Given the previously discussed similarities between parenting, for example, a child with a chronic health condition to parenting an autistic child, future research should aim to explore the potential similarities and differences between different parent groups in the experience of having subsequent children when a previous child has received a physical health or developmental diagnosis.

The findings of this study carry broad implications for researchers working with the parents of autistic children. Building a better understanding of the experience of parents in this situation is imperative for clinicians and researchers—in particular given the focus of an ongoing field of research conducted with this population. The findings from this study indicate that the development of supports could help empower families in this situation going forwards. In considering the support needs discussed by families, we can identify both the importance of and the requirement for different types of social needs; with emotional, instrumental, information, and appraisal supports (Heaney & Israel, 2008) all identified by families as needed during this time period. Many families reported that supports of this nature were obtained through their social networks; with family (importantly grandparents) and other parents (importantly other parents of autistic

children), being relied upon to meet support needs rather than having access to supports through formal structures, as has been previously indicated (Prendeville & Kinsella, 2019). For those families whose social networks were less able to meet these needs, further supports are required, including: improved information and appraisal supports to provide clarity for parents around what is best practice for the monitoring and assessment of infant siblings of children diagnosed with autism, in order to provide more information about whether their child's development is typical and when they might need to intervene; and better systems of access for support through the emotional and instrumental challenges of this time period.

Further, with parent-mediated pre-emptive interventions gathering more evidence of efficacy within early infant development (from 9 months; e.g., Whitehouse et al., 2019, 2021), the critical role of parents' support in shaping their children's development is increasingly highlighted. These interventions provide an opportunity to support the challenges identified by parents throughout the experience of parenting an infant after having a child diagnosed with autism, in particular considering the integration of informational and appraisal supports through these interventions. Next steps in this space would ideally be to evaluate the efficacy of such a pre-emptive intervention within an earlier perinatal phase.

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Declarations

Ethics approval This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted from The University of Western Australia ethics committee reference number RA/4/20/4767. Written informed consent for the participants' involvement in the study was obtained from all participants.

Conflict of Interest The authors declare no competing interests.

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