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Parents' Experiences after Their Child's Autism Diagnosis: A Reflexive Thematic Analysis

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Abstract: A child's autism diagnosis is life-changing for their parents, due to the complex and long-term nature of the condition. Furthermore, research about the increased prevalence of autism suggests that more parents are being affected globally. However, limited studies have investigated parents' lived experience of their child being diagnosed with autism. This study aimed to explore the first-hand experience and concerns of parents when their child has been diagnosed with autism. The study employed a qualitative, exploratory design. Parents of a child who had received an autism diagnosis at least 12 months prior were invited to a video interview. Eleven parents participated in an hour-long interview. The interviews were transcribed, and an inductive reflexive thematic analysis was performed. The analysis resulted in four main themes: "Shock and control", "A thousand little conversations", "Put your own oxygen mask on first", and "Reforged identities", orientating around the period surrounding diagnosis, ongoing communication requirements, the need for self-care and reorientation of identity. These findings identify areas of heightened concern for parents and provide professionals with practical insight when evaluating their engagement approaches with these groups of parents. Findings can help psychologists, therapists, educators and parents themselves to identify strategies to support the well-being of parents who have an autistic child.

Keywords: autism; parenting; lived experience; autism diagnosis; inductive reflexive thematic analysis



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1. Introduction

Autism spectrum disorder (ASD) is a lifelong, complex disorder manifesting a broad range of behavioural, neurological and cognitive developmental disorders, including restricted and repetitive behaviours and deficits in social interaction and communication [1]. Autism presents heterogeneously, with characteristics and severity varying by individual from mild to severe [2].

Autism is estimated to affect 1.68% of the eight-year-old child population in the US [3], 1.76% of school pupils in England [4], and 0.9% in Australia [5,6]. In Singapore and Hong Kong, it is estimated at 1% [7] and 0.16% [8], respectively. A meta-analysis by Loomes et al. [9] found a male-to-female ratio of diagnosed autism was 3:1, while Baio et al. [10] suggested a 4:1 male-to-female ratio in the US. Rates of autism diagnosis are increasing globally; in the US, the Centers for Disease Control and Prevention Centers for Disease Control and Prevention [CDC] [11] reported a 380% increase between 2000 and 2018. Reviews of prevalence studies reported a consistent upward trend globally [12]. However, Tsai [13,14] and Fombonne [15] suggest this increase in incidence may be explained by factors such as inconsistent survey methodologies and broader diagnostic and classification criteria [16,17].

While the rate of autism incidence may be debated [15,18], for parents, an autism diagnosis for their child is a life-changing event precipitating therapeutic, emotional, social, financial, and cultural pressures [19–21]. Due to the life-long nature and heterogeneity

of autism-related traits impacting an autistic person's ability to function independently, parents and families are likely to experience long-term challenges in many aspects of daily life, such as dietary restrictions, fixed timetabling of activities and unpredictable moods and behaviours [22–24]. Volkmar and Pauls [25] suggested that approximately 85% of individuals with autism present with cognitive and adaptive limitations that affect their ability to live independently, and between 36 and 40% of children with autism in the US and UK are estimated to have intellectual disabilities [10,26].

Furthermore, previous studies have indicated that parents of children with autism experienced more mental health challenges than parents of children with other clinical diagnoses or neurotypical children [27–29], including elevated and sustained levels of stress due to factors related to their child's autism and the whole life nature of the condition [30,31]. This stress is cumulative [32] and experienced across therapeutic [33], social [28], familial [34], cultural [35] and personal domains [36]. Approximately 96% of parents of autistic children [37] notice early developmental atypicality in their child [38], before seeking clinical evaluation and diagnosis [22,39]. Parents then progress through a process of passive concern to actively seeking expert opinion through engagement with clinicians and multiple stakeholders [40]. Timely and efficient diagnosis is significant in supporting positive parent education, acceptance and mental well-being outcomes [39]. However, diagnosis may take several years due to healthcare access limitations, denial and unfamiliarity with autism presentations [33,41] and be a period of elevated stress [42].

Previous studies examining parent and clinician interactions during diagnosis found evidence of long-term consequences for parents' understanding, coping and support service engagement. Moses [43] suggested clinicians have an essential role in conveying factual information and minimising inappropriate parental guilt. Moreover, Abbot et al. [44] found that diagnosis sessions with clinicians required clear and sensitive information sharing as parents were often distracted due to their emotional state. In contrast, the qualitative study by Ryan and Salisbury [40] found that premature reassurance by clinicians suggesting no developmental concerns indicating autism often subsequently generated feelings of isolation and guilt in parents. As a consequence of more recent research into parent and clinical interaction in the diagnostic process [45], greater institutional recognition has been given to the importance and role of parents in developing improved outcomes for autistic children, including being the first to be alerted to their child's early development challenges, engagement in the screening process and having input to therapeutic planning [46].

Parent's experiences of autism diagnosis are not restricted to young children, with increasing incidence of late diagnosis of autism in adolescents and adults [47]. However, strategies used by autistic individuals, such as camouflaging [48,49], especially by females [50] to mask autistic behaviours, may hinder parental and professional recognition of autistic traits at younger ages [51,52].

Stigma in various forms has been identified as a consistent feature of the parental experience [53,54]. Goffman [55] suggested that stigma occurs when an individual displays attributes considered different from society's expectations of "normal", potentially resulting in discrimination [56–58]. Stigma specific to autism is shaped by the historical evolution of clinical understanding and definitions of autism [59–61]. Autistic behaviours were initially classified as a symptom of schizophrenia [62]; however, it was Leo Kanner's 1943 study [63] of infantile autism that first distinguished schizophrenia from autism, shaping the foundational concepts for autism diagnosis. However, these early studies had negative connotations for parents of autistic children. Kanner described the stereotypical parent of an autistic child as intellectual, emotionally cool and driven, with mothers especially displaying a lack of maternal warmth [64,65] which was later popularised as the "refrigerator mother" theory [66,67]. A contemporary of Kanner, Hans Asperger also described autistic traits [68,69], although Asperger suggested they resembled a personality disorder, while Kanner considered autism a developmental condition [70].

During the 1960s, research shifted towards understanding autism as having biological and neurological causes [71–73] and more recently, the "deficit" view of autism has been

challenged [74,75]. Autism was first given an official category in the DSM–III (American Psychiatric Association, 1980). Lorna Wing [76] proposed the classification of Asperger Syndrome, which was later incorporated into the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) in 1994. It was not until the publication of DSM-5 [1] in 2013 that all autism conditions were merged under the collective term autism spectrum disorder (ASD) [77].

Stigma is experienced by parents in various forms through internalised and social processes [54,78,79], including “enacted” stigma as negative treatment and social exclusion due to the stigmatising condition, while “felt” stigma refers to feelings of embarrassment and shame associated with negative treatment [80]. Additionally, “courtesy” or “affiliate” stigma occurs by association with the autistic individual [81,82], such as when an autistic child displays “atypical” behaviour in public [32,83], while also being perceived as “looking normal” [78,84,85]. Parents’ gender has been found to influence their experience of stigma, with mothers often the primary carers [86,87], reporting greater exposure and susceptibility to “enacted” and “felt” stigma [53,88]. However, reviews by Braunstein et al. [89] and Lashewicz et al. [90] caution that considerably more research has been conducted with mothers than with fathers. In comparison, Alareeki et al. [91] suggest that fathers experience stigma; however, it has differing drivers than for mothers, including expectations around masculinity and reluctance to support seeking, while Paynter et al. [92] found fathers felt stigmatised due to their child’s behaviour causing perceived questioning of their parenting competence.

The personal and social identity of parents and their families is profoundly impacted by having a child with autism, as suggested by Cridland, Jones, Magee and Caputi [41]. The shock of diagnosis can manifest feelings of grief, guilt and anger in parents as a result of the “ambiguous loss” of the child they have and expected to have [93] and changed expectations of parent–child relationships [94]. In many cases, parents reconstruct both their concept of family [95] and their specific family identity [96].

The parent–couple identity and relationship are impacted [97], with Hartley et al. [98] finding that amongst US parents with an autistic child, the divorce rate was 23.5% compared with 13.8% amongst parents with neurotypical children and the risk of divorce remained high throughout childhood and adolescence. These findings have been influential in professional and public perception of the breakdown of couple relationships [99]. However, Freedman et al. [100] found that in the US divorce rates were broadly similar to the general population.

In comparison, studies have shown positive parental relationship outcomes. The scoping review by Saini et al. [101] revealed that shared goals, active listening, and increased partner respect strengthened parent–couple relationships. Similarly, Altieri and von Kluge [102] noted parents’ surprise at their ability to foster a strong family unit, while Bayat [103] found increased family unity and a greater appreciation of life reported by parents.

Parental communication around autism is challenging and multifaceted. Crane et al. [104] found that most parents emphasised the importance of early, open and positive framing of the diagnosis and that they felt able to manage disclosure without professional support, while Austin et al. [105] found that parents adopted adaptive disclosure approaches according to their specific circumstances. Alternatively, Sosnowy et al. [106] emphasised the need for clinicians to provide parental support during this process and made recommendations on approaches.

The study by Sosnowy, et al. [106] exploring parents’ explanation of autism to their diagnosed children found it to be complex, while Benson and Karlof [107] suggested parents are also sensitive to the impacts on neurotypical siblings. Furthermore, early communication of diagnosis may have long-term implications for an autistic individual’s mental health; Hosozawa et al. [108] found a significant positive relationship between depression and self-harm in autistic adolescents, particularly where disclosure occurs after age 11. In addition, studies have found that the autistic child’s transition to adulthood places additional diverse demands on parents [109–111]. For example, parent–child discussions

about relationships, romance and sexuality [112] are complicated by the challenges often faced by autistic youths [113].

In summary, the impacts of autism are far-reaching for parents, and numerous discrete aspects of autism parenting have been examined from experiential, social and clinical perspectives. However, there remains a need to understand which aspects parents themselves identify as having the most significant impact and influence on their lived experience of parenting an autistic child.

This study aimed to identify the range of concerns parents experience after an autism diagnosis of their child and to explore how their lived experiences have helped them navigate the stresses associated with these concerns. A further purpose of this study is to provide psychologists, therapists, educators and parents with an experientially informed landscape of parental concerns that provides a basis for exploring routes to inform and support parents of autistic children and implications are discussed. The following research question is explored: What are the experiences and concerns of parents with autism-diagnosed children?

2. Materials and Methods

2.1. Design

This study explored the experiences of parents of autistic children and employed a qualitative design using reflexive thematic analysis (RTA). A qualitative study was determined as most suitable compared with quantitative methods, providing greater flexibility to capture the range of participant experiences required to address the research question. The underlying epistemology of this study is social constructionism since it orientates inquiry toward identifying the various ways in which individuals construct their social reality in the context of their culture, experience, and personal observation [114,115]. Gergen [116] suggested that from a social constructionist perspective, we cannot be certain what is universally true or false, nor objectively and empirically evaluate what is good, bad, right, or wrong. Social constructionism advocates that since psychology is a socially constructed discipline based on the researchers' interaction with their historical, cultural and social context, we should be critical of the assumption that we base our knowledge on unbiased observation [117]. Whereas Willig [118] suggests that from a social constructionist perspective, there are knowledges rather than single sources of truth, and these knowledges allow for investigation and interpretation in the study of the participant's lived experiences and behavioural patterns. Therefore, the study design was required to provide a framework to contextualise parents' experiences while providing freedom to explore the subjective experiences of individual participants.

An inductive reflexive thematic analysis (RTA) was selected as the analytical approach since it can accommodate social constructionist framing [119,120], the psychological theories relevant to the research question [121], it is suited to addressing questions related to experience and understanding [122], and it is therefore consistent with the research aims of this study. Reflexivity, the researcher's subjectivity of data interpretation, is consistent with social constructionist epistemology and with reflexive thematic analysis [119] and is relevant to this study as the researcher is a parent of an autism-diagnosed child.

Semi-structured interviews with open-ended questions were used to allow freedom for participants to discuss the range of experiences they felt most significant while staying within the broad parameters of the study topic [123], orientate answers that offered insight into the research question and to be consistent with Braun and Clarke's guidelines [120,124] and the study's epistemological base [125,126].

2.2. Participants

The study interviewed a purposive sample of 11 parents based in 4 locations; Australia (2), Singapore (2), Hong Kong S.A.R (1) and the United Kingdom (6). Nine parents were British, and two were Australian. This sample size meets guidelines to provide sufficiently rich data for analysis [121,124,126–128] and informational power [129] for the scope and

focus of this study. Participants included seven mothers and four fathers; 2 participants had multiple children with an ASD diagnosis. This study included 3 male participants since a high proportion of previous studies have samples comprised primarily or only of female participants [32,130,131]. The parents' ages ranged from 34 to 63 years, with the median age being 46 years. Children's ages ranged from 7 to 30 years, with a median diagnosis age of eight years, while the median current age of the children was 15 years. The profiles of the parents interviewed, and their children are included in Table 1. All participants did not have any pre-existing relationship with the interviewer, RH.

Table 1. Profile of parent participants and their ASD-diagnosed child.

Parent ID ^a	Nationality	Gender	Parent			Child			
			Age—(Yrs)	Occupation	Family Location	Gender	Age (Yrs) ^b	Age—Diagnosis (Yrs)	Age—Current (Yrs)
1	UK	F	63	Educator—Retired	UK	M	18–24 months	3	30
2	UK	F	44	Fashion Design	HK	M	3	3	7
3	UK	F	45	Educator—SENCO	UK	M	9 months	5	11
4	AU	F	53	PhD Psychologist	AU	M	4	8	23
4	AU	F	53	PhD Psychologist	AU	F	10–11	11—ADHD, ASD—16	16
5	UK	M	51	Management	UK	M	5	9	19
5	UK	M	51	Management	UK	F	14	16	17
6	UK	F	46	Local Government (SEN)	UK	F	17	18	19
7	AU	F	45	Self-Employed	AU	M	4	9—ADHD, 11—ASD	12
8	UK	F	34	Occupational Therapist	UK	M	18–24 months	5.5	8
9	UK	M	55	Management	UK	M	7–8	10	15
10 *	UK	F	42	Educator	SG	F	12–18 months	4	9
11 *	UK	M	43	Banking	SG	F	12–18 months	4	9

^a Same parent ID number indicates that more than one child in the family has received an ASD diagnosis.

^b "Noticing" refers to the age of the child when potential developmental challenges were first consciously observed. * Parent couple.

2.3. Materials

All research materials and interviews were in the English language. A participant invitation was produced for distribution by email and posting on social media platforms to recruit participants. Interviews were conducted using online video and required an internet connection and a PC, tablet or smartphone. Qualtrics was used to host, distribute and capture responses for the participant information, consent and debrief forms. On completion, the video interview and Qualtrics response files were stored on the researcher's University of Derby network drive. An interview guide was developed composed of seven semi-structured questions. Copies of interview transcripts were printed for manual review and coding. Quirkos and Atlas.ti 22 software were then used to organise codes and themes.

2.4. Procedure

The study was conducted in accordance with the Declaration of Helsinki and approved by the Ethics Committee of the University of Derby (ETH2021-4517, September 2021). Participants were recruited using social media platforms and invited to make contact via the researcher's University of Derby email account. A video appointment time of one hour was scheduled with the participant, and a link to this study's Qualtrics area was emailed to them. On accessing Qualtrics, the participant was required to generate a unique identifier code and to access the participant information sheet that provided details of the study, including topic, aims, ethical policies, participant anonymity and confidentiality, and right to withdraw.

The participants were screened by asking them to confirm they met the study participant criteria; that they were the parent or primary caregiver of the child, that they were aged 18 years or above, and that their child had a formal autism diagnosis conducted at least 12 months prior by relevant qualified professionals such as a paediatric psychologist. It was not possible to verify the diagnosis independently. The participants were requested to confirm consent prior to the interview being conducted.

All interviews were conducted over video to take account of health considerations due to COVID-19 restrictions, different geographic locations of participants and limited time availability [132,133]. The videos were recorded for later review and transcription. The diagnosed child’s age and gender were collected verbally during the interview. After the interview, the participant was directed to the debrief form on Qualtrics and to reconfirm their consent to use their data in the study. The debrief form detailed the process to withdraw from the study without reason up to 14 days after the interview and provided contact details if the participant had any questions regarding the study. The debrief form stated that the researcher could not provide advice; however, contact details for relevant support organisations were provided. Printed copies of interview transcripts were used for manual analysis and coding, and Quirkos and Atlas.ti 22 software to support coding and transcript data organisation.

2.5. Analytical Strategy

A six-phase thematic analysis was used to examine the data for this study following the procedure suggested by Braun and Clarke [120,134]: (i) dataset familiarisation, (ii) data coding, (iii) initial theme generation, (iv) theme development and review, (v) theme refining, (vi) writing up. The interview guide provided a rich source of participant data for code generation and theme development (Table 2).

Table 2. Interview questions, illustrative codes and themes.

Interview Questions and Prompts	Codes	Theme
To start with, please can you share your family set-up and about your child—gender, how old were they when you received a diagnosis?		
When you received the diagnosis how did you feel? Can you share the various aspects that came to mind during that period? <ul style="list-style-type: none"> • Which aspects felt challenging to you? • Had you any previous experience of ASD? 	There is something different, mourning and loss, guilt, anger, resentment, institutional inconsistency, coping through learning, disclosure to others	Theme 1: Shock and Control
I would like to understand more about your concerns around your child’s ASD. Which aspects have been more challenging or positive for you? <ul style="list-style-type: none"> • Any surprising or unexpected aspects? Why were they surprising or unexpected • How have these concerns changed over time? • What has influenced them 		
I would like to understand your experiences outside of your immediate family positive or otherwise. <ul style="list-style-type: none"> • in more formal settings <ul style="list-style-type: none"> ○ Doctors, psychologists and therapists—did you feel supported? why and in what way? If not, why? • and socially, what aspects have been positive or challenging, with friends and peers • do you feel “different” as an ASD parent—why and in what way? If not, why? • have you experienced prejudice, please describe this? 	Always on, cultural and social expectations, sensing prejudice, case administrator, sibling impacts, what is next for you	Theme 2: A thousand little conversations

Table 2. Cont.

Interview Questions and Prompts	Codes	Theme
What advice would you share as an ASD parent? <ul style="list-style-type: none"> • For other parents; • For health professionals and educators. 	Always available, my mental and physical health, trust your compass, presentation is not fixed, different futures, the fixer, play and joy alleviate stress	Theme 3: Put your own oxygen mask on first
Moving closer to home, how has being the parents of and ASD child affected your experiences with your immediate family and partner? <ul style="list-style-type: none"> • How has your family responded to your child's ASD—what has been positive/negative? Why did they respond in that way? • How has your partner dealt with the situation? <ul style="list-style-type: none"> ○ In relation to you? ○ What other significant areas? ○ How has this changed over time? 	Loneliness and isolation, in the workforce, changing priorities, teamwork, life trajectory, redefining success, in and out of the club, therapy as investment, our relationship	Theme 4: Reforged identities
Considering your experiences to date, what are your hopes for your child's future?		
Is there anything else that you would like to add or ask me?		

(i) Familiarisation

Multiple readings of the transcripts were conducted prior to commencing coding.

(ii) Data coding

Coding required several iterative rounds of revisiting the transcripts and refining the codes to produce a workable and differentiated data set. This was necessary given the range of perspectives required to address the research question and to expand the points of analysis beyond those reflexively anticipated by the researcher, for example, different contexts and manifestations of stigma experiences. The codes were generated through an inductive lens, which allowed nuanced interpretation of the latent meanings underpinning the experiences shared by participants, compared with utilising pre-conceived codebooks present in alternative thematic analysis techniques [135–137].

(iii) Initial theme generation

Clustering of the codes suggested four broad patterns of meaning contributing to parental experience: identity, expectations, caring requirements, and personal well-being. Since this study aimed to explore the range of parental experience, data from each cluster was further analysed to develop themes that reflected these broader dimensions. It was noted that while the interview question structure elicited the data for theme development, participants' responses did not have a strict linear alignment.

(iv) Theme development and review

Further organisation of codes through mind mapping was used to develop a set of candidate themes that were representative of the range of experiences conveyed by the participants.

(v) Theme refining

The codes and associated extracts from interviews underlying each of the candidate themes were further reviewed to reduce duplication and provide a data-differentiated basis for the four themes selected as most appropriate to fulfil the aims of the study.

3. Results

The research question addressed by this study is "What are the experiences and concerns of parents' with autism-diagnosed children?" and the reflexive thematic analysis

generated four distinct themes that capture dimensions significantly forming the lived experience related by these parents of autism-diagnosed children (Table 3).

Table 3. Themes, scopes and examples of participant excerpts.

	Theme	Scope	Illustrative Quote
1	Shock and control	The period surrounding diagnosis and the reactive responses of parents and carers	<i>my first reaction was okay, now we have this big piece of information about our son and his how his brain works [...] but my husband had a very different attitude [...] he was worried about stigma and discrimination</i>
2	A thousand little conversations	The need for ongoing and holistic communication requirements	<i>I tell people, he's got autism, I have zero shame. [...]. I don't need to go into the specifics of what that means. But you need to know, right, that his brain is wired differently. His dad would never say anything. His dad would never disclose it.</i>
3	Put your own oxygen mask on first	The necessity for self-care for parents and carers	<i>put your own oxygen mask on first, before you help others, it's really important. [...]</i> <i>professionals are focused on the person with the special needs, that is their job [...], the parent needs to be in a good place to be able to handle that information properly</i>
4	Reforged identities	The reorientation of self and external identity that parents and carers experience	<i>this process of, you know, coming, realising that we're all neurodivergent has been really, really helpful for me, and as a practitioner as well.</i>

3.1. Theme 1 (T1)—Shock and Control

This theme is informed by parents' experiences and responses to the transitional period around the diagnosis. P10 relates concern about behaviours before diagnosis and the shock and mourning they felt when the diagnosis of autism was confirmed [138].

"we [...] knew that she was potentially autistic even before we had the diagnosis. And it was, yeah, just that sort of sense of just grief [...], it was a loss of, [...] not of the human, but it was a loss of everything that we as parents' had hoped and dreamed for [...]"

[P10, F, Age 42, p. 5].

Many parents described being emotionally overwhelmed and conveyed a sense of isolation, as P7 poignantly recounts:

"I've definitely had moments where I've been really crying in my car, and I felt really overwhelmed"

[P7, F, Age 45, p. 21].

That feeling of individuality was observed when participants compared their response to the diagnosis with their partner's, often compounding their feelings of emotional isolation.

"my first reaction was okay, now we have this big piece of information about our son and his how his brain works [...] but my husband had a very different attitude [...] he was worried about stigma and discrimination"

[P4, F, Age 63, p. 8].

However, participants reported supportive responses from partners and extended family that mediated some participants' feelings of being alone with the diagnosis [139].

"we both complement each other really nicely in terms of our like, skill deficits and our strengths. [...], both sets of [Grand] parents' are very different, but they're very good in different areas"

[P8, F, Age 51, p. 13].

While P5 described his initial reticence to engage with the diagnosis and recalls an underlying sense of guilt noted by several other parents.

"[. . .] I was slightly reluctant to accept it. It didn't feel comfortable saying, 'Oh, my son is on the autistic spectrum, or has Autistic Spectrum Disorder'"

[P5, M, Age 51, p. 3].

Some parents found the reduction of uncertainty with the formal diagnosis was beneficial.

"is that ADHD? Is that autism? Or is that just who he is? [. . .]. And so I was really relieved when he got diagnosed with autism"

[P7, F, Age 45, p. 8].

Parents described the challenges of interacting with and coordinating different groups of professionals.

"They [teachers] barely did the questionnaire for the Ed Psych [. . .]. One teacher refused to do it, and the other one agreed to do it. So that was probably the worst, the most frustrating part of the process for me"

[P3, F, Age 45, p. 4].

In contrast, flagging of potential autism by educators was often positively received, especially when combined with guidance on the next steps.

"The teacher came to us fairly quickly, [. . .] and said, I think there's something about A, [. . .] autism, whatever it is, is somewhere on the spectrum. I think we should get him into this program [. . .], I'll help you get it started"

[P9, M, 51, p. 3].

While most parents discussed educator interactions, there was less emphasis on clinical interactions around diagnosis. The data suggested participants usually recalled these as transactional exchanges to obtain the formal diagnostic "piece of paper" [P2, F, Age 44, p. 7].

"she was given a moderate to severe diagnosis of autism. Yeah. And then we left the building with that. [. . .] there wasn't a huge amount of conversation in the car on the way home, [. . .]"

[P10, F, Age 42, p. 3].

P4 described her extensive work with family support groups and shared her experience of clinicians' impact on parents' adjustment to diagnosis.

"there's a two-year grieving arc that parents' go through and how severe that grief is, depends on how abruptly they were given the diagnosis from the treating professional. And some of them are shocking"

[P4, F, Age 53, p. 10].

Post-diagnosis, participants frequently described an intense and sustained period of knowledge-seeking about autism [140].

"My coping strategy was a lot of reading and research and in fact, to the point where I thought that I was going to be that person on a TED talk to say that I'd been the first person to cure my daughter of autism [. . .], I was that kind of mother [. . .]"

[P10, F, Age 42, p. 10].

These data extracts indicate that beyond the clinical diagnosis, this is a complex period for parents emotionally and socially, with parents employing a variety of response strategies to cope with the confirmation of their child's autism.

3.2. Theme 2 (T2)—A Thousand Little Conversations

Parents commented on the ubiquitous influence of their child's autism requiring ongoing communication and explanation while recognising that parenting in general is

challenging, “Yes, it’s hard. But all parenting is hard. We’ve all got our challenges. Mine’s just got this particular label” [P4, F, Age 53, p. 16].

Opportunities to socialise prompted anxiety about how their child would fare in that situation and affected their interaction with parental peers, “so it’s that alertness right. The world we live by” [P9, M, Age 55, p. 21].

“I know he’s gonna perhaps be standing out, he’s different, or whatever, I would perhaps, you know, just sort of stay quiet”

[P2, F, Age 44, p. 14].

P3 vividly described spousal and family tensions experienced at a family gathering.

“[. . .] everyone’s talking and they’re all quite loud. And he [son] was getting increasingly irritated, and went under the table [. . .] so my sister-in-law was a bit more responsive [. . .], the rest of the family were just, let’s ignore it. She was like, ‘look, if you want him to come out from under the table, you’re going to have to lower your voices a bit, because I think that’s what’s, you know, stressing him out’. And I’d said, we should take his ear defenders and my husband, before the meal, [. . .] had said, No, I don’t want the ear defenders.”

[P3, F, Age 45, p. 11].

Parents reported the need to explain their child’s autism-related behaviours in public settings [78], however, there were variances described in how parents approached disclosure.

“I tell people, he’s got autism, I have zero shame. [. . .]. I don’t need to go into the specifics of what that means. But you need to know, right, that his brain is wired differently. His dad would never say anything. His dad would never disclose it”

[P7, F, Age 45, p. 20].

“I’m very open with people that I know, like, and trust. But if somebody is not in that category, it’s of no importance to them, I’m not gonna mention it”

[P2, F, Age 44, p. 17].

This participant described the responsibility of acting as an advocate and coordinator across multiple stakeholders as a source of stress.

“there is so much pressure [. . .], we have to be case administrators, [. . .] you have to become a SEN lawyer yourself to basically understand the system”

[P8, F, Age 34, p 6].

Participants described the benefits of linking with relevant groups to increase knowledge about support processes and other parents’ experiences.

“being part of a community or using professionals in that community, is really important. [. . .] other people’s stories of how their lives are [. . .]. That’s really important for a parent that and I think most parents’ don’t access it”

[P3, F, Age 45, p. 19].

Additionally, P3 described their continual quest to support their child’s development through myriad educational and therapeutic interactions.

“I’m constantly trying to get to the bottom of, or why, why do you behave like that? Why do you look at things that way? Why do we find this so difficult when I know that other children don’t find this difficult?”

[P3, F, Age 45, p 6].

This participant recalled the challenges of organising daily activities for the family and the impacts on family members [23].

“we would try and take him out for the day and doing sort of normal family kind of things. But there was always some complication, there would always be tension [. . .], days out would be largely around him, which was a bit frustrating for the older two”

[P1, F, Age 63, p. 6].

P6 described the self-monitoring required to balance being supportive, encouraging independence, and being conscious of autism-related vulnerabilities as their child transitions to adulthood.

“she’s 19 and a half, she’s got to, she’s got to learn, hasn’t she, [. . .] regardless of any diagnosis, you know, she’s got to find her own path. [. . .], that’s hard just when your baby grows up, and they usually go on their own life, let alone when they’ve got those kinds of needs [. . .]”

[P6, F, Age 46, p. 17].

All aspects of a parent’s life are impacted by their child’s autism [141]. These comments illustrate not only the range of situations in which parents have to engage in relation to the condition but also that they are in a constant state of alert and situational monitoring over the long term.

3.3. Theme 3 (T3)—“Put Your Own Oxygen Mask on First”

When participants were asked what advice they would share with other parents, many highlighted the need to prioritise self-care to offset the physical and emotional toll of caring for an autistic child [102].

“put your own oxygen mask on first, before you help others, it’s really important. [. . .] professionals are focused on the person with the special needs, that is their job [. . .], the parent needs to be in a good place to be able to handle that information properly”

[P2, F, Age 44, p. 19].

Most parents recalled that demands were exacerbated by parenting other young children concurrently. P7 related the impact of having a newborn baby and the simultaneous diagnostic period of her son.

“And I did go and kind of really slip into this period of postnatal depletion. I won’t say depression, but I was really teetering on the edge of that [. . .]”

[P7, F, Age 45, p. 7].

P1 shared the negative effects on her mental health and self-confidence resulting from criticism received due to her son’s repeated and challenging behaviours [142].

“we did get a fair amount of support but we also got a lot of people who felt they needed to tell me what I was doing wrong. [. . .]. I would be devastated by people just saying you know, you should be doing this or you should be doing that, or that’s disgusting”

[P1, F, Age 63, p. 11].

Few parents reported seeking professional support for themselves. P4 recounted her work with parents when discussing support options with autism support groups.

“Often, you know, people say, Oh, I tried psychology, and I didn’t like it. It’s like, how many psychologists did you try all? Well, just the one. But no, I hated it”

[P4, F, Age 53, p. 17].

The overriding focus on their child was reported as an impediment to self-reflection and awareness of strain, *“I’m just run ragged trying to keep an eye on him”* [P9, M, Age 55 p. 24]. P7 recognised the urgent need to consider their well-being.

“you get to a point where you’re kind of, like, if I don’t get help and support, I’m just not gonna get to serve anyone, I’m just gonna get some horrible autoimmune disease”

[P7, F, Age 45, p. 12].

P2 reflected on changed expectations and coming to accept the autism in their lives *“there’s a place for all of us, and they are all valid”* [P2, F, Age 44, p. 19], while P11 shared that objectivity is often challenging to achieve when overwhelmed.

“celebrate the wins, celebrate the victories. But you’re so sort of wrapped up in it, [. . .], it’s only when [. . .], a video or a picture is showing years later, do you realise how far you’ve come”

[P11, M, Age 43, p. 10].

Nevertheless, P1 brought stark attention to the severity of the presentation that, for some parents, can require urgent and significant child and parent support.

“he [son] was a big lad by this time, he became aggressive. And he broke my nose twice. He nearly drowned me when we were on holiday”

[P1, F, Age 63, p. 17].

P7 related that sharing care with professionals had benefits for her child and her personal understanding and well-being.

“with the OT, I’m able to just hang out in the background. And I love what she’s teaching him [. . .], she taught me more about perception. [. . .]. And I would have been frustrated about the fact that he can’t see what I can see”

[P7, F, Age 45, p. 13].

Parents spoke of conscious shifts in their priorities that had helped reduce stressors. P10 noted reduced concern with others’ approval and *“the channelling of how things should look”* [P10, F, Age 42, p. 11], while many parents had intentionally evolved their expectations as summarised by P3.

“your expectations as to what you think the trajectory of your child’s progress, achievement, life, mental health is, has to permanently fluctuate to match what they’re actually going through, not what you think it should be, or where you think it should be”

[P3, F, Age 45 p. 17].

These parents’ comments indicate their awareness of the potential negative impacts on their well-being; however, they also illustrate the contextual challenges they face to incorporate well-being measures into their daily lives, with many reporting shifts in their attitude towards their child’s autism as central to their coping approach.

3.4. Theme 4 (T4)—Reforged Identities

Participants suggested that their experiences affected their identity across multiple dimensions, including their sense of self, in their family, and in society [95].

“I really struggled with the loss of identity, being so focused on my career and thinking I was going to go big places, you know. Then resigning was so hard, losing my own pay packet was devastating”

[P4, F, Age 53, p. 15].

P3 indicated that there were implications for both parents in sharing responsibilities due to increased caring demands.

“because my husband’s self-employed, he did a lot of the care stuff. [. . .]. No one talked to him because it was drop off and pick up, and they’re all mums [. . .]. And even my father-in-law made a comment once about my husband being a kept man”

[P3, F, Age 45, p. 14].

P10 illustrated the tension between accepting their child’s autism and their struggle with being wholly identified and defined by it.

“I’m not one of those autism warrior mums who say it’s a gift and a blessing. [. . .] she’s my child, and I will do what I need to do to keep her safe [. . .], it wasn’t a natural

transitional role that I came into. And if I'm honest, if I could take it all away from her, I would in a heartbeat"

[P10, F, Age 42, p. 11].

Whereas P8 emphasised positive impacts on their personal growth and greater insight gained toward their professional practice.

"this process of, you know, coming, realising that we're all neurodivergent has been really, really helpful for me, and as a practitioner as well"

[P8, F, Age 34, p. 10].

Participants also reflected upon the broader consequences for family dynamics and identity and the need to shape these actively.

"H [child] couldn't consume us, she had to be part of the whole family"

[P11, M, Age 43, p. 10].

P7 described adjusting their social networks towards those they felt were better attuned to their situation and supportive.

his friends [...] some of them are not diagnosed. But the parents' know. They're like we know that, we don't care. Yeah, they are who they are

[P7, F, Age 45, p. 23].

Participants reported the impact of their autistic children on sibling relationships. Here, P1 described the challenge of the severe behavioural presentations experienced with her son.

"[...] it impacted on the youngest child because she was always frightened of him. [...] he was genuinely quite a content child, but [...] he had a temper, he would get very frustrated if we didn't know what he wanted, which was quite a lot of time"

[P1, F, Age 63, p. 5].

Additionally, P4 described bullying of the autistic child observed by the younger brother at school [143].

"He [autistic son] literally had red marks around his neck because they had been choking him. He had wet his pants, he was so distressed. [...] he wasn't able to tell anybody what had happened"

[P4, F, Age 53, p. 20].

Nonetheless, P6 described the accepting response of siblings to their sister's recent autism diagnosis.

"her sisters were sort of like, oh yeah okay fair enough, [...] she's still A"

[P6, F, Age 46, p. 7].

Parents reported imbalances in their availability to siblings, *"I'm aware of giving A [autistic] a lot more time and support than I do R [neurotypical]"* [P9, M, Age 55, p. 13]. However, P10 expressed the need to explain their autistic child's condition and family considerations, especially for neurotypical siblings.

"I think if they feel seen, and they feel that you're being honest about your capacity, [...] perhaps you overshare you know, but in an appropriate way"

[P10, F, Age 42, p. 21].

Participants described involvement in supporting their autistic child's efforts to establish their confidence and identity [113]. P3 recalled the frustration expressed by her son, *"I'm rubbish at everything. And I can't do anything. And I wish I was like other people." [...]* you have to help him reframe that" [P3, F, Age 45, p. 7]. While P6 described her daughter's (Year 13, UK) request to be assessed for autism, *"I'd really like to have an assessment just so*

that I know when I go to uni if there is actually a need, or whether it is [. . .], the way I am" [P6, F, Age 46, p. 2].

P7 and P9 recognised online culture as significant for their children's identity exploration related to autism and making connections and friendships.

"I've seen him watching videos on YouTube about autism, he wants to know about it"

[P7, F, Age 45, p. 21].

"He doesn't play on his PlayStation with the kids from his school, who he doesn't like, he actually prefers to wait and play with the kids from Canada [. . .]"

[P9, M, 53, p. 23].

Participants reported that through their parenting experience, they had recognised autistic traits in their own behaviour.

"I think we're all somewhere on the autistic spectrum. [. . .]. And I recognise in myself, some of the things that J suffers with"

[P5, M, Age 53, p. 4].

P4 expressed her hopes and ambition for their child's identity as an autistic individual in society, reflecting those of all the participants.

"That they gather friends around them [. . .], people who see how wonderful they are in their own unique ways and love them for that. Not in spite of it, but for it"

[P4, F, Age 53, p. 22].

After an autism diagnosis for their child, many parents' sense of personal and family identity changes [95]. These extracts indicate that the process of recognising and accepting these changes is challenging and deeply personal and affects their perceptions of social interaction for themselves and their family members.

4. Discussion

This qualitative study aimed to explore parents' experiences and concerns after their child was diagnosed with autism. We interviewed eleven parents and identified four themes: shock and control, a thousand little conversations, put your own oxygen mask on first, and reformed identities. Each theme will be discussed in turn.

4.1. Shock and Control

A central finding of this study was that participants did not experience diagnosis as a single shocking event. Many participants described increasing anxiety from initially noticing developmental differences in their child compared to their expectations and observations of child peers and building throughout the formal diagnostic process. This finding is consistent with earlier studies focusing on this specific period of parental experience [20,39]. However, while some participants expressed relief on gaining a formal diagnosis [38], all participants reported heightened and sustained levels of stress and anxiety once autism became a factor in their parenting, a finding that supports previous studies [27,30].

When exploring experiences around diagnosis, participants reported the influential role of early years educators for parents in several respects: bringing autism considerations to the parent's attention, validating parental concerns about child developmental delays, and enabling preliminary official support for the child [46,144]. Most parents related positive experiences; however, for some participants, variable attitudes and engagement methods degraded the quality of interaction and increased their stress and frustration. Meanwhile, interaction with clinical professionals was, for many participants, a transactional experience to obtain an official diagnosis with little attention given to the emotional and life impacts on the parents and family. This finding complements the studies by Austin, Galijot and Davies [105], Smith et al. [145] and Mulligan et al. [19] providing guidance to professionals. Whether they described a positive or negative experience, all parents

suggested that specific training for professionals is critical to the effectiveness of their interactions with children and parents [146].

An additional finding suggested differences between mothers' and fathers' responses to the diagnosis. Mothers tended to recall that although they were deeply distressed by the diagnosis, they quickly moved to a process of information gathering about the condition and organising daily logistics to gain a feeling of control, displaying a problem-focused coping approach. This contrasted with fathers noting their initial difficulty accepting and engaging with the diagnosis, citing reasons such as peer stigma and guilt [147]. Moreover, most mothers recounted this emotion-focused coping reaction described their male partner's responses. While these coping strategies have been previously reported [102,139,148], this study found that even where participants reported they had moved on from these strategies, the data indicated that differing degrees and definitions of acceptance within some couples remained a pernicious source of tension influencing their approach to therapeutic, education and social engagement choices. This finding suggests that parent couples may benefit from ongoing support beyond the diagnostic period and broadly supports similar findings [139,149].

An important finding within this theme is that participants associated this period with an intense sense of isolation [142] with contributory factors including well-intentioned but misinformed advice from friends, comparing developmental milestones with peers' children, perceived distancing of friends [53], partner response and their own coming to terms with the diagnosis. As observed in the data, participants reacted to this isolation by calibrating their interactions with others through diagnosis disclosure [150], avoiding certain social activities, and progressively reorientating their social networks. Participants highlighted their use of social media in this process, which is novel compared with earlier studies [79,151].

4.2. *A Thousand Little Conversations*

This theme explored the finding that all participants reported that their child's autism affected most aspects of their daily lives and required continuous consideration and attention [152]. The data suggested that ongoing communication is a primary component of meeting these demands and is necessary for parents to manage and navigate social, familial, educational, and therapeutic domains.

Parents described a process of mental reconnaissance and discussions with their partner for upcoming social occasions to map and anticipate how their child may react or feel in that environment. Further questioning revealed individual variances in how parents typically approached explaining their child's condition to others, from being extremely open with others to being selective about whom they told and expressing that they would not tell anyone. Furthermore, a latent interpretation of the data [120,153] suggested that participants mediated their approach to disclosing or discussing their child's condition due to concerns about stigma affecting the child, family or parents. This finding suggests that disclosure of diagnosis is a highly individual and sensitive decision for parents [105] and is consistent with previous research examining autism-related stigma, including the literature review by Liao et al. Liao, Lei and Li [54] and numerous qualitative studies [78,142]. Autism is described as a hidden disability [60], and it was anticipated that the extent of social disclosure might be related to the severity or outwardly apparent presentations of autistic behaviour by the participant's child [79]. However, this study found that the combination of parental outlook, the heterogeneous nature of autism and the qualities of the child's specific presentation were of more significant influence in this sample.

These participants felt pressure to frequently engage with professionals to advocate for their children and coordinate multiple professional stakeholders to optimise outcomes [144,154] and the roster of professionals regularly changed. A characteristic of this sample was that most of the children discussed were of school age; however, those participants with older or adult children were still actively involved with support stake-

holders [155]. This finding indicates that clear policies and guidelines can help parents navigate support processes more effectively and plan for longer-term care requirements.

All parents in this sample proactively sought reliable information about autism, and most saw benefits in being regularly connected to relevant parent and professional groups. The data suggested that parents attributed value to bonding through shared experience, reduced feelings of isolation, learning from other parents' experiences and accessing new or updated therapeutic information. While this study did not sample neurotypical parents, this finding contrasts with the review by Vernhet et al. [140] that suggested parents with autistic children use relatively fewer social support strategies and more social avoidance strategies. This may be explained by the composition of the sample in this study.

Analysis of the data exploring family communication found that participants regularly discuss aspects of their child's autism with two groups, siblings [2] and extended family [95]. Participants described addressing frustration and feelings of deprioritisation in siblings since family activities were frequently organised around the autistic child, however, the data also suggested that most siblings were accommodating overall, as Moss et al. [156] have shown. However, a review of comments on the extended family found a mixed picture, and while actively hostile responses were rare, several parents suggested that their relatives were neutral or did not engage with the diagnosis. In contrast, other participants noted positive responses and active support. This suggests that parents, in addition to adapting to their child's autism, have to evaluate their immediate support networks [157].

4.3. Put Your Own Oxygen Mask on First

This theme reflects that self-care was considered essential in this sample of parents, however, a struggle to prioritise this was a consistent finding in the data and consistent with previous research [102,158,159]. This sample recognised parenting as a demanding activity in general; however, participants reported that autistic parenting brought additional demands, limiting the time available for relaxation and pursuing their own interests. Several parents in this sample had more than one child with autism, and they described that each child had different support needs, placing further demands on them [160].

Clusters within the data revealed that parents felt they were "always on" and susceptible to feeling overwhelmed. Mothers and fathers related that they had struggled when they had other young children concurrently, and several participants recalled dealing with autistic behaviours prior to diagnosis and consequently had little support [37]. A small number of the mothers reflected that they would have avoided becoming pregnant, at least during this period, if they had known their existing child had autism. In discussing older children, this study, similar to studies by Baghdadli et al. [161] and McStay et al. [162], found the teenage years are especially challenging for parents, with constant requirements to oversee academic studies and social activities such as online gaming and parties where autism might make their child vulnerable to inappropriate behaviours.

Building upon previous studies examining the benefits for parents taking part in therapeutic modalities [149,163], a notable finding in this study was that few participants sought out or were receiving professional psychological support for themselves. The data also indicated that when parents become emotionally and physically depleted, they become more sensitive to stigma, resulting in increased distress. For some parents in this sample, this manifested in negative behaviours that included social withdrawal and increased alcohol intake. This finding supports research indicating increased vulnerability to anxiety and depression in this population [27,164] and suggests that parents actively monitor their well-being. However, there was also evidence that participants felt their well-being improved when they observed progress in their child's development [103,165].

Furthermore, this study did not find that increased autism severity, as described by the participants, increased their support-seeking activities. Further analysis of individual transcripts indicated that limited resources and access to support might underlie this finding, suggesting that specific family contexts should be considered in evaluating parental support programmes. In comparison, Beurkens et al. [166] found that parental feelings of

“relatedness” to their child were significant in offsetting parental stress related to autism severity, while McStay et al. [162] found that child hyperactivity was a more significant stressor for parents than autism severity.

An encouraging finding suggests that as participants gained experience with their child’s needs and therapeutic options, they could engage with professionals more confidently, forming a caring team for their child. Participants noted enhanced well-being due to the respite gained by sharing or delegating aspects of caring with professionals. Additionally, they learned from these professionals, which increased their knowledge and scope for engaging with the child.

An important finding within this theme was that learning to accept and live with autism was an attitudinal perspective adopted over time by participants to manage stress related to immediate challenges, develop emotional resilience and reduce anxiety when projecting their child’s future care [22,167]. Participants described as essential to their acceptance of the realisation that there were limits to their ability to manage all aspects of their child’s life and that their child should, where possible, have a responsibility to take a deterministic role in how their life develops [168,169].

4.4. *Reforged Identities*

Having an autism-diagnosed child had significant implications for participants’ self-identity, family identity, and how they felt they were perceived in society. Parents described a process of grief and mourning for their child’s development and unrealised futures [138]; however, they also experienced the loss of personal identity as their expectations of how they anticipated their life trajectory changed. Several participants highlighted that reduced ability to commit to their careers had negatively impacted their self-identity. In contrast, other participants noted positive benefits from this reprioritisation, supporting findings by Ooi et al. Ooi, Ong, Jacob and Khan [141].

This study found increased demarcation of roles in couples compared to before diagnosis, particularly impacting mothers as they tended to reduce employment commitments and assume more of the caring responsibilities, with fathers focusing on breadwinning [86]. However, the data were nuanced regarding the impacts of these changes, with some participants noting that resentment built up around this subject in their couple relationship, whereas other participants reported that it had transformed and strengthened their relationship into a collective team identity. Additionally, in this sample, four participants had subsequently separated or divorced from their partner after an autism diagnosis; however, two suggested that the strain of autism parenting did not contribute to the couple’s breakup. This observation lends some support to Shtayermman’s study [34], indicating multiple variables such as parents’ age and mental health are significant in marital satisfaction. However, due to the small sample size of this study, conclusions cannot be made about divorce rates.

Participants consistently experienced periods when they felt their identity was subsumed by autism. However, while most participants did not embrace autism, they had reconciled that it would feature throughout their lives and was a part rather than the whole of their identity. In contrast, two participants recognised through their experiences that they were undiagnosed autistic and welcomed this realisation [170]. An encouraging finding was that participants largely considered this experience had caused them to grow spiritually and emotionally and have greater confidence to deal with adversity and enjoy life [103]. Additionally, they described acceptance of their child’s autism as positive to their family’s identity [95], and they had deprioritised comparison with other families.

This study established that participants were concerned about the development of identity in their autistic and neurotypical children. The data signalled consistent patterns of engagement by parents to balance the inclusion of all children in activities, provide individual time and attention [171], and educate all the children about autism to facilitate positive sibling dyadic relationships [172]. However, discussing out-of-home experiences, participants frequently reported concern about bullying of their autistic child and the effects

of affiliate stigma on siblings [173]. This concern is well-founded with studies showing that bullying and stigmatisation are 2–4 times higher in school than for neurotypical children [143] and discrimination may transfer from school [174] to the workplace [175,176], where only 22% of UK autistic adults are in any kind of employment [177,178].

Another important finding was that participants placed high importance on supporting their child's self-identity and relationship-building as an autistic individual [104,170]. This is crucial given the deficit perspective of autism [173] historically influencing the treatment of autistic people, for example, clinical assumptions regarding the theory of mind [179], and in the public domain perceptions skewed by extreme representations of autism in the media such as savant abilities [180,181]. Furthermore, these associations affect parents' experiences, from the emotional impact of diagnosis to their daily life experiences.

Building upon this, the participants expressed hope that their children would be respected, included and valued in society. This finding complements the relatively recently developing body of studies by autistic and neurotypical researchers into autistic identity [182,183].

4.5. Practical Implications

This study aimed to improve understanding of the experiences of parents with autistic children by exploring the dimensions they considered most relevant informed by their lived experience. The findings provide an annotated landscape of practical parental considerations and address the study's aims of providing other parents and relevant professionals with a curated range and context of the psychological and practical impacts experienced. The study provides value in validating findings from previous research reflecting commonalities in experiences; however, this study reinforces findings that suggest that experiences of autism are diverse and rapidly become specific to the individuals and families affected. A further contribution compared with earlier studies is surfacing the growing importance of online media for parents and autistic individuals by providing channels to raise awareness, challenge long-held beliefs about autism and provide opportunities for education, self-awareness and exploration of autistic identity.

4.6. Suggestions for Future Research

The findings in this study suggest directions for future research with practical applications for parents of autistic children and associated professionals. Firstly, an intriguing area for further investigation is the self-diagnosis of autism and the initiating factors, information sources and validation processes involved. Secondly, examining the factors that influence professionals' attitudes to parents would benefit both professional and parent groups. A third area of research suggested by the low employment rates for autistic people is the consideration and prioritisation of neurodiversity in corporate diversity programmes. Fourthly, a longitudinal study could examine the impact of critical experiences at the time on parents and the evolution of their responses.

4.7. Strengths and Limitations

This study has several strengths; the qualitative design and thematic analysis provided rich insights that reflect the real-world experiences and priorities described by affected parents; additionally, the study meets its aims of providing parents and professionals with a basis for education and support grounded in parents' lived experiences. However, there are limitations to note. Firstly, in addition to the small sample size, and despite the international recruitment of participants, all participants had Western cultural backgrounds and higher levels of education, and their experiences may not be representative of parents of autistic children in the general population [184]. Secondly, parents' experiences may be affected by the level of governmental support in their location, and this was not factored into the analysis [185]. A third limitation is that participation in this study required an autism diagnosis by qualified clinicians but did not specify severity or focus on comorbidities that may influence aspects of parental experience, nor the clinical method used for diagnosis.

5. Conclusions

While an increasing number of parents have a child diagnosed on the autism spectrum, there are limited studies investigating a parent-centred perspective of which aspects of autism have been most significant to their lived experience. Previous research has examined discrete elements of parents' experiences, such as stress and anxiety levels, exposure to stigma, and response to the specific period of diagnosis. This study aimed to expand our understanding of the parental experience of autism by exploring which aspects parents themselves identify as having the most impact on their lived experience and discussing the underlying dimensions that inform their experiences. This investigation revealed four areas that were meaningful in constructing a landscape of their experiences: the emotional and clinical process around diagnosis; ongoing communication requirements related to their autism caring demands; the need for self-care over the long term; and fundamental reorientations around their identity. These findings identify areas of heightened concern for parents of autism-diagnosed children, measures they have taken to mediate challenges and provide professionals with a parent-based analysis to aid the evaluation of engagement and support approaches with these groups of parents. Given the growing rates of autism diagnosis globally, an increasing number of parents require credible information and professional support.

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