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Parents' experiences of an early autism diagnosis: Insights into their needs

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ABSTRACT

Background: Little research has directly examined parental needs following their child's early diagnosis of autism.
Method: The experiences and support needs of 13 mothers and fathers who had a young child diagnosed (< 36 months) were explored via a series of semi-structured interviews and a focus group.
Results: Thematic analysis identified four key themes: emotional response to diagnosis, ability to manage the uncertainty post-diagnosis, resourcefulness, and experiences of sharing the diagnosis.
Conclusions: Parents highlighted that receipt of an early diagnosis triggered an array of emotions, which influenced their coping. Charting parents' lived experiences following an early diagnosis provides valuable insights that have important implications for the development of resources and supports for families at this time.

1. Introduction

The rate of Autism Spectrum Disorder (ASD) diagnoses in Australia and across the world has increased sharply over a decade (Australian Bureau of Statistics, 2012; Bent, Barbaro, & Dissanayake, 2017; Lord & Bishop, 2010; Randall et al., 2016). Symptoms that characterise ASD not only affect the individual, but also significantly impact their family. However, interventions to support affected families are comparatively limited.

To develop appropriate interventions and ensure adequate support is provided to parents of young children following early diagnosis (< 36 months-of-age), it is important that parental experiences and coping post-diagnosis are better understood. By having this understanding, we may also be able to better support family adaptation and improve family quality of life. Existing literature indicates that an ASD diagnosis has a significant emotional impact on parents (Abbott, Bernard, & Forge, 2012; McGrew & Keyes, 2014), who report feeling confused and overwhelmed. A diagnosis of ASD also affects families' perceptions of themselves and their child, their quality of life, support system and family coherence and adaptation (McStay, Trembath, & Dissanayake, 2014).

Qualitative studies focused on understanding parents' needs have found that communicating with a professional who listens, recognises strengths and difficulties, and conveys a sense of hope is important (Abbott et al., 2012; Woodgate, Ateah, & Secco, 2008). Speaking about the diagnosis is highly valued, often more so than the provision of information. Woodgate et al. (2008) reinforced the need for more sensitive and comprehensive care by professionals, arguing that a more enduring and supportive relationship between parent and professional is important to promote a greater sense of competence in parents.

Abbott et al. (2012) explored parents' experiences soon after their child's diagnosis. Findings suggested methods for conveying

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news sensitively to families, including a structured feedback session with the opportunity to ask questions, be listened to, and given time to absorb information. However, Abbott et al. (2012) did not explore barriers or protective factors that may affect a family's progress after diagnosis, such as coping mechanisms. Furthermore, children in this study were aged between 8 and 15 years at the time of diagnosis, beyond the typical age (< 5 years old) children enter early intervention (Dawson, 2008).

In an effort to understand their 'lived experience', Woodgate et al. (2008) examined parents' experiences via interview prior to, during, and after their young child's diagnosis (< 3.5-years- old). Parents retrospectively reported on their experiences following diagnosis, when their children were aged between 3 and 9 years old. Parents revealed that having a child with autism not only affected their parenting role but defined how they lived, often describing "living in their own world". A general theme of isolation and loneliness emerged, and parents expressed difficulty preserving their sense of self. In trying to achieve a sense of normality, they focused their energy on maintaining a routine in family life.

Hennel et al. (2016) investigated parents' information needs and clinicians' practice, with findings suggesting clinicians tailor their consultation to provide optimal support. The importance of developing individualised 'autism action plans' with written materials to improve parents' understanding and satisfaction with children's diagnoses was highlighted. While some research has examined the coping mechanisms that assist with moderating parents' daily stress, studies have not specifically investigated coping mechanisms used by parents soon after receiving a child's diagnosis (Pottie & Ingram, 2008).

A growing literature highlights that early diagnosis leads to better outcomes later in life (Anderson, Liang, & Lord, 2014; Clark, Vinen, Barbaro, & Dissanayake, 2017; Dawson et al., 2012; Harris & Handleman, 2000; Itzchak, Lahat, Burgin, & Zachor, 2008; Vivanti & Dissanayake, 2016), whereby children diagnosed early (< 48 months) access more intervention, demonstrate better verbal and cognitive skills at school age, and require less ongoing support than children diagnosed later. This substantial body of research supports the notion that early is best when it comes to intervention, with timely access also key to promoting positive developmental gains (MacDonald, Parry-Cruwys, Dupere, & Ahearn, 2014). As we strive to improve early diagnosis, we need to ensure that parents of young children are adequately supported to make the next steps necessary for their child and family, such as accessing early intervention.

Crane, Chester, Goddard, Henry, and Hill (2016) surveyed over 1000 parents in the United Kingdom about the diagnostic process for their child with autism. They identified that parents' greatest concern was the unsatisfactory standard of post-diagnostic support. Although Crane et al. (2016) shared important insights, further examination of responses was not possible due to use of an online survey. Interviewing parents provides the unique opportunity to listen to and record their lived experience and ask follow-up questions. Accessing detailed accounts is important to build adequate supports and to fill the gaps that parents identify within service systems. Furthermore, identifying 'unsatisfactory' and 'unhelpful' elements for families post-diagnosis can inform improvements in clinical practice and post-diagnostic support.

Resolution with diagnosis is important to help parents foster acceptance of their child and promote caregiving that embraces the child's unique characteristics. Wachtel and Carter (2008) investigated the relationship between mothers' acceptance and resolution of their child's ASD diagnosis and their interaction style. Results showed that mothers who were more emotionally resolved rated higher in cognitive and supportive engagement during play interactions with their child and provided greater verbal and nonverbal scaffolding - crucial skills for the development of attention and play. Furthermore, mothers who were more emotionally resolved showed greater reciprocity and overall mutual enjoyment with their child. In another study, mothers who were both insightful and resolved were more likely (83% vs. 30%) to have securely attached children compared to those who were neither (Oppenheim, Koren-Karie, Dolev, & Yirmiya, 2009). These results highlight the importance of parental resolution with the child's diagnosis, suggesting that emotions and cognitions associated with the diagnosis are potential areas of intervention. Acceptance has also been identified as a protective response in mothers, where it was associated with lower depressive symptoms over-time (Da Paz, Siegel, Coccia, & Epel, 2018).

Further research examining parents' experiences during diagnosis and forward planning has highlighted that this process is extremely stressful (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010), with some parents showing increased levels of despair and self-blame that lead to worsening of mental health and life satisfaction (Da Paz et al., 2018). The stress identified during this period may also contribute to parents' difficulties in reaching a resolution with the diagnosis. Keenan et al. (2010) explored families' diagnostic experiences via a mixed-methods approach of questionnaires and focus groups. Parents reported that the diagnostic process was prolonged, with future planning rarely including their input. This period was described as distressing, unclear, and difficult to understand, leading to uncertainty about how to proceed post-diagnosis.

Despite prior studies on parents' experiences of an autism diagnosis (Abbott et al., 2012; Crane et al., 2016; Midence & O'Neill, 1999; Woodgate et al., 2008), very little research has directly examined the lived experience and needs of parents of very young children (< 36 months), soon after an early diagnosis. This is particularly important as many professionals report that these parents may not be ready to hear that their young child has autism, and commonly delay the diagnosis (Ward, Sullivan, & Gilmore, 2016), subsequently leading to delayed access to early intervention and potentially diminishing the possibility of positive developmental gains (MacDonald et al., 2014). Qualitative research is essential to understand, firsthand, the experience of parents prior to developing programs that target their needs. Literature to date has highlighted the gaps that exist between 'diagnosis' and 'intervention', and the absence of a clear pathway post-diagnosis. By examining parents' experiences who receive a child's early diagnosis we may be better positioned to close this gap. Therefore, the aims of the current study were twofold; firstly, to examine parental experiences and support needs soon after receiving a child's early diagnosis of ASD (within 24 months) when aged < 36 months-of-age. Secondly, by identifying these needs, we aimed to gain the knowledge and understanding required to develop appropriate interventions to support parents post-diagnosis. In using a qualitative framework, we aimed to capture and understand the needs of parents at a time when they are highly vulnerable, and to identify any barriers encountered on their journey from diagnosis through to early intervention, and beyond.

2. Method

2.1. Participants

Thirteen parents (10 mothers, three fathers) of children diagnosed with ASD were recruited from a larger research project entitled Social Attention and Communication Study - Revised (SACS-R). An email invitation was sent to 49 parents of children diagnosed within the last 24 months, who had previously granted permission to be contacted for future research studies; children were all 36 months of age or younger at the time of diagnosis. Twenty-eight (57%) families who expressed interest in participation were provided with detailed information about the study; thirteen (46%) participated in the focus group/interviews.

Four participants attended a face-to-face focus group, two being a couple. The remaining nine who did not attend the focus group participated in individual semi-structured phone interviews.

2.1.1. Demographics

All parents received their child's diagnosis between 7 and 20 months prior to their participation. All children were diagnosed at ≤ 31 months of age. There was a broad age range of parents. However, the sample was somewhat limited in diversity as most parents were married and of Australian ethnicity. Despite the small sample size, several other ethnicities were also represented in our population, reflecting the cultural diversity of Melbourne, Australia. Although 38% of participants did not indicate their financial situation, the majority (62%) had a diverse range of household income from AUD$55,000-75,000 through to over AUD$175,000 per annum (Table 1).

2.2. Materials and design

A qualitative study design was used with convenience sampling of participants. An initial list of themes was identified from the literature as applicable to the current research, including reaction to diagnosis, coping, support, knowledge, and understanding of autism. A 'moderator guide' was created for the focus group and interviews, with the objective of informing the development of a family support program. Twenty questions were developed to elicit information about parental experiences and key needs post-diagnosis; Table 2 lists example questions (see Appendix for complete list of questions). The first author (ASR) facilitated the focus group and conducted all individual interviews to ensure consistency.

Table 1
Parent characteristics.

N	13 (10 mothers; 3 fathers)
Mean age (SD)	37 years (6) Range 27 – 46 years
Marital status	Married = 12, Domestic Partnership = 1
Ethnicity	Australian = 8, Assyrian = 2, Indian = 1, Palestinian = 1, Iraqi = 1
Mean time elapsed since child's diagnosis	13 months (5) Range 7 – 20 months
Child's diagnosis	ASD = 8%, ASD & LD = 54%, ASD & GDD = 38%
Child mean age (SD) at diagnosis	23 months (5) Range 17 – 31 months
Child gender (female: male)	4:9
Household income	$55,000 – 75,000 = 23% $95,000 – 115,000 = 15% $115,000 – 135,000 = 8% $135,000 – 155,000 = 8% Over $175,000 = 8% No response = 38%

Key: *M* = Mean, *SD* = Standard Deviation, ASD = Autism Spectrum Disorder, LD = Language Delay, GDD = Global Developmental Delay.

Table 2
Examples of focus group/interview questions.

Thinking back: What was the most difficult thing to deal with after your child's diagnosis of ASD? [a]
How did you deal with the diagnosis?
Self-care: How have you been caring for yourself since receiving your child's diagnosis?[a]
Sharing: When did you first talk about the diagnosis?[a]
What is the greatest challenge facing parents after they receive their child's diagnosis today? What should we do about it?
What would you recommend to parents going through this process now?
In an ideal world what should be provided to families after they receive their child's diagnosis?

[a] Prompts used related to parent response to the initial question and ensuing discussion.

2.3. Procedure

Ethics approval was obtained from the University Human Ethics Committee. The focus group was conducted at La Trobe University in a secure, private room to ensure confidentiality. It comprised a single session that lasted 1 h and 42 min, with an individual facilitator (ASR) and note taker. Nine individual phone interviews were conducted in a secure, private office and lasted between 27 to 47 min. An Olympus WS-450 s digital voice recorder was used to record these sessions, following informed consent.

Two independent researchers transcribed the audio recordings, one of whom was also trained in NVivo10 software (QSR International 2014), used to analyse the data. The digital recordings were then analysed by ASR and a research assistant (RA).

2.4. Data analysis

During transcription, filler words, such as “um”, “I guess”, and “you know”, were eliminated to aid reading fluency and data analysis (Cai & Richdale, 2015). Prior to analysis, transcriptions were cross-referenced by the facilitator for accuracy, and inconsistencies corrected.

An inductive approach to content analysis was adopted as an efficient process that produces results to address specific objectives and questions (Raspa et al., 2015; Thomas, 2006) with raw data coded, categorised, and key themes identified. A framework was developed based on the themes, and processes identified during coding. The aim was to produce three to eight summary categories that capture, and are assessed to be, the most important themes arising from the raw data (Thomas, 2006).

The 20 questions within the *Moderator Guide* were used to categorise the data prior to coding. ASR and RA independently coded three transcripts to establish interrater reliability (Raspa et al., 2015), with at least 80% agreement achieved on all codes prior to further coding. The coded transcripts were reviewed, and data categorised into themes. Following the initial coding iteration, a revised list of themes was identified, where some were added with others removed. ASR and RA reviewed the themes and consulted with each other, and a second iteration of coding was conducted by organising information into sub-themes to refine the data and identify key themes. Each theme was systematically assessed to determine the extent to which it accounted for participants' experiences. Themes were added or removed to best fit the data and to reduce overlap and redundancy, with any differences resolved through discussion (Cai & Richdale, 2015; Thomas, 2006).

3. Results

3.1. Focus group and interviews

A total of four key themes and 15 sub-themes emerged to account for parents' experiences following their child's diagnosis. A framework was constructed based on these themes; a thematic map illustrates the key findings in Fig. 1 (Braun & Clarke, 2006).

The four themes related to participants': (a) emotional response to diagnosis, (b) ability to manage their uncertainty post-diagnosis, (c) resourcefulness, and (d) experiences of sharing the diagnosis are displayed in Fig. 1. The key themes and sub-themes are presented under each sub-heading using the participants' own words (with pseudonyms used to maintain anonymity). A complete list of parents' experiences is presented in Table 3.

3.1.1. Emotional experiences following diagnosis

Parents reported a range of emotions following their child's diagnosis. Through exploring the nature of these emotional experiences, several key sub-groupings emerged: (a) overwhelmed; (b) low mood/sadness; (c) shock/denial; and (d) acceptance, with ‘overwhelmed’ being reported by the majority (66%) of participants.

Thalia, mother of four, whose youngest child was diagnosed at 18 months, described the influx of information: “*I felt I got a bit overwhelmed with all the paperwork and pamphlets and I'll be honest, I didn't read anything. Because, I just didn't want to read.*”

Similarly, Khalid stated “*I was probably very overwhelmed with the whole… situation, …it basically set in stone that there was something…different about our child.*”

Lucia, whose son was diagnosed at 20 months of age, reported “*This overwhelming sense of…I don't want to say helplessness but, kind of like your brain is over-loaded and you can't see the wood from the trees.*” Father of two, Patrick, described the lack of direction as “A hundred rooms with a hundred doors with no key and no signs on any of the doors. You've got to work out how to get out.”

‘Low mood’ was frequently reported, but described in different ways, including “*upsetting”, “mourning”, “very teary”, “didn't want to do anything”, “depressed”, and “angry*”.

Acceptance was another common theme. Thalia described her challenge with acceptance: “*I just found it very difficult to accept the diagnosis, I didn't want to accept it initially. I… couldn't cope well with the decision, I was very emotional about it.*” Fatima, whose child was diagnosed at 2 years, explained the denial that was evident in her family: “*I didn't want to believe that he was autistic. And my Mum didn't believe it, everyone would say he's alright, he's just a bit funny or he's just a bit slow. You make excuses for your child. Or you try to put it down to something else.*”

3.1.2. Managing the uncertainty following a child's diagnosis

Fear of the unknown and an uncertain future was the source of much distress and anxiety for many parents. Sarah, whose daughter was diagnosed soon after she turned two, explained the lack of control felt over her daughter's future and the strategy she used to manage the uncertainty:

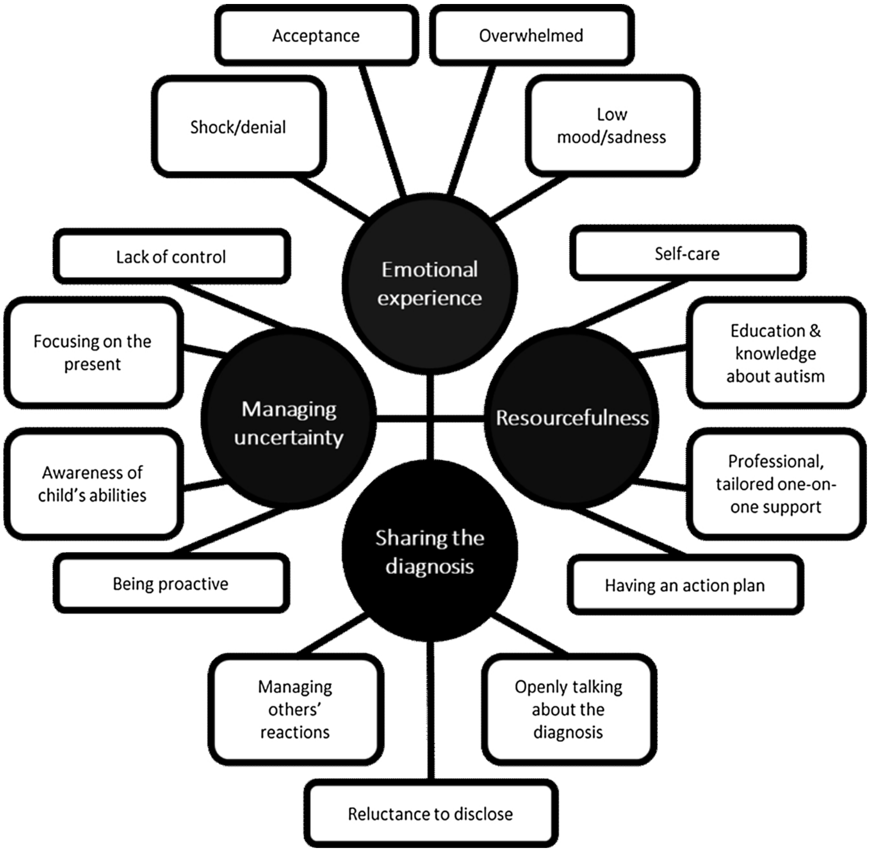

Fig. 1. Thematic map of parental experiences post-diagnosis.

> *"For me…it was the not knowing…is my child going to have an intellectual disability, is my child going to be able to SPEAK, is my child going to be able to attend school…at first that's all I could think of. It just made me come up with a thousand different questions that no one can answer because….we don't KNOW yet, whereas now, a year and a bit later…we're just taking one step at a time…let's deal with today."*

Fatima explained "*We both felt quite devastated initially, thinking just how am I going to live through this, day to day, and my partner was probably more worrying about the future*." Lucia echoed this uncertainty "*…what to do next. That whole thing of what do I do. And if someone can tell you what you should be doing then that would make life a lot simpler because then you don't have to think. You can't think, everything is so overwhelming, and you're not just looking now you're looking twenty years down the line…*"

3.1.3. Being resourceful post-diagnosis

Parents identified positive strategies and resources for coping post-diagnosis. The sub-themes that emerged included: 1) education and knowledge about ASD, 2) professional support, 3) self-care and 4) organising an action plan.

Lucia focused on what can be done. She was very practical and proactive in her coping style: "*okay, I can't do anything about the diagnosis, but I CAN do something about this. And it's quite cathartic, even just making a list and then being able to check things off the list…*"

Sarah found that educating herself about autism was helpful, *"I knew about* Amaze (key autism organisation) *so I automatically went to* their *website. And they've got videos, so I found that really useful. I didn't get too carried away with my research but, we did some research."* She highlighted that *"it was a combination of research and having some sort of plan"* that was most helpful to her and her partner.

Alana, mother of a 3-year-old girl said that despite being provided with information, she felt a person to speak to would have been ideal: *"someone that they (parents) can talk to, to guide them through everything. I think someone that sits there and says, "look at this and that" and just guidance and support."* Thalia agreed that parents need to speak to someone after receiving the diagnosis: *"the first step is to make sure that they are okay with the diagnosis because if they're not, they can't go to the next step."* She also said: *"But if they're not (okay with the diagnosis), they need to get help within themselves in knowing that it's going to be okay. They need that reassurance."*

Fatima emphasised the importance of self-care, and the positive impact this had on her wellbeing. She said, "Having time off parenting has been really important. I get two days off a week. They're just school days but that's been REALLY important. So, I've got time to recharge. I do one or two things that make me feel good about myself. Swimming, and I do some yoga as well."

Table 3
Emotional Experiences, Managing Uncertainty, Resourcefulness, Benefits/Difficulties of Sharing the Diagnosis.

Experiences, uncertainty, resourcefulness, sharing	Parents of children with Autism
Emotional response	Shocked Overwhelmed Sad Depressed Relief Perspective shift (optimistic) Acceptance Denial
Managing uncertainty	Readiness of hearing the diagnosis Awareness of child's difficulties Fear of unknown Lack of control Proactive Sought information Sought support Maintaining hope Finding the positives (focusing on what the child can do, not what they cannot)
Resourcefulness	Professional support (case manager) Peer to peer support (other families with similar experience) Family (partnerships, grandparents, siblings) Action plan Education and knowledge about Autism Being re-assured Maintaining a life outside of Autism Self-care Maintaining sense of identity
Benefits/difficulties of sharing diagnosis	Helping parents feel empowered Giving parents tools to advocate for their child Managing disbelief or denial within family/social setting Resilience Looking at direct benefits to self and family (when explaining diagnosis) Managing other's sympathy

3.1.4. Sharing the diagnosis

The importance of disclosure and discussing the diagnosis with others was a common theme. Fatima explained how she and her partner dealt with this: *"Yeah we're both pretty open with how we feel, we don't tend to hold these things. We told the neighbour pretty soon after because she works with autistic children, so we told her and had a chat with her about a week or so after the diagnosis about what we should do."*

In contrast, Lucia discussed her difficulty with sharing the diagnosis: "I need you to support me in supporting him to get through this. So, knowing how to speak to the people who care about you and who care about your child…to know what to say to people so you can deal with their denial? Because you've worked through yours, you've got the diagnosis, and then it's like you've got to go around and CONVINCE people who don't want to know because they want everything to be okay."

Managing others' disbelief or denial in family/social settings was identified as a sub-theme. Rajit's only daughter was diagnosed at 20 months of age; his family found it difficult to comprehend. Most of his extended family lives overseas so he and his wife only had each other. With few friends in Australia, they were only able to turn to their doctor and their parents overseas. When asked about sharing the diagnosis he said, *"we didn't speak to anybody else except our doctor and mother in law."* He also spoke about other people's reluctance to accept the diagnosis: *"If they accept then it is good, but sometimes they don't believe, they don't accept what the professional is saying, they're thinking no no no, they're just professionals who want to say these words."*

4. Discussion

The current study aimed to understand the experiences and needs of parents whose young children (< 36 months) received a diagnosis of ASD within the last 2-years to inform the development of appropriate and timely supports for these families. Thirteen parents willingly shared their stories. After receiving their child's diagnosis, many of these families felt "left in the dark" to discover what might be best for them. Similar to past research (Woodgate et al., 2008), the current reports suggest that a collaborative partnership between parents and empathic professionals is important. Our findings showed that parents are seeking education and knowledge about autism and professional support that is tailored to their individual needs. This support may be what some families require at this vulnerable time to instill confidence and engender a feeling of competence in their ability to tackle what lies ahead. Parents identified a need for a streamlined approach post-diagnosis. Specifically, access to one key person who assisted in clarifying concerns, providing direction, and generally debriefing with them about the diagnosis would have been beneficial.

Although Woodgate et al. (2008) examined parents' experiences prior, during and after their child's diagnosis, they relied on retrospective accounts where parents may have received their child's ASD diagnosis up to six years prior to the interviews. Further to this, as we move toward earlier detection and diagnosis of autism (Barbaro & Dissanayake, 2010; Clark et al., 2017), it is important to better understand this unique population of parents, so we are equipped to provide better support that may positively impact the child and family's future. For example, if parents understand autism and feel reassured at the time of diagnosis this may help them begin early intervention sooner. Since no prior studies have examined this young cohort (< 36 months), it was important to ascertain the influence of an early autism diagnosis on parents, to ensure we are adequately addressing their needs.

A recent study that examined practitioner's views of assessment and diagnosis of autism found that the majority (92%) of clinicians prefer to "watch and wait" rather than provide a diagnosis (Ward et al., 2016), particularly when children are very young. This is one of the fundamental reasons behind later diagnosis (Ward et al., 2016). As some professionals remain hesitant to diagnose, parents are left waiting and wondering what to do, which may contribute to further uncertainty, delays to early intervention, and subsequently increased parenting stress. Diagnosticians need to be better equipped to deliver an autism diagnosis confidently with sensitivity and compassion at an early age.

4.1. Emotional response

Consistent with the findings from Abbott et al. (2012) and McGrew and Keyes (2014), parents in the current study identified that receiving an early diagnosis had a significant emotional impact at the time and afterwards. The construct acceptance, also known as resolution with the diagnosis, has been found to positively impact parent-child relationships (Wachtel & Carter, 2008), making it an ideal target for parent and/or family-based interventions.

Adding to previous research (Crane et al., 2016; Poslawsky, Naber, Van Daalen, & Van Engeland, 2014; Woodgate et al., 2008), parents in this study reported that the "emotional aftermath" from a diagnosis served to prevent them moving forward due to their sense of helplessness, and a seeming lack of validation from close family members. Although some parents described naturally falling into a 'mourning' period, others were ambivalent about the diagnosis, shifting between denial and acceptance. On face value, the emotional responses described in the present study can be compared to the stages of grief (Kübler-Ross, 1969). Recent studies by Fernańdez-Alcántara et al. (2016) and Wayment and Brookshire (2017) investigated feelings of grief, loss and general distress in parents following their child's later diagnosis of ASD (mean age at diagnosis = 8 and 11 years, respectively). Grief reactions were found to be positively associated with perceiving autism as an unexpected loss, and as unjust. Consistent with prior research, the current study revealed that parents' who receive a child's early diagnosis respond with a similar grief reaction to parents of children who receive a later diagnosis, including feelings of shock, negation/denial, fear, anger and/or sadness. Taking this grieving experience into consideration, there is a need for healthcare professionals to acknowledge feelings that may require further referral for family intervention to ease the grieving process.

Although parents of children with a disability are expected to grieve, they are at the same time reluctant to articulate their loss, with a pressure to protect others from the real lived, emotional experience (Broberg, 2011). Overall, participants' responses in the current study indicated that there is no "one size fits all" approach to post-diagnostic support. This study adds to the current literature by identifying important clinical implications for the delivery of an ASD diagnosis and the support that follows. It appears that a greater emphasis should be placed on dealing with and managing emotions rather than providing families with an influx of information that they find difficult to process at this time. Indeed, parents reported that too much information was detrimental rather than beneficial, as intended.

4.2. Managing uncertainty

Unlike other diagnoses, where there is often a distinct treatment or intervention pathway (e.g., diabetes), a diagnosis of ASD does not come with a clear intervention plan, making it even more difficult for families to cope. Instead, parents are left with many unanswered questions, which naturally gives rise to uncertainty about their child's future, and subsequently becomes a major source of distress and anxiety.

Participants consistently described their uncertainty about the *future* and reflected, retrospectively, on the negative impact this uncertainty had on their day-to-day living, and for some, continues to do so. However, due to the inherent heterogeneity of autism, it is often difficult for professionals to provide clear pathways and specific prognostic information to ease parents' concerns about the future. This inability to prospectively plan clearly has an adverse effect on families, which needs to be sensitively managed. In worrying about the distant future, parents miss the opportunity to learn and understand their child's diagnosis and current presentation, which can limit their progress towards planning intervention. Similar to previous research (Keenan et al., 2010), our findings showed that the mere thought of planning was enough to create extreme anguish for parents.

Among the key factors that influenced a parent's ability to manage uncertainty, 'focusing on the present' was described as the most beneficial, presenting important insight into parents' coping at this vulnerable time. Other factors included understanding a child's strengths and difficulties and focusing on the "here and now". The 'lack of control' associated with their child's diagnosis was also identified by parents as having a substantial impact on their ability to manage the situation, which subsequently affected their anxiety, mood, and their ability to be proactive. Similar to Woodgate et al. (2008), parents identified that maintaining a sense of routine in family life assisted in their coping. For example, making small progress (i.e., booking appointments) elicited a *proactive* feeling. By helping parents create a 'sense of control' their feelings of 'lack of control' can be managed.

Important clinical implications can be drawn from these findings. Perhaps if practitioners and service providers managed parents' expectations and made realistic plans together with families some of the distress brought about by uncertainty may be alleviated.

Furthermore, implementing mindfulness into family-based interventions may help ease parents' anxieties about the future by teaching them strategies to stay in the present (Shapiro, Carlson, Astin, & Freedman, 2006). Encouraging parents to focus on the present and empowering them in their parenting role may further assist in achieving healthy adaptation for themselves and family.

4.3. Resourcefulness

Despite significant emotional distress, and high levels of uncertainty, it was evident that the combination of seeking information and having an 'action plan' had a positive impact on parents' coping and emotional wellbeing in the current sample. However, it is important to acknowledge that significant health disparities continue to exist in access to ASD services (Liptak et al., 2008; Pickard & Ingersoll, 2016), and that resourcefulness may therefore be limited by the very resources available to families at this time. This finding provides critical insight into the role professionals may play in supporting families to seek help, information and plan- ahead based on their individual and unique circumstances. Similar to previous literature (Abbott et al., 2012; Pottie & Ingram, 2008) with children who were older at the time of diagnosis (8–15 years old), participants in the current study also stressed the importance of talking to someone after receiving their child's diagnosis. They described this person as an individual who understood autism, but who also empathised with parents and could reassure them about the future. This opportunity to debrief in a non-judgmental, safe, and warm environment was one that many parents felt would have been ideal in retrospect. Based on these findings, important considerations for clinical practice can be drawn. Specifically, family support programs that target the diagnostic period may benefit from utilising a case worker or peer-support worker to reassure parents and provide them with an opportunity to debrief post-diagnosis.

Another crucial factor that is often underestimated is self-care; a unique finding identified in the current study. Mothers and fathers agreed that 'time off' parenting was important to their overall wellbeing; describing it as an opportunity to 'recharge'. This notion of recharging not only impacts on the parent's wellbeing, but the entire family. Self-care is an important construct associated with overall wellbeing; however, to date little research has examined the impact of self-care on parents of children on the autism spectrum. Future studies exploring self-care in parents of children on the spectrum may provide researchers and clinicians, alike, with greater insight into its benefits and possible role as a protective factor to parents' mental health. Using a qualitative methodology can be helpful in identifying previously unidentified themes that may assist in providing more targeted family support.

The identified theme of 'resourcefulness' provides insight into parents' current coping strategies, but also highlights avenues of support that should be further explored. The sub-themes (a. self-care, b. education and knowledge, c. professional tailored support, and d. having an action plan) suggest potential intervention pathways to assist parents in forward planning.

4.4. Sharing the diagnosis

'Sharing the diagnosis' emerged as a fundamental part of the post-diagnosis journey. This process may be more acute for families of very young children as symptoms are often subtle, with fewer co-morbid issues apparent, and less time for others to notice them. For some participants, it was a relatively straightforward process, perhaps due to being more accepting of the diagnosis initially, or because they had already considered the possibility of autism prior to diagnosis. For others, it marked a very difficult time; this may have been because they did not understand autism, they were still processing what a diagnosis meant, or they may have been in denial or shock. The process of disclosure was expressed as a significant hurdle, but once overcome led to understanding, knowledge, and support. Watermeyer (2009) suggests that it can be difficult to reach self-acceptance and integration of one's own unpleasant and painful experiences if you are not able to disclose, examine and share these experiences with others. This may be true in the case of autism, where lack of disclosure may then limit a family's acceptance of the diagnosis. The difficulty in sharing the diagnosis not only affected parents individually but also impacted on their social and family life, suggesting that this may be one of the earliest periods of isolation that parents experience. This finding signifies that the time of diagnosis is one of 'crisis', but also opportunity, representing a critical time for intervention, including social support. As other studies have noted (Woodgate et al., 2008), social isolation can have detrimental effects, leaving parents with a diminished sense of hope.

Managing others' disbelief was cause for much family frustration, as parents had to not only manage their own distress but become advocates for autism overnight. Talking about it with family members who themselves were ambivalent and trying to gain support was a difficult task. Some parents explained that they had to 'convince' others of their young child's diagnosis, or try and justify it, whilst simultaneously processing the diagnosis themselves. Previous research (Poslawsky et al., 2014) has found that parents are generally capable of adapting to the challenges of raising a child on the autism spectrum using social (i.e., family and community) support as an effective coping strategy. However, what happens when in sharing the diagnosis, families are instead faced with denial and disbelief from their support network? Establishing compassionate, caring, and understanding social support post-diagnosis is important. With specific guidance from professionals, parents can be empowered to make decisions around who (i.e., friend, cousin, neighbour) can best support them after their child's diagnosis and how best to share the diagnosis.

Given the opportunity to discuss, disclose and debrief in a supported and nurturing environment, parents can be assisted to overcome some of the initial obstacles associated with the new-found diagnosis. Through this process they can become confident in their own understanding of autism, and the next steps to accessing support may become easier.

5. Future directions

The current study was conducted, as a first step, to inform the development of a tailored 'Family Support Program' for parents of young children post-diagnosis. As early detection of autism becomes more prevalent, we need to ensure that this unique and vulnerable population of parents is well-supported post-diagnosis.

Research has shown that a delayed diagnosis means a delay in access to interventions and supports, leading to a decline in family quality of life and general wellbeing (Howlin & Asgharian, 1999; Keenan et al., 2010). On the other hand, research on early identification and diagnosis has identified better outcomes for children (Clark et al., 2017) and their families. Taking into account prior literature (Abbott et al., 2012; Woodgate et al., 2008), similarities between parents' experiences of an early autism diagnosis can be drawn to parents' experiences of a later diagnosis. However, despite this fact when families reflected on their experiences of diagnosis, it was clear that they preferred to receive a diagnosis as early as possible to implement interventions and therefore optimise their child's developmental outcomes (Howlin & Asgharian, 1999).

Based on the current accounts, and literature to date, the time of diagnosis *feels* like a crisis period. Implementing a "crisis intervention" model may be useful to ease parents' fears and provide them with immediate and acute support post-diagnosis. Fortier and Wanlass (1984) proposed a five-stage model (Impact, Denial, Grief, Focusing Outward, and Closure) of crisis intervention with the aim of understanding how family members progress through crisis resolution after receiving a child's diagnosis of a disability. This model shares similarities with the well-known Kübler-Ross (1969) grief model. Fortier and Wanlass (1984) noted that each family members unique reaction to the crisis affects the response of other family members, which has important implications for the way that we deliver support: that is, who receives it, how is it shared, and what discussions follow. One of the most important steps may be provision of a good listener; parents need a chance to verbalise their feelings to disentangle the cognitive and emotional confusion that comes with receiving a child's diagnosis. Following this, they can discuss their child's needs and discover solutions on how to address them. Based on our findings, we can see that managing uncertainty post-diagnosis is a challenge for parents; clinical practice would benefit from future studies that examine the possible association between uncertainty and parenting stress following a child's diagnosis, and the potential mediators that may prevent parents from developing further anxiety and distress at this time. Furthermore, we suggest future research explore the relationship between feeling 'emotionally overwhelmed' post-diagnosis versus feeling 'emotionally acceptant' of the diagnosis, as this may provide us with a greater understanding about the factors contributing to family resilience and wellbeing.

Provision of tailored family support in a timely manner offers parents the opportunity to discuss their child's diagnosis and their own emotional response to it, whilst also having their questions answered. A recent study emphasised the importance of the diagnostic consultation; parents want specific, easily comprehensible information that can be conveyed in a single consultation (Hennel et al., 2016). The challenge faced by professionals is how to provide this in an effective and efficient manner. Hennel et al. (2016) suggested professionals develop a tailored 'autism action plan' with written materials to improve parents' understanding of and satisfaction with their child's diagnosis. However, it is important to note that a 'written autism action plan' may not be helpful to all families. For example, a family where parents have low health literacy may not have the same ability as other families to gain access to, understand, and use information in ways which promote and maintain good health (Talbot & Verrinder, 2017). Therefore, we have a challenge here to contest current practices and deliver tailored support that addresses individualised needs and capabilities. In this instance, it may be that the 'autism action plan' is delivered and described in an alternative format (i.e., audio, visual, online, 'in-person') with an empathic and supportive individual (i.e., case worker, peer-support worker).

6. Limitations

Although the present study offers rich qualitative description of parental experiences through use of their *own words*, it is not without its limitations. Given the qualitative nature of the data presented, it is important to acknowledge that with a reduced sample size the claims cannot be widely generalised, as the findings are limited to the experiences of those parents who participated in this study. As the sample only included parents who received their child's diagnosis within the last 24 months this limited our population by excluding potential participants who may have received their child's diagnosis more than 2 years ago. However, this timeframe was selected for recency to diagnosis, such that participants would have more accurate recollection of their experiences; with questions focused on the 'time of diagnosis', regardless of time lapsed. A further limitation is the differential data collection methods (i.e., focus group vs. interviews) used to accommodate participants. Specifically, results from a focus group may not equate with information gained in individual interviews. However, inter-rater reliability was utilised to ensure consistent thematic analysis across the sample population, regardless of the qualitative method used for data collection.

7. Conclusions and implications

The current findings confirm and extend those in the previous literature by providing further insight and awareness of families' experiences following a young child's diagnosis of autism. Through qualitative data analysis, participants' key concerns and needs were extracted, which led to a description of four overarching themes: 1) the emotional impact of diagnosis, 2) managing uncertainty, 3) being resourceful, and 4) sharing the diagnosis. Qualitative research studies, such as this, provide fundamental steps to understanding parents' experiences by listening to their voices directly. Consideration should be given to the important implications that can be drawn from this research, which are particularly useful to inform professionals in their delivery of diagnosis. Although an 'autism action plan' with tailored written materials may be beneficial (Hennel et al., 2016), support may be further enhanced by professionals providing or referring the family for an individualised crisis counselling session to address their specific support and intervention needs, identify next steps and, in turn, reduce parent distress.

The understanding gained from this study will have a pivotal role in informing the diagnostic process and the development of appropriate resources for parents of newly diagnosed children. With this additional knowledge and awareness, professionals can develop a more compassionate approach to delivery of diagnosis; they can provide families with information on how best to disclose the diagnosis, and examine and share their experiences with the goal of helping them reach self-acceptance (Poslawsky et al., 2014; Watermeyer, 2009; Woodgate et al., 2008). Without listening to the voice of those with a lived experience, we can only speculate what supports and services are required.

Ethics approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This article does not contain any studies with animals performed by any of the authors.

Informed consent

Informed consent was obtained from all participants included in the study.

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