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## REVIEW

# Experiences of fathers regarding the diagnosis of their child with autism spectrum disorder: A narrative review of the international research

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## Abstract

**Aim and objectives:** The aim of this systematic review was to identify the views and experiences of fathers regarding their child's Autism Spectrum Disorder diagnosis.

**Background:** The diagnosis of a child's Autism Spectrum Disorder may be a stressful experience, creating uncertainty for parents. There has been a limited research focus on the views and experiences of fathers in relation to the diagnosis of Autism Spectrum Disorder of their child.

**Design:** A systematic literature review of quantitative, qualitative and mixed-methods research studies.

**Data Sources:** Academic Search Complete, CINAHL, MEDLINE and PsycINFO.

**Methods:** From August to October 2020, two authors independently performed a systematic data extraction and appraised the studies using a recognised instrument. The PRISMA checklist was used in the review.

**Results:** Nine papers met the inclusion criteria. Four themes emerged: (a) gradual recognition of developmental delay, (b) an emotional time, (c) coping and adaptation and (d) ongoing adjustments to the fathering role.

**Conclusions:** Nurses and other professionals need to work collaboratively with fathers to improve their experiences and provide supports at the time of Autism Spectrum Disorder diagnosis.

## KEYWORDS

ASD, autism spectrum disorder, diagnosis, fathers, nurses, support, systematic review

## What does this paper contribute to the wider global clinical community?

This study highlights the importance of a recognising and responding to the specific needs of fathers of children with ASD during the diagnostic process.

- The diagnostic process can be a stressful and emotional time for many fathers with their needs and concerns often overlooked by nurses and other health professionals.
- Fathers want access to nurses and health professionals who are knowledgeable about ASD and the future prognosis and sensitive to their specific needs and concerns.

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- Nurses and other health professionals require access to education and practice development that enhances their knowledge regarding the distinct needs of fathers of children with ASD. Fathers need to be afforded the opportunity to discuss their needs and concerns when an ASD diagnosis is confirmed.

## 1 | INTRODUCTION

Autism Spectrum Disorder (ASD) is a common, lifelong neurodevelopmental disability which affects how individuals communicate and interact with the world. It is an umbrella term used to describe the presentation of a core set of features including persistent deficits of social communication and interaction, restricted and repetitive behaviours, activities and interests (American Psychiatric Association, 2013). The World Health Organisation reports that globally, one in 160 children has an ASD, while highlighting that prevalence rates vary across studies (World Health Organization, 2013). Research evidence shows a higher prevalence of ASD in boys than girls by a ratio of three to one (Christensen et al., 2018). The specific cause of ASD remains unknown; however, genetic and environmental factors are thought to play a significant part (Hiremath et al., 2021; Loomes et al., 2017).

ASD is generally diagnosed in childhood during the first 5 years of life and includes developmental, behavioural and family history, with a number of diagnostic tools available to assist. These include the *Diagnostic Interview for Social and Communication Disorders* (DISCO), *Autism Diagnostic Interview-Revised* (ADI-R) and the *Autism Diagnostic Observation Schedule* (ADOS) (Brian et al., 2019). Some children do not receive an ASD diagnosis until school age or later, due to inconsistency of assessment, misdiagnosis of other conditions such as Attention Deficit Hyperactivity Disorder (ADHD) or Pervasive Developmental Disorders (PDD) (Centre for Disease Control & Prevention, 2015). Parents reported receiving the ASD diagnosis from a range of healthcare professionals including paediatricians, psychologists, child psychologist and other multidisciplinary team members (Crane et al., 2016). Additionally, other conditions such as epilepsy and sensory impairments may delay parents from accessing diagnostic services due to a lack of knowledge and awareness of the ASD (Ghaderi & Watson, 2019). Early diagnosis of ASD is important to enable access to psychoeducation, information, services, additional education and life skill supports and to facilitate referrals to agencies such as speech and language therapy and education and clinical psychology (Kim et al., 2020; Martinez et al., 2018).

To date, much of the research undertaken has focused on the views and experiences of mothers and fathers as co-parents and mothers of children with ASD (Jackson et al., 2020). For many parents, having a child with ASD is a life-enhancing and positive experience (Keenan et al., 2010). A recent systematic review reported the effects of parenting a child with ASD, including, avoidance strategies and less use of social supports, with a need for problem-focused coping to reduce stress and enhance quality of life (Vernhet et al.,

2019). Another systematic review identified lengthy delays experienced by some parents in obtaining an ASD assessment and diagnosis, further contributing to their stress and anxiety (Legg & Tickle, 2019). The review also identified that mothers and fathers reported using problem-focused coping strategies, participating in 'me time' activities, and avoiding stressors as a way to cope with their parenting role of their child with ASD. Traditional gender roles may be an important issue in developing the understanding how different coping strategies are used by mothers and fathers (Pepperell et al., 2018; Simelane, 2020).

From the perspective of mothers, many reported positive care giving experiences regarding their child with ASD, such as spending quality time, supporting developmental gains and celebrating new achievements (Corman, 2009). However, the reaction to an ASD diagnosis can have a negative impact on the health and well-being of mothers and the prognosis and developmental progress of the child, with a need to more fully understand the impact of the diagnosis process (Reed & Osborne, 2019). Regarding the care and support of their child with ASD, mothers reported difficulties obtaining a diagnosis, once disclosed resistance to the ASD diagnosis and feeling judged as a result of disability related behaviours perceived by professionals as 'poor' parenting. (Nicholas et al., 2020). In terms of social supports, mothers highlighted the positive benefits of access to formal and informal support, a positive diagnostic experience and access to information about ASD (McIntyre & Brown, 2018).

Recent decades have seen many social changes regarding families and the parenting roles of both fathers and mothers. Despite these changes, the primary caring role continues to be undertaken by mothers. The existing evidence regarding parenting of children with ASD has so far focused predominantly on the care experiences of mothers or both mothers and fathers (Legg & Tickle, 2019). There is an evolving evidence-base regarding the involvement of fathers' during the early years of their child's life, their parenting style and ability to adapt to the role of becoming a father and the coping skills and supports required (Marsh et al., 2020). With more fathers taking on the primary caregiver role, it is important to understand their views and experience of being a father of a child with ASD and their specific support requirements (Rankin et al., 2019). A recent systematic review identified that while often overlooked, fathers of young people with ASD can and want to contribute to their development and care of their children, with a need to proactively identify their distinct support needs. There is evolving research evidence of the effects on fathers when parenting their child with ASD, including the impact on their physical and psychological health and well-being, with a need for individualised support and father-focused programmes (Rafferty et al., 2020).

Despite the developing understanding of the needs of parents and mothers of children with ASD, the distinct views and experiences of father, notably at the time of diagnosis, remains to be more fully understood to inform the development and delivery of the supports necessary to meet their specific needs and concerns.

### 1.1 | Aims

The aim of this systematic review was to highlight the views and experiences of fathers regarding their child's Autism Spectrum Disorder (ASD) diagnosis and to identify their care and support needs.

## 2 | METHODS

Before undertaking this systematic review, Cochrane, PROSPERO and Joanna Briggs Databases were checked to identify if a similar topic had already been completed; none were identified. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) was used in the review process (Moher et al., 2015).

### 2.1 | Review objectives

The objectives were to:

- Identify the views and experiences of fathers in relation to their child's ASD diagnosis.
- Evidence the care and support needs of fathers following a diagnosis of their child's ASD.

### 2.2 | Ethics statement

The current study is a systematic review of published research evidence; therefore, ethical approval was not required.

### 2.3 | Search and selection strategy

A subject librarian provided expert guidance with the literature search. From August–October 20th databases searched were Academic Search Complete, CINAHL, MEDLINE and PsycINFO. Search terms used across all databases were *father\**; *diagnos\**; *autism*; *ASD*; *autistic spectrum disorder*. The search criteria included academic journals, papers

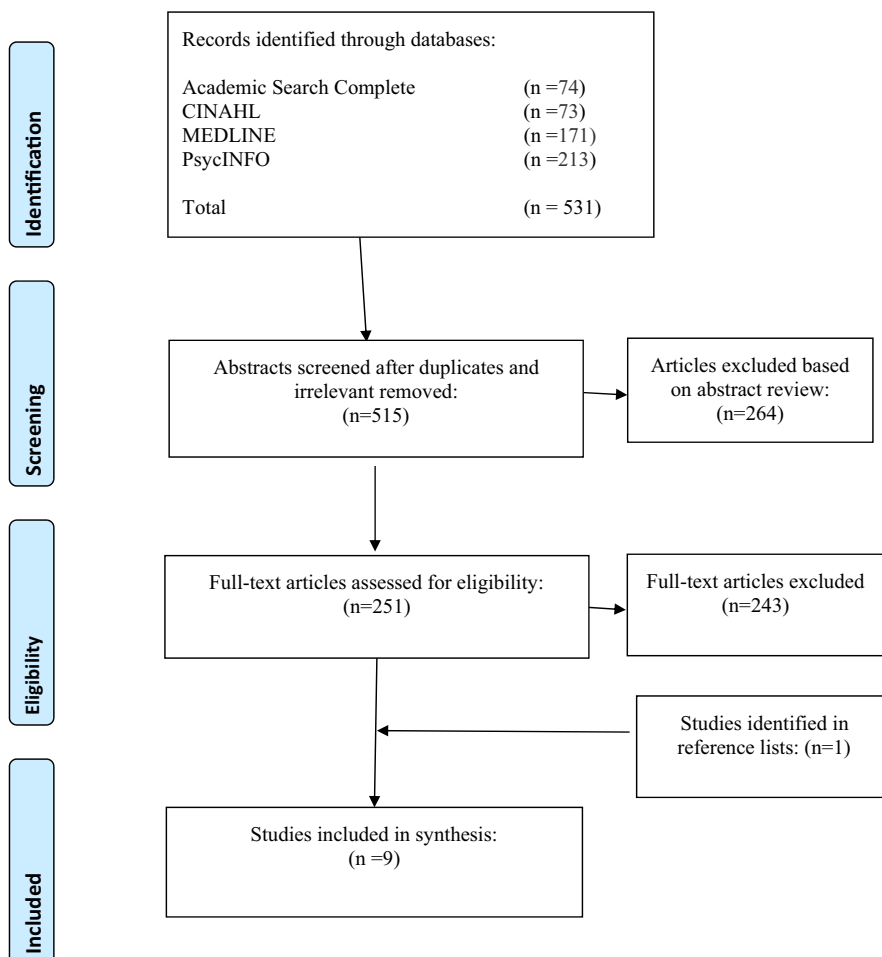


FIGURE 1 PRISMA flow diagram [Colour figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]

written in English and published between January 2000–October 2020. To identify further relevant studies, Google Scholar was used and hand-searching of reference lists undertaken. Studies focusing explicitly on the views and experiences of fathers of children with ASD regarding their diagnosis were included. Studies that used quantitative, qualitative and mixed-methods approaches were considered for inclusion. Studies were excluded that did not make reference to the diagnosis of ASD in relation to fathers of children with ASD. Studies that were not empirical research, were not published in the English language and were grey literature or thesis were excluded. The search results are presented in Figure 1. The PRISMA checklist was used to guide the review process (see Supporting Information File S1).

## 2.4 | Data extraction and synthesis

Data were extracted by author and country, study aim, participants, data collection method, key findings and recommendations. The data were thematically analysed across the emergent themes to identify the key issues and concerns. The review process was facilitated by the use of Covidence (Veritas Health Innovation, 2020). The data were verified by the research team through a process of comprehensive analysis and coding. To enable comparisons and differences to be identified between and across the studies, the emerging concepts were grouped into themes. The research team agreed and verified the final themes to minimise the potential for bias (Terry et al., 2017).

## 2.5 | Quality assessment

The papers included in the review were evaluated using the *Critical Appraisal Skills Process* (CASP; Critical Appraisal Skills Programme, 2013). They were assessed independently by each author in terms of relevance to the inclusion criteria and aims of the review. Studies were critically appraised against the ten CASP questions and allocated a score of 0, 1 or 2; a maximum score of twenty points could be achieved. The quality appraisal of the studies is presented in Table 1. Questions were scored zero if no details were provided, one if some information was provided and two if evidence was provided in full (Rushbrooke et al., 2014). All studies included in the review were deemed to be of high-quality with a score of 17 and above achieved. Two studies scored 17 and 18, six studies 19, with the remaining achieving a maximum score of 20. Reasons for not achieving the maximum scores across studies related to research relationships not being explicit and the rigour of the data analysis.

## 3 | RESULTS

### 3.1 | Characteristics of the studies

The characteristics of the included 9 studies that addressed the study aims are presented in Table 2. Studies were conducted in Australia ( $n = 1$ ), Canada ( $n = 1$ ), Ireland ( $n = 1$ ), Israel ( $n = 1$ ), the

TABLE 1 CASP quality scores

CASP criteria	Burrell et al., (2017)	Cheuk and Lashewicz (2016)	Hannon and Hannon (2017)	Manor-Binyamini (2019)	O'Halloran et al., (2013)	Paynter et al., (2018)	Pottas and Pedro (2016)	Potter (2017)	Vacca (2013)
1. Clear statement of aims	2	2	2	2	2	2	2	2	2
2. Appropriate methodology	2	2	2	2	2	2	2	2	2
3. Appropriate research design	2	2	2	2	2	2	2	2	2
4. Appropriate recruitment strategy	2	2	2	2	2	2	2	2	2
5. Appropriate data collection methods	2	2	2	2	2	2	2	2	2
6. Research relationships considered	1	0	1	1	2	1	0	1	1
7. Consider ethical issues	2	2	2	2	2	2	2	2	2
8. Rigorous analysis	2	2	2	2	2	2	1	2	2
9. Clear findings	2	2	2	2	2	2	2	2	2
10. Value of the research	2	2	2	2	2	2	2	2	2
Total scores out of 20	19	18	19	19	20	19	17	19	19

TABLE 2 Characteristics of the included studies

Citation and country	Aim	Participants	Data collection method	Key findings	Recommendations
Burrell et al., (2017) UK	Identify fathers' experiences of children with ASD.	Fathers (n = 8) of children aged 8–24 years with ASD	Qualitative: semi-structured interviews	A gradual realisation something was 'wrong' with their child leading to a sense of loss experienced and the need for further support and information.	Engage in discussion with fathers about ASD, perceptions, support services, access, education, with time allowed for deliberation. An increased need for both professional and public awareness of the needs of people with ASD and improved service provision.
Cheuk and Lashewicz (2016) Canada	Examine fathers' experiences of children with ASD and how they compare to their perceptions of fathers of typical developing children.	Fathers (n = 28) of children aged 2–13 years with ASD	Qualitative: semi-structured interviews	Fathers modified their expectations regarding their child, coming to terms with the ASD diagnosis, with a need for education and information.	Further research on the needs of fathers needs with tailored supports provided. Engagement with peer support from fathers with a child diagnosis of ASD. Involve fathers within research, policy and practice initiatives to ensure their needs and concerns are reflected.
Hannon and Hannon (2017) USA	Explore fathers' experiences of the diagnosis of autism in their child.	Fathers (n = 16) of children aged 1.5–36 years with ASD	Qualitative: semi-structured interviews	Healthcare professionals lacked knowledge regarding ASD, resulting in fathers self-educating. Opportunity to educate and support other fathers about ASD and their experiences.	Further research involving different methods and samples including culturally diverse ASD populations to more fully understand the experiences fathers, mothers and siblings' experiences of the assessment and diagnostic process to inform healthcare practice.
Manor-Binyamini (2019) Israel	Examine fathers' experiences of raising children with ASD.	Fathers (n = 19) of children aged 6–15 years with ASD	Qualitative: semi-structured interviews	ASD as a condition was an unfamiliar to many fathers. Fathers had an awareness there was something 'different' with their child. Fathers had to seek out ASD information and wanted access to further education and supports.	An awareness of ASD from a cultural perspective is required, with the need for further research reflecting the range of experiences and essential cultural perspective.
O'Halloran et al., (2013) Ireland	Identify fathers' perceptions of parenting a child with ASD.	Fathers (n = 9) of children aged 9–18 years with ASD	Qualitative: in-depth interviews	Fathers had an awareness there was something 'different' about their child and often experienced lengthy delays in obtaining a diagnosis, with a need for further information and support.	Fathers want their role in their care giving role to be recognised and their concerns and needs addressed. Education and practice development required for healthcare professionals regarding the ASD assessment and diagnostic process.
Paynter et al., (2018) Australia	Identify the experiences of fathers caring for a young child with ASD.	Fathers (n = 18) of children aged 2.5–6 years with ASD	Mixed-methods: survey and interviews	The main source of support comes from partners and within families, with fathers requiring further external support to provide information and support at what can be an emotional time.	Fathers require improved supports and information with a need for policy developments to better support from services. Future research needs to reflect the distinct needs of fathers.

(continues)

TABLE 2 (Continued)

Citation and country	Aim	Participants	Data collection method	Key findings	Recommendations
Pottas and Pedro (2016) South Africa	Identify the experiences of fathers caring for their child with ASD.	Fathers (n = 8) of children aged 5–8 years with ASD	Qualitative: in-depth interviews	The time of ASD assessment and diagnosis is a challenging time for fathers resulting in changing expectations of the fathers, the child and family regarding their futures. Fathers want further information about ASD and the available supports.	Fathers want access to information, support and recognition of their caring role to enable them to meet the needs of their child with ASD.
Potter (2017) UK	Examine the experiences of fathers' regarding a diagnosis of ASD.	Fathers (n = 184) of children aged 11–19 years with ASD	Quantitative: survey	The assessment and diagnosis processes were perceived as 'stressful and emotional' for fathers, with delays in assessments evident and a lack of information and supports specific to their specific needs.	Fathers want access to support specific to their needs and the opportunity to discuss the positive aspects of having a child with ASD.
Vacca (2013) USA	Identify the perspective of fathers regarding the parenting process and ASD.	Fathers (n = 8) of children aged >20 months of age with ASD	Qualitative: semi-structured interviews	The assessment and diagnosis process is a 'stressful and emotional' time for fathers, with a recognition of the lifelong commitment to their child with ASD.	Fathers want to have their parental role recognised and provided with access to support and family-centred services. Future research needs to include a specific focus on fathers of children with ASD and their views and experiences.

United Kingdom (n = 2), South Africa (n = 1) and the United States of America (USA) (n = 2). The samples sizes in these studies ranged from 8 fathers (Burrell et al., 2017; Pottas & Pedro, 2016; Vacca, 2013) to 28 fathers (Cheuk & Lashewicz, 2016), with one study using an online survey involving 184 participant fathers (Potter, 2017).

A range of data collection methods were used including surveys, questionnaires and interviews. A total of seven studies used qualitative methods (Burrell et al., 2017; Cheuk & Lashewicz, 2016; Hannon & Hannon, 2017; Manor-Binyamini, 2019; O'Halloran et al., 2013; Pottas & Pedro, 2016; Vacca, 2013), and one mixed-methods (Paynter et al., 2018), with one part of a larger study reporting an open-ended question regarding ASD (Potter, 2017).

### 3.2 | Data analysis and synthesis

Based on the aim of this review about the experiences of fathers regarding the diagnosis of their child with Autism Spectrum Disorder, four analytical themes were identified and are presented in Table 3. The four themes that emerged following the analysis of the data were (a) gradual recognition of developmental delay (b) emotional time, (c) coping and adaptation and (d) ongoing adjustment to the fathering role.

#### 3.2.1 | Gradual recognition of developmental delay

Across the studies, the 'journey' or 'pathway' into the world of autism for fathers began before the assessment was undertaken and the ASD diagnosis confirmed (Burrell et al., 2017; Manor-Binyamini, 2019; O'Halloran et al., 2013). For some fathers, delays in speech and language and the achievement of other developmental milestones were the first indication that there was a concern about their child (Manor-Binyamini, 2019). For others, the child presented with dietary issues, skin conditions, and asthma, thereby masking an early access to assessment and an accurate diagnosis (O'Halloran et al., 2013). Behavioural difficulties were evident in early childhood and was a concern for some fathers with some seeking to exclude possible physical and sensory causes (Burrell et al., 2017). The absence of a visible disability lead to some delaying consultations with healthcare professionals as they thought the child would 'catch up' once physical or sensory cause was addressed. When physical and sensory health needs were addressed, it was reported in two studies that it took from 3–8 years to obtain a definitive ASD diagnosis (O'Halloran et al., 2013; Potter, 2017). Some fathers reported a misdiagnosis of Attention Deficit Hyperactivity Disorder (ADHD) or Pervasive Developmental Delay (PDD), rather than the ASD diagnosis. Fathers continued to report that '*things were not quite right*' with their child before the diagnosis was confirmed (O'Halloran et al., 2013). The ASD diagnosis was seen as a turning point by changing expectations of their child, their roles and responsibilities as fathers and of being the father of a child with a disability (Pottas & Pedro, 2016).



TABLE 3 Themes identified in each study

Theme	O'Halloran et al., (2013)	Vacca (2013)	Cheuk and Lashewicz (2016)	Pottas and Pedro (2016)	Burrell et al., (2017)	Hannon and Hannon (2017)	Paynter et al., (2018)	Potter (2017)	Manor-Binyamini (2019)
Gradual recognition of developmental delay	YES	-	-	YES	YES	-	-	YES	YES
Emotional time	YES	YES	YES	YES	YES	-	YES	YES	YES
Coping and adaptation	YES	-	YES	YES	YES	YES	YES	YES	YES
Ongoing adjustment to the fathering role	YES	YES	YES	YES	YES	YES	-	-	-

### 3.2.2 | An emotional time

Despite the gradual realisation that their child may have ASD, fathers described receiving the diagnosis as a difficult and emotional time in their lives, equating it to grief and loss of the child they had been expected and prepared for (Burrell et al., 2017; Pottas & Pedro, 2016; Potter, 2017). ASD was not a familiar condition for some fathers, stating they had limited knowledge other than the media portrayal, that was not always viewed as positive (Manor-Binyamini, 2019; O'Halloran et al., 2013). Some fathers described healthcare professionals not discussing the diagnosis and prognosis with them, with a need to provide information in language they could understand (Manor-Binyamini, 2019). It was reported that some health professionals lacked detailed knowledge about ASD and the implications arising from the condition, thereby provoking emotions including denial, confusion, shame and disbelief in some fathers (O'Halloran et al., 2013; Vacca, 2013). For many fathers, a period of adjustment was necessary to come to terms with their child's diagnosis of ASD, necessary to enable them to reflect upon and modify their expectations, hopes and aspirations (Cheuk & Lashewicz, 2016). Fathers in one study undertaken by Potter (2017) described a sense of relief upon receiving the ASD diagnosis, a finding also reported by Vacca (2013) and Paynter et al., (2018), following the initial 'shock' of receiving the diagnosis. For many, the ASD diagnosis confirmed what fathers suspected, thereby allowing time to reframe the expectations of their child and their role as a father by starting to adapt and adjust to their new and changing situation (Burrell et al., 2017; Vacca, 2013).

### 3.2.3 | Coping and adaptation

In terms of coping and adapting to the child's diagnosis of ASD, fathers identified partners, spouses and family members as the most important sources of support (Burrell et al., 2017; Manor-Binyamini, 2019; Paynter et al., 2018; Potter, 2017). Many fathers described feeling ignored by professionals in services, highlighting the view that there were more supports provided for mothers than fathers (Potter, 2017). Fathers also detailed how they struggled with the limited knowledge about and implications of an ASD diagnosis and prognosis by some healthcare professionals (Manor-Binyamini, 2019; Potter, 2017). This was further compounded by a lack of accessible information about ASD supports available and the insensitive way some healthcare professionals disclosed the diagnosis, with an overemphasis on the negative aspects of the condition (Burrell et al., 2017; Potter, 2017). Consequently, coping and adapting to the ASD diagnosis provoked some fathers to learn more about the condition of their child as a means to improve their own knowledge and understanding and share their new knowledge with other family members as well as healthcare professionals (Cheuk & Lashewicz, 2016; Hannon & Hannon, 2017; Manor-Binyamini, 2019). This process was viewed by some as important as a means to cope and adapt to the changing role of being a father of a child with ASD. The development of new knowledge and understanding about ASD was

achieved by some fathers by sourcing websites with information and resources about the condition (Hannon & Hannon, 2017; O'Halloran et al., 2013; Pottas & Pedro, 2016). Fathers described how they preferred to draw on informal supports from other fathers of children with ASD and found this to be informative and beneficial (Burrell et al., 2017; Manor-Binyamini, 2019).

### 3.2.4 | Ongoing adjustment to the fathering role

There was a realisation that once a diagnosis of ASD was confirmed, the expectations of their child and of their roles and responsibilities as fathers changed. This was viewed as part of the period of adjustment and coming to terms with the new family circumstances and the future needs of their child (Burrell et al., 2017; Cheuk & Lashewicz, 2016). There was a reframing of how many fathers had envisaged their child's life, leading to a change in their own attitudes and expectations (Burrell et al., 2017; Cheuk & Lashewicz, 2016; O'Halloran et al., 2013). There was a growing recognition that the changes and adjustments would be an ongoing lifelong process, supported by the need for fathers to understand their child's prognosis and support needs (Hannon & Hannon, 2017; Vacca, 2013). This was necessary so that they could plan for the future and make changes to support their child, the other parent and their family. The often-initial emotions of denial, confusion, shame and disbelief regarding their new situation changed overtime to one of 'acceptance and love' for their child in the context of the ASD (Burrell et al., 2017; O'Halloran et al., 2013; Pottas & Pedro, 2016; Vacca, 2013). The 'love' for their children was evident when fathers described the personal and positive changes that came about as a consequence of being a father of a child with ASD (Burrell et al., 2017; O'Halloran et al., 2013). Fathers reported how they had become a more 'tolerant, accepting and patient' as a parent and were grateful for what they learned from their child (Burrell et al., 2017; O'Halloran et al., 2013).

## 4 | DISCUSSION

These findings from this systematic review provide valuable insights that develop the understanding of the experiences of fathers at the time of assessment and diagnosis of ASD for their child. This is important as globally, the prevalence of children and adults with ASD is increasing with a growing recognition of the full scope of their education, care and support needs and the associated impact on parents (Christensen et al., 2018; Legge & Tickle, 2019). The findings highlight that needs of fathers in the assessment and diagnostic process are often overlooked, with a need for them to be fully included and their specific needs recognised and responded to. The evidence supports that view that many parents had a gradual recognition that their child was not achieving the expected developmental milestones, which in turn led them to discuss their concerns with health professionals (Burrell et al., 2017; O'Halloran et al., 2013). This led to seeking an ASD assessment, and for many

this was a lengthy process that was often a protracted and at times frustrating (Manor-Binyamini, 2019; Potter, 2017). The protracted wait for the ASD assessment and subsequent diagnosis created further anxiety and stress for many fathers, at what was an emotional time, where their main concern was on accessing care and support for their child (Cheuk & Lashewicz, 2016; Potter, 2017). Receiving the ASD diagnosis was, for many fathers, a shock, despite awareness of their child not meeting developmental milestones and appearing to be 'different' (Burrell et al., 2017). Their situation was further compounded by health professionals who lacked detailed knowledge about ASD, the prognosis and the supports required and those available (Manor-Binyamini, 2019). Fathers often felt ignored and excluded in the assessment diagnosis process, with a desire to be more fully included and their views and concerns heard and responded to (Potter, 2017). Over time, many fathers adapted to the ASD diagnosis and began to seek information and support that would enable them to more effectively support their child (Paynter et al., 2018). With the adaptation process came the recognition that their child would most likely have lifelong support needs that would be different from other typically developing children (Hannon & Hannon, 2017; O'Halloran et al., 2013). Therefore, arising from this systematic review, there are clear implications for nursing policy, practice, education and future research.

### 4.1 | Implications for nursing policy

With the growing recognition of the scope and extent of the needs of people with ASD, there have been a range of legislative, policy and strategy initiatives aimed at improving their life opportunities (Precious, 2020; World Health Organization, 2013). Within this context, it is apparent from the findings of this systematic review that the needs and concerns of fathers are often overlooked. Fathers want to play a full role in the parenting of their child with ASD yet many describe feeling excluded and ignored with the focus predominantly being on the role of mothers (Martins et al., 2013). There is therefore a need and opportunity for professionals in education, health and social care to contribute to the development, implementation and operationalisation of policies and strategies to ensure that the specific concerns of fathers are reflected and effectively responded to. This is important given the range of physical and mental health issues, communication and sensory needs and behavioural concerns experienced by people with ASD, and the barriers to accessing appropriate assessments, diagnosis and ongoing supports (Pottas & Pedro, 2016). It is therefore necessary for policies such as those regarding paternity leave to be reflective of and responsive to the needs of fathers, thereby removing obstacles that may inhibit their parenting role for their child with ASD (Broomhill & Sharp, 2012).

Fathers identified the need for increased professional, public and cultural awareness and education regarding ASD and the need to improve service provision and access (Burrell et al., 2017; Cheuk & Lashewicz, 2016; Manor-Binyamini, 2019). The specific needs

of fathers require to be recognised and their needs fully reflected within government education, health and social care policies, thereby seeking to improve the social support provided to fathers and their families (Seymour et al., 2020). Following on from this, is the opportunity for nursing-specific policies to fully reflect the needs of fathers. For example, health visiting, public health nursing, child health nursing and mental health nursing policies need to make explicit their commitment to ensuring that fathers are fully involved in the assessment and diagnostic process. Nursing policies also need to promote full access to information, psychoeducation and supports that are responsive to their specific needs and concerns of fathers (Cheuk & Lashewicz, 2016; Dunlap & Filipek, 2020).

## 4.2 | Implications for nursing practice

A recurring theme across the studies in this review is the need for professionals to listen to the concerns of fathers from the outset and support them in the diagnostic process as they are often the first to recognise that developmental milestones were not being reached. Nurses are central to the diagnostic process, and they are in a unique position to respond to the specific psychological, physical and mental health needs of fathers, thereby ensuring they are fully engaged and involved (Barnard-Brak et al., 2017). Fathers need nurses and other healthcare professionals to fully involve them during and after the ASD assessment and diagnostic process. Nurses, such as public health nurses, health visitors, school nurses and child health nurses are often the first point of contact when parents of a child with ASD seek diagnosis and support (Tinsley, 2020). There is therefore a need for nurses and other healthcare professionals to ensure that care and support is timely, sensitive, supportive and evidence-based, with early signposting to, for example, information about ASD prognosis, interventions, education and local services and support networks (Crowe & Salt, 2015). In terms of design and delivery, nurses are in a prime position to co-produce services with fathers of children with ASD (Kong et al., 2020). This would enable nurse to develop and deliver evidence-informed programmes and local support groups and networks to provide information regarding ASD that are specific and responsive to the distinct needs of fathers (Dunlap & Filipek, 2020; Frye, 2016).

## 4.3 | Implications for nursing education

Due to the scope and extent of the needs of people with ASD and their families, multiagency collaboration between organisations including education, employment, housing, health and social care is required to ensure the effective coordination of care and support (Hyman et al., 2020). Despite these identified needs, professionals, including health practitioners, may lack the necessary knowledge and skills required to meet the ongoing needs of people with ASD and their families (Urbanowicz et al., 2020). The often-limited

knowledge of health professionals regarding ASD and the specific needs and concerns of families, including fathers, at the time of assessment and diagnosis is an education gap that needs to be addressed (Ghaderi & Watson, 2019). Therefore, the education of nurses and other healthcare professionals is necessary and needs to be embedded within undergraduate and postgraduate programmes for nurses, doctors, social workers and allied health professionals involved in the diagnostic process and subsequent support (Hend, 2017). A knowledgeable, skilled and confident nursing workforce that is responsive to the concerns of fathers of people with ASD is required to ensure that their needs are sensitively and comprehensively addressed (Dunlap & Filipek, 2020; Ward et al., 2016). There is also an opportunity to involve fathers in multiagency continuing professional development programmes for nurses, healthcare professionals and other specialists in ASD services that develops and improves their knowledge and understanding of the distinct needs of fathers and their specific ongoing social support requirements following diagnosis (Seymour et al., 2020).

## 4.4 | Future nursing research

Across the studies included in this review is the need for research that increases and develops the knowledge and understanding of the specific concerns of fathers of children with ASD at the time of diagnosis. There is a lack of international multi-centre research studies that allow for comparisons of what works in effectively meeting the needs of fathers of children with ASD. There is an opportunity to conduct education research studies that identify improvements in the knowledge and skills of nurses and other health professionals throughout the ASD diagnostic process. Therefore, future research initiatives need to include a specific focus on the views, experiences and concerns of fathers of children with ASD to ensure that future care and support is evidence-based.

## 4.5 | Strengths and Limitations

This review has highlighted important findings about the experiences of fathers regarding the diagnosis of ASD. The findings help develop nurses and other health professionals' knowledge and understanding of the responses required during the ASD diagnostic process to effectively address the future needs of fathers. With the evolving and changing role of fathers in society and within the family context, this review offers new insights about the roles of nurses and other health professionals at this critical period that requires further attention and development. The authors acknowledge the potential limitations, including the small sample sizes across the included studies and the implications and application of the findings to other settings. In addition, all the studies were cross-sectional in design and therefore present a 'snapshot' of the views and experiences of the fathers who participated. They may not therefore reflect those of fathers more generally.

## 5 | CONCLUSION

The current research evidence supports the view that many fathers actively want to be involved in the care of their child with ASD, recognising that parental commitment and involvement may be lifelong. Fathers want to be engaged in the diagnostic process thereby ensuring that they are fully involved and with their issues and concerns heard and addressed. This review of the available international research highlights the role of nurses and other healthcare professionals during the diagnostic process and provides important insights that develop the understanding of the views and experiences of fathers. There are specific areas of policy, practice and education where developments are required to ensure the needs of fathers are effectively addressed. Nurses and other healthcare professionals have a central role in terms of supporting father's physical and emotional needs during and after the diagnostic process and on into childhood and beyond.

## 6 | RELEVANCE TO CLINICAL PRACTICE

### Relevance to clinical practice:

The findings from this systematic review will enhance the knowledge and understanding of nurses and other professionals of an Autism Spectrum Disorder diagnosis and the effects on fathers and their ongoing support needs.

- Fathers need access to education and support from nurses and other professionals at the time of diagnosis of Autism Spectrum Disorder.
- Nurses and other professionals require access to practice development regarding the distinct needs of fathers at the time of diagnosis of Autism Spectrum Disorder.
- Further research is required of the care and support needs of fathers at the time of diagnosis of Autism Spectrum Disorder diagnosis and their specific support needs.

### CONFLICT OF INTEREST

None declared by the authors.

### AUTHOR CONTRIBUTIONS

Review design, searches, critical appraisal and data analysis: EM, MB and LM. Draft reviewing and the final approval of review for publication: All authors.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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