




Identifying and managing care for children with autism spectrum disorders in general practice: A systematic review and narrative synthesis

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Abstract

Many healthcare systems are organised such that General Practitioners (GPs) often have a key role in identifying autism spectrum disorders (hereafter collectively referred to as autism) in children. In this review, we explored what GPs know about autism and the factors that influence their ability to identify and manage care for their patients with autism in practice. We conducted a systematic narrative review using eight electronic databases. These included Embase and MEDLINE via Ovid, Web of Knowledge, PsycINFO via Ebscohost, PubMed, Scopus, ProQuest Dissertations and Thesis, and Applied Social Sciences Index and Abstracts (ASSIA) via ProQuest. Our search yielded 2,743 citations. Primary research studies were included, and we did not impose any geographical, language or date restrictions. We identified 17 studies that met our inclusion criteria. Studies included in the review were conducted between 2003 and 2019. We thematically synthesised the material and identified the following themes: *the prototypical image of a child with autism; experience, sources of information, and managing care; barriers to identification; strategies to aid in identification; and characteristics that facilitate expertise*. Together, the findings from this review present a mixed picture of GP knowledge and experiences in identifying autism and managing care for children with the condition. At one end of the continuum, there were GPs who had not heard of autism or endorsed outmoded aetiological theories. Others, however, demonstrated a sound knowledge of the conditions but had limited confidence in their ability to identify the condition. Many GPs and researchers alike called for more training and this might be effective. However, framing the problem as one of a lack of training risks silences the array of organisational factors that impact on a GP's ability to provide care for these patients.

KEYWORDS

ASD, autism, experiences, family practice, general practitioners, GPs, knowledge, neurodevelopment, primary care, systematic review

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1 | BACKGROUND

Autism spectrum disorders (hereafter collectively referred to as autism; Fletcher-Watson & Happé, 2019) are a constellation of neurodevelopmental differences characterised by atypical social communication and circumscribed interests or restricted and repetitive behaviours (American Psychiatric Association, 2013; World Health Organisation, 2018a). The WHO estimates that 1 in 160 children have autism (World Health Organisation, 2018b). Current estimates in high- or middle-income countries place autism rates between 1% and 2.5% (Centers for Disease Control & Prevention, 2014; Idring et al., 2015; Kim et al., 2011). The apparent proliferation of 'autism' has brought the condition into public discourses, with mixed results. On the one hand, greater awareness has helped autism acquire substantial research investment (Pellicano, Dinsmore, & Charman, 2014), propelled the neurodiversity movement and helped many families access supports and services. Yet, public and media discourses about autism have often propagated aetiological misconceptions and unhelpful stereotypes (Dixon & Clarke, 2013; Jones & Harwood, 2009; Pellicano et al., 2014). Although most people get information about autism from the media (Mitchell & Locke, 2015), healthcare professionals are widely viewed as authorities on child development. Therefore, it is crucial that healthcare professionals across the assessment pathway have a sound understanding of autism.

Yet changes in our understanding of autism have made it difficult to codify autism knowledge (Gillespie-Lynch et al., 2015). 2017 found 67 studies in 21 countries attempting to quantify autism knowledge. Common assessment tools included the Autism Knowledge Survey (AKS; Stone, 1987) and the Knowledge about Childhood Autism among Health Workers (KCAHW; Bakare, Ebigbo, Agomoh, & Menkiti, 2008). Strikingly, the authors identified 44 bespoke instruments across the studies. This apparent lack of consensus, therefore, raises persistent questions about what primary healthcare professionals should know about autism.

Many healthcare systems are configured such that General Practitioners (GPs) have an important role in identifying autism in children and managing their care. In the primary care model 'gatekeeping' is a routine activity for GPs (Hobbs et al., 2016). *Gatekeeping* can be broadly defined as the act of deciding whether patients get access to secondary care services or diagnostic assessments (Franks, Clancy, & Nutting, 1992). The gatekeeping system has been adopted by many countries including Australia, Canada, the Netherlands, New Zealand and the UK. Despite its apparent popularity, others have questioned the effectiveness of this model (Brekke, Nuscheler, & Straume, 2007; Greenfield, Foley, & Majeed, 2016). For example, concerns have been raised in other areas of medicine, such as cancer research, where gatekeeping principles and the 'wait and see' approach have been linked with adverse outcomes (Brown et al., 2014; Vedsted & Olesen, 2011).

Nevertheless, research on pre-diagnostic experiences of autism confirms that identification often starts with GPs (Crane, Chester, Goddard, Henry, & Hill, 2016; Howlin & Moore, 1997; Ryan & Salisbury, 2012). During such consultations, parents often present

What is known about the topic?

- Knowledge of autism is variable in primary care professionals
- GPs often have an important role in identifying and managing care for people with autism
- Recommendations for 'more training' are common in primary care literature

What this paper adds?

- The studies in this review offer a mixed picture of GP knowledge and experiences regarding autism
- Several factors constrain GPs' ability to identify and refer children with autism
- It is unclear how GPs' wishes for autism training compare to desires for training in other areas
- We speculate that the successful sharing of information between cognate services could constitute one of the most positive public health initiatives of our time

with specific and non-specific developmental or behavioural queries (Crane et al., 2016). Much of the literature on parental experiences of the pre-diagnostic period indicates that this is a challenging and stressful time for families (Boshoff, Gibbs, Phillips, Wiles, & Porter, 2018; Ryan & Salisbury, 2012). a review by Boshoff et al. (2018) showed that parents often report that their initial concerns were dismissed, minimised or otherwise not acknowledged by frontline healthcare professionals.

Organisational factors associated with primary care (e.g. limited time for consultations, heavy workloads) add to the complexity of identifying autism in general practice (Hobbs et al., 2016). Practitioners are consequently expected to rely on best practice guidance (Johnson & Myers, 2007; National Institute for Health & Care Excellence, 2011). One point of divergence across best practice guidelines concerns universal screening. Proponents of universal screening have called the implementation of universal screening one of the most beneficial public health policies ever developed for children with autism (Pierce, Courchesne, & Bacon, 2016) (p. 1). Yet others have expressed concerns regarding such screening programmes (Al-Qabandi, Gorter, & Rosenbaum, 2011). The nature of these concerns can be categorised as practical (e.g. cost-effectiveness; Yuen, Carter, Szatmari, & Ungar, 2018) and time-constraints; Bauer, Carroll, Saha, & Downs, 2015) and psychometric (Charman et al., 2016; National Institute for Health & Care Excellence, 2011). Moreover, even within contexts where universal autism screening is recommended, epidemiological evidence suggests that screening rates remain low (Bethell, Reuland, Schor, Abrahms, & Halfon, 2011; Roux et al., 2012).

In addition to identification, GPs also have a key role in managing care for children with autism and their families. Previous work demonstrates that children and adolescents with autism often

present with relatively high and complex health needs compared to neurotypical peers (Foley, Pollack, Britt, Lennox, & Trollor, 2018). Further, given some of the challenges often associated with autism (e.g. sensory sensitivities) adjustments to clinical settings (e.g. scheduling appointments at less busy times) are sometimes required to make practices more assessable for these patients (Buckley, 2017).

In an effort to facilitate identification and make services more accessible, numerous commentators have also identified a need for GP training in autism. In response, professional bodies such as the Royal College of General Practitioners (2019) in the UK have published the Autism Toolkit, which contains information about autism and e-learning modules for GPs. Tailored resources are available in other countries including Australia (Australian College of Rural & Remote Medicine, 2019) and Canada (Autism Canada, 2015). Although these tools are valuable, it is likely that usage varies considerably. Nevertheless, studies on autism-related educational programmes for primary care professionals (PCPs) suggest that training might lead to increases in autism knowledge, changes in referral behaviour and screening practices (Bordini et al., 2015; Carbone, Norlin, & Young, 2016; Major, Peacock, Ruben, Thomas, & Weitzman, 2013).

Recently, McCormack, Dillon, Healy, Walsh, and Lydon (2019) conducted a systematic review of PCPs' knowledge of autism and evidence-based interventions for autism. This review found only 23% of PCPs were considered to have adequate knowledge of autism with greater knowledge scores being observed in higher income countries. Regarding interventions, McCormack and colleagues found relatively few studies on knowledge of evidence-based interventions. It is important to note that the category of PCP includes GPs and paediatricians. In their review of different but related topic, ADHD in general practice, Tatlow-Golden, Prihodova, Gavin, Cullen, and McNicholas (2016) exclude studies of first-contact paediatricians on the basis that paediatricians and GPs differ significantly in terms of training. Therefore, we believe that there is ample scope for a review which exclusively focuses on GPs and explores other topics such as attitudes towards screening and managing care. In short, this review is positioned to make a unique contribution by exploring these other adjacent topics and conducting a narrative synthesis of the data. The primary aims of this study were to explore issues around identifying autism in children in general practice by systematically reviewing qualitative and quantitative material on the topic. A secondary aim is to explore issues around managing care more generally for children with autism and their family.

2 | METHOD

2.1 | Overview

In line with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009), we carried out a systematic search of available literature. Searches were run in eight electronic databases, including

TABLE 1 Search terms

No.	Domain	Search terms
1	Professional Group	1. General adj2 Pract* 2. Primary adj2 Care 3. Primary Healthcare 4. GP* 5. Family medicine 6. Family Physician* 7. Family adj2 doctor 8. Family adj practi*
2	Outcomes	9. Experience* 10. View* 11. Perception* 12. Opinion* 13. Attitude* 14. Knowledge* 15. Understand* 16. Idea* 17. Perspective*
3	Condition	18. Autis* 19. ASD 20. Asperger* 21. Pervasive developmental 22. PDD-NOS*

Note: NB Query operators (e.g. adjh2, wildcards et cetera) were modified and tailored for each database.

Embase and MEDLINE via Ovid, Web of Knowledge, PsycINFO via Ebscohost, PubMed, Scopus, ProQuest Dissertations and Thesis, and Applied Social Sciences Index and Abstracts (ASSIA) via ProQuest. Terms relating to (a) the professional group of interest (i.e. 'General Practitioners'), (b) outcome of interest (i.e. 'experience', 'knowledge') and (c) the condition of interest (i.e. 'autism') were combined. Potentially relevant citations were identified by applying these terms to Title/Abstract searches in the aforementioned electronic databases. A description of the search strategy and terms is available in Table 1. Searches were conducted on the week of the 12th June 2019 and no date limits or language restrictions were employed.

2.2 | Inclusion and exclusion criteria

Studies were included that explored GP knowledge or experience caring for children with autism. To this end, we developed a list of

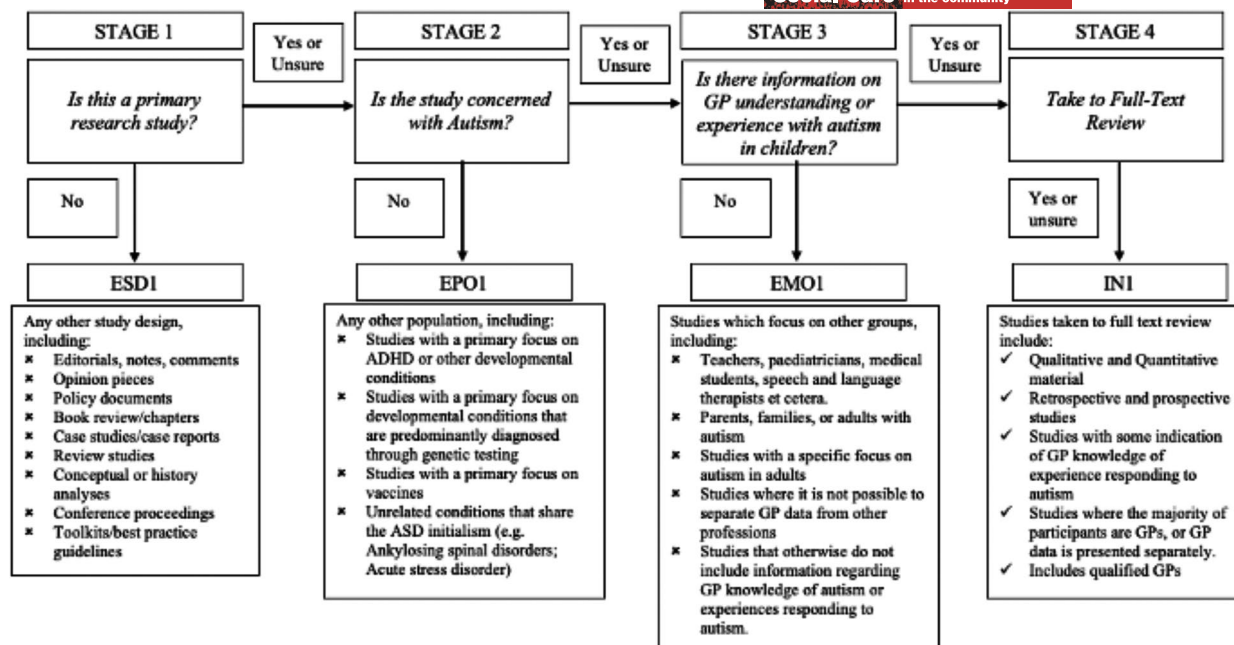


FIGURE 1 Title/abstract screening decision flow chart

various inclusion and exclusion criteria. We then grouped these into sections regarding study design (i.e. primary research study), condition (i.e. autism) and outcome of interest (i.e. GP knowledge and experiences identifying and managing care for children with autism). In order to capture a comprehensive and global picture, we did not impose any geographical restrictions or language restrictions. We identified one study that was not published in English, which was translated using computer software. In contrast to nosologically similar conditions such as ADHD, we are not aware of any contexts where GPs diagnose and provide pharmacological intervention for autism. Instead, GPs refer children for formal assessment. See Figure 1 for further details on inclusion and exclusion criteria.

2.3 | Title/abstract screening

The initial search produced 2,743 citations across the eight databases. Through reference management software and manual comparisons, 995 duplicates were identified and removed. This resulted in 1,748 citations for title and abstract screening. In an effort to guide and standardise the screening process, we developed a decision flow chart based on three topics (see Figure 1). Two authors BC and MOC piloted the flow chart on the first 100 citations. This allowed us to identify any systematic differences or errors in coding. During the collaborative pilot-screening we identified 7 papers that met the inclusion criteria. BC and MOC screened the remaining 1,648 citations separately to establish interrater reliability. This resulted in a Cohen's kappa (Cohen, 1960) of 0.84, which is considered adequate (Landis & Koch, 1977). Where conflicts did arise, these were discussed and resolved between BC and MOC. In total, 62 citations were taken to full-text review.

2.4 | Full-text review

Both BC and MOC read the 62 studies brought through to full-text review. Of these papers, twenty-four citations were excluded

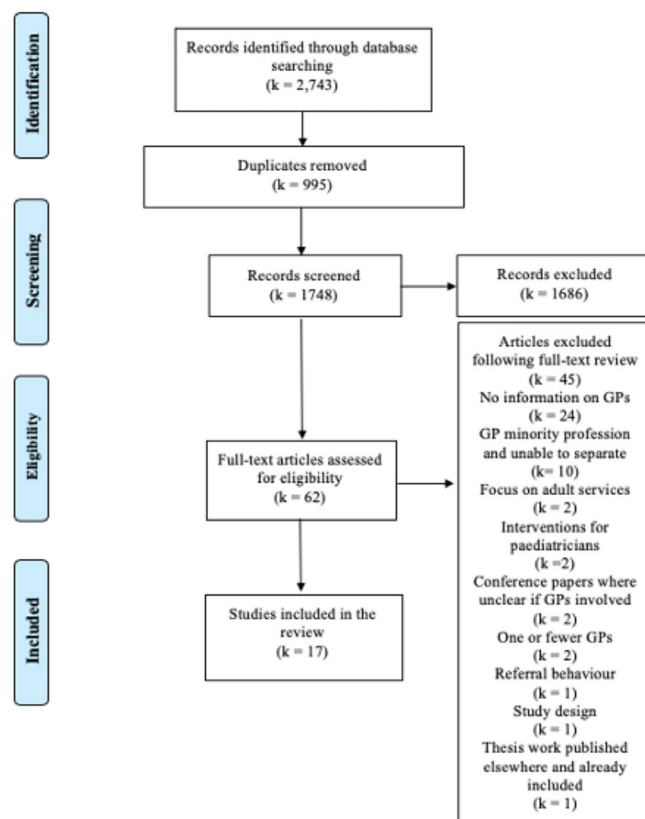


FIGURE 2 PRISMA flow chart [Colour figure can be viewed at wileyonlinelibrary.com]

TABLE 2 MMAT quality assessment

Author(s) (year)	Screening questions		Study type										Mixed methods						
	All studies		Qualitative					Quantitative non-randomised**/descriptive											
	S.1	S.2	1.1	1.2	1.3	1.4	1.5	3.1/4.1	3.2/4.2	3.3/4.3	3.4/4.4	3.5/4.5							
Al Maskari (2018)*																			
Altay (2019)																			
Berenstein (2012)*																			
Campbell (2008)																			
Eray and Murat (2017)**																			
Eseigbe et al. (2015)																			
Fenikile et al. (2015)																			
Garg et al. (2014)*																			
Garg et al. (2016)																			
Kirby et al. (2005)																			
Lian et al. (2003)																			
Limbos et al. (2012)																			
Martinez et al., (2013)																			
Muhammad et al. (2013)																			
Rahbar et al. (2011)																			
Hend (2017)																			
Unigwe et al. (2017)*																			

Note: Red indicates a negative response ('no'), green a positive response ('yes'), orange indicates there was inadequate information provided in the study, 'can't tell' and grey indicates the question was not applicable. *Mixed methods. **Non-randomised intervention

because the studies did not include GPs. A total of ten studies were excluded as it was not possible to separate GP data from other professional groups and GP was not the majority profession. Two studies were excluded because they focused solely on adult services. Two intervention studies were excluded because they focused solely on paediatricians, rather than GPs. Two conference papers were excluded as it was unclear whether the participants included GPs and there was no further information available. One study was excluded because it only included information on one GP. Similarly, another paper was excluded because it included information on one GP who was also the parent of a child with autism. One study on physician referral behaviour was also excluded as it did not include information on knowledge or experiences. One study was excluded on the basis of study design as it was a confirmatory factor analysis (CFA) and literature review. We excluded this paper as the questionnaire data on which the CFA was conducted were already presented in another paper which we included. One thesis was excluded as the data therein had been published by the authors in a peer-reviewed journal prior to completion of the dissertation. Thus, we opted to include the peer-reviewed paper and exclude the thesis. Overall, 17 papers were included in the current review (see Figure 2 for PRISMA). For a description of the included material, please see Table S2.

2.5 | Approach to synthesis

Given the diverse nature of the material included in the study, data were synthesised thematically. We followed the three-step coding and analytic process outlined in Thomas and Harden (2008). This includes 'line-by-line' coding, generation of descriptive themes and analytical themes. As such, results sections were coded 'line-by-line' for quantitative material. Regarding qualitative material, similarly results sections were coded 'line-by-line' as were for any appendices or other materials containing quotations. BC read all the relevant material twice before starting the initial round of coding. Material was coded for explicit and implicit meaning. Preliminary descriptive themes were discussed with RD. These were then developed into preliminary conceptual themes which were reviewed and refined by the research team. The analytic software NVivo 12 was used to facilitate coding. Quantitative (e.g. responses to questionnaire items regarding the symptomology of autism) and quantitative material (e.g. typifications about children with autism) were brought together using a narrative approach (Elliott, 2005).

2.6 | Quality assessment

The Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018) was used to appraise the quality of material included in the review (see Table 2). This tool has demonstrated sound psychometric properties elsewhere (Pace et al., 2012). BC and MOC independently screened the included studies, with disagreements discussed and resolved by RD. We treated studies with qualitative and quantitative material as

'mixed methods studies' for the purposes for this assessment. It is important to note that some of these papers had more of a focus on the quantitative elements. Additionally, several of the studies did not contain enough information to answer 'yes' or 'no' to the appraisal questions. We emailed several of the authors and received one response, yet we remained unable to answer some of the items.

3 | RESULTS

Ultimately, 17 primary research studies met our inclusion criteria. These included journal articles ($k = 13$), doctoral dissertations ($k = 2$), a dissertation submitted in fulfilment for a master's degree ($k = 1$) and an academic poster ($k = 1$). A combination of quantitative, qualitative and mixed methods studies was identified. These spanned sixteen countries and included 1,900 GPs. Studies were conducted between 2003 and 2019, traversing two editions of the Diagnostic and Statistical Manual (DSM).

3.1 | Quality assessment

Overall the quality of the studies was variable. Common limitations included sample representativeness and risk of nonresponse bias. In addition, given the use of bespoke assessments it was at times difficult to determine whether the outcome measures were appropriate. Finally, regarding mixed method research, it is important to acknowledge that often the emphasis was unevenly weighted on the quantitative elements.

3.2 | Quantitative findings

3.2.1 | Knowledge

Thirteen studies assessed GP knowledge of autism. Two studies (Campbell, 2008; Unigwe et al., 2017) used an adapted version of the ASK (Stone, 1987), two studies (Eseigbe et al., 2015; Hend, 2017) used the KCAHW (Bakare et al., 2008), and the remainder ($k = 8$) used a bespoke assessment developed by the research team (Altay, 2019; Berenstein, 2012; Eray & Murat, 2017; Garg, Lillystone, Dossetor, Kefford, & Chong, 2014; Kirby, Davies, & Bryant, 2005; Lian, Ho, Yeo, & Ho, 2003; Martínez, Tadeo, Montero, & Antonio, 2013; Rahbar, Ibrahim, & Assassi, 2011). In one study (Muhammad, Dhia Al-Deen, & Abdul Muhsin, 2013) the authors cite Heidgerken, Geffken, Modi, and Frakey (2005) in the method, and yet the results reflect the structure of the KCHAW (Bakare et al., 2008). In studies that used bespoke measures, 'autism knowledge' was explored in a variety of ways. Five studies (Berenstein, 2012; Eray & Murat, 2017; Garg, Lillystone, Dossetor, Eastwood, & Liaw, 2016; Lian et al., 2003; Martínez et al., 2013) used true or false questionnaires, one study (Rahbar et al., 2011) used Likert scales delivered via interview, three studies (Altay, 2019; Kirby et al., 2005; Martínez et al., 2013) used free-text responses, and one

(Martínez et al., 2013) used a combination of true or false questions, free-text responses and statement matching.

Given the array of knowledge assessments, it is unsurprising that autism knowledge was rendered in a variety of ways across the studies. For instance, Lian et al. (2003) surveyed GPs ($n = 48$) in Singapore about child development using a bespoke survey with five items related to autism. The average correct responses on the autism items (i.e. MMR misconceptions; prevalence; dietary modifications; learning style; local arrangements) was ~66%. This increased to ~82% when the item about local service arrangement was removed. In the UK, Unigwe et al. (2017) surveyed ($n = 304$) GPs about their knowledge of autism using an adapted version of the ASK (Stone, 1987) and confidence providing care for patients with autism. The mean knowledge score in this study was 88.1%. Yet participants tended to report limited levels of confidence responding to autism in practice. In Australia, Garg et al. (2014) used a bespoke measure to assess autism knowledge in a sample of 191 GPs. This assessment consisted of 14 questions on diagnostic criteria, aetiology, prevalence, screening tools and co-morbidities. The authors set a benchmark score of 11 out of 14 as the cut-off criterion. In total, 62% of the participants scored above this threshold.

Regarding early markers, a Canadian doctoral research project (Berenstein, 2012) reports that GPs ($n = 126$) on average scored 62% in terms of identifying red flag features. Commonly identified markers were response to name (64%); babbling (65%); use of gestures (65%); single words (71%). Relatedly, Altay (2019) asked GPs based in Turkey ($n = 48$) to describe diagnostic markers for autism. The three most commonly endorsed markers were atypical eye-contact (72.9%); repetitive movements (47.9%); delayed speech (47.9%). However, a number of features which were not part of autism were received endorsement such as attention deficit disorder (34.6%); learning disability (23.1%); singing (11.5%); and irritability (11.5%). Elsewhere, Martínez et al. (2013) surveyed GPs ($n = 20$) in Cuba and found that none of the GPs in this study were able to indicate a correct early marker of autism using free-text methods.

In Pakistan, Rahbar et al. (2011) surveyed 332 GPs regarding knowledge and attitudes towards autism. Strikingly, only 44% ($n = 148$) of the participants were familiar with the term 'autism'. Of these only 42% ($n = 62$) reported having a working knowledge of the condition. Regarding aetiology, 38.3% ($n = 23$) endorsed the statement *autism is preventable* and a further 16.7% ($n = 10$) were unsure. In terms of clinical features, over 60% agreed that children with autism *show detachment from their parents*.

We identified one study (Eray & Murat, 2017) that directly explored the effectiveness of training to increase GP knowledge. Eray and Murat (2017) conducted a two-hour training programme with GPs ($n = 79$) in Turkey. Autism knowledge was surveyed pre- and post-programme using a questionnaire developed by the authors. The survey explored knowledge and misconceptions regarding prevalence, aetiology, clinical features and interventions. Improvements were observed in terms of perceived knowledge and correct responses pre- and post-test on several items including prevalence

(12% pre; 88% post) and endorsement of aetiological misconceptions such as *exposure to heavy metals* and/or *too much television* reduced from 62.7% and 36% respectively pre-intervention to 16% and 14% respectively post-training.

3.2.2 | Attitudes towards screening autism

Issues regarding standardised screening for autism appeared across many of the studies. Here we focus on reports of GP attitudes and perceptions towards standardised autism screening.

Al Maskari (2018) surveyed 299 nurses and 217 GPs regarding perceived barriers and facilitators to screening for autism in Oman. The most frequently endorsed organisational barriers to screening were resources issues (82%) and autism training (80%). A total of 73% of participants indicated that unclear referral pathways posed a significant barrier to screening for autism. Time constraints were endorsed by 69% of participants. In terms of sources of autism knowledge, between 70% and 75% of participants attributed their knowledge to professional training and continuing professional development. Increasing public and professional awareness to tackle stigma, strengthening ties between services, and incorporation of a screening tool in the developmental health check were endorsed by over 90% of participants as strategies to facilitate screening.

An academic poster by Limbos, Joyce, and Nguyen (2012) explored GP attitudes towards standardised screening in Canada. Regarding identification, over 30% of GPs indicated that parental concern was a good substitute for standardised screening, while under 20% indicated they had sufficient expertise to identify developmental conditions without standardised assessments. Fewer than 5% indicated concerns about the evidence base for standardised developmental screening. Regarding barriers, a *lack of time* was endorsed by the highest number of GPs (approx. 80%). Lack of familiarity with existing screening instruments and a lack of sufficient reimbursement followed in second and third respectively with between 60% and 70% of GPs endorsing these barriers.

Berenstein (2012) explored attitudes to screening autism in Canada ($n = 126$). Firstly, in response to a clinical vignette, 52% of participants indicated that they would use traditional modes of screening (e.g. clinical judgement, parental reporting). The remaining 48% used a combination of standardised screening tools as well as the more traditional methods. Of those who did endorse using a standardised tool, fewer than 10% endorsed using an autism-specific screening tool as a matter of routine. Instead the participants tended to opt for general developmental screening instruments. Again *lack of time* was the most commonly endorsed (79%) barrier to screening 79%.

3.3 | Qualitative findings

Seven studies analysed qualitative data from questionnaires, interviews and focus groups. Al Maskari (2018) offered two sources of

qualitative data regarding GPs' views on standardised screening of autism in Oman: focus groups with nurses ($n = 7$) and GPs ($n = 6$), and free-text responses on a questionnaire. Using focus group data, Al Maskari identified three categories of barriers to screening for autism: (a) organisational, (b) professional and (c) social or contextual barriers. Short appointments and caseloads reaching upwards of 60 patients per day were described as some of the practical barriers to screening. Despite being able to indicate a number of markers for autism, some GPs suggested that it was difficult to apply what they had learned in practice. Of the participants who returned questionnaires ($n = 490$), 217 were GPs, although it is unclear how many offered responses to the free-text section. Nevertheless, drawing upon the available responses, Al Maskari identified three themes: 'constraints', 'family' and 'professional education'. Strategies such as media campaigns, health education programmes were suggested to increase awareness and decrease stigma.

In Berenstein (2012), 72 GPs responded to an open question about barriers to recognising autism in primary care. The most frequently indicated barrier to screening was 'time'. GPs also showed a tendency to internalise the challenges with screening autism, stating that they had a lack of knowledge, experience and confidence identifying the condition. Relatedly, in the USA, Fenikile, Ellerbeck, Filippi, and Daley (2015) conducted focus groups and interviews with 15 GPs in the Kansas City metropolitan area to explore view on autism and routine screening. There was little consensus between GPs. Most, however, advocated for a general developmental screening rather than an autism-specific screening. GPs with less experience tended to endorse using standardised screening tools. Each participant indicated that time was a significant barrier to screening, and most felt they did not have adequate knowledge or expertise in autism in terms of early markers and available screening instruments. Several solutions were offered to improve screening including embedding screening tools in health records, providing adequate compensation for physicians, better training and developing a stronger evidence base for autism screening.

In Garg et al. (2014), qualitative data were collected from a questionnaire in order to identify training needs for GPs. In terms of recognising autism, the GPs indicated that they needed to know more about the hallmark features at both ends of the spectrum and referral pathways. In another paper published from this study, Garg et al. (2016) explored GP perceptions of prescribing medication to children with autism. Approximately 47% of participants' responses were coded under the theme of 'safety concerns'. Adverse effects such as weight gain, subsequent dependency and medicalising non-medical behaviours were some of the concerns expressed by practitioners. Between 10% and 15% of GPs indicated some concern with shouldering the clinical responsibility for prescribing medications to children with autism citing lack of experience, confidence and knowledge as mediating factors.

In Unigwe et al. (2017), 186 GPs responded to an open question about their experiences working with people with autism and their families. The authors identified two categories of themes: system-level factors and the role of the GP. GPs expressed dissatisfaction about long waiting lists and unclear referral pathways. Several

GPs also expressed frustration with the lack of post-diagnosis support and the lack of continuity between child and adult services. Given the current structure of general practice, many participants indicated that they did not have enough time to screen for autism. Here, GPs appeared in agreement regarding their wish for further training.

3.4 | Narrative thematic synthesis

Using the techniques drawn from Thomas and Harden (2008), we identified 5 topics for further discussion and synthesis. These broad themes were the prototypical image of a child with autism; experience, sources of information and managing care; barriers to identification; strategies to aid in identification; and characteristics that facilitate expertise.

3.4.1 | Prototypical image of a child with autism

During focus groups in Oman, Al Maskari (2018) GPs were asked to describe the markers they might expect in a child with autism. These GPs speculated that the child may be socially withdrawn, have a preference or interest in one item or toy, have difficulty with following instructions, have limited if any language and may also have cognitive difficulties. Meanwhile in Altay (2019), nearly a quarter of GPs indicated that 'learning disability' was a diagnostic marker for autism. Similarly, Eray and Murat (2017) reported that prior to an educational intervention, 23.3% of GPs agreed that autism is 'always' accompanied by a learning disability, while 12% were unsure. In the UK (Unigwe et al., 2017), despite showing sound knowledge of autism overall, nearly a third of participants indicated that most people with autism also have learning disability, while 6% indicated that most people with autism 'do not talk'. Such findings might call into question whether GPs are considering the full range of presentations and symptom manifestations inherent in the autism spectrum. Views on widening of diagnostic criteria came to the forefront during interviews and focus groups with GPs in the US (Fenikile et al., 2015). Reflecting on trends in diagnosis, one GP explained, 'What we were taught in a medical school, an autistic child was one who had no communication skills, hardly any relationship to reality, and now they're pushing it ... any child with social sharing issues has autistic tendencies'. (p. 361) This indicates that, in some cases, GPs are conflicted about considering the spectrum of presentations and balancing this with concerns about overdiagnosis.

Relatedly, in the UK and Ireland (Kirby et al., 2005), one GP considered Asperger's syndrome as a *more severe form of ADD*. Further, in Altay (2019), over a third of GPs indicated that 'hyperactivity' was a clinical feature of autism. In Oman (Al Maskari, 2018), one GP suggested that observing hyperactivity in the clinic might be a way to screen for autism. By contrast, Rahbar et al. (2011), of those familiar with autism, nearly a third indicated that autism was a precursor to schizophrenia while nearly 30% were unsure and under half agreed that autism is mostly attributable to neglect in early development. Similarly, in Eray

and Murat (2017), around a fifth of participants, pre-intervention, indicated that changes in caregivers cause autism. These views indicate that retrograde aetiological theories may be still held in mind by some GPs. Yet, it is important to note that there was variation between the studies. For instance, in the UK (Unigwe et al., 2017) fewer than 2% agreed that autism was caused by maladaptive parent-child bonding. Furthermore, overall survey studies in the UK, Turkey, Singapore and Australia suggest that the vast majority, but not all, of GPs recognised that autism was not linked to the MMR vaccine.

3.4.2 | Experience, sources of information and managing care

Results from survey studies indicate variation regarding the extent of previous experience with autism. In the UK, for instance, Unigwe et al. (2017) found that over 90% of GPs surveyed ($n = 304$) had at least one patient with autism. Further, over 90% had been approached by one patient in the previous year with a query of autism, and 78% reported being approached by up to five patients. This stands in contrast to findings from Egypt (Hend, 2017) and Nigeria (Eseigbe et al., 2015), where less than 25% of GPs reported having been involved in the care for a child with autism. Similarly, in Canada, a master's dissertation (Campbell, 2008) found that of the GPs surveyed ($n = 33$), a third reported having less than 1-year experience with autism and over 90% had fewer than 10 patients with an established diagnosis. In Pakistan, Rahbar (Rahbar et al., 2011) found that the majority of GPs surveyed ($n = 332$) were not familiar with the term 'autism'. In Iraq (Muhammad et al., 2013), however, 95% of participants indicated that they were familiar with the term autism, though it was unclear how much direct experience these practitioners had working with patients with autism.

Three studies asked GPs to cite sources of knowledge regarding autism. In Pakistan (Rahbar et al., 2011), medical training and scientific journals were indicated by 45%–50% of GPs as sources of information. The most commonly endorsed source was 'media', which was mentioned by 53.4% of participants. Meanwhile in Oman (Al Maskari, 2018) and in a context where healthcare professionals were generally critical of the lack of public awareness around autism, most GPs and nurses described 'self-updates' and 'professional training' as important sources of knowledge. Nearly two-thirds of participants considered their experiences working with parents and families as important sources of knowledge. In the UK (Unigwe et al., 2017), many GPs indicated that they had not received training in autism, yet 47% of participants had a personal connection with autism.

Taken together this does raise questions about how GPs manage care for children with autism. Indeed, in some studies (Limbos et al., 2012; Unigwe et al., 2017), this was an area where GPs reported limited confidence. One recurrent topic on the subject of management was the role of pharmacological medications. In the UK (Unigwe et al., 2017), the aspect of care GPs reported lowest self-efficacy with was prescribing medications. Meanwhile in Australia (Garg et al., 2016), nearly half of GPs reported safety

concerns around prescribing medications for children with autism. In some settings (Eray & Murat, 2017; Lian et al., 2003), a substantial minority of GPs endorsed dietary modifications as helpful in terms of addressing some of the challenges associated with autism. Few studies explored the role of GPs beyond knowledge, identification and medication. One exception was Unigwe et al. (2017). In this study some GPs suggested that signposting families to additional supports is part of the remit of GPs and, moreover, that it would be beneficial to receive more information to inform this signposting.

3.4.3 | Barriers to identifying autism

Studies in Oman (Al Maskari, 2018), Canada (Berenstein, 2012), the US (Fenikile et al., 2015), Turkey (Eray & Murat, 2017) and the UK (Unigwe et al., 2017) between 2013 and 2019 found that some GPs felt a lack of knowledge and training impacted on their ability to identify or manage care for children with autism. During focus groups in Oman, two GPs pointed to a possible bandwidth problem. For instance, one GP explained the situation as follows: 'The problem is we are in the GP clinic, and we see all ages...all genders...all diagnoses...everything at the same time'. (p. 115) Time constraints seemed to resonate with GPs across contexts as a significant obstacle to identification. This was particularly the case in situations where standardised screening as part of routine care was being discussed. For instance in the US, practitioners questioned why autism should be screened specifically over other developmental conditions. Similarly in Canada, practitioners tended to indicate familiarity and preference for general developmental screening tools, rather than autism-specific instruments. Further, some practitioners in Oman, the US and Canada questioned the benefit of screening, citing a lack of access to beneficial supports and services once they received the diagnosis. Concerns about financial reimbursement for screening time were also raised in a number of studies.

At times, organisational shortcomings were expressed in the form of tensions between services. These tensions were typically expressed through the conceptualisation of waiting lists for diagnostic assessment as 'lengthy' and critical reference to referral pathways. Concerning the former, three studies identified 'waiting lists' as a key obstacle to screening and identifying autism. In Canada (Berenstein, 2012), waiting lists were the most commonly endorsed barrier to referral, finding resonance with 64% of participants. Similarly, in Australia (Garg et al., 2014), GPs showed a tendency to describe waiting lists as lengthy. Qualitative data from studies in Oman (Al Maskari, 2018), and the UK (Unigwe et al., 2017), indicated a degree of dissatisfaction with the configuration of referral pathways. For example, some GPs in Unigwe et al. (2017) were particularly critical of the waiting lists, referral pathways and the compartmentalisation of expertise. One GP commented, 'Diagnostic pathways for children are complex locally, with the hospital paediatricians now rejecting referrals completely. The community paediatricians will not see someone for assessment if they are under CAMHS and vice versa;

the community paediatricians will also reject referrals that are not sent with a multidisciplinary referral form, which requests information we do not have access to (for example, school, nursery information)'. (p. 450)

In some contexts, socio-cultural factors such as stigma, childcare practices and difficulties working with parents were conceptualised as barriers to identification. In the US (Fenikile et al., 2015), some GPs felt that parents were reluctant to have the 'label of autism' applied to their children due to stigma. Additionally, some GPs argued that some parents were reluctant to have their children diagnosed with autism as it might negatively impact on the child's chances of obtaining medical insurance cover. In Pakistan (Rahbar et al., 2011), the majority of GPs felt that having a diagnosis of autism would lead to discrimination against the child. In Oman (Al Maskari, 2018), the prevailing view among GPs and nurses was that the term 'autism' holds some social stigma.

3.4.4 | Strategies to facilitate identification

On balance, GPs offered more barriers than facilitators to identification. Nevertheless, GPs did speculate on an array of strategies that could aid them in recognising autism. Many GPs, for instance, expressed a desire to have more autism-specific training in medical school and as part of continuing professional development. In Australia (Garg et al., 2014) indicated that training in early features, referral pathways and how autism presents across the spectrum would be beneficial. In Oman (Al Maskari, 2018) and the US (Fenikile et al., 2015), GPs praised the advent of electronic health records and some suggested that an autism screening tool could be embedded within the current system. In Oman, GPs tended to agree that the initiation of standardised screening would require a multi-pronged approach involving public and social awareness campaigns around autism.

3.4.5 | Characteristics that facilitate expertise

Several studies explored whether participants' characteristics mediated autism knowledge and screening practices. Results were equivocal and difficult to harmonise; an inverse relationship between age and autism knowledge was observed in some studies (Garg et al., 2014; Hend, 2017; Rahbar et al., 2011), but not in others (Eseigbe et al., 2015; Lian et al., 2003; Unigwe et al., 2017). Years of professional practice were significant in some studies (Eseigbe et al., 2015; Garg et al., 2014; Hend, 2017; Rahbar et al., 2011), but not all (Unigwe et al., 2017). One study (Berenstein, 2012) observed a significant relationship between age and screening practices. That is, participants who were 50 years or younger were more likely to indicate using standardised screening assessments. Regarding gender, one study indicated a significant difference between male and female participants in terms of screening practices. That is, female GPs were more likely to use standardised assessment tools. Finally,

one study (Eseigbe et al., 2015) found a significant difference on autism knowledge between male and female participants. However, this analysis was done on the entire sample of healthcare professionals ($n = 175$), rather than just GPs ($n = 76$). Overall, there was no strong evidence to suggest any gender differences regarding GP knowledge of autism (Garg et al., 2014; Hend, 2017; Lian et al., 2003; Rahbar et al., 2011).

4 | DISCUSSION

Many healthcare systems throughout the world are configured such that GPs often have a crucial role in recognising developmental conditions in children, including autism. This is within a context where questions have been raised about the 'gatekeeping model' and the GPs' role in recognising developmental and mental health conditions in children. Therefore, the aim of this review was to explore GP knowledge and experiences identifying and managing care for children with autism in general practice. We synthesised the literature and identified the following five themes: (a) *prototypical image of a child with autism*; (b) *experience, sources of information and managing care*; (c) *barriers to screening*; (d) *strategies to facilitate identification*; and (e) *characteristics that facilitate expertise*. Together, these studies offer a mixed picture of GP knowledge and experiences regarding autism. At one extreme, there were GPs who had not heard of the condition, endorsed retrograde aetiological theories or held misconceptions about diagnostic features. Though, in middle- and high-income countries, this tilted towards the minority. In some of these contexts, practitioners demonstrated sound knowledge of autism but had limited confidence in their ability to provide care for these patients and described an array of local, organisational or socio-cultural obstacles. Most of the studies called for more autism-specific training and these calls were often echoed by many of the GPs.

Our review provides some measure of support for some of the findings of McCormack et al. (2019) through validation and replication of findings regarding gaps in autism knowledge. Whereas McCormack and colleagues focus on GPs and paediatrician's knowledge of autism and the impact of interventions in increasing knowledge, our review offers additional insights into screening and managing care and a narrative synthesis of the literature. Together, the findings from both reviews offer some measure of explanation for the marked diversity in pre-diagnostic experiences of children and families with a query of autism (Boshoff et al., 2018; Crane et al., 2016; Ryan & Salisbury, 2012). Much like in Tatlow-Golden et al. (2016) review of GPs and ADHD, aetiological theories about parenting also persisted with some GPs when thinking about causes of autism. This is concerning given that these views are rarely seen even in lay populations (Furnham & Buck, 2003; Holt & Christensen, 2013; Mitchell & Locke, 2015). Where training and experience is often limited, enduring questions surface regarding the material and sources which shape the GPs' understanding of autism. Moreover, given the GPs' role to support families and provide other

healthcare services for children with autism, it is striking how few studies explored these topics explicitly. Therefore, we speculate that it would be beneficial for future work to explore GPs' experiences of making clinical adjustments to meet the needs of this group (e.g. making sensory adjustments to clinic rooms) as well as providing support to parents and families

We identified three studies which directly explored sources of information about autism. These sources included 'media' and 'personal connections'. This requires particular attention given that doctors are viewed by lay populations as authorities regarding autism (Mitchell & Locke, 2015). Further, it is consequential if GPs are supplementing their clinical decisions with the representations of autism in the media. One issue is that media offers a frame of discourse about autism that might not be situated in clinical literature (Jones & Harwood, 2009). Personal connections may offer practitioners invaluable insight when working with patients with autism. Yet, we are in agreement with Unigwe et al. (2017) in that doctors cannot be expected to respond to autism effectively and to needs of patients with autism confidently if they are predominantly reliant on these connections.

It is somewhat predictable that most studies recommend autism-specific training for GPs. McCormack et al. (2019) suggest that the available literature indicates that short educational programmes might be helpful in terms of increasing PCPs' knowledge of autism. We also speculate that training would be beneficial. Online training is effective with other populations in terms of tackling stigma and increasing knowledge (Gillespie-Lynch et al., 2015). Nevertheless, only one study (Eray & Murat, 2017) in our review directly assessed the impact of educational training on GP knowledge of autism. Although the authors did observe significant improvements in terms of 'autism knowledge', it is unclear whether these effects will endure.

However, what is even less clear is how GPs' wishes for autism training compare to their desire to receive training on other areas. Perceptions about a 'lack of training' permeate primary care literature and, as such, are not unique to autism. Several studies have described a lack of training or education in GPs across an array of topics including ADHD (Tatlow-Golden et al., 2016), dementia (Gove, Downs, Vernooij-Dassen, & Small, 2016), intrauterine contraceptive devices (Lodge, Sancu, & Temple-Smith, 2017), suicide (Foggin et al., 2016) and palliative care (Le et al., 2017). Naturally, this raises questions of practicality in terms of rolling out a suite of GP training programmes to tackle a myriad of clinical issues. Within this context, therefore, it is important to consider whether general training in child development, rather than autism or ADHD-specific training, would be more feasible and as effective in practice. Further, the focus on training may direct attention away from other avenues such as embedding toolkits or screening tools in technologies used by GPs.

Moreover, to treat the problem as the lack of training for GPs risks silencing organisational and socio-cultural factors that constrain a practitioner's ability to care for patients with autism in practice. For instance, when taken together, the results of our review indicate

that GPs are in general working under significant time pressures. Indeed, in the UK, healthcare bodies have identified difficulties in recruiting and retaining GPs (Baird, Charles, Honeyman, Maguire, & Das, 2016). Further, several studies also identified problems with the flow of information between GPs and specialist assessment services and ambiguous referral systems and pathways. These issues are not confined to the care for children with autism (Gandhi et al., 2000; Smith et al., 2005). The advent of electronic health records may be particularly helpful in this regard (Bodenheimer, 2008; Gandhi et al., 2008). We speculate that the sharing of information between primary and secondary care as well as social, forensic and educational services could constitute one of the most beneficial public health initiatives of our time. Taken together these system-level changes, in our view, would likely strengthen the integration of GPs into care pathways for children with autism.

5 | LIMITATIONS

There are some methodological limitations that require consideration. First, although we regard it as a strength of our study that we include unpublished material, it is also important to acknowledge that some of the work has not undergone peer review in academic journals. Second this review focuses predominantly on assessing and managing care for children with autism. Therefore, we did not include studies which focused exclusively on adults. This, we envisage, is a crucial piece of work and deserving of a review in and of itself. In addition, there is variation regarding the ways adequate autism knowledge is rendered between the studies in this review. The apparent reluctance of researchers to use existing measures merits reflection. Harrison and colleagues speculate that the continuing advent of tools indicates a lack of collaboration between countries, and this may well be a contributing factor. However, the lack of consistency across studies also illustrates the elasticity of the term 'autism'. Therefore, it is crucial to consider what understanding of 'autism' is practically useful for the GP in their context.

Additionally, primary care systems vary throughout the world and thus caution is due in terms of extrapolating findings across contexts. For instance, Irving et al. (2017) recently reviewed the international literature on GP consultation times and found that, in 19 countries, consultation times were five minutes or less. In settings such as Pakistan, China and Bangladesh, a GP undertakes up to ninety consultations in a day. Naturally, this raises questions about feasibility and the role of the GPs in referring children with autism in these contexts. By contrast, Sweden and the US had the longest average consultation times, with an average length of over twenty minutes in each case. Nevertheless, common to each system is that GPs are often the first contact healthcare professionals and as such might be called upon to make decisions about the care and identification of children with autism.

Finally, our study is not epistemologically positioned to indicate whether cognate disciplines (e.g. health visitors, educational professionals) might be better placed to undertake some of the referral

duties. Future work including service evaluations on care pathways which relieve GPs of their gatekeeping duties is urgently required in order to determine whether such pathways best meet the needs of children with autism and their families.

6 | CONCLUSION

Our findings illustrate variation both in GP knowledge of autism and the way researchers conceptualise autism knowledge across studies. As such, more work is required to help us better understand what GPs know about autism. We identified surprisingly few qualitative studies regarding GPs' experiences in identifying and managing care for children with autism. Within a context where GPs often control access to specialist assessment, this would seem to be a topic that merits further exploration. Studies using narrative case-based discussions, chart-stimulated recall and clinical vignettes could produce important insights in this regard. More autism-specific training for GPs might yield some benefits, yet continued efforts are required to relieve some of the organisational pressures on GPs.

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CONFLICTS OF INTEREST

No conflicts of Interest to declare.

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SUPPORTING INFORMATION

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

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