Autism Spectrum Disorders in the work of General Practitioners: a systematic narrative review

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Abstract

Background Many healthcare systems are organised such that General Practitioners (GPs) often have a key role in identifying autism spectrum disorders (autism) in children. Yet a systematic understanding of GP knowledge and experiences identifying autism is currently lacking. 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.

Methods 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.

Results We identified 17 studies that met our inclusion criteria. These were published between 2003-2019. We thematically synthesised the material and identified the following themes: the prototypical image of a child with autism; experience and sources of information; barriers to identification; strategies to aid in identification; and characteristics that facilitate expertise.

Conclusion Taken together, the findings from this review present a mixed picture of GP knowledge and experiences 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 silencing the array of organisational factors that impact on a GPs ability to provide care for these patients.

Background

Autism spectrum disorders (hereafter collectively referred to as 'autism') are a constellation of neurodevelopmental differences characterised by atypical social communication and circumscribed interests or restricted and repetitive behaviours (1, 2). This definition has been adopted in recent iterations of psychiatric classification systems to reflect the diverse array of presentations considered 'autism-related'. The World Health Organisation (WHO) estimates that, globally, approximately 1 in 160 children have autism (3). Yet, understanding the worldwide prevalence of autism is challenging because the data are often limited or not available for many countries and there is considerable methodological variation between studies (4). Much of what is known about autism prevalence, therefore, comes from studies in the 'Western World' and other high-income countries. In such settings, current estimates tend to place autism rates between 1–2.5% (5–8). Notwithstanding this variation, collectively fifty years of epidemiological data have shown a steady and sometimes dramatic increase in the condition (9–12). The apparent proliferation of 'autism' has brought the condition firmly into public discourses, with somewhat mixed results. For instance, greater awareness has helped autism acquire substantial research investment (13), propelled the neurodiversity movement, and ultimately, helped many families access supports and services that otherwise may not have been available. Yet, public and media discourses about autism have often propagated aetiological misconceptions and unhelpful stereotypes about people with the condition (13–16). Enduring misconceptions include retrograde theories about parenting or materials used in the production of vaccines. Although most people tend to get their information about autism from the media (17), healthcare professionals are widely viewed as authorities and will be consulted and required to advise on neurodevelopmental differences, including autism. Therefore, it is crucial that healthcare professionals across the assessment pathway have a sound and shared understanding of the condition.

As others have pointed out (18), rapid advances in our understanding of autism have made it difficult to codify 'correct' autism knowledge. In a recent review of international studies, Harrison and colleagues (19) found 67 studies in 21 countries attempting to quantify autism knowledge. Common assessment tools included the Autism Knowledge Survey (AKS) (20) and the Knowledge about Childhood Autism among Health Workers (KCAHW) Questionnaire (21). Somewhat strikingly, the authors identified 44 bespoke instruments across the set of studies. This led them to conclude that researchers who are interested in quantifying 'autism knowledge' are more likely to create their own measure, rather than use an existing method. Harrison and colleagues speculate that the proliferation of assessment tools is likely explained by poor collaboration between research groups (19). In addition, this diversity might also signal a lack of agreement between researchers regarding the important dimensions of autism knowledge. 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. Following the declaration of Alma-Ata in 1978(22), the primary care model has become a popular method of delivering healthcare throughout the world. In the primary care model 'gatekeeping' is a routine activity for GPs (23). '*Gatekeeping*' can be broadly defined as the act of deciding whether patients get access to secondary care services or diagnostic assessments (24). As such, GPs are tasked with making referral decisions about a plethora of physical, mental health and developmental conditions, including autism. The gatekeeping system has been adopted by many countries including Australia, Canada, Netherlands, New Zealand and the UK. Despite its apparent appeal and popularity, some clinically focused researchers and practitioners have questioned the effectiveness of this model (25–27). 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 and lower overall cancer survival rates (28, 29). In a recent analysis, Greenfield and colleagues (25) argue that moving these gatekeeping responsibilities for certain populations, such as children, may relieve some of the pressure on an already strained health service. According to Greenfield et al [19], some clinical commissioning groups in the UK do allow for direct referral for child services. Whether this approach will be rolled out on a national basis or adopted internationally remains to be seen. In the meantime, therefore, in many contexts, a referral from a GP might be required in order to access specialist assessment services for children and families with a query of autism.

Research on pre-diagnostic experiences of people with autism and their families confirms that the pathway to diagnosis often starts with the family GP (30–32). During such consultations, parents can often present with an array of specific and non-specific developmental or behavioural queries (30). These include questions regarding their child's language and motor development, socialisation, eye-contact, behavioural issues, difficulties with sleep, and atypical sensory interests/issues (30, 33, 34). Often, parents tend to monitor these differences for up to a year before discussing them with a healthcare professional (30). Much of the literature on parental experiences of the pre-diagnostic period indicates that this is a challenging and stressful time for families (31, 35). A recent review (35) showed that parents often report that their initial concerns were dismissed, minimised, or otherwise not acknowledged by frontline healthcare professionals. This has led some parents to feel marginalised and silenced.

However, changes to diagnostic criteria (2), the diverse array of features considered 'autism-related', and organisational factors associated with primary care (e.g. limited time for consultations, heavy workloads (23) each add to the complexity of identifying autism in general practice. Practitioners are consequently expected to rely on best practice guidance (36, 37) when identifying autism in children. However, a recent review of international clinical guidance material found considerable variation in terms of recommendations for assessment practices (38). One notable point of divergence across best practice guidelines concerns the recommendations around universal screening. *The American Academy of Paediatrics*, for instance, advocate for universal screening of autism using

psychometric assessments (37). Such questionnaires include the Checklist for Autism in Toddlers (CHAT) (39) and Modified Checklist for Autism in Toddlers (M-CHAT) (40), both of which are freely available. Proponents of this model have called the implementation of universal screening one of the most beneficial public health policies ever developed for children with autism (41)^(p1). Elsewhere, others have expressed concerns regarding such screening programmes (42). Broadly speaking, the nature of such concerns can be categorised as practical (e.g. cost-effectiveness (43) and time-constraints (44)) and psychometric (45, 46). Moreover, even within contexts where universal autism screening is recommended, epidemiological evidence suggests screening rates remain low or inconsistent (47, 48). Further, the extent to which the outcomes of standardised screening assessments shape subsequent clinical behaviour is not immediately clear. An important source of information comes from a recent randomised control trial of GPs/Family Physicians (hereafter collectively referred to as GPs) in Canada. In this study, Thomas and colleagues (49) compared detection and referral rates of two groups of GPs using either evidence-based standardised assessments (i.e. screening questionnaires) or usual means (i.e. informal clinical judgment). The results indicated that 16% of the usual care group compared with 62% of the evidence-based group were flagged as having some developmental concern or difference. Yet, there was no significant difference in referral rates (49). These results, it is argued by the authors, indicate that practitioners are still likely to favour their clinical judgment over the outcomes of standardised assessments. Whether universal screening results in a net benefit for people with autism remains a deeply contested issue with important arguments on both sides. In the interim, frontline healthcare professionals are, nevertheless, tasked with making referral decisions in the face of contradictory best practice guidance.

Numerous commentators have also identified a need for GP training in autism. In response, professional bodies such as the Royal College of General Practitioners (50) in the UK have published the Autism Toolkit, which contains information about autism and e-learning modules for GPs. Similar tailored resources are available in other countries including Australia (51) and Canada (52). Although these are undoubtedly valuable tools for GPs, there is likely to be substantial variation in their usage. In the current paper we will systematically collate and analyse the available literature involving GP knowledge or experiences of recognising and managing care for children with autism. Therefore, our objective is to provide an overview of GP knowledge of autism and factors that enable or impede their ability to recognise and manage care of children with this condition. With these goals in mind, it is envisaged that this review will generate material which may be of interest to clinically focused researchers, healthcare professionals and policy makers, as well as people with autism and their families attempting to navigate primary healthcare systems around the world.

Method

Overview

In line with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (53), we carried out a systematic search of available literature. Searches were run in eight electronic databases, including 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 these applying these terms to Title/Abstract searches in the aforementioned electronic databases. A full 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.

[Insert Table 1 about here]

Inclusion and Exclusion Criteria

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

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 (54) of .84, which is considered adequate (55). Where conflicts did arise, these were discussed and resolved between BC and MOC. In total, 62 citations were taken to full-text review.

[Insert Figure 1 about here]

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 because the studies did not include GPs. A total of ten studies were excluded as it was not possible separate GP data from other professional groups and GPs were 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. A further 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. A 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, was 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 2.

[insert figure 2 about here]

Approach to Synthesis

Given the diverse nature of the material included in the study, data were synthesised thematically. To this end, we followed the three-step coding and analytic process outlined in Thomas and Harden (56). Results sections and findings were coded 'line-by-line' for quantitative material. Regarding qualitative material, results sections were coded

'line-by-line' as were any appendices or other materials containing quotations. These codes were then used to develop descriptive themes. Using these descriptive themes, we then developed analytical or conceptual themes. The analytic software NVivo 12 was used to facilitate and assist with coding.

[Insert Table 2 here]

Quality Assessment

The Mixed Methods Appraisal Tool (MMAT) (57) was used to appraise the quality of material included in the review (see Table 3). This tool has demonstrated sound psychometric properties elsewhere (58). 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. In addition, 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.

[Insert Table 3 about here]

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 were identified. These spanned sixteen countries. Studies were published between 2003 and 2019, traversing two editions of the Diagnostic and Statistical Manual (DSM). Most studies (k = 12) included some objective measure of GP knowledge and/or awareness of autism. Several studies (k = 5) presented information which offered insight into perceived confidence and self-efficacy with autism. Four studies sought to explore attitudes, barriers and facilitators to recognising autism within the context of general practice.

Quantitative Findings

Knowledge

Thirteen studies included some quantitative measure of GP's perceived and basic knowledge regarding autism. The earliest of these was a 2003 study by Lian and colleagues (59). Here, the researchers surveyed 48 GPs in Singapore with a view to assessing basic knowledge of child development. To this end, the authors developed a child development questionnaire with five items relating to autism. The majority of GPs (95.8%) correctly reported that the link between autism and the old the old the measles, mumps and rubella (MMR) vaccine was false. Regarding prevalence, 83% of GPs endorsed a statement which placed rates of autism at approximately "1 to 2 per 1,000" [P399]. This statement was considered, by the authors, correct. Just over 40% of participants indicated that outcomes in children with autism can be "helpfully" modified by dietary changes. This was considered incorrect. Overall, 60% of participants endorsed two or more incorrect items on the autism block of questions.

In UK and Ireland, Kirby and colleagues (60) in 2005 asked teachers (n = 105) and GPs (n = 105) to qualitatively define a number of childhood developmental conditions including Asperger's syndrome. In total, 62.6% of GPs correctly defined Asperger's syndrome. Incorrect responses included "*an extremely badly behaved child*" and "*same as a clumsy child*" [P125]. One GP defined Attention Deficit Disorder as "*Asperger's syndrome*" [P125]. Kirby and colleagues

maintained that a basic knowledge of these conditions is required and as such recommended more education on specific learning difficulties for health and education professionals.

In Pakistan, Rahbar and colleagues (61) in 2011 surveyed 332 GPs in an effort to examine knowledge and attitudes towards autism. Only 44% (n = 148) of the participants were familiar with the term “autism”. Of these between 45–50% cited medical training and scientific journals as sources of information. By contrast, 53.4% described the media as a source of knowledge and just over 5% got information from pharmaceutical companies. Moreover, of those who were familiar with the term autism, only 42% (n = 62) reported having a working knowledge of autism. Regarding aetiology, 38.3% (n = 23) endorsed the statement “autism is preventable” and a further 16.7% (n = 10) were “unsure”. In addition, 45.2% of GPs agreed with the statement autism “*is mostly attributed to neglect in early childhood parenting*” while 6.4% were unsure. Over 30% of participants indicated that children tend to “*grow out of autism*”. In terms of clinical features, over 60% agreed that children with autism “*show detachment from their parents*” and just over 30% agreed that children with autism are not affectionate. Over 60% of participants agreed that there is social stigma associated with autism. Like Lian and associates (59) study, Rahbar et al (61) suggested that continual professional training and education would be an effective method of increasing GP knowledge. Indeed, the finding that practitioners who had psychology or paediatric training during their degree were more likely to report a knowledge of autism does support this recommendation.

Along a similar line of inquiry, Martínez and Montero (62) in 2013 surveyed 20 GPs in Cuba regarding knowledge of autism. Here the objective of the authors was to identify possible training needs of GPs in relation to autism and generalised developmental delay. To this end, the authors developed a questionnaire which asked participants about the early markers and core features of autism. In addition, the authors asked GPs to summarise the key detection stages outlined in *The American Academy of Paediatrics* guidelines on detection and screening, as well as the fundamental characteristics of various standardised diagnostic and screening assessment tools. The final sections asked GPs to distinguish core features of autism from features of other distinct conditions and describe pharmacological interventions. One of the most salient findings of this study was that none of the GPs were able to indicate an early marker of autism. This led the authors to conclude that knowledge regarding detection was limited. None of the GPs were able to recapitulate any of the stages outlined in the aforementioned practice guidelines. Further, none of the GPs surveyed matched the most notable characteristics of the tools with the correct tool. Nevertheless, all GPs correctly linked descriptions of clinical aspects of autism (e.g. presentation and age of onset) with the correct diagnosis, and excluded distractor items. In closing, the authors recommended GP training as a first line approach to overcoming the perceived gaps in knowledge.

Also in 2013, Muhammad et al (63) published a survey study of GPs in Baghdad, Iraq. Specifically, the authors surveyed 200 medical doctors including 110 GPs regarding their knowledge of autism. Here, the authors delivered a questionnaire to participants via interview. Across the sample, 95% of participants reported that they were familiar with autism, which as the authors pointed out, was an improvement from the previously discussed study in Pakistan. From the available information, it seems that the authors used Heidgerken and colleagues (64) updated version of ASK (20). As such, the questionnaire was divided into sections on social interaction (total score = 18), communication (total score = 6), circumscribed and repetitive behaviours (total score = 18), and signs and symptoms of autism (total score = 15). On average GPs scored 13.33, 4.37, 12.91 and 10.53 respectively on each of these domains. GPs averaged the lowest score on each domain, compared to other professional groups including paediatric residents, paediatric specialists, and family and community specialists. The authors present total scores for knowledge, rather than percentages for each item. As such, item level analysis and discussion were not possible. Yet the authors did underline the finding that 40.5% of GPs did not indicate that autism could be associated with epilepsy. In conclusion, Muhammad and colleagues appeared to be in concert with other researchers in suggesting that training courses had

an important role in filling the perceived knowledge gap. Further, the authors emphasised the value of incorporating autism in the general medical curriculum and increasing community awareness.

An Australian paper by Garg and colleagues (65) in 2016 offered further information regarding GP knowledge of autism. In this mixed methods study, Garg et al assessed knowledge of autism in a sample of 191 GPs. Citing limitations with previous surveys, the authors developed a True/False questionnaire, which consisted of 14 questions on diagnostic criteria (DSM-IV-TR), 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. Interestingly, the item which elicited the least number of correct responses (19.3%) asked participants whether DSM-IV criteria allowed for onset of features after 3 years. This is noteworthy because the subsequent edition of the DSM (2) broadened this criterion to the *“early in the developmental period”* [P⁵⁰]. In addition, approximately 10% of GPs indicated that diagnosis could be done on the basis of parental descriptions of behaviour at home. This signals a possible knowledge gap regarding the diagnostic process. Regarding interventions, 60.2% of GPs described early intervention behavioural interventions as effective. In light of these findings, the authors argued that further GP education focusing on early markers and identification was required.

In the UK, Unigwe and colleagues (66) in 2016 conducted a similar survey study (n = 304) exploring GP knowledge and confidence identifying and managing care for patients with autism. Here the researchers developed a corpus of statements about autism, to which the participants were asked to indicate whether the statements were true or false. The ASK (20) provided the foundations for these statements. Topics included prevalence, diagnostic markers, co-morbidities and misconceptions. In most cases, participants received high scores on this questionnaire with a mean of 88.1%. The item which prompted the least number of correct responses at 54.3%, stated *“an autism diagnosis cannot be made before a child is 3 years old”*. These results are similar to findings of Garg and collaborators.^[71] Regarding clinical features, just over 5% of participants indicated that a lack of eye contact was *“necessary”* for a diagnosis of autism and only 64.5% indicated that a child failing to respond to their name when called could be an early marker of autism. Fewer than 2% of participants suggested that autism was caused by parenting or the MMR vaccine. Using a ten-point Likert scale, the mean score for self-efficacy in recognising the features of autism in children was 5.2. The mean score for knowing to whom to refer a patient was slightly higher at 5.7, yet the mean score for perceived knowledge of referral pathways was 4.8. The authors concluded that GPs had sound knowledge about autism but limited confidence in their ability to respond to autism. They were also struck that, within a context where GPs have good knowledge of autism, it was curious that 39.5% of respondents reported not having received any autism training. One explanation offered by Unigwe and colleagues (66) was that GPs were drawing upon knowledge acquired from personal connections to autism, defined as experience with people with autism outside of a professional context. Indeed, nearly 50% of participants reported some personal connection with autism. Moreover, a personal connection to autism and prior autism training were significant predictors of self-efficacy.

An adapted version of ASK (20) was also used in Campbell's (67) in 2009 masters research project on autism knowledge of medical students and practitioners in Canada. The author surveyed medical residents (n = 59) and practicing physicians (n = 34, 21 of whom were practicing GPs) and 8 research and clinical experts. In total, 91% of the GPs had seen fewer than 10 patients with autism. When asked about perceived knowledge of autism, 15 GPs (71%) rated their knowledge as *“minimal”*.

Another Canadian research project offered further insight into GP knowledge of autism (n = 126). As part of a piece of work on GP attitudes to screening, Berenstein (68) in 2013 examined GP knowledge regarding the early markers of autism. The marker which received the greater level of endorsement (71%) was *“no single words by 16 months”*. Limited use of gestures, lack of babbling and lack of response to own name at 12 months were identified by 60–65%

of participants as possible indicators of autism. The author underlined that only 20% of participants noted “lack of joint attention” as a marker for autism.

The most recent paper included in the review was a Turkish study conducted in 2019 by Altay (69). Reflecting the lack of methodological convergence in this area of research, the author developed another bespoke survey designed to examine GP awareness of autism. This questionnaire asked participants to outline diagnostic features of autism using DSM–5 criteria (2), common presenting developmental differences, and the age at which these differences are most often communicated to GPs. Altay found that 70.8% of GPs had not referred any children to a child and adolescent psychiatrist with a query of autism. Of the 29.2% who had referred a child, Altay states that these GPs had referred approximately 1 to 3 children. Regarding clinical features, participants were asked to identify five clinical features of autism. Of these, “inability to make eye contact” was the most commonly identified marker with 72% (n = 35) of GPs endorsing this feature. Over 50% of GPs described features which are not DSM–5 characteristics of autism. The most common of these were “*hyperactivity*” and “*learning disability*” which were identified by 34.6% and 23.1% of GPs respectively, perhaps signalling an unclear boundary regarding clinical features and co-morbidities. A further 11.5% of GPs endorsed “*singing*” and “*irritability*” as diagnostic features of autism. In closing, Altay (69) argued that GP knowledge of these conditions was not satisfactory. Echoing the recommendations of others, Altay called for an increase in autism training programmes for GPs, with a particular focus on clinical features, comorbid conditions, and recent aetiological evidence. Like Unigwe and colleagues (66), Altay did ask participants to indicate previous training. The majority of GPs (66.7%) indicated that they had not received previous training in autism and of those who had, 27.1% indicated that it was not sufficient. In total, 6.3% of GPs were trained and described this training as “sufficient”.

Two studies opted to use the KCHAW to survey professional’s knowledge of autism. This questionnaire includes a total of 19 items which are grouped into four domains. These domains are i) social interaction ii) communication iii) circumscribed and repetitive behaviours and (iv) autism characteristics and comorbidities. The first of these studies was conducted by Esegbe and colleagues (70) in Northwest Nigeria. Here, 167 health care professionals, including 76 GPs completed the KCHAW. Interestingly, 20 out of the 76 GPs reported having seen a case of autism. Overall, the mean total knowledge score was 13.5 and 66% of GPs were classified as having ‘poor autism knowledge’. Over 30% of participants indicated incorrect responses to age of onset, which the KCAHW conceptualises as “childhood”. The same number also did not indicate an association between autism and epilepsy. Meanwhile, 28.7% did not report an association between autism and abnormal eating habits. The authors advocated for a multi-pronged approach to increasing knowledge of autism among healthcare professionals and achieving better outcomes for people with autism in Africa. In particular, the authors underscored the importance of education in the medical school curriculum and teaching first-contact healthcare providers about autism. Furthermore, the authors emphasised that training should be supplemented by governmental initiatives to promote awareness and understanding of autism.

Similarly, Salama (71) used the KCAHW to explore knowledge of autism among a group of GPs (n = 70) in Egypt. In this study, the overall the mean score was 11.2, which is a lower mean than Esigbe and colleagues observed. This may be explained by the fact that Esigbe included professionals from secondary services (e.g. psychiatrists), which may have increased the mean score. In this study, the statement “*Autism could be associated with epilepsy*” elicited the highest number of incorrect responses, with 70% of participants disagreeing with the statement. Interestingly, only 21% of GPs reported having prior experience being involved with the assessment and management of autism. Like Rahbar and colleagues (61), a considerable number of participants incorrectly answered the question regarding age of onset of autism. Salama concluded that GPs in this study displayed a lack of knowledge regarding autism. Consequently, Salama joined the chorus of other researchers in advocating for more autism training programmes for GPs.

Issues regarding standardised screening for autism appeared across many of the studies. In some studies (62, 65) awareness and familiarity with autism screening tools were treated as a metric of autism knowledge. These studies will not be the focus of this section. Instead, we focus on reports of GP attitudes and perceptions towards autism screening.

Al Maskari (72) in 2018 surveyed 299 nurses and 217 GPs regarding perceived barriers and facilitators to screening for autism in Oman. Using data collected from two focus groups, Al Maskari (72) developed a questionnaire that explored organisational, professional, and social barriers to screening, as well as possible strategies to facilitate screening. Here, the most frequently endorsed organisational barriers to screening were a lack of resources and autism training. These were endorsed by 82% and 80% of participants, respectively. 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, yet participants were somewhat divided regarding 'staff shortages', with 55% disagreeing with this barrier. In terms of sources of autism knowledge, between 70–75% of participants attributed their knowledge to professional training and continuing professional development. There was a significant difference between nurses and GPs. GPs were more likely to attribute their knowledge to training and self-updates, whereas nurses were more likely to indicate that their knowledge came from children and families they had worked with. 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. Nearly 95% of participants emphasised the importance of collaboration between health and educational services to facilitate early diagnosis.

An academic poster by Limbos and colleagues (73) in 2012 shed light on GP attitudes toward standardised screening in Canada. Regarding methods of assessment, just over 30% of GPs indicated that parental concern was a good substitute for standardised screening, while under 20% endorsed the statement "*I have the clinical expertise to identify most children with developmental delays in my practice without the use of a formal screening instrument*". Fewer than 5% indicated concerns about the evidence base for standardised developmental screening. Turning to perceived 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 60–70% of GPs endorsing these barriers.

The doctoral project by Berenstein (68) in 2013 offered further insight regarding GP 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. Similarly to Limbos et al (73), "*lack of time*" was the most commonly endorsed barrier to screening, finding resonance with 79% of participants. Further mirroring the findings of Limbos and colleagues, "*lack of familiarity with available screening tools*" was also endorsed by 79% of participants. Across both Limbos et al and Berenstein, access to screening tools was endorsed by over 40% of participants as a barrier to screening.

Training

Despite receiving much endorsement, we only identified one study that directly explored the effectiveness of training to increase GP knowledge. Eray and Murat (74) in 2017 invited 215 GPs to an autism training programme in Van, Turkey.

Of these, 79 attended and were surveyed before and after the two-hour programme, which was delivered by two psychiatrists. The survey explored knowledge and misconceptions regarding prevalence, aetiology, clinical features and interventions. The same questionnaire was administered pre- and post-training. In total, data from 75 participants was included in the final analysis. At baseline, the authors reported that 34.7% (n = 26) of GPs felt that they had sufficient information about autism, whereas 65.3% (n = 49) indicated that they did not. Post-training, 88% (n = 66) of participants indicated that they had sufficient knowledge about autism for their practical needs.

The authors deemed that 12% of participants answered the question about prevalence correctly prior to training, which improved to 88% post-training. Regarding aetiology, prior to training *“heavy metal exposure”* and *“exposure to television”* were endorsed by 62.7% and 36% of participants respectively as potential causes of autism. These figures reduced to 16% and 14% respectively post-training. Turning to diagnosis and service provision, at baseline 50.7% of participants correctly identified that typical eye contact does not preclude a diagnosis of autism. This increased to 72% after training. In agreement with the findings of Altay, 21.3% of participants pre-training indicated that autism was *“always accompanied by a learning disability”*. Moreover, this was one of the items where the authors did not observe a significant difference between pre- and post-training. In terms of service provision, only 37.3% of GPs indicated that children with autism could attend mainstream education, though this increased to 78.7% post-training. In the context of these findings, Eray and Murat endorsed autism-specific training for GPs during their medical training or after.

Qualitative Findings

Seven studies included some analysis of qualitative data, whether from questionnaires, interviews and focus groups. Al Maskari 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 in Oman. These included a) organisational b) professional and c) social or contextual barriers. Many nurses and GPs suggested that the current service configuration was not well equipped to introduce autism screening as part of routine care. Short appointments and caseloads reaching upwards of 60 patients per day were described as some of the practical barriers to screening. Many GPs suggested that their overall knowledge about autism needed ‘updating’. 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. Nurses and GPs alike expressed that the social stigma attached to a diagnosis of autism in Oman presented an obstacle to screening.

Compared to barriers, considerably fewer facilitators to screening were identified during the focus groups. Only two facilitators were identified: i) interest in identifying autism and ii) the current recording system (Pink Card). 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 overarching themes. These were termed *“constraints”*, *“family”*, and *“professional education”*. Taking *“constraints”*, similar to the focus groups, many participants described a lack of time as a significant obstacle to screening. Much like in the focus groups, participants reflected that there was a lack of public awareness regarding autism and a social stigma attached to the condition. In terms of increasing awareness and tackling stigma, strategies such as media campaigns, health education programmes were suggested.

In Berenstein (68), 72 GPs responded to an open question asking them to indicate significant barriers to recognising autism in primary care. Here, 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. Nearly a fifth of participants felt that the available screening tools were problematic or difficult to use, with one GP simply remarking *“No good tools”*^[P101]. Tensions between services also

surfaced, with GPs expressing dissatisfaction with waiting lists for diagnostic assessment and with some maintaining that there was a lack of appropriate professionals to refer to. Further, some GPs stated that convincing parents that their child may have autism could be an obstacle to screening.

In the USA, Fenikilé and colleagues (75) 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. One newly qualified GP reasoned *"We're fresh out of residency so we don't have experience... So for me I tend to be a little more detailed and if there is a screening tool,"*^[P359]. Some GPs expressed reluctance to preferentially screen autism over other developmental conditions. Without exception, participants 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. Some participants were sceptical about the effect of changes to diagnostic criteria and several implied that autism was being *"over-diagnosed"* and the definition was yet to establish *"its home turf"*^[P361]. At the same time, parental reluctance to "label" their child was also identified as a barrier to screening. An array of solutions were offered to improve screening. These included incorporating 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 (65), qualitative data was 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. The role of GPs in identification was thrown into question by one GP who remarked that children are typically picked up by other professions and services. In another paper published from this study, Garg and colleagues (76) 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 10–15% 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 and colleagues (66), 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. Regarding system factors, tensions between services came to light with participants expressing 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. The compartmentalisation of services coupled with complex configuration of referral pathways services was conceptualised as a core challenge to obtaining appropriate supports and services for people with autism. Consequently, there was a call for clarity regarding referral pathways and appropriate service which was echoed by several participants. Given the current structure of general practice, many participants indicated that they did not have enough time to screen for autism. Nevertheless, the GPs appeared in agreement regarding their wish for further training.

Narrative Thematic synthesis

Using the techniques drawn from Thomas and Harden (56), we identified 5 topics for further discussion and synthesis. These broad themes were: the prototypical image of a child with autism; experience and sources of information; barriers to identification; strategies to aid in identification; and characteristics that facilitate expertise. Qualitative and quantitative material were brought together using narrative methods(77).

1) Prototypical image of a child with autism

In many studies, GPs were asked to identify, describe or respond to clinical features that may be related to autism. While these data were most often used as a metric or indicator of autism knowledge, it also offers insight into the GP's prototypical image of a child with autism.

- End of the spectrum

During focus groups in Oman (72), for example, 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 (69), nearly a quarter of GPs indicated that 'learning disability' was a diagnostic marker for autism. These findings were buttressed by another Turkish study (74) which 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 (66), 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. Indeed, views on widening of diagnostic criteria came to the forefront during interviews and focus groups with GPs in the US (75). 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."*^[P361]. This perhaps signals that, in some cases, GPs are conflicted about considering the spectrum of presentations and balancing this with concerns about overdiagnosis that they perceive as valid.

- Nosological boundaries and aetiology

Some GPs intimately linked autism with learning disability, while some also associated autism with other nosologically distinct conditions. For instance, in the UK and Ireland (60), one GP considered Asperger's syndrome as a *"more severe form of ADD"*. Further, in Altay (69), over a third of GPs indicated that 'hyperactivity' was a clinical feature of autism. While in Oman (72), one GP suggested that observing hyperactivity in the clinic might be a way to screen for autism. Whereas in Rahbar (61), of those familiar with autism, nearly a third indicated that autism was a precursor to schizophrenia while nearly 30% were unsure and just under half agreed that autism is mostly attributable to neglect in early development. Similarly, in Eray and Murat (74), 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 (66), fewer than 2% agreed that autism was caused by maladaptive parent-child bonding. In Cuba (62), despite not describing specific early markers for autism, none of the GPs matched autism to symptoms of schizophrenia. Furthermore, overall survey studies in the UK, Turkey, Singapore and Australia suggest that the vast majority, but not all, GPs recognised that autism was not linked to the MMR vaccine.

2) Experience and sources of information

It seems that there may be some misconceptions about autism symptomology and aetiology in play for some GPs. Though proportions differ across contexts, a vast majority of studies have identified a 'lack of training' contributing to limits on GP's relevant expertise. It is, therefore, necessary to consider how much experience GPs report having with autism and also where they are getting their information.

-Routine experience with Autism

Results from survey studies indicate variation regarding the extent of previous experience with autism. In the UK, for instance, Unigwe 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 (71) and Nigeria (70), 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 (67) found that of the GPs surveyed (n = 33), a third reported having less than one-year experience with autism and over 90% had fewer than 10 patients with an established diagnosis. Whilst, in Pakistan, Rahbar et al (61) found that the majority of GPs surveyed (n = 332) were not familiar with the term "autism" and a total of 62 participants reported a working knowledge of autism. In a 2013 study in Iraq (63) 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.

- Sources of autism information

Three studies asked GPs to cite sources of knowledge regarding autism. In Pakistan (61), participants suggested a variety of sources, including medical training and scientific journals which were indicated by 45–50%. The most commonly endorsed source was 'the media', which was mentioned by 53.4% of participants. This indicates that GPs are potentially leaning on lay sources to supplement their understanding of autism. Meanwhile in Oman (72) and in a context where health care 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 (66), many GPs indicated that they had not received training in autism, yet showed sound knowledge of the condition. Here, 47% of participants had a personal connection with autism. In concluding, the authors reasoned that GPs were relying on personal experiences and connections with autism to supplement their knowledge of the condition.

3) Barriers to identifying autism

We identified three themes relating to barriers to identification. These were 'GP and practice specific', 'tensions between services', and 'socio-cultural' factors.

- GP and practice specific

Studies in Oman (72), Canada (68), the US (75), Turkey (74) and the UK (66) between 2013 –2019 found that some GPs felt a lack of knowledge and training impacted on their ability to identify 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"*^{P115}. 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.

- Organisational and service tensions

At times, organisational shortcomings tended to find expression 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. For example, in Canada (68), waiting lists were the most commonly endorsed barrier to referral, finding resonance with 64% of participants. Similarly in Australia (65), GPs showed a tendency to describe waiting lists as lengthy, citing evidence from parental-report. Qualitative data from studies in Oman (72) and the UK (66) indicated a degree of dissatisfaction with the configuration of referral pathways. For example, some GPs in the UK (66) were particularly critical of the waiting lists, referral pathways and the compartmentalisation of expertise. One GP described the situation as follows: *"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)"* [p450].

- Socio-cultural factors

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 (75), some GPs felt that parents were reluctant to have the 'label of autism' applied to their children due to stigma. Additionally, and perhaps somewhat unique to the American context, 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 (61), the majority of GPs felt that having a diagnosis of autism would lead to discrimination against the child. In this study, GPs also agreed that there was a social stigma around autism and children with a diagnosis would tend to be viewed negatively. Likewise in Oman(72), the prevailing view amongst GPs and nurses was that the term 'autism' holds some social stigma.

4) Strategies to facilitate identification

On balance, GPs tended to offer 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. Specifically, a sample of GPs in Australia (65) indicated that training in early features, referral pathways and how autism presents across the spectrum would be beneficial. In Oman (72) and the US(75), 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.

5) Characteristics that facilitate expertise

Several studies explored whether participants' characteristics mediated autism knowledge and screening practices. Results were somewhat equivocal and difficult to harmonise; an inverse relationship between age and autism knowledge was observed in some studies (61, 65, 71), but not in others (59, 66, 70). Years of professional practice were significant in some studies (61, 65, 70, 71), but not all (66). Moreover, studies tended to use different benchmarks for experience. For instance, Esegbe et al (70) drew a dichotomy between participants with fewer than eight years' experience, whereas Rahbar et al (61) classified participants as those within five years of graduation and those with more than five years' experience post-graduation. One study (68) 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 (70) 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 (59, 61, 65, 71).

Discussion

Summary of key findings

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. To this end, we synthesised the literature and identified the following five themes: i) prototypical image of a child with autism; ii) experience and sources of information; iii) barriers iv) strategies to aid in identification; v) participant characteristics. Taken together, these 17 studies, spanning 2003–2019, offer a somewhat 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, across the set of studies, this tilted towards the minority. Many 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.

Comparison with the literature and implications

The findings from the current review offer some measure of explanation for the marked diversity in pre-diagnostic experiences of children and families with a query of autism (30, 31, 35). Essentialist views towards diagnostic markers and comorbidities perhaps explain why some children with less classic features or more adaptive functioning are diagnosed later (30). Much like in Tatlow-Golden and colleague's (78) review of GPs and ADHD, aetiological theories about parenting also persisted with some GPs when thinking about causes of autism. This is particularly concerning given that these views are rarely seen even in lay populations (17, 79, 80). Further, all studies included in the review were published within the last fifteen- twenty years. As such, during this time, aetiological theories regarding parenting and autism have largely been discredited. Within a context where training and experience is often limited, enduring questions surface regarding the material and sources which shape the GPs understanding of autism. In the current review we only identified three studies which explored this directly, with sources including 'the media' and 'personal connections'. This requires particular attention given that doctors are viewed by lay populations as authorities regarding autism (17). Further, it is consequential if GPs are supplementing their clinical decisions with the representations of autism in the media. One potential problem with this approach is that media offers a frame of discourse about children with autism and their families, which may not be situated in clinical literature (15). As such, misconceptions or unhelpful attitudes about the condition may be propagated, while the full range of presentations is neglected. Personal connections may offer practitioners invaluable insight when working with patients with autism. Yet, we are in agreement with Unigwe and colleagues (66) in that doctors cannot be expected to respond to autism effectively and to needs of patients with autism confidently if they are predominantly reliant these connections.

In light of the above, it is somewhat predictable that most studies recommend autism-specific training for GPs. Indeed, we also speculate that training would be beneficial, particularly in contexts where GPs are gatekeepers for specialist

assessment or where there are misconceptions about the condition. As discussed previously, there are a suite of credible and helpful online resources for GPs who want to know more about autism (50). Indeed, online training has been shown somewhat effective with other populations in terms of tackling stigma and increasing knowledge (18). We echo and amplify the cautionary caveats of Tatlow-Golden and colleagues (78) regarding the educational approach. For instance, only one study (74) 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. Therefore, whether such training will be clinically meaningful remains unclear. Other factors have also been shown to influence the extent to which knowledge is put into practice. For instance, a qualitative study (81) of family medicine residents at the University of Toronto found that their sense of urgency and clinical certainty influenced whether the residents referred a child for specialist autism assessment. These findings therefore suggest that some clinicians may not feel comfortable or equipped to refer children with less pronounced developmental differences. Whether educational training is likely to have an impact on this remains an urgent question.

However, it is not clear how GPs' wishes for autism training compares to their desire to receive training on other areas. Several studies have described a lack of training or education in GPs across an array of topics including ADHD (78), dementia (82), intrauterine contraceptive devices (83), suicide (84), and palliative care (85). 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. But moreover, it might be the case that perceptions about a 'lack of training' permeates general practice and, as such, is not particularly unique to autism. This is consequential for understanding barriers and designing educational programmes and as such requires future work. Further, the focus on training may direct attention away from other avenues such as embedding toolkits or screening tools in technologies used by GPs and information sharing solutions between services.

Moreover, to treat the problem as the lack of training for GPs in autism risks silencing the array of 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 (86). This is within a context where the number of consultations is increasing (23) and funding for primary care has reduced (86). 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 (87, 88). Rather, this speaks to organisational shortcomings with coordinating healthcare. The advent of electronic health records may be particularly helpful in this regard (89, 90). We speculate that the successful sharing of information between primary and secondary care as well as social, forensic and educational services could constitute one of the most positive and beneficial public health initiatives of our time.

Limitations and Strengths

An issue that requires further discussion is the conceptualisation of 'autism knowledge' across studies. That is, only two studies explicitly described using the same standardised tool, while others updated previous tools or created a new assessment. Therefore, findings regarding 'autism knowledge' cannot be extrapolated to all GPs. This is not unique to the current paper and is in-keeping with the previously discussed review by Harrison and colleagues (19). This trend obviously makes it difficult to synthesise and generalise findings across studies. In response, Harrison and colleagues advocate for more consistency in measuring autism knowledge and, broadly speaking, we are in agreement. Although, 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'. With autism in mind, therefore, it is crucial to consider what understanding of 'autism' is practically useful for the GP in their context. That is, a shared understanding is needed that will facilitate communication between GPs, patients and families as well as colleagues in primary and secondary care and is, to some extent, anchored in the clinical and research literature.

Consideration of both qualitative and quantitative material may be regarded as a potential strength of our review. Yet, the qualitative data were somewhat limited and often confined to open-ended responses on a survey. Regarding the review method, our reliance on electronic databases and primary research studies means that our coverage was somewhat restricted. Nevertheless, we believe our search strategy was robust and was a core strength of the review. We included diverse material (e.g. journal articles, theses, an academic poster), applied no date or language restrictions, and followed a standardised process for screening studies which resulted in good interrater reliability. Including studies from various healthcare services means that we are able to present an overview of the topic.

Yet it is important to note that there is variation regarding the nature, scope and delivery of primary care systems throughout the world. For instance, Irving and colleagues (91) recently reviewed the international literature on GP consultation times and found that, in 19 countries, consultation times were five minutes or less. The authors pointed out that in settings such as Pakistan, China and Bangladesh, a GP might undertake 90 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. Additionally, data from the Organisation for Economic Co-Operation and Development (OECD) shows substantial variation regarding the number of GPs per 1,000 between countries. Yet, these OECD data(92) are not available for several low- and middle-income countries. Recently, the WHO commissioned several reports on Primary Health Care Systems in low- and middle-income countries including Nigeria, Pakistan, and Indonesia, identifying a diverse array of gaps in service provision. For instance, the report in Nigeria(93) identified a shortage of primary and secondary care facilities in rural areas and characterised the referral system as 'weak' and 'fragmented'. Relatedly, the report in Pakistan(94) identified disparities in urban and rural service coverage with 14.5 physicians per 10,000 in urban areas and 7.6 per 10,000 in rural regions. This is within a context where over 60% of the population live in rural areas, and is in contrast to other contexts such as Columbia(95) where the majority of the population live in urban areas.

Nevertheless, common to all systems 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 suspected autism. Moreover, most healthcare systems are configured such that GPs refer children for diagnostic assessment, rather than conduct this assessment or provide treatment themselves. This is in contrast to contexts where GPs may provide treatment for conditions such as anxiety, depression. Additionally, within every healthcare system, GPs will have some role in managing care for patients with autism even if they are not involved in the assessment. Furthermore, our findings do indeed elucidate common areas of knowledge and barriers to identification across cultures and contexts.

Conclusion And Future Directions

Our findings illustrate marked variation both in GP knowledge of autism and the way researchers conceptualise autism knowledge across studies. As such, more empirical and conceptual 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 structural and organisational pressures on GP

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Abbreviations

WHO, World Health Organisation; ASK, Autism Knowledge Survey; KCAHW, Knowledge about Childhood Autism among Health Workers, GPs General Practitioners/Family Practitioners; UK, United Kingdom; CHAT, Checklist for Autism in Toddlers; M-CHAT, Modified Checklist for Autism in Toddlers; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analysis; ADHD, Attention Deficit Hyperactivity Disorder; CFA, confirmatory factor analysis, MMR measles, mumps and rubella; DSM, Diagnostic and Statistical Manual; US, United States of America

Declarations

1. Ethics approval and consent to participate

- Not applicable

2. Consent for publication

- Not applicable

3. Availability of data and materials

- See additional information for searches

4. Competing interests

- “The authors declare that they have no competing interests”

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6. Authors’ contributions

BC led the project and was heavily involved in each stage of the review including developing the search terms, performing searches, screening studies, analysing data, and writing the manuscript. RD assisted with designing the review, analysing the findings, and was a major contributor in writing the manuscript. ME OC assisted with developing the search strategy and was heavily involved with each stage of screening papers and quality checks. MW provided clinical expertise and contributed significantly to writing the manuscript. All authors read and approved the manuscript.

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