

Barriers, facilitators, and experiences of the autism assessment process

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Abstract

Experiences of professionals diagnosing Autism Spectrum Disorder (ASD) have been significantly under-researched. Around 1-2% of children in developed countries receive a diagnosis of ASD. Early diagnosis is crucial as delayed diagnosis risks missing the opportunity to receive early interventions which can improve developmental outcomes and quality of life. The purpose of this article was to identify systematically and summarise the experiences and perceptions of health professionals who diagnose ASD. Seven articles were identified, through a systematic search of four databases and the reference lists of identified articles. The articles were critically appraised, and their results summarised. All papers scored well on the risk of bias assessment. The papers included research from the United States of America, the United Kingdom, Canada, and Belgium. Themes from papers were considered under five topics: barriers, facilitators, diagnostic process, informing of a diagnosis, and post-diagnosis. Clinical implications emphasise the need for clear guidelines, multi-disciplinary teams, and a clear process for providing information on the diagnosis and relevant services to parents. Training implications highlight the need to train health professionals on how diagnostic tools and professional judgements can be integrated. Training should also help make professionals aware of the barriers that they may face when diagnosing ASD. Future research is needed to increase the literature on professionals' experiences of diagnosing ASD and focus on the impact this can have on the health professionals themselves.

Key words: autism spectrum disorder, diagnosis, professional, qualitative research, systematic literature review

Introduction

Autism Spectrum Disorder (ASD)* is a neurodevelopmental condition that impacts behaviour and communication (Lai et al., 2014). It is characterised by differences in social communication and social interaction, and repetitive or restrictive behaviours and interests (American Psychiatric Association, 2013; World Health Organization, 2018). Diagnostic manuals also require evidence of functional impairment or difficulty (APA, 2013; WHO, 2018). Though ASD has been diagnosed since the middle of the 20th Century, recent changes in diagnostic criteria have required professionals to change their understanding of ASD (American Psychiatric Association, 2013; Ramsey et al., 2016; World Health Organization, 2018). The current prevalence rate of ASD has been estimated at around 1-2% in developed countries, with males being three to eight times more likely to be diagnosed than females (Baio et al., 2018; Lai et al., 2015; Lyall et al., 2017). There is no agreement on the biological mechanisms underlying the onset and development of ASD, and no single predictive biomarker to aid diagnosis of ASD (Bjorklund et al., 2018). Clinical guidelines recommend using a range of assessment measures and methods. Gold-standard assessment tools for diagnosing ASD include the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview-Revised (ADI-R), alongside a diagnostic examination by a clinician (Kamp-Becker et al., 2018; Lord et al., 2012; Lord et al., 1989; Lord et al., 1994). The ADOS (first version) is a semi-structured observation instrument consisting of four “modules” – with differing procedures based on chronological age and expressive language ability (Kamp-Becker et al., 2018). The ADOS-2 is a revised version of the ADOS, consisting of five modules (Kamp-Becker et al., 2018). The ADI-R is a diagnostic interview

* Throughout this paper, we use the terms Autism Spectrum Disorder (ASD) and person/children with autism. This is in line with the journal preferences and the diagnostic labels used within the diagnostic criteria discussed in the article. We recognise that this is not the language preference of everyone in the autism community and that readers will have their own legitimate preferences in this area.

completed by parents or carers (Rutter et al., 2003). It explores someone's early development; social development and play; language acquisition; current functioning of language and communication; and interests and behaviours (Rutter et al., 2003). By using these standardised assessments, ASD is often assessed by someone's level of deviation from the norm, however, this can be culturally insensitive (Norbury & Sparks, 2013). These assessments can be culturally insensitive, as they assume social behaviour is consistent across groups. For instance, it is difficult to measure pragmatic language skills using a standardised measure, due to these skills being susceptible to cultural variation (Norbury & Sparks, 2013). Therefore, a diagnosing clinician is expected to be able to mediate between the family's views, whether the person meets diagnostic criteria, and whether any 'deviations' may be explained by other factors.

The ASD diagnostic process can be long, and there is often a delay between the first identification of ASD in a child and the diagnosis, with studies suggesting it can be years before a diagnosis is made (Shrestha & Shrestha, 2014; K. Zuckerman et al., 2015). Parents' concerns play an important role throughout the process (Legg & Tickle, 2019). Recent research in the United States of America (USA) found early parental concern about verbal communication predicted an earlier ASD diagnosis (Zablotsky et al., 2017). The importance of the parents' role in diagnosis can put a strain on diagnosing clinicians, as clinicians rely on parents to report behaviours that may not be observed in clinic. Additionally, professionals must mediate the expectations of parents, and support both the parents and the person being diagnosed, which can be stressful for both clinicians and parents. Further complicating this situation, children whose diagnosis is delayed miss the opportunity to receive early interventions which can improve their developmental outcomes and quality of life (Daniels et al., 2014). Therefore, there is additional pressure on professionals to recognise when parent

reported behaviour requires further assessment to ensure a timely diagnosis, if required, is made.

The experience of parents of the diagnostic process has been given significant attention. A recent systematic review of parents' experiences of an ASD diagnosis in the United Kingdom (UK) found that parents find the diagnosis stressful, and the authors suggest that this may be due to wait times and a lack of post-diagnostic support (Legg & Tickle, 2019). Parents express the need for both professional and social support, and access to information about their child's condition (Derguy et al., 2015; Hodgetts et al., 2015). A Canadian study found that parents experienced significant difficulties obtaining a diagnosis for their child, with parents seeing an average of 4.5 professionals and the average wait between their first visit to a professional and the diagnosis being almost 3 years (Siklos & Kerns, 2007). In the USA the average age of diagnosis is after 4 years (Zablotsky et al., 2015) and in the UK the median age of diagnosis is about 4.5 years (Brett et al., 2016). Within the UK and Canada there is a publicly funded healthcare system, responsible for diagnosing ASD. In the USA insurance is typically needed to access assessment for ASD. Emerson et al., (2016) completed research in the USA and found lower socioeconomic status significantly predicted age of diagnosis; they suggested families of a lower socioeconomic status may encounter financial difficulties with affording medical co-payments.

Guidelines on which professionals can diagnose ASD vary across countries. In the USA paediatricians, psychologists, psychiatrists, and neurologists may diagnose ASD (American Psychological Association, 2017). In contrast, in the UK only paediatricians, psychologists and psychiatrists accompanied by allied health professionals may diagnose ASD (National Autistic Society, 2020). In Canada, trained psychological associates and nurse practitioners may also diagnose ASD.

The majority of the research literature on ASD diagnosis focuses either on the development of technical diagnostic tools, or on quantitative descriptors associated with diagnosis, such as prevalence, demographic covariates, and associated comorbidity. The experience of those involved in the diagnostic process is often neglected. A study researching ASD diagnostic certainty in the USA found that 59.2% of the clinicians were completely certain of the diagnosis made (McDonnell et al., 2019). Furthermore, clinicians were 1.85 times more likely to be certain of a diagnosis for a child with private insurance than a child with public insurance and child age correlated negatively with certainty (McDonnell et al., 2019). Further quantitative research from a study of 116 health professional who diagnosed ASD in the UK (Rogers et al., 2016) found that 59% of health professionals were satisfied with their service availability and that standard diagnostic tools were perceived as helpful. Additionally, 32% of the professionals stated that would 'never' give a false positive diagnosis, but the majority of the professionals recognised that they did practice 'upgrading' ASD diagnoses to some degree (Rogers et al., 2016, pg 825).

Much of the literature that does exist on the experience of ASD diagnosis has focussed on parental experiences. Although it is crucial to understand how parents experience the diagnostic process, we also need to understand the experiences and perceptions of professionals and people with autism themselves. In the current paper, we focus on professionals' experiences. Professionals' experiences may have a significant impact on diagnostic accuracy, as they must weigh up competing hypotheses to explain a person's presentation. Professionals' experiences also impact on their interactions with service users. These initial interactions may be crucial in how children/ adults with autism, and their families understand their diagnosis and potential avenues for future support. The objectives of this review were to identify and summarise the literature on the experiences and perceptions of diagnosing ASD for health professionals, and to support future health

professionals by summarising the facilitators and barriers to diagnosing ASD. The systematic review focussed on qualitative research to allow for the context of the findings of the quantitative research recognised earlier to be discussed.

Method

Search Strategy

The search strategy was developed using Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009). The databases of PsychINFO, MEDLINE®, Embase, and CINAHL Plus were searched using a variety of search terms to locate literature from January 1994 to December 2019. The year 1994 was chosen as it marked the release of the Diagnostic and statistical manual of mental disorders IV (DSM-IV), which was the first manual to categorise ASD as a spectrum (American Psychiatric Association, 1994). Evaluating research from this date would allow for understanding how experiences have changed over time, though note that final papers returned reflected that interest in this topic has only developed recently. The terms were developed after reviewing research within the topic area (Legg & Tickle, 2019). Terms within a key concept were combined using ‘OR’ and the key concepts were combined using ‘AND’, these were all searched under key words. Full search terms are listed in table 1. To ensure the research found was based on the diagnostic guidelines that were available between the dates searched, Autism Spectrum Disorder and abbreviations of this were used. Generic terms were used, such as health professionals, to include all professionals that might be involved in the diagnosis of ASD, such as Speech and Language Therapists (International Labour Office, 2012). Specific terms for professions were used, such as physician, psychologist and psychiatrist, as these professionals have an extensive role in the diagnostic process in some countries but are not classified under the *health professional* group

(International Labour Office, 2012; National Autistic Society, 2018). A hand search of the reference lists of the articles kept after screening by title and abstracts was completed.

Table 1

Search Terms Used

Key concept	Search Terms used
Health	profession* OR physician OR psychologist OR psychiatrist OR
Professional	clinician OR practitioner OR health profession* OR health personnel*
ASD	asc OR asd OR autis* OR asperg*
Diagnosis	diagnos* OR recognition OR assess* OR evaluat* OR measure*
Methodology	Qualitative OR mixed methods

Selection Criteria

The inclusion criteria for articles were as follows: 1) studies in English Language, 2) studies using qualitative or mixed methods, 3) studies where the participants were professionals involved in the diagnosis of ASD, and 4) studies focusing on the experiences and/or perceptions of an ASD assessment or diagnosis. Articles were excluded if: 1) the results were collected using only quantitative methods, 2) participants were not health professionals, 3) data collected were on experiences other than the ASD assessment or ASD diagnostic process, 4) data collected did not focus on the professionals' views of the overall diagnostic process, and 5) they were not published in a peer reviewed journal. Two authors (AH and MB) completed independent checks on the initial records excluded and reasons for this. They then met to discuss and agree on these. They then independently hand searched the

references lists and assessed the full-text articles for eligibility and reasons for exclusion and met to discuss and agree on these.

Data Extraction

After duplicates were removed, the titles and abstracts were screened and studies that did not meet the inclusion criteria or met any of the exclusion criteria were excluded. The remaining full-text papers and subsequent reference lists from these papers were assessed for eligibility. The study characteristic data extracted from the final set of studies were the title, author, date, country of study, study design, qualitative analysis method, and participant characteristics. The number of participants, age range, range of experience, setting of work, profession, and the people they diagnose were recorded as participant characteristics.

A meta-synthesis of the studies was not possible due to the heterogeneity of the methods employed across the studies, such as the diagnostic process in differing countries and differing roles each profession performed in an ASD diagnosis. With this in mind, data were extracted in a theory neutral manner. Due to the studies being completed in differing countries, any country specific information was not included to allow for a broader picture of the views, experiences, facilitators, and barriers. To extract data from each of the papers, the lead author (AH) recorded the experiences and perceptions of the professionals reported in each paper in detail. Further to this, she recorded themes and subthemes presented in each article. Once data extraction was complete, the themes and subthemes from the reviewed articles were collated. The themes and subthemes were sorted into broader topic areas based on their descriptions – this was done on the basis of the explicit content reported for themes and subthemes, rather than through trying extract or determine underlying meaning. These topic areas were provided with a label representative of the content covered within the topic – for instance those themes reflecting on things that made the assessment process easier were

considered within *facilitators*, whilst those that related specifically to the post-diagnostic process were considered within *post-diagnosis*. Topic areas were therefore not mutually exclusive; a theme could reflect a facilitator to assessment, but also relate to post-diagnosis. The lead author was provided with supervision throughout this process, the final topic areas and their contents were also checked against the original papers by a second author (AS). This process was employed to provide a structure through which to discuss the findings as reported by the original authors, rather than unitary meta-synthetic themes. All but one theme from the papers were included; the one theme (from Jacobs et al., 2019) was not included due to a focus on professionals view of ASD and therefore, it not in keeping with the scope of the review. No additional themes/ sub-themes were created.

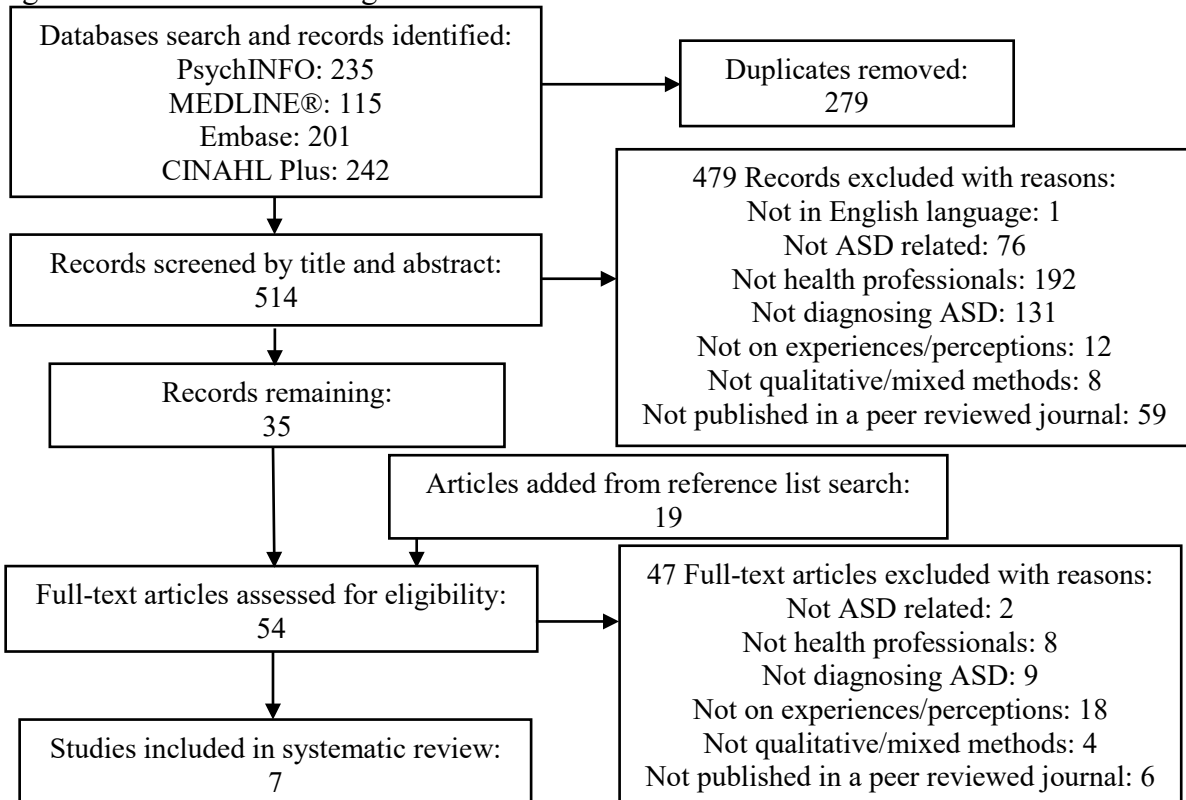
Risk of Bias Assessment

Risk of bias was assessed using the Critical Appraisal Skills Programme Qualitative Checklist found in the appendix (Critical Appraisal Skills Programme, 2019). This tool was chosen as it is widely used and fit the methodology used in the articles. Two of the researchers independently rated the sample and any discrepancies were discussed and a consensus reached.

Results

Figure 1 shows the results from the search strategy presented using PRISMA guidelines, the results from each of the databases can be found in the appendix (Moher et al., 2009). Overall, 793 articles were identified from the searches and 279 duplicates were removed. After screening the remaining 514 by title and abstract, 479 records were excluded. The reference lists of the remaining 35 were hand searched and 19 additional articles were added to the final 54 records for full text review. The reasons for exclusion are included in Figure 1.

Figure 1. Flow chart detailing the selection of studies



Study Characteristics

Six of the studies used qualitative methodology and one study used a mixed methods approach (table 2). The six studies obtained their results using interviews and the mixed methods study received their qualitative data from questionnaires, in which participants were given a free text box to add to any of the information they had supplied (Rogers et al., 2016). Two of the articles (Jacobs et al., 2018, 2019) were created from the same study but focused on different areas of the qualitative data-set. One of the studies did not identify a specific qualitative analytical method but did discuss where the analytical method was adapted from and the stages of it (Finke et al., 2010).

Participant Characteristics

As displayed in table 3, there was a range of professions within the participant samples. Four studies reported the age range of their participants (range 20-65). Two studies reported participants' years of experience in diagnosing ASD, which ranged from 2-40 years.

The majority of participants from the studies were involved in the diagnosis of ASD in children. The mixed methods study had 116 participants but did not specify how many of these participants provided qualitative information.

Study Quality

All papers scored highly for the risk of bias assessment, according to the qualitative checklist (Critical Appraisal Skills Programme, 2019) – indicating a low risk of bias. Scores on the checklist ranged between 23 and 27 out of a possible 27 (see table 4). A score of three was given if the criteria were met, a score of two if it was unclear, and a score of one if the criteria were not met. Some papers scored one in a criterion; however, they were included due to different qualitative methods focusing on different areas which are of strength in the checklist. Overall, all seven papers were considered to be of good quality, and, as there was only a 4-point difference amongst the papers, no papers were excluded from the review.

Table 2

Study Characteristics

Study #	Author	Title	Year	Country	Study Design	Analysis Method
1	Crane et al.	Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals	2018	UK	Qualitative interviews	Thematic Analysis
2	Finke, Drager, and Ash	Paediatricians' perspectives on identification and diagnosis of autism spectrum disorders	2010	USA	Qualitative interviews	*
3	Jacobs, Steyaert, Dierickx, and Hens	Physician View and Experience of the Diagnosis of Autism Spectrum Disorder in Young Children	2019	Belgium	Qualitative interviews	Interpretative Phenomenological Analysis (IPA)
4	Jacobs, Steyaert,	Implications of an Autism Spectrum Disorder Diagnosis: An Interview Study	2018	Belgium	Qualitative interviews	IPA

	Dierickx, and Hens	of How Physicians Experience the Diagnosis in a Young Child				
5	Karim, Cook, and O'Reilly	Diagnosing autistic spectrum disorder in the age of austerity	2014	UK	Qualitative interviews	Thematic Analysis
6	Penner, King, Anagnostou, Shouldice, Moore, and Hepburn	Community General Paediatricians' Perspectives on Providing Autism Diagnoses in Ontario, Canada: A Qualitative Study	2017	Canada	Qualitative Interviews	Grounded Theory
7	Rogers, Goddard, Hill, Henry, and Crane	Experiences of diagnosing autism spectrum disorder: A survey of professionals in the United Kingdom	2016	UK	Mixed methods	Thematic Analysis

*Characteristic not specified

Table 3

Participant Characteristics

Study #	N	Professions	Age range (years)	Experience range (years)	Setting	Age diagnosed
1	10	3 clinical psychologists, 2 paediatricians, 2 educators, 1 educational psychologist, 1 psychiatrist, 1 speech and language therapist, 1 specialist early years practitioner	*	<5 to >20	7 National Health Service (NHS), 2 education sector, 1 local authority	8 child, 2 adult
2	5	General practice paediatricians	35 to 56	*	*	Children
3	16	9 child psychiatrists, 4 child neurologists, 2 disability physicians, 1 paediatrician	30 to 65	*	4 centres for developmental disorders, 4 hospital, 2 private, 2 special boarding schools, 2 ambulatory centres, 2 Flemish Fund for disabled people, 1 university	Children

4	16	9 child psychiatrists, 4 child neurologists, 2 disability physicians, 1 paediatrician	30 to 65	*	4 centres for developmental disorders, 4 hospital, 2 private, 2 special boarding schools, 2 ambulatory centres, 2 Flemish Fund for disabled people, 1 university	Children
5	26	Child and adolescent psychiatrists, community paediatricians, educational psychologists	early 20s to early 50s	*	*	Children
6	11	Community general paediatricians	*	2 to 40	Community	Children
7	116	38 psychologists, 22 speech and language therapists, 21 paediatricians, 15 psychiatrists, 7 nurses, 6 specialist teachers, 13 other	*	*	92 NHS, 15 education, 11 local authority, 15 private, 1 charitable organisation, 2 other	All age ranges covered

*Characteristics were not available

Table 4

Risk of Bias Assessment

Quality Criteria	Study Number						
	1	2	3	4	5	6	7
Clear statement of aims	3	3	3	3	3	3	3
Appropriate methodology	3	3	3	3	3	3	3
Appropriate research design	3	3	3	3	3	3	3
Appropriate recruitment strategy	3	3	3	3	3	3	3
Data collection	3	3	3	3	2	3	2
Relationship between researcher and participant	3	1	2	2	1	3	1
Ethical issues considered	3	2	3	3	3	3	3
Rigorous data analysis	3	3	3	3	3	3	2
Clear statement of findings	3	3	3	3	3	3	3
Total	27	24	26	26	24	27	23

Findings

Across the seven papers, themes were listed, described, and sorted into five broad topic areas: barriers; facilitators; diagnostic process; informing of a diagnosis; and post-diagnosis. The barriers often identified in the papers were a lack of time and knowledge and training, with the main facilitators being multidisciplinary teams, clear processes, and parental knowledge. Tools and professionals judgements and individual differences were acknowledged frequently in the experience of the diagnostic process for health professionals. Within informing of a diagnosis, the families response, and positive and negative aspects of ASD seemed to be important aspects to several of the papers. Difficulties with services was

identified to be a factor of the post-diagnosis experience for many of the papers. A summary of the findings can be seen in table 5.

Table 5

Topic areas and main findings of the review

Topic Areas	Main Findings	Papers Included
Barriers	Lack of time, lack of resources, funding, lack of knowledge and training, lack of parental knowledge, lack of facts, difficulties with parents, diagnostic tools and guides, multi-agency working, referring	Crane et al. (2018); Finke et al. (2010); Jacobs et al. (2018, 2019); Karim et al. (2014); Penner et al. (2017); Rogers et al. (2016)
Facilitators	Multidisciplinary teams, clear processes, parental knowledge	Finke et al. (2010); Karim et al. (2014); Penner et al. (2017); Rogers et al. (2016)
Diagnostic Process	Tools and professional judgements, referral waiting time, wait and see method, individual differences, referring	Finke et al. (2010); Jacobs et al. (2019); Karim et al. (2014); Penner et al. (2017)
Informing of a diagnosis	Informing the family, impact on the child, disclosure to the person with autism, family's response, positives and negatives of the diagnosis	Finke et al. (2010); Jacobs et al. (2018); Karim et al. (2014); Penner et al. (2017); Rogers et al. (2016)
Post-diagnosis	Diagnosis as an entrance ticket to services, difficulties with services, the satisfaction of both professionals and family	Crane et al. (2018); Jacobs et al. (2018); Penner et al. (2017); Rogers et al. (2016)

1. Barriers

All the papers returned themes which related to “barriers” professionals found regarding the diagnostic process. These were factors that made achieving an appropriate or efficient diagnostic decision more difficult. Professionals discussed time as a recurring barrier throughout the diagnostic process in three of the studies (Karim et al., 2014; Penner et al., 2017; Rogers et al., 2016). Professionals acknowledged that completing an ASD assessment required a significant amount of time, particularly when working within a multidisciplinary team (Karim et al., 2014; Penner et al., 2017; Rogers et al., 2016). This was in a context of participants being given a lack of time to complete such assessments (Karim et al., 2014; Penner et al., 2017). Some professionals discussed how the appointment time slots were not “adequate to assess an autistic spectrum”, which was a recurrent perspective in professionals who diagnosed other conditions in their practice (Karim et al., 2014, p. 117).

Additionally, the time taken to diagnose was further scrutinised under the context of services lacking the capacity to meet the demand, such that people are referred into services but then wait a long time to be assessed and receive a diagnosis (Rogers et al., 2016). The time taken to be seen by other professionals, for participants who did not make the diagnosis alone, was discussed as a barrier and professionals stated that this impacted their ability to diagnose early (Finke et al., 2010). A lack in capacity of services was also mentioned (Rogers et al., 2016). Communicating the diagnosis to the person and their family was described as time consuming and was a barrier to the decision to diagnose, as it meant a “whole separate visit” (Penner et al., 2017, p. 601) was needed in addition to the necessary visits during the assessment. The use of the limited time professionals had needing to be used effectively was highlighted by Karim et al. (2014).

A perceived lack of knowledge of how a person with autism presents was suggested to cause a delay in autistic traits being noticed (Crane et al., 2018; Rogers et al., 2016). However, Crane et al. (2018) identified that a balance was needed between raising awareness and sensitivity being used to inform parents of a possibility that their child may be displaying autistic traits. For example, one professional in Crane et al. (2018) identified that they sometimes had parents be told their child might have autism because they had “put their hands over their ears when they heard a loud noise” (Crane et al., 2018, p. 3766) and that in reality there are many reasons for this behaviour not just autism. Furthermore, a difference in training between professionals involved in the diagnostic process meant different stances could be needed to be reconciled, such as working from medical training or working “psychotherapeutically” (Finke et al., 2010; Jacobs et al., 2019, p. 5; Rogers et al., 2016). A lack of opportunity to continue education alongside a lack of interest in spending continuing education time on ASD was also recognised as a barrier (Finke et al., 2010).

Additionally, too little parental knowledge was a barrier to giving a diagnosis because it would mean additional time was needed to explain the diagnosis, whilst too much knowledge of the challenges a child with autism might face could indicate that the family would not accept a diagnosis if it was given (Penner et al., 2017). A lack of facts on ASD meant that some professionals felt they could not convey clear messages to parents about the diagnosis (Jacobs et al., 2019). Furthermore, language or cultural differences were reported to increase the difficulty of diagnosing, such as needing a translator if there was a language barrier (Penner et al., 2017). There were additional concerns regarding parents persisting with multiple assessments until they received a diagnosis, and some professionals felt that communicating the diagnosis to the person and their family was a significant emotional burden (Penner et al., 2017).

Some professionals stated that weaknesses in diagnostic tools and guides meant that tools were often not “subtle” enough (Rogers et al., 2016, p. 827) when trying to diagnose someone with an atypical presentation. Additionally, professionals reported difficulties with consistency of diagnostic categorisation, and that the different sources of expertise on ASD were difficult to integrate into one uniformed view (Jacobs et al., 2018, 2019). Finally, one study found that multi-agency working can be a barrier, as it relies on good relationships between the agencies (Karim et al., 2014).

2. Facilitators

Four papers reported on facilitators to assessment. These were factors that made the assessment processes easier or more efficient. The benefits of multidisciplinary teams were noted. Multidisciplinary teams helped compensate for the clinical setting of a formal diagnostic assessment, by allowing observations to take place in a variety of environments (Karim et al., 2014). For a pervasive developmental disorder, like ASD, assessing across context is crucial. Multidisciplinary teams also allowed staff access to other professional opinions and expertise, when faced with uncertain cases (Penner et al., 2017). Further, Multidisciplinary teams were thought to support parents’ experience of the diagnostic process, as they allowed parents “time to talk” and gave clarity about the diagnostic process (Rogers et al., 2016, p. 827). Referral pathways also influenced professionals’ experiences of the assessment process. A clear process for referral pathways allowed for a single point of referral, helping facilitate the diagnostic process (Rogers et al., 2016). Finally, parental understanding was understood to impact assessment processes. Participants in Finke et al. (2010) acknowledged the importance of listening to parents as their awareness of their child’s behaviours could be important in heightening the professional’s ‘concern’ that a diagnosis should be explored, “parents tend to pick up on things a lot sooner, in my experience, than do the questions that I ask” (Finke et al., 2010, p. 261). Parents having some knowledge of ASD

was thought to facilitate communication between the professional and the family (Penner et al., 2017).

3. Diagnostic Process

Four papers considered professionals' experiences and perceptions throughout the assessments necessary to diagnose ASD. Jacobs et al. (2019) and Karim et al. (2014) recognised that professionals felt that a mediation between the outcome of the diagnostic tools and their own professional judgement was necessary. This process was discussed by two professionals in Karim et al. (2014, p. 118) as necessary, due to the "subjective impressions" that were being "objectified" by the diagnostic tools. In these studies, professionals explained that standard assessments need to be supplemented with a personal approach to decide what works for the child (Jacobs et al., 2019; Karim et al., 2014).

When faced with long referral times, some professionals chose to diagnose themselves, rather than refer to a specialist (Penner et al., 2017). They explained that getting support for people with autism as quickly as possible was a key priority (Penner et al., 2017). Additionally, professionals in the Finke et al. (2010) study indicated a preference of which specialists they would refer to, but a lack of these specialists meant this was not always possible. Some professionals also used a "wait and see" approach towards diagnosis, due to the worry that putting a family through the diagnostic process and the outcome not being ASD is "not a wonderful thing to go through" (Finke et al., 2010, p.260).

Participants reported some individual differences in the people they were diagnosing, such as age and gender, as difficulties during the diagnostic process. Penner et al. (2017) described that professionals experienced diagnosis of both very young children and older children to be more challenging, and that girls were felt to be more difficult to diagnose, due

to the differences in their presentation. Additionally, co-morbid conditions increased diagnostic difficulty, and so did “milder” presentations of ASD (Penner et al., 2017).

4. Informing of a Diagnosis

Five papers reported on professionals’ experiences of informing the person and their family of a diagnosis of ASD. When informing the family of an ASD diagnosis, one study found that terminology is crucial, and some professionals suggested that they used the term “Asperger’s” as they perceived the information available about Asperger’s Syndrome to be less frightening than “autism” (Karim et al., 2014, p. 120). A professional in the Finke et al. (2010) study discussed that he would attempt to facilitate parents in their internet searching by telling them what they might see on the internet.

Some professionals believed that a diagnosis for a teenager was more consequential, due to adolescents being in a critical stage of identity formation (Jacobs et al., 2018). Furthermore, professionals depended on parents to disclose a diagnosis to the child, but would tell an adolescent of their diagnosis (Jacobs et al., 2018). Other professionals argued that hiding a diagnosis could cause future problems for the person with autism (Jacobs et al., 2018).

The family response was a crucial experience for professionals, with Jacobs et al. (2018) identifying a dual effect where parents who had actively pursued an ASD diagnosis were relieved when they received the diagnosis, but not giving a diagnosis for these parents was seen as bad news. Additionally, some professionals acknowledged that parents viewed the practical use of the diagnostic label, such as an explanation for why their child might behave in a certain way, to be more important than it being an explanation of their child’s condition (Jacobs et al., 2018).

The most important implication of informing a diagnosis for the professionals from the Jacobs et al. (2018) study was the function of lifting the blame on parents for their child's behaviour; this was also discussed in Finke et al. (2010). Additionally, the professionals in the Finke et al. (2010) study stated that a discussion around the worries of the causes of ASD, such as vaccines, was crucial to informing the family of a diagnosis. Further to this, it was recognised that the family's response to the diagnosis may reduce parents' expectations for their child (Jacobs et al., 2018). Additionally, the professionals perceived parental readiness to receive an ASD diagnosis as closely related to their understanding of ASD (Penner et al., 2017). Rogers et al. (2016) reported that in cases of diagnostic uncertainty, professionals would put the needs of the child and family first, such as giving a 'false positive diagnosis' (Rogers et al., 2016, p. 827), due to diagnosis being a gateway for some services.

Both Jacobs et al. (2018) and Rogers et al. (2016) discussed the positive and negative implications of informing of a diagnosis of ASD. The professionals in Jacobs et al. (2018, p. 8) acknowledged that a professional "affirming" that the child is "different" can have both positive and negative outcomes. Whereas, professionals in Rogers et al. (2016) recognised the need to communicate both the positive and negatives of the ASD diagnosis with both the person with autism and their family.

5. Post-diagnosis

Four papers considered professionals' experiences and perceptions of the post-diagnostic process. Within the post-diagnosis topic, the difficulties with support services were acknowledged, along with the satisfaction of both the professionals and families. Diagnosis was described as an entrance ticket to services and it was suggested that professionals may feel coerced to make an ASD diagnosis due to the link between diagnosis and service support (Jacobs et al., 2018). Difficulties with both access to and provision of

services were discussed by three of the reviewed studies (Crane et al., 2018; Penner et al., 2017; Rogers et al., 2016). Professionals stated they were often unable to offer support, even though they wanted to, and that they were put under “pressure” not to offer post-diagnostic support due to the demands that were already on them (Crane et al., 2018, p. 3768). It was noted by some professionals that there was a lack of family support available, although, some services offered “whole family support needs” but this was not consistent across all the services discussed within Crane et al. (2018, p. 3768) study. The professionals from Rogers et al. (2016) wanted to offer long-term support to people with autism, but acknowledged that this is not possible for many services and that in-service support was also lacking for people who had received a diagnosis.

Furthermore, within Rogers et al. (2016, p. 828) study, professionals stated that there needs to be specialist provision, as no services existed for people with autism and other services “including special need education, speech and language therapy, LD [learning disability] nursing” have very little understanding or awareness of ASD. Additionally, professionals emphasised that access to system navigation support for families of people with autism would support feelings of satisfaction and improve the confidence of families (Penner et al., 2017). Regarding satisfaction of professionals, professionals in Penner et al. (2017) felt that managing a new diagnosis of ASD involved a large amount of work behind the scenes and that this did not provide professional satisfaction in the form of adequate remuneration; professionals managed this by re-examining their definition of satisfaction. Professionals also felt they could not alleviate families’ frustrations of the waiting lists for services (Penner et al., 2017).

Discussion

This review explored the experiences and perceptions of health professionals when diagnosing ASD. After a systematic search of the literature, risk of bias assessment, and data extraction, the findings were placed into topics. A summary of the topics and main findings is displayed in Table 5.

As discussed in the introduction, parental knowledge and concerns have an important role in the age a child with ASD is diagnosed (Zablotsky et al., 2017). Within the reviewed studies, a lack of parental knowledge was perceived as a barrier by professionals, as it meant they had to spend more time explaining what the diagnosis meant (Jacobs et al., 2019; Penner et al., 2017). Research has also suggested that an increased amount of knowledge can mean parents may have a preconceived idea of what a child with ASD acts like and the challenges related to ASD and therefore, may dismiss the diagnosis (Zuckerman et al., 2015).

Although the gold-standard ASD assessments and tools (Bjorklund et al., 2018; Kamp-Becker et al., 2018) are well-evidenced, the professionals in the review sometimes found them to be barriers due to their weaknesses of picking up atypical presentations of ASD (Rogers et al., 2016). Professionals would overcome these by supplementing these assessments with their own judgement or personal approach (Jacobs et al., 2019; Karim et al., 2014). Although professionals being aware of the weaknesses is positive, some professionals struggled to integrate the different sources on ASD presentations into a singular view, meaning that there may be the risk of false positive and false negative diagnoses based on these views.

Difficulty in integrating different sources of information may add to the weaknesses of the assessments, for example, alongside research discussed earlier, restrictive and repetitive behaviours are less predictive of an ASD diagnosis for females than for males and therefore a tool that focuses on these scores may not score appropriately for females

(Duvekot et al., 2017; Hiller et al., 2014). However, McDonnell et al. (2019) found that child gender was not related to diagnostic certainty for the clinicians in their study; meaning if this did impact the diagnostic accuracy it did not impact how the clinicians rated the certainty of their judgement. Therefore, the awareness of difficulties with diagnosing atypical presentations of ASD and integrating differing views of diagnosing rather than diagnostic certainty may be useful in ensuring positive diagnoses are made. Additionally, from the papers that reported age range and experience range of professionals there was a wide range, with ages ranging from early 20s to 65 years of age and experience ranging from about 2 to 40 years (Jacobs et al., 2019; Karim et al., 2014; Penner et al., 2017). The difference in ages and experience may have impacted the findings of the papers, such as experience of integrating the differing methods of diagnosis, however the papers did not explore this.

Informing the family of a diagnostic decision was an important experience for many of the professionals in the reviewed studies (Finke et al., 2010; Jacobs et al., 2018; Karim et al., 2014; Penner et al., 2017; Rogers et al., 2016). The family having both positive and negative responses to the outcome was discussed (Jacobs et al., 2018; Rogers et al., 2016) and this is also something that has been identified in research aimed at understanding the parents' experiences (Legg & Tickle, 2019). The acknowledgement of the practicality of the autism label by professionals in Jacobs et al. (2018) was shared with the relief felt by parents at an explanation of their child's difficulties, identified by Abbott et al. (2013). Additionally, the identification of some parents' persistence with multiple assessments until they received a diagnosis may be due to the need to receive a formal diagnosis to receive accommodations that will support their child, such as support in school or insurance coverage in countries that require this (Douglas et al., 2017; Penner et al., 2017; Renty & Roeyers, 2006)

Implications for Clinical Practice and Training

The findings discussed from this systematic review have implications for both clinical practice and the training of professionals. The review found some professionals used a “wait and see” approach (Finke et al., 2010, p. 260). For children who ultimately receive a diagnosis of ASD, an unnecessary wait can prove detrimental, as it may prevent them from accessing appropriate support. Additionally, the practices of professionals choosing to diagnose themselves, rather than referring to specialists, when faced with long referral times (Penner et al., 2017) could negatively impact the accuracy of the diagnosis depending on the health professional’s current knowledge, training, and participation in supervision and consultation. The review identified that some professionals prefer to use the term Asperger’s when discussing a diagnosis. Asperger’s Syndrome is not included in the most recent version of American (the DSM-5; American Psychiatric Association, 2013) and international (World Health Organisation, 2018) classifications. On the one hand, clinicians’ preferences in this area may reflect contemporary local understanding of attitudes to different diagnostic labels. Crucially though, by not using clearly-defined, current diagnostic categories, they risk later confusion for children and parents, and potentially prevent effective access to services.

A further concerning finding is that some professionals would provide a “false positive diagnosis” (Rogers et al., 2016, p. 827), where this benefited the family and the child when the professional was uncertain. Failure to diagnose ASD correctly is problematic, as it can direct the limited resources that are available away from people that need the services and may create stress and confusion for the person that has been falsely diagnosed and their family (Randall et al., 2018). Professional guidelines for ASD assessments of young children in New York, USA, suggest that if a child does not meet the diagnostic criteria professionals should consider observing the child in different settings and considering including another expert opinion within the decision (New York State Department of Health, 2017). Further

guidelines in the UK suggest that if a child has features of behaviour that are seen within ASD but does not reach the diagnostic criteria for a definitive diagnosis they should be referred to services that will support them with the behaviours they are experiencing (National Institute for Health and Care Excellence, 2017).

In clinical practice, multidisciplinary teams have been recognised as a facilitator to allowing observations to take place in a variety of settings and for access to other professional opinions and expertise. Multidisciplinary teams should be used to allow professionals to support one another throughout the diagnostic process, but also to provide additional information on the behaviours of the person being diagnosed in different environments (Karim et al., 2014; Penner et al., 2017; Rogers et al., 2016). Additionally, clear guidelines for diagnosing ASD should be implemented to support professionals throughout the diagnostic process and inform them clearly of the steps required to provide an informed diagnostic outcome (Mayer et al., 2019). Having clear guidelines will also support professionals when providing information to parents about the diagnostic process, especially when parents do not have much knowledge of ASD. Additionally, guidelines on what professionals are required to do if they are unsure in their diagnostic decision making, and where they can refer the people they are assessing to if they do not meet diagnostic threshold, may prevent false positive diagnoses as professionals may feel they are still able to support the people they are assessing and their families without providing a false positive diagnosis.

The findings of the impact parental knowledge can have on the diagnostic process (Penner et al., 2017) suggest that professionals need to be aware of this impact and be prepared with information to answer any questions parents may have and provide a detailed explanation of ASD. The information could be provided to parents in written format as research has shown this helps improve their experience and it may reduce the time it takes for the health professionals to explain the diagnosis (Braiden et al., 2010). Additionally,

information on services and their availability should be available to professionals providing the diagnosis, to allow them to inform parents of what support is available for their child (Legg & Tickle, 2019). Providing service information may prevent some of the frustrations that parents experience (Legg & Tickle, 2019).

The varying perceptions of health professionals on the use of diagnostic tools and their own professional judgements suggest additional training should be provided to health professionals on how to integrate these different methods in the diagnosis (Jacobs et al., 2019; Karim et al., 2014). Furthermore, additional training should be provided to professionals who may identify autistic traits to improve awareness of what to look out for and how to inform parents of this sensitively. This might mean a diagnosis is given earlier and ensure that support can be put in place as soon as possible, or alternatively, it may prevent appointments for discussion of an ASD diagnosis when there is little evidence to support this.

Training should be provided to professionals involved in the diagnostic process on the barriers that they may experience. Being aware of these barriers means that future health professionals may be able to prepare for any difficulties they may face. It could also foster conversations around self-care as a way of ensuring they do not experience burnout (Posluns & Gall, 2020). The health professionals could also provide information to the referrers on these guidelines to encourage timely and efficient referrals which include the information required and ensure the person is seen as soon as possible.

Furthermore, supervision could be utilised to discuss the barriers that trainees may face in their work, these supervision discussions could also focus on the diagnostic tools. Supervision can ensure high quality care, and ensure that care and supervisee wellbeing is not impacted by their experiences (Kilminster et al., 2007; Lyth, 2000; Milne, 2007), therefore,

effective supervision which discusses these challenges would support the training of future diagnosing health professionals. Group-based support, such as group consultations made up of diagnosing professionals, could also provide practical supervision to trainees and also to practicing health professionals unable to establish an MDT on the challenges they face and how these are managed. Additionally, the current trainees are potentially future managers, who could improve the services to reduce the barriers of which they have been made aware.

Implications for Future Research

Further research is needed on the experiences and perceptions of health professionals to allow for future guidelines to be informed by research. More research would allow for the differences in experiences and perceptions between countries to be explored systematically, rather than integrated as has been done in the current review. Research could also use mixed methods approaches to explore how the capacity of diagnostic services are impacted by the health professionals' experiences and perceptions of the diagnostic process. Future research should also focus on the improvements necessary to remove the barriers, which can help inform clinical practice further. Finally, little attention has been paid to the impact of professionals' approaches on the experiences of people with autism themselves. Facilitators and barriers to successful diagnosis tend to have been understood in relation to process-efficiency and professional-judged outcome success. Ultimately, the success of the ASD diagnostic process must be understood in terms of what is most beneficial for people with autism.

Limitations

Due to the heterogenous sample of the papers, we were unable to complete a meta-synthesis for this systematic review. Therefore, the findings from the literature used could not be re-interpreted based on this review's objectives. Furthermore, due to the varying roles of the health professionals and the varying countries the literature was from, some findings were only specific to one country due to the guidelines on who can diagnose and the services available. Although the review was based on the experiences and perceptions of the process that did not relate to specific local processes and procedures, there may be contextual factors that may underlie these experiences and perceptions.

There are also limitations of the literature. The articles did not necessarily focus on the experiences and perceptions of the whole diagnostic process and therefore more specific findings from the professionals might have been missed. Additionally, further information on the characteristics of the people being assessed for ASD, such as age ranges and gender, was not available which limited us in our understanding of whether the findings had been influenced by these factors. Additionally, in 2013 there was a change in diagnostic criteria from DSM-IV (American Psychiatric Association, 1994) to DSM-5 (American Psychiatric Association, 2013) and significant changes were made (Linton et al., 2013). Therefore, these changes may have influenced the findings of the studies used in the systematic review and thus, the findings of this systematic review. There was also little mention of insurance companies and no mention of schools within the literature and as discussed in the introduction different types of insurance can have an impact on the certainty of diagnosing health professionals (McDonnell et al., 2019). However, four of the seven papers included in the systematic review are unlikely to use a healthcare services that requires insurance, potentially influencing this finding.

Regarding the risk of bias assessment, three articles received a one for their considerations of the relationship between the researcher and participant, indicating that this

relationship could not have been considered and may have impacted the findings. Given the differences in the qualitative approaches used, there may have been different requirements for this relationship to have been considered, for example in Interpretative Phenomenological Approach the relationship is strongly considered (Smith et al., 2009). However, the overall totals of these studies were still similar to the other articles.

Conclusion

The present systematic review has summarised research on the experiences and perceptions of health professionals who diagnose ASD. The facilitators and barriers of the diagnostic process have been discussed, along with the experiences and perceptions during the diagnostic process, when communicating the diagnosis, and post-diagnosis. The recommendations and implications identified within this review are not country specific, such training suggestions will improve health professionals diagnosing ASD regardless of the country they are working in and the guidelines suggested may be developed with specifics, such as insurance information, to suit the relevant healthcare system they are supporting. The main clinical implications of the findings are the importance of multidisciplinary teams throughout the diagnostic process, the need for guidelines to be implemented to support and inform health professionals' work, and the awareness of how parental knowledge can impact the process. Future health professionals should also be aware of the barriers and how these could impact them. Finally, more research on this topic area would allow for future researchers to have a homogenous sample to integrate the findings when reviewing the literature and future research should focus on how the experiences and perceptions impact the professionals.

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