Original Article

General paediatric practice in autism spectrum disorder screening in Ontario, Canada: Opportunities for improvement

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Abstract

Background: Screening is important for early identification of children with autism spectrum disorder (ASD), potentially leading to earlier intervention. Research has identified some barriers to early identification of ASD, however, information about ASD screening in Canadian general paediatric practice is lacking.

Objectives: The aim of the study is to better understand ASD screening practice patterns by examining the use of ASD and general developmental screening tools by general paediatricians.

Methods: The research team conducted a cross-sectional survey of general paediatricians.

Results: Two-hundred and sixty-seven paediatricians responded and 132 were eligible for the study. Ninety-three per cent of the responders used a developmental screening tool. Eighty-five per cent of the responders used an ASD screening tool when there were concerns for ASD, and 15% never used one. The most commonly used ASD screening tool was the M-CHAT. Children suspected of having ASD were referred to specialists not only to confirm the diagnosis but also to facilitate access to resources. General paediatricians were keen to incorporate formal ASD screening tools in their practice but identified the need for clearer guidelines.

Conclusion: Previous studies have shown that children at risk of ASD continue to be missed through developmental surveillance and targeted screening. Paediatricians are interested in implementing an ASD screening tool and cite brevity and forms that can be completed by parents as factors that would support the use of a screening tool. Clearer guidelines and tools to support ASD screening and access to resources are needed.

Keywords: Autism spectrum disorder; Child development; Community medicine; Paediatrics; Screening

Autism spectrum disorder (ASD) is defined by persistent deficits in social communication and interactions and the presence of restricted, repetitive patterns of behaviours, interests, or activities (1). ASD prevalence is estimated to be 1 in 59 children in the USA (2) and 1 in 66 children in Canada (3).

Early intervention is crucial in the management of ASD, as it has the potential to improve a child's IQ and adaptive skills (4,5). The presence of early intervention programs in Canada underscores the importance of early identification of children with ASD and the use of standardized screening tools may play

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a critical role in identifying these children. Few studies have examined the use of these tools among general paediatricians.

In 2007, The American Academy of Pediatrics (AAP) published a clinical report recommending using ASD-specific screening tools at the 18- or 24-month visit with routine developmental surveillance (6). In contrast, the UK National Screening Committee's policy is that universal screening for autism should not be offered, citing lack of evidence for use in the general population (7). In Canada, the Canadian Paediatric Society and College of Family Physicians endorse the use of the Rourke Baby Record where specific ASD screening is considered when there are ASD risk factors (8). A survey of paediatricians in the USA prior to the AAP recommendations revealed that 8% of practitioners routinely screened for ASD (9). A study of paediatricians and family physicians after the AAP statement publication found that 28% of physicians used ASD screening tools. Lack of familiarity with screening tools and time were identified as main barriers to ASD screening in both studies (9,10). Another study examining practitioners from six US states identified an increasing trend with 59.8% of paediatricians screening for ASD (11) although the findings are limited by potential sampling bias as the response rate of the survey conducted by the researchers was 10%, possibly reflecting physician time limitations. Qualitative studies of paediatricians in Canada and the USA also identified time limitation, lack of familiarity with screening tools, a perceived redundancy between developmental surveillance and formal screening, and difficulties in accessing ASD services and treatments as barriers to ASD screening (12,13). These studies highlight a need to better understand practice patterns around ASD screening among paediatricians including how individual practices affect screening tool use.

Overall, there is a paucity of data on general paediatricians' ASD screening practices. The contrast in screening policies brings to light controversies around ASD screening that require further examination. Due to differences in health care systems and ASD service provision, a larger study of practices around ASD screening is needed to better understand barriers and supports for ASD screening within a Canadian context and inform recommendations around ASD screening. The primary aim of the study was to understand ASD screening practice patterns by examining paediatricians' use of general developmental screening and ASD screening tools. We also secondarily explore diagnostic practices and potential challenges in navigating ASD resources to better understanding of how screening practices fit into paediatricians' general practice.

METHODS

Participants

Using a cross-sectional survey design, all general paediatricians in the Greater Toronto Area, a large multicultural urban centre were invited to participate. We identified paediatricians by postal

code on the College of Physicians and Surgeons of Ontario (CPSO) online directory. Eligible participants had to have an active general paediatric practice. Those who only practiced in a paediatric subspecialty were excluded. Consultant general paediatricians, paediatricians who only saw children by referral, were also included. We identified 560 potential participants. To capture all eligible participants, we chose to use the CPSO directory, which included all paediatricians, knowing that we would have an over-estimate of eligible participants as paediatricians who were only in subspecialty practice (i.e., paediatric nephrologist) may be listed in the directory as a paediatrician.

To encourage participation, notices were e-mailed through the Canadian Paediatric Society Community Paediatrics Section as well as posted on the Ontario Medical Association Pediatrics Section website. The survey was mailed again to initial nonresponders. Electronic and letter reminders and phone calls were also used.

Questionnaire development

The questionnaire included questions based on themes previously identified as potential factors affecting ASD screening and diagnosis (12) and questions from the dosReis et al. study used with permission (9). The questionnaire focused on 6 main areas: 1) demographic data, 2) use of developmental screening tools, 3) use of ASD screening tools, 4) factors influencing ASD screening, 5) screening tool characteristics, and 6) practices around ASD screening and diagnosis. Ethics approval was obtained from the Bloorview Research Institute (Toronto, Canada).

A subgroup of $n=5$ general paediatricians and $n=5$ subspecialist paediatricians with training in developmental paediatrics and interest in ASD reviewed the initial questionnaire. These reviewers were not included in the final study group. Refinement of the questionnaire was guided by the paediatricians' feedback on the clarity of the questions, length and ease of use of the questionnaire, and relevance to Canadian paediatricians. Twenty-seven general paediatricians completed the subsequent questionnaire in a pilot study to ensure ease of use. The final questionnaire cover page specified that the questionnaire was intended for 'general paediatricians in primary care' and listed a yes or no question to determine eligibility, thereby excluding all paediatric subspecialists. Questionnaires were coded with a unique study identifier for confidentiality and to monitor the response rate. Surveys were returned in the provided self-addressed stamped envelope.

The questionnaire consisted of 15 questions about ASD and developmental screening and management and 5 demographic questions that took about 10 minutes to complete. Participants self-identified their practice type as 'Primary Care' or 'Consultant General Paediatrics' and could pick both. Items included open-ended, checklist, and multiple-choice formats.

Checklists of screening tools were derived from the dosReis et al. study (9), review of the literature, consultation with developmental paediatricians, and additional tools suggested during the questionnaire development process. Participants could also name a tool not listed in the questionnaire.

Analysis

All data from the questionnaires were double entered and inconsistencies identified and corrected. Descriptive statistics were used to describe the responses. We calculated the distribution of answers for each survey question using SAS 9.3 (2002 to 2010 by SAS Institute Inc., Cary, NC). Fisher's exact test (two-sided test, $\alpha=0.05$) was used to test for an association between practice type and use of ASD screening tools, and practice type and making an ASD diagnosis.

RESULTS

The final analysis included 132 participants (Figure 1).

Developmental screening tools

Ninety-three per cent (123/132) of the participants reported that they routinely used developmental screening tools. Although the M-CHAT is not a developmental screening tool, 7% of participants reported using it as such (Table 1).

Figure 1. Participant enrolment and practice type. Eligible participants had to have an active general paediatric practice, meaning that they had an active practice at the time of the survey and that their practice included general paediatrics. Those who only practiced in a paediatric subspecialty were excluded. General consultant paediatricians, paediatricians who only saw children by referral, were also included. To capture the maximum number of participants, we chose to use the College of Physicians and Surgeons of Ontario directory, which included all paediatricians, to identify participants. We therefore likely had an over-estimate of eligible participants because some paediatricians who were only in subspecialty practice, for example a paediatric nephrologist, may be listed in the CPSO directory as a paediatrician.

ASD screening tools

One hundred and eleven participants (84%) reported using ASD screening tools in their practice while 20 (15%) did not. Data were missing from one participant. There was no significant difference between primary care and consultant general paediatricians in ASD screening tool use (Fisher's exact test $P=0.54$). The M-CHAT was the most frequently used ASD screening tool (78%) (Table 1). Administration of an ASD screening tool was most common when ASD was suspected based on history or examination (85%). Other reasons identified were when parents voiced concerns (78%) or when a child failed a general developmental screen (65%). Eighteen per cent of the participants routinely used ASD screening tools in their practice.

Factors influencing ASD screening tool use

Among participants who did not use an ASD screening tool ($n=20$), the main reasons reported were that they 'refer to a specialist' for definitive diagnosis ($n=16$), they were not familiar with ASD screening tools ($n=9$) or did not having time to screen ($n=7$).

Participants also reported agreement with statements related to their views on ASD screening tools and ASD-specific resources (Figure 2). In general, participants felt they were aware of community ASD resources (65%) but that resources were inadequate (80%). Participants reported being confident in identifying ASD (89%). Many participants perceived ASD screening tools as useful (85%) and were interested in incorporating them in their practice (74%). Participants also expressed the need for clearer guidelines regarding the use of ASD screening tools (65%).

Participants identified paediatricians (98%), family physicians (80%), and speech-language pathologists (70%) as lead personnel in screening for ASD.

Screening tool characteristics

The screening tool characteristics rated most important by participants were reliability, sensitivity, and specificity (77%). Questionnaires that are brief (53%), easy to complete by the family (60%), and embedded in a general developmental screening tool (39%) were rated important.

Referral patterns among general paediatricians

When referral to a clinical specialist was made, 89% of participants referred to a developmental paediatrician, 66% to a speech-language pathologist, 19% to a psychologist, 16% to a neurologist, and 11% to a psychiatrist. Other referrals were made to an occupational therapist, a tertiary care centre, a multidisciplinary team, early intervention, or to another paediatrician with more experience in ASD for a second opinion. The top two reasons reported for referring to a specialist was to confirm the diagnosis (44%) and to facilitate access to resources (20%).

Table 1. General paediatricians reported use of screening tools for developmental screening and ASD screening

Tools participants used for developmental screening*	Absolute number* (n=123)	Percentage [†]
Nipissing Developmental Screen	110	89.4
Rourke Baby Record	57	46.3
Ages and Stages Questionnaire (ASQ)	19	15.4
Modified Checklist for Autism in Toddlers (M-CHAT)	9	7.3
History taking	8	6.5
Denver-II	6	4.9
Parents' Evaluations of Developmental Status (PEDS)	5	4.1
Tools participants used for ASD Screening*	Absolute number (n=111)	Percentage
Modified Checklist for Autism in Toddlers (M-CHAT)	87	78.4
Checklist for Autism in Toddlers (CHAT)	26	23.4
Childhood Autism Rating Scale (CARS)	13	11.7
History and Assessment	8	7.2
Autism Behaviours Checklist (ABC)	7	6.3
Social Responsiveness Scale (SRS)	5	4.5

ASD Autism spectrum disorder.

*Only tools used by five or more participants are reported in this table.

[†]Some participants reported use of multiple tools.

Figure 2. General paediatricians' opinions regarding ASD screening tools and resources. ASD Autism spectrum disorder.

ASD diagnosis

Fifty-three participants made the diagnosis of ASD in their practice (41%) while 77 did not (59%). Consultant paediatricians (63%) were more likely than primary care paediatricians (33%) to make a diagnosis of ASD (Fisher's exact test $P=0.04$). Among the participants who did not diagnose ASD, the main reasons reported were that they prefer a second opinion (42%) or were unsure of the diagnosis (25%). Of note, 19% reported difficulty

navigating ASD resources and 8% reported lack of access to interventions as the main reason for not diagnosing ASD.

DISCUSSION

The study provides insight into the patterns of use of ASD screening by Canadian general paediatricians. The majority of participants (93%) used a formal tool for general developmental

surveillance or screening. The use of ASD screening tools was restricted to when there were concerns, which is consistent with targeted screening as per national guidelines. In fact, participants were divided regarding universal ASD screening, which is not surprising given conflicting recommendations from international groups. It is also important to note that there is some confusion between screening and developmental surveillance, the continuous process of recording a child's development to identify potential concerns (14).

Eighty-nine per cent of paediatricians felt confident in recognizing symptoms of ASD although the literature shows that cases of ASD continue to be missed. In a study of the M-CHAT in the primary care setting, only 4 of the 21 children identified through screening and diagnosed with ASD were initially flagged by their paediatrician (15). Another study showed that in focused 10-minute observations, even licensed psychologists experienced in working with children with ASD miss 39% of cases of ASD (16). Therefore, incorporating formal screening into a paediatric practice has the potential to identify more children with ASD not otherwise identified by clinical judgment or caregiver concerns (17–19).

When asked to report the use of developmental and autism screening tools, a minority of paediatricians reported history taking as a screening tool which may be a less reliable way to identify children with ASD (15). Some paediatricians also reported using the M-CHAT for developmental screening which highlights a potential knowledge gap that can be targeted in continuing medical education. The use of nonstandardized instruments for ASD screening was also reported, so paediatricians may be relying on less reliable strategies to screen for ASD (6).

ASD screening can also be sustainable within a paediatric practice with supported training (20). Participants were interested in using formal ASD screening tools (74%) indicating an opportunity to work with paediatricians to incorporate ASD screening tools into their practice and measure effects on patient care. Participants also wanted clearer guidelines for when and how to screen for ASD. Thus, continued use of standardized tools such as the M-CHAT for ASD screening paired with evidence informed developmental surveillance should be encouraged and made clear in paediatric practice guidelines. For paediatricians desiring to use a standardized screening tool, the M-CHAT R/F is available for free (<https://m-chat.org/>) (21). One limitation of this tool is that its use is limited to children less than or equal to 30 months of age.

Given paediatricians' interest in using a screening tool and the characteristics identified by paediatricians that could facilitate the use of screening tools, future design, and implementation of screening tools and guidelines should consider reliable and sensitive screening tools that are brief, can be completed by parents,

are free, and easily accessible online. For example, the use of a digital M-CHAT among paediatricians may improve accuracy of documentation and rates of appropriate referrals (22).

This study also explored diagnostic practices and paediatricians' comfort in navigating ASD-specific resources in their community, an important topic to explore because using a screening tool implies that paediatricians will need to follow up and make decisions on whether further diagnostic assessments for ASD are needed. In Ontario, paediatricians can make the diagnosis of ASD in their own practice. However, our questionnaire responses suggested that paediatricians need further support in navigating ASD-specific resources in their community. Participants' answers reflected challenges in accessing ASD resources including difficulties navigating ASD resources and limited access to interventions. A qualitative study of Ontario paediatricians also identified time and supporting families through a new diagnosis as factors that influence practice around ASD diagnosis (23). Addressing this significant barrier for paediatricians may produce benefits that impact the economics of services and wait times resulting in earlier access to interventions.

Limitations

This study provides important data on ASD screening tool use, among a sample of Canadian general paediatricians in one major urban city, which has not previously been examined on this scale. The response rate for this study, 48%, is at the higher end of the range for this type of study where response rates typically range from 10 to 50% (9–11). While qualitative data was also collected, the study design limits examination of the reasons behind participants' practice patterns. Also, nonresponders may be different than participants in their interest and knowledge of ASD; the response rate was lower for primary care paediatricians, who may have less experience in identifying and diagnosing ASD than consultant paediatricians. Nonresponders may also be different in other non-measurable ways which may affect the generalizability of the findings. Also, many children are first assessed by a family physician and this study does not capture the barriers that occur at that step. ASD diagnostic practices and access to interventions also differ across the country and different jurisdictions face different challenges.

This is the first Canadian study to provide quantitative data on ASD screening practices among general paediatricians. The results suggest potential educational and resource gaps that can be targeted in future studies and interventions. They also provide a basis for the development of programs and policies that are in line with physician and community needs, and highlight gaps for which we may be able to leverage current technologies, such as digital applications, to facilitate ASD screening and resource navigation.

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