Barriers to autism screening in family medicine practice: a qualitative study

Tsehaiwork Sunny Fenikilé^{1,2}, Kathryn Ellerbeck^{1,2}, Melissa K. Filippi^{3,4,5} and Christine M. Daley^{3,4,5,6}

Aim: We explored potential barriers to adoption of recommended screening for autism by family physicians at 18- and 24-month well-child visits. Background: The American Academy of Pediatrics recommends early detection and intervention of autism through the use of a standardized autism-specific screening tool on all children at the 18- and 24-month well-child visits. However, not all family physicians screen for autism. Methods: Three focus groups and six semi-structured interviews were conducted with 15 family physicians in the Kansas City metropolitan area. Verbatim transcripts were inductively coded; data were analyzed using standard text analysis. Findings: Participants had differing views on the increased incidence of autism. Most participants attributed the increase to changes in diagnostic criteria. There was no consensus on the benefit of implementing universal screening for autism during the 18- or 24-month visit. Many preferred to identify potential problems through general developmental assessments and observations. No participants used specific screening tools for autism, and only one participant was aware of such a tool (M-CHAT). Lack of adequate training on child development and screening methods as well as limited availability of community-based resources to manage children with autism was seen as major barriers to routine screening. Suggested solutions included working toward a stronger evidence base, improving physician training and continuing education, and making systemic changes in healthcare. In conclusion, universal screening for autism at the 18- and 24-month visits is not widely accepted, nor is it implemented by family physicians.

Key words: autism; autism screening; barriers; family medicine

Received 21 December 2012; revised 13 February 2014; accepted 10 October 2014; first published online 4 November 2014

Introduction

Developmental disabilities, including autism, affect an estimated 15% of children in the United States (Boyle *et al.*, 2011). The Centers for Disease Control and Prevention's (CDC) most recent

Correspondence to: Melissa K. Filippi, Research Assistant Professor, Center for American Indian Community Health, University of Kansas Medical Center, MS 1030, 3901 Rainbow Boulevard, Kansas City, KS 66160, USA. Email: mfilippi@kumc.edu

prevalence estimate indicates that 1 out of every 110 children (2009) has some form of autism, declaring it to be 'an urgent public health concern.' Studies have shown that appropriate and timely interventions for children diagnosed with autism improve communication, social interaction, cognitive ability, and quality of life (Woods and Wetherby, 2003; Dawson, 2008; Pierce et al., 2011). Recognizing the importance of early detection and intervention, the American Academy of Pediatrics (AAP) made a recommendation to perform screening for autism using a standardized autism-specific screening tool

© Cambridge University Press 2014



¹Department of Pediatrics, University of Kansas Medical Center, Kansas City, Kansas, USA

²Center for Child Health and Development, University of Kansas Medical Center, Kansas, USA

³Department of Family Medicine, University of Kansas Medical Center, Kansas City, Kansas, USA

⁴Center for American Indian Community Health, University of Kansas Medical Center, Kansas City, Kansas, USA ⁵Department of Preventive Medicine & Public Health, University of Kansas Medical Center, Kansas City, Kansas, USA

⁶Department of Indigenous Studies, University of Kansas, Lawrence, Kansas, USA

on all children at the 18- and 24-month visits (2006; Johnson and Myers, 2007). Currently, fewer than 25% of pediatricians screen for developmental delay using recommended tools (Sand et al., 2005) and fewer than 10% screen for autism on a regular basis (Johnson and Myers, 2007).

A number of studies have looked at barriers to developmental and autism-specific screening in pediatric practice (Flores et al., 2000; Sand et al., 2005; Dosreis et al., 2006; Pinto-Martin et al., 2008). Very little is published on barriers to screening for developmental disorders, including autism, in family medicine practice. According to Glascoe and Dworkin (1993), physicians are influenced by their unique experiences, beliefs, and attitudes when selecting clinical information from an array of data. Physicians' experiences, beliefs, and attitudes about autism have not been systematically explored, and little is known about how physicians' beliefs contribute to attitudes for autism screening. In this study, we examined the process of autism screening as perceived by family physicians using a critical medical anthropology (Singer and Baer, 2011) framework. This study explored potential barriers to the adoption of AAP-recommended autism screening at 18- and 24-month visits in a family medicine practice.

Method

A convenience sample of family practice physicians in the Kansas City metropolitan area was obtained through a letter of invitation to participate in the research, with a supporting letter from the president of the Kansas chapter of the American Academy of Family Physicians (AAFP). The AAFP president identified family physician practices that interacted with pediatric patients; he believed that the selected establishments were very likely to be interested in the research topic. Of the 45 letters mailed, 15 providers agreed to participate. A series of six interviews and three focus groups were conducted between December 2007 and August 2009 at locations determined by the participants. Practice settings of participants varied; four participants practiced in academic settings, three participants had private (solo) practices in the community, and eight participants were in group practices. There were three participants in each focus group. Participant's ages

ranged from 34 to 60 years, and six of them (40%) were women. Their work experiences ranged from 5 to 27 years. Fifty-dollar gift cards were offered to focus groups and interview participants and they were accepted by a few, but not all. The Human Subjects Committee at the University of Kansas Medical Center reviewed and approved the study protocol.

Data collection consisted of interviews and focus group discussions. Originally, the research was designed for focus groups only. However, it was impossible to gather enough practicing family physicians at the same location and time. In an effort to accommodate schedules and increase participation, interviews were conducted as well. Using both methods was advantageous because data gathered included in-depth descriptions and explanations, as well as ideas that came about through participant interactions. Using interviews and focus groups allowed us to view the results in both settings (and there was little difference in the outcome). Participants completed a brief demographic survey with information about personal experience with autism before focus group discussions and interviews. Focus group discussions and interviews took place at the participants' practice sites. Dr Fenikilé, who has been formally trained in qualitative data collection techniques, conducted all interviews and moderated all focus group sessions. It is important to disclose that Dr Fenikilé and Dr Ellerbeck are developmental pediatricians and have a bias toward autism screening implementation. The remaining authors are trained researchers who do not have an agenda toward the promotion of autism screening.

Semi-structured questions based on the CMA framework were used to address needs and barriers to autism screening and referral at four levels, including macro-social, intermediate-social, micro-social, and the individual (Table 1). The same questions were used in both interviews and focus groups to allow us to more easily analyze across the two methods of data collection. Focus groups and interviews were conducted in English and lasted for 40-60 min. Each session was audio recorded and transcribed verbatim. Verbatim transcripts were independently read and inductively coded by the first and third author. The first author made an initial list of coding topics; then, the third author made suggestions and the two agreed on a revised coding scheme. After each author completed

Table 1 Topics covered during interviews and discussions

Level of analysis	Topics to be covered
Individual	Beliefs about autism prevalence
	Beliefs about outcomes for patients with ASD
Micro-social	Parent anxiety about screening and diagnosis of ASD
	Parent and physician beliefs about etiology and treatment options
Intermediate-social	Practice protocols for screening
	Time/volume issues as relate to ASD screening
	Referral options and limitations
Macro-social	AAFP/AAP screening guidelines/CPG
	EPSDT (KBH) requirements
	Insurance company practices

ASD = autism spectrum disorder; AAFP = American Academy of Family Physicians; AAP = American Academy of Pediatrics; CPG = clinical practice guidelines; EPSDT = early and periodic screening, diagnostic and treatment.

coding the data, the two compared their coded transcripts to ensure that the coding was done in a consistent way. Each author wrote themes separately. These were sent to the PI for review. All authors met and discussed the initial themes and then combined these into final thematic statements. Transcripts were analyzed for common themes following a grounded theory approach of qualitative text analysis (Singer and Baer, 2011). No additional interviews or focus groups took place after data saturation was achieved on our main research question – that is, 'what autism screening tools do family physicians use (if any) and why?' Autism screening is a difficult topic to saturate because of the huge variation in the activities undertaken by family physicians. Trustworthiness criteria including member checks and peer debriefing were employed to ensure validity of findings. For example, the results were shared with groups of individuals who were interviewed or with those who participated in focus groups. During the analysis phase, several meetings took place between the two analysts (i.e., the first and third authors) and additional meetings took place with clinical faculty in the Department of Family Medicine at the University of Kansas Medical Center for feedback.

Results

A total of 6 out of 15 participants were women. All participants saw pediatric patients; about half of the participants estimated that 25% of their

Primary Health Care Research & Development 2015; 16: 356-366

patients were in the pediatric age group, whereas the remaining participants had ~15% pediatric patients. All participants provided well-child care; none administered autism-specific screening tools to screen for autism during well-child care visits. Overall, there was no consensus among the participants regarding routine screening for autism during well-child visits. Description of themes within the topic areas and supporting quotes are reported below.

Views on autism prevalence

Participants described autism prevalence in three main ways: an expanded definition, change in diagnostic category, and the need for service eligibility.

Expanded definition

When asked about their views on the increasing prevalence of autism, all participants agreed that increased awareness by both professionals and the public plays a significant role. In addition, most participants agreed that the increase in the prevalence of autism is due to diagnosis based on the current expanded definition. There was no agreement on whether autism is over- or underdiagnosed. Statements such as 'I think we are more aware of it (autism) because we are learning more about it' and 'I question whether the diagnosis of autism is the most appropriate for all of those children that it's been applied to' represent the vast array of opinions expressed in the interviews and focus groups.

Change in diagnostic category

In addition, the majority of participants stated that there is a shift in diagnostic category. They believed that most children who previously would have been labeled as having a speech/language problem with behaviors different from the norm are now moved to the autism spectrum category. Most emphasized the descriptive nature of the diagnosis, which is believed to have significant impact on the reported prevalence of autism.

Need for service eligibility

Some also believed that the increased diagnosis of autism is influenced by the need for service eligibility. Most participants agreed that families have problems accessing required services for their children without a diagnosis that meets eligibility criteria. 'I think the frequency of diagnosis and the broadening of the definition has been affected by politics, by parent and child need, by the medical profession's desire to see that the child gets the things he needs.'

Views on routine autism screening

Participants revealed a wide range of screening preferences and practices. Specific autism-screening tools and developmental assessments were discussed, including the pros and cons of using such instruments. The implications of implementing a tool were examined as well.

Screening preferences and practices

Participants preferred general developmental assessment over autism-specific screening. In general, participants did not agree with routine screening for autism during well-child visits. Most participants preferred to administer general developmental assessment tools, along with direct observation during clinic encounters. In general, participants who have been in practice longer agreed that the decision to screen for autism should be based primarily on concerns raised by parents and/or physicians' observation rather than the AAP's universal screening recommendation for a specific condition. An experienced physician stated, '... a general sensitivity to the parent's concern accompanied by some formalized developmental assessment will give a sensitive physician a sense that there is or there is not something wrong.' This sentiment was shared among other physicians who

had been in practice longer. Physicians who more recently completed residency training favored using screening tools to identify concerns that could otherwise be missed. A physician with less than five years of experience stated his/her uneasiness with a reliance on accumulated knowledge: '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, then I document it in my notes so that I can compare it to when I see them again.'

For those physicians who did not endorse routine autism screening, reasons differed. Some participants viewed screening for a specific condition, such as autism, to be an inefficient use of a physician's time, because a finite amount of time exists for a routine visit and other issues need to be addressed. The trepidation relates to screening for every possible condition a child may have. Some participants did not think screening for numerous individual conditions is realistic in the time allotted. Other participants stated that individualizing care and addressing what is important to that particular child adds more value to a well-child care visit.

A few participants expressed concern that identifying 'mild' cases in children whose parents are not concerned and who might not qualify for services could cause more harm than good. 'I am concerned about that with autism that, if I detect something thing that the parents aren't concerned about, will I actually get a service that results in less harm than if I wait until the behavior is bothering the parent?'

Screening implementation and implications

Some participants indicated that they are not aware of any AAFP guideline recommending routine screening for autism. 'I haven't seen a push in my medical journals to discuss and go aggressively for the diagnosis of autism.' Therefore, the perception of insufficient evidence for the benefit of routine screening influenced some individuals' decision to screen.

On the other hand, those who supported autism screening suggested incorporating the tool in the electronic medical record (EMR) to improve efficiency and compliance. In addition, the EMR was believed to be of great value for patient follow-up and for research purposes, '... if we can pull in the screening tool in the EMR and just do the screens right there and then, that would be of great value.

And plus for research issues too that you can just pull it all electronically and depending on the screening tool, it will help with the false positives or negatives as well.'

Others stated that having a tool that compares a child with normal peers adds to the credibility of the physician when communicating concern to parents. Also, the tool provides the parents with an objective measure. 'I think when you use a specific tool; the parent is more apt to believe what you say, if you can show this is where most of the children are at this age group and your child is functioning here to here. Then the parents have something concrete to look at and hold on to.'

Major barriers to autism screening

Overwhelmingly, participants discussed three major barriers to autism screening – lack of time, lack of knowledge (training), and lack of funding.

Lack of time

All participants cited lack of time as a barrier to implementing routine screening in a well-child care encounter. Well-child care visits are loaded with many recommendations, including immunizations. A participant who is part of a university hospital-based practice stated the time constraint issue: 'Every new thing you put in place, another screen, another form, another ... and it may be the same question but even a different iteration of the same questions that comes up with screening tool, still requires somebody to consolidate that information.'

Limited time involves more than the time used to administer the screening and combine collected information. Constraints are compounded by compiling several sources of data. For example, most participants expressed the dilemma faced between eliciting and addressing parents' concerns while at the same time addressing the recommended health directives outlined in practice guidelines. A participant who struggles with this balance stated, '... there is more and more things put in our laps and appropriately so in many cases, but we don't have two hours to spend with each patient or an hour for that matter.'

Lack of knowledge/inadequate training

More than half of the participants indicated that they lack knowledge about both the early signs and symptoms of autism and the specific ages when

Primary Health Care Research & Development 2015; 16: 356–366

autism-specific screening is recommended. The uneasiness with family physicians implementing screening measures was captured in the statement '... I don't even know that I'd know the right questions to ask ... I don't know what I'd look for at 18 months.'

Most participants lacked familiarity with autism screening tools and were not aware of any specific guidelines recommending routine autism screening. In part, participants agreed that this deficit relates to the lack of emphasis on developmental issues received in residency trainings. 'I think family physicians are so uncomfortable with child development ... they don't have comfort with the formalized tools, they are not comfortable with the diagnosis, and they are not comfortable with the treatment.'

In addition to the lack of knowledge about autism screening tools, some participants indicated that general lack of knowledge about causes of autism and the inability to explain the etiology to parents create a barrier. Some participants reported that parents raise concerns about autism during well-child visits that involve vaccine administration. This belief, that vaccinations cause or contribute to autism, has become somewhat common in the general population because of individual reports in the media of a possible link. Despite the lack of evidence linking vaccination to autism demonstrated in the medical literature, the lack of knowledge about causes of autism is believed to exacerbate communication difficulties concerning issues related to autism.

Lack of funding

Inadequate funding was perceived as a barrier for both physicians and families, although the challenges were different. Generally, participants stated that the jobs of primary-care providers are not highly valued and pay rates for ambulatory practices are 'dismal.' All clinicians indicated that additional time spent in screening is not reimbursed because it is bundled with the preventive-care visit.

Most participants highlighted the need for changes in the healthcare delivery system, calling for a system that allows primary-care providers to spend more time interacting with families and children. Participants envisioned a system that values time spent addressing parental concerns, observing the child and his/her interaction with the family, and providing quality evidence-based care to all children and families. 'I think that the health

policy, the legislation needs to incorporate behavioral disorders as more of a primary focus of prevention ...'

Some of the participants also stated the need for increased funding and a social component to be incorporated into the treatment process via networks and support systems. 'I don't think society really cares about kids. I think that ... like to say we care about kids but in reality we don't fund it. We don't make sure that no child is left behind ... if we really cared we'd fund it and make sure that there were resources.'

Other perceived barriers to routine autism screening

Although lack of time, lack of knowledge, and lack of funding emerged as major barriers to routine autism screening, participants mentioned other significant issues such as lack of resources, changes in diagnostic criteria, and stigma.

Lack of resources

The perception of limited resources available to children with autism and lack of funding for those services influenced the decision of some participants to routinely screen for autism. One participant stated, 'If there are resources to refer them to, sure. But I don't want to screen for something I can't get services for.' Reluctance toward screening became more pronounced among some participants when the suspected case was a 'mild form of autism' - that is, the child was unlikely to qualify for available services. One family physician discussed his/her fear in screening a child with a positive result: '... I would love if the resources were there that if I screen, I could get the service. But I'm pretty sure that if I screen and I find something parents aren't complaining about, that if I tried to get the service I wouldn't get it anyway.'

In addition, insurance status of the child was also believed to play a role in accessing available resources. 'And the problem in the medical system is very specific to the fact that our insurance companies in the United States are private ... they are not required to cover anybody, and people with various types of diseases or disorders are discriminated against ...'

Furthermore, some clinicians believed that, in addition to resources overall being limited or scarce, services provided through the school system are inferior to the services provided through

the Early Intervention (EI) programs. This is believed to be directly linked to the financial status of the local school districts, which determines the quality and availability of services required by families and their children. 'Well the personalized service, the one-on-one that the zero- to- three get is always a gold standard the schools have trouble reaching ... my sense of the school's success is directly related to the funds available.'

Not all of the participants referred patients to community-based services like EI. Some awaited recommendation from a specialist before sending a child suspected of having autism. This may suggest the lack of knowledge about available resources that the family could be referred to.

Change in autism diagnostic criteria

The perceived changes in the diagnostic criteria for autism were regarded by some participants as a barrier to routine screening. This was also reflected by the lack of consensus regarding the increase in autism prevalence. '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.'

In addition, change in diagnostic criteria was believed to lead to the mislabeling of some children as having autism spectrum disorder. As a result, some participants voiced their reluctance to routinely screen because of incorrect diagnosis. A frequently expressed opinion describes overdiagnosis: 'Everyone whose child isn't quite right now potentially is being labeled autistic to some degree or form ... In particular, I think speech delays labeled quickly to be autism before it's really worked up.'

Autism was perceived as a condition that is not well defined. Participants acknowledged the difficulty of making a diagnosis because of symptom variation and overlap. '... I think the condition, however you define it, hasn't quite established its home turf, its home definition. And so a lot that otherwise can't be assigned to something is dumped in.' Therefore, the perception of autism spectrum disorder's complex definition resulted in uncertainty when classifying behaviors.

Labeling effect

Although some participants believed that a physician may be inclined to make a diagnosis of autism to ascertain service eligibility, others

reported concerns expressed by parents about having their child labeled with a chronic condition. Parental reluctance was believed to arise from the following: (1) the fact that much is still not known about what causes autism; (2) the wide range of observed symptoms; (3) the stigma of the diagnosis; and (4) fear of rejection by insurance companies.

Although the majority of participants stated that insurance companies may not cover services for children having autism spectrum disorder, there were a few who did not see insurance eligibility influencing parents' decision to seek evaluation or diagnosis.

General developmental assessment tools preferred over an autism-specific screening tool

None of the participants used autism-specific screening tools at the 18- and 24-month well-child visits. All but one lacked awareness of recommended autism screening tools. Most clinicians used the Denver Developmental Screening tool and some used questionnaires (developed by their practices) to assess overall development during well-child care encounters. Statements such as 'I've heard of Denver Screening, but not for autism specifically, 'We don't have a specific tool that we use (for autism), we do the Denver Developmental Screen,' and 'I don't know what other screens there are but I haven't looked into it that much' demonstrate the preference for a general developmental assessment screening tool over the autism-specific screening tool. Some participants expressed concern about using a screening tool designed to assess for one specific condition within a limited amount of time. '... I've got a tool I'm comfortable with and adding on something, especially when it is so focused becomes an inappropriate use of time.' Some participants stated that they would have to omit certain things to add another task.

Those who believed extra time is justified to implement recommended screening had concerns about reimbursement, whereas some clinicians did not view autism screening as a priority in their practice. Assessing overall development and focusing on issues of concern was viewed as more efficient and practical.

Views on treatment for the management of autism

Most participants had difficulty deciding whether medical insurance companies or the educational system should pay for autism screening and services.

Primary Health Care Research & Development 2015; 16: 356-366

Many agreed that it should be a joint effort between medical and educational service providers. 'Ours has to be a team, it has to be. Everybody has to share responsibility. I mean we can help with diagnosis but we can't provide the developmental services that are needed, so that has to be either educational or psychiatric or psychological and not through our office.'

Just as the cause of autism is not fully understood, so is the role of medication in treating autistic children. Most participants believed that medication does not play a significant role in the management of children with autism. 'I certainly think education is the way to go. I do not think there's any documented medical treatment for autism that I know of.'

Physicians were asked about their management of children suspected of having autism or developmental problems. Almost all of the participants indicated that they refer patients to subspecialists for evaluation and management of conditions associated with autism. Some expressed their reliance on specialists' recommendation before referring children for interventions.

Participants' suggestions to improve autism screening by their primary-care providers (see Table 2)

Systemic change

Access to care and an equitable healthcare system were among the highlighted issues. Participants voiced the need for change in the healthcare delivery system to implement additional health directives. Participants who agreed to routinely screen for autism suggested incorporating the recommended screening tool (M-CHAT) into the EMR to improve efficiency and compliance. Some also expressed the need for a care coordinator within a family medicine practice to facilitate referral and communication between provider, families, subspecialists, and community programs.

Better physician reimbursement

Inadequate reimbursement for physician time was a recurring theme in all focus group discussions and interviews. Physicians felt that there are too many health directives that require their attention in a limited amount of time. All participants believed that better compensation for the physician's time spent providing comprehensive

Table 2 Participants' suggestions to improve screening practices

System Change

Since we do electronic medical record, if it could be incorporated in to the screening of our exam ... we'd pull up the exam and go through the screening ... '

'I think we probably need sophisticated systems (EMR) that will help providers remember (screening)'

Emphasis on developmental issues during residency training and continued physician education

I think the physician needs to be trained in the tool, comfortable in the tool, encouraged to believe this is a critical part of the well child check ...'

"... I think they need to be comfortable with the tool before they're out of residency. They need to be forced to use it and be comfortable with it.

'we all have national meetings and in those meetings they always have break out sessions, we should have something like that for autism ...'

Stronger evidence base to support universal screening

'If indeed treatment does make a difference and finding it earlier is the key to the best end result, then I would do the screening on everybody.'

'I'm not sure of the outcome of screening ... it would need a long term intention to treat. We have no idea if there are any bad outcomes ...'

'It would be really nice if there was more pediatric evidence that one could actually rely on'

Adequate reimbursement for physician time

"... we don't get paid enough and that's what it comes down to, reimbursement. You should get decent reimbursement for the time that it takes ...

FMR = electronic medical record.

and quality care would improve implementation of the recommended surveillance and routine screening procedures.

Better physician training

Physician training on developmental issues and recommended screening tools was emphasized. All participants agreed that residency programs should place more emphasis on developmental and behavioral issues, as well as provide training on the use of screening tools. To help bridge the knowledge gap for practicing physicians, participants emphasized the importance of continuing education through local or national CME programs.

Stronger evidence base supporting the benefit of screening

Participants who did not endorse routine screening argued that the current recommendation by the AAP is based on consensus and expert opinion rather than on strong evidence showing the benefit of routine screening. They indicated that more outcome studies on the benefits of screening involving diverse populations are required to support routine autism screening.

Discussion

This qualitative study provides details necessary to understand family physicians' beliefs and attitudes about autism and autism screening, and their potential role as barriers to implementing screening. Family physicians play a significant role in providing care to US children, despite the increase in the pediatric work force (Freed et al., 2004; Cohen and Coco, 2010). This is particularly true for children living in rural and smaller communities, where the majority often receive their healthcare services from family physicians (Backer, 2005). Overall, ~15% of children younger than two years are seen by family physicians for well-child visits (Randolph and Pathman, 2001).

In this study, we found that family physicians generally do not support routine screening for autism during well-child visits. None of the participants interviewed use autism-specific screening tools during well-child visits. Participants expressed a lack of awareness concerning routine autism screening and autism screening tools. In addition, the prevailing notion that screening should follow concerns raised by parents or physicians' own

observations (developmental surveillance) has hindered implementation of screening. This finding is in contrast with previous studies, which have primarily stated lack of knowledge and time as the major barriers (Sand *et al.*, 2005; Dosreis *et al.*, 2006; Elliott, 2007). Participants generally favored using a general developmental assessment tool coupled with direct observation rather than screening for a specific condition.

The most significant challenge highlighted by family physicians is a balance between implementing recommended health directives, staying focused on parental concerns, and remaining mindful of time limitations. Participants expressed the challenge in orchestrating these needs into a practical framework. There was widespread recognition of the need to individualize care and address parental concerns. Participants with more experience often expressed their desire to have more observation time with the child than go through checklists. Screening was favored among participants with fewer years of experience who do not feel as confident about their ability to identify developmental concerns, especially autism, which has variable presentations.

Regardless of years of experience and practice setting, lack of awareness of the AAP's recommendation to screen routinely and lack of awareness of the recommended tools were evident among all participants. The paucity of discussions on such issues in family medicine journals reflects the limited attention given to the topic. The need for stronger evidence to support routine screening based on outcome studies was strongly expressed among participants, similar to the reports by Al-Oabandi et al. (2011) and Williams and Brayne (2006). The current strength of recommendation taxonomy (Ebell et al., 2004) rating for autism screening described in family medicine journals reflects what participants described as a weak evidence base in support of routine screening. For some, applying the recommendation to a culturally and socioeconomically diverse population was also in question. Among the concerns were the following: parents' levels of education (literacy) potentially limiting their understanding of what the screening question is asking, the influence of culture on parent's interpretation of their child's behavior, and language barriers. This is in contrast to the finding by Schonwald et al. (2009) and King et al. (2010), which showed the feasibility of

Primary Health Care Research & Development 2015; 16: 356-366

implementing routine developmental screening in an urban community with diverse socioeconomic backgrounds.

All participants felt pressure to accomplish more in less time. Despite the brief nature of the screening tool, many see the task as timeconsuming. The dilemma of balancing parental concern and individualized care with the many preventive health directives for well-child care visits is an ever-present issue (Tanner *et al.*, 2009). Limited time generally seemed to go hand in hand with two issues: the value of a specific screening tool and reimbursement by insurance companies. However, in some instances, the decision to screen was not a matter of time or reimbursement but rather it was linked to available and affordable resources for children and their families. The argument made was 'what good will it do to screen if we can't provide services?' Some expressed the need for an equitable health system that promotes early recognition of developmental problems, as well as provides appropriate and adequate intervention. According to Radecki et al. (2011), a significant portion of the pediatricians interviewed use informal checklists and do not use the recommended developmental screening tools with children younger than 36 months. The departure from AAP-recommended guidelines reflects the significant challenge that lies ahead. Similar to the findings by Tanner et al. (2009), participants acknowledged the need to emphasize developmental issues during residency training and continued professional education to improve well-child care practices.

Because of the small sample size and the selection of participants practicing in a metropolitan area, our results may not represent the larger family physician community. Thus, limitations to this project include the transfer of results to similar geographic locations – that is, urban areas in the Midwest, rather than rural areas. The next step for this research is to examine family physician screening practices of pediatric patients in rural areas. Continuation of the project is essential as family physicians in rural areas see more pediatric patients. Although the research presented does not lead to definite conclusions, the expressed opinions are nonetheless revealing as they provide important perspectives on the impact that beliefs and attitudes have on physicians' decision-making process.

Conclusion

In this qualitative study, family physicians expressed their beliefs about autism and their attitudes about autism screening in their practices. Universal screening for autism at 18- and 24-month visits is neither widely accepted nor is it implemented by family physicians. Despite efforts made by parent groups, the CDC (Centers for Disease Control and Prevention, 2012), and the AAP to promote early identification of children with autism spectrum disorder through routine screening, implementation of screening and referral in the medical home continues to be challenging. The gap between the age at which children can be identified with developmental problems, including autism, and when they actually are identified is large (Shattuck et al., 2009). This gap is even more significant for children of low-income families (Fountain et al., 2011). A number of studies conducted among primary-care providers have attributed this pitfall to lack of knowledge, time, and inadequate reimbursement (Mandell et al., 2005; Rhoades et al., 2007). The current study adds views and perspectives that received little attention in previous studies. Participants in this study frequently expressed the lack of autism knowledge, specifically concerning the following: recommended screening, screening tools, etiology, and effective treatment. Another barrier to routine autism screening is the lack of available resources for families within their communities. Finally, most participants called for stronger outcome studies supporting the benefit of screening as a necessary prerequisite to implementation of systematic autism screening.

Acknowledgments

The authors acknowledge the family physicians who shared their time and invaluable insight. In addition, the authors have nothing to disclose.

References

- Al-Qabandi, M., Gorter, J.W. and Rosenbaum, P. 2011: Early autism detection: are we ready for routine screening? Pediatrics 128, e211–217.
- **Backer, L.A.** 2005: Caring for children: re-examining the family physician's role. Family Practice Management 12, 45-52.
- Boyle, C.A., Boulet, S., Schieve, L.A., Cohen, R.A., Blumberg, S.J., Yeargin-Allsopp, M., Visser, S. and Kogan, M.D. 2011:

- Trends in the prevalence of developmental disabilities in US children, 1997-2008. Pediatrics 127, 1034-42.
- Centers for Disease Control and Prevention. 2012. Learn the signs. Act early. Atlanta: Centers for Disease Control and Prevention. Retrieved 12 April http://www.cdc.gov/ncbddd/ actearly/index.html
- Cohen, D. and Coco, A. 2010: Trends in well-child visits to family physicians by children younger than 2 years of age. Annals of Family Medicine 8, 245-48.
- Council on Children With Disabilities; Section on Developmental Behavioral Pediatrics; Bright Futures Steering Committee: Medical Home Initiatives for Children with Special Needs Project Advisory Committee. 2006: Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. Pediatrics 118, 405-20.
- **Dawson, G.** 2008: Early behavioral intervention, brain plasticity, and the prevention of autism spectrum disorder. Development and Psychopathology 20, 775–803.
- Dosreis, S., Weiner, C.L., Johnson, L. and Newschaffer, C.J. 2006: Autism spectrum disorder screening and management practices among general pediatric providers. Journal of Developmental and Behavioral Pediatrics 27, S88-94.
- Ebell, M.H., Siwek, J., Weiss, B.D., Woolf, S.H., Susman, J., Ewigman, B. and Bowman, M. 2004: Strength of recommendation taxonomy (SORT): a patient-centered approach to grading evidence in the medical literature. American Family Physician 69, 548-56.
- Elliott, V. 2007: Early autism screening urged, but barriers exist. American Medical News, 19 November. http://www.amednews.com/article/20071119/health/311199975/6/
- Flores, G., Lee, M., Bauchner, H. and Kastner, B. 2000: Pediatricians' attitudes, beliefs, and practices regarding clinical practice guidelines: a national survey. Pediatrics 105, 496–501.
- Fountain, C., King, M.D. and Bearman, P.S. 2011: Age of diagnosis for autism: individual and community factors across 10 birth cohorts. Journal of Epidemiology and Community Health 65, 503-10.
- Freed, G.L., Nahra, T.A. and Wheeler, J.R. 2004: Which physicians are providing health care to America's children? Trends and changes during the past 20 years. Archives of Pediatrics & Adolescent Medicine 158, 22-26.
- Glascoe, F.P. and Dworkin, P.H. 1993: Obstacles to effective developmental surveillance: errors in clinical reasoning. Journal of Developmental and Behavioral Pediatrics 14, 344-49.
- Johnson, C.P. and Mvers, S.M. 2007: Identification and evaluation of children with autism spectrum disorders. Pediatrics 120, 1183-215.
- King, T.M., Tandon, S.D., Macias, M.M., Healy, J.A., Duncan, P.M., Swigonski, N.L., Skipper, S.M. and Lipkin, P.H. 2010: Implementing developmental screening and referrals: lessons learned from a national project. *Pediatrics* 125, 350–60.
- Mandell, D.S., Novak, M.M. and Zubritsky, C.D. 2005: Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics* 116, 1480–486.

- Pierce, K., Carter, C., Weinfeld, M., Desmond, J., Hazin, R., Bjork, R. and Gallagher, N. 2011: Detecting, studying, and treating autism early: the one-year well-baby check-up approach. *The Journal of Pediatrics* 159, 458–65, e451–e456.
- Pinto-Martin, J.A., Young, L.M., Mandell, D.S., Poghosyan, L., Giarelli, E. and Levy, S.E. 2008: Screening strategies for autism spectrum disorders in pediatric primary care. *Journal* of Developmental and Behavioral Pediatrics 29, 345–50.
- Radecki, L., Sand-Loud, N., O'connor, K.G., Sharp, S. and Olson, L.M. 2011: Trends in the use of standardized tools for developmental screening in early childhood: 2002–2009. *Pediatrics* 128, 14–19.
- **Randolph, G.D.** and **Pathman, D.E.** 2001: Trends in the ruralurban distribution of general pediatricians. *Pediatrics* 107, E18.
- **Rhoades, R.A., Scarpa, A.** and **Salley, B.** 2007: The importance of physician knowledge of autism spectrum disorder: results of a parent survey. *BMC Pediatrics* 7, 37.
- Rice, C. 2009: Prevalence of autism spectrum disorders Autism and Developmental Disabilities Monitoring Network, United States, 2006. MMWR Surveillance Summaries 58, 1–20.
- Sand, N., Silverstein, M., Glascoe, F.P., Gupta, V.B., Tonniges, T.P. and O'connor, K.G. 2005: Pediatricians' reported practices

- regarding developmental screening: do guidelines work? Do they help? *Pediatrics* 116, 174–79.
- Schonwald, A., Huntington, N., Chan, E., Risko, W. and Bridgemohan, C. 2009: Routine developmental screening implemented in urban primary care settings: more evidence of feasibility and effectiveness. *Pediatrics* 123, 660–68.
- Shattuck, P.T., Durkin, M., Maenner, M., Newschaffer, C., Mandell, D.S., Wiggins, L., Lee, L.C., Rice, C., Giarelli, E., Kirby, R., Baio, J., Pinto-Martin, J. and Cuniff, C. 2009: Timing of identification among children with an autism spectrum disorder: findings from a population-based surveillance study. *Journal of the American Academy of Child and Adolescent Psychiatry* 48, 474–83.
- Singer, M. and Baer, H. 2011. Introducing medical anthropology: a discipline in action. Lanham: AltaMira Press.
- Tanner, J.L., Stein, M.T., Olson, L.M., Frintner, M.P. and Radecki, L. 2009: Reflections on well-child care practice: a national study of pediatric clinicians. *Pediatrics* 124, 849–57.
- **Williams, J.** and **Brayne, C.** 2006: Screening for autism spectrum disorders: what is the evidence? *Autism* 10, 11–35.
- Woods, J. and Wetherby, A. 2003: Early identification of and intervention for infants and toddlers who are at risk for autism spectrum disorder. *Language, Speech, and Hearing Services in Schools* 34, 180–93.