

A Study of Physician Knowledge and Experience with Autism in Adults in a Large Integrated Healthcare System

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Published online: 3 September 2015
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Abstract We conducted an online survey of adult health care providers at Kaiser Permanente Northern California and semi-structured interviews with a subset of physicians. The survey assessed providers' ability to recognize autism spectrum disorder (ASD), asked them to rate their autism knowledge, comfort level in treating affected patients, and evaluated training and resource needs. 922 providers completed the survey (response rate 25.3 %), and 9 were interviewed by telephone regarding their autism training and experiences caring for patients with autism. Most providers reported lacking skills and tools to care for this adult patient population. A high proportion of adult providers were not aware that they had patients with ASD. These findings underscore the need to educate physicians caring for adults with ASD.

Keywords Adults · Survey · Autism spectrum disorder · Healthcare providers · Knowledge

Introduction

Autism spectrum disorders (ASD), a group of developmental disabilities typically diagnosed in childhood, are associated with high prevalence of comorbid medical conditions and mental health problems (Croen et al. 2015; Gurney et al. 2006; Hofvander et al. 2009; Kohane et al. 2012). With the exception of a small minority of children who lose their diagnosis (Fein et al. 2013), the vast

majority of children with ASD grow up to become adults with ASD (Billstedt et al. 2007). The prevalence of ASD in children has been increasing over the years (Baio 2012; Kim et al. 2011), suggesting that the prevalence in the adult population, estimated at 1 % (Brugha et al. 2011), will also increase.

Previous surveys among various groups of healthcare providers reported gaps in knowledge about ASD, deficiencies in diagnostic abilities, and a lack of self-perceived competency in treating children with autism (Bakare et al. 2009, 2008; Esegbe et al. 2015; Garg et al. 2014; Golnik et al. 2009; Hartley-McAndrew et al. 2014; Heidgerken et al. 2005; Igwe et al. 2011; Imran et al. 2011; Khanna and Jariwala 2012; Nicolaidis et al. 2015; Oskoui and Wolfson 2012; Rahbar et al. 2011). Parents of children with autism also expressed low confidence in (Harrington et al. 2006) and dissatisfaction with their children's physicians (Liptak et al. 2006).

As children with ASD age, their healthcare services move from the pediatric department to adult medicine, yet very little is known about providers' readiness to provide optimal care for adults with ASD. In a previous survey of adult primary care providers, only 36 % of physicians indicated receiving some training about caring for adults with ASD, and 53 % expressed the need for more training (Bruder et al. 2012). Not surprisingly, adult patients with ASD report lower satisfaction, and express more unmet healthcare needs than non-autistic adults (Nicolaidis et al. 2013; Pellicano et al. 2014). The vast majority of previous studies that surveyed providers' knowledge and comfort levels about treating patient with autism were limited to those in the pediatric department, included small samples, and did not include direct interview data.

The objectives of the present study were to determine adult healthcare providers' general knowledge about

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autism, to assess their comfort level treating patients with ASD, and to gauge their specific needs in caring for adults with ASD. Additional aims were to evaluate the variability in provider knowledge, comfort level, and needs across three types of providers (internal/family medicine, obstetrics/gynecology, and mental health) and to identify themes regarding physician knowledge and experiences through the use of direct interview data. The overall goal of the study was to gain knowledge that can guide the development of provider education and strategies for improving the delivery of healthcare to adults with ASD.

Methods

Study Overview

A brief survey was conducted of adult health care providers at Kaiser Permanente Northern California (KPNC), the largest and oldest group model pre-paid, integrated health care delivery organization in the United States providing health care to over 3 million residents of the San Francisco and Sacramento metropolitan areas and surrounding counties. To explain survey responses, and to gain insight into physicians’ experiences treating adults with ASD, the survey was followed by a small number of semi-structured telephone interviews with a subsample of providers who had indicated a willingness to participate in a follow-up telephone interview.

Study questions were identified by an interdisciplinary group of Kaiser Permanente stakeholders, who also designed and pilot-tested survey questions and data

collection instruments, and provided insights at different stages of data analysis. The Autism in Adults Workgroup included physicians in family medicine, internal medicine, child and adolescent psychiatry, and adult psychiatry; regional leadership for ASD clinical services; ASD case managers; an Employment Assistance Program coordinator; parents of adult children with ASD; an adult health plan member with ASD; epidemiologists and a doctoral level anthropologist. The Workgroup met quarterly, and while not formally structured as a focus group, served a similar purpose: to formulate questions for the survey and for the semi-structured interviews, and to contribute to the interpretation of data.

The study design and sequence of study activities are summarized in Fig. 1. The Kaiser Foundation Research Institute Institutional Review Board approved the study and waived the need for written consent.

Study Population

KPNC clinicians in the departments of family and internal medicine (n = 1841), adult mental health (n = 1030), and obstetrics/gynecology (OBGYN) (n = 768) were eligible to participate in the survey. They included physicians, psychologists, social workers, and nurses. The term “health care providers” is used to identify them collectively. A total of 922 completed the survey.

For the qualitative interview, a non-probabilistic purposive sampling approach (Teddlie and Yu 2007) was used to select physicians representing different characteristics of sex, self-rated knowledge of autism, facility, years of medical practice, and awareness of number of patients with

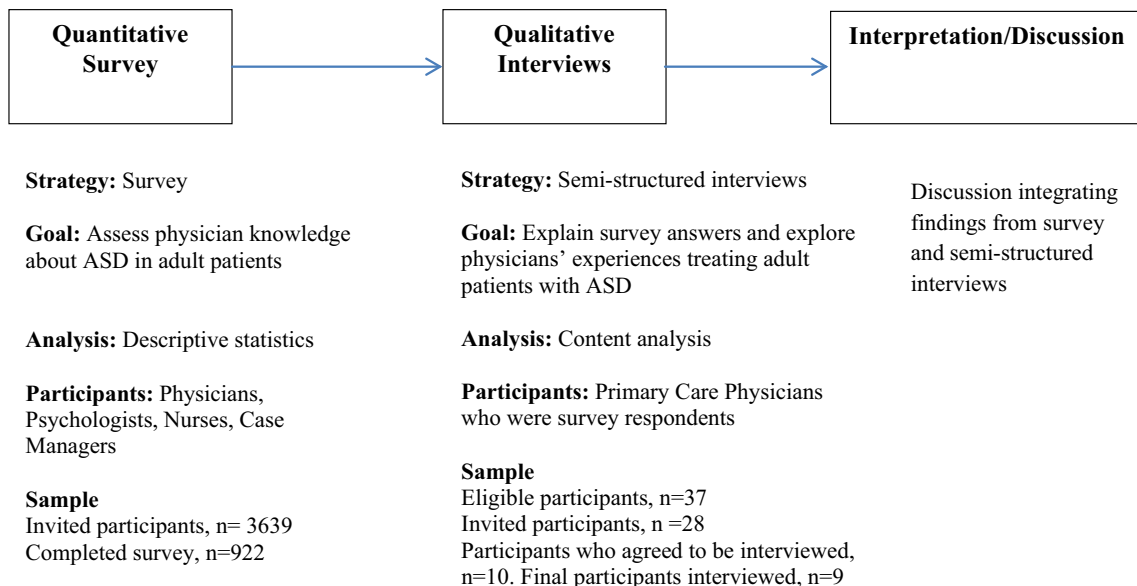


Fig. 1 Procedures in the investigation of physician knowledge about autism spectrum disorder in adults

autism in their panel. Of the 395 providers across specialties who indicated their willingness to be contacted for a follow-up interview, only primary care physicians were interviewed because of the likelihood that they would see their patients with ASD more often. There were 37 family and internal medicine providers who wrote comments in response to question two of the survey (see below), and from this group 28 whose comments represented different themes were selected. Of those 28, interviews were completed with 9.

Instrument

The 11-question online survey was designed to be completed by healthcare providers who serve adult patients (“Appendix”). The final questions were retained by consensus after months of discussion and pilot testing among members of the Autism in Adults Workgroup. The survey assessed health care providers’ ability to recognize autism characteristics, asked them to rate their knowledge of autism and their comfort level in treating patients with autism, and inquired about their training and resource needs. Questions were formatted using either Likert scales with forced-choice ($n = 4$), multiple choice ($n = 4$), or select-all-that-apply ($n = 3$). In one case (Question number 2, which asked: “When you suspect ASD in a patient, do you? [Check all that apply]”), there was a free-text section where respondents had the option of writing their answers in addition to the multiple choices offered. The last question asked respondents to provide contact information and availability if they were interested in participating in a follow-up telephone interview. The survey was designed using DatStat Illume software (<http://www.datstat.com/wpcontent/uploads/2012/09/Illume-in-detail.pdf>), and was tested for readability and completion time prior to launching by two primary care and mental health physicians at two Kaiser Permanente clinics who were not members of the Workgroup.

A very general guide for the follow-up interviews was developed by the anthropologist and the Workgroup based on the general responses to the survey and themes that emerged in the free-text answers to survey question 2. While the goal was to have a free form conversation with the physicians, the initial question was the same for all: “Tell me about autism training that you received during or after medical school.” The conversation continued naturally with probes from the anthropologist to cover two additional topics: (1) comfort-level and experience in caring for patients with autism, including making accommodations during visits for persons with autism, and (2) suggestions for resources and training. The interviewer also probed about challenges of clinical care, impact on the physician’s schedule, clinical screening for chronic

diseases, patient adherence to treatment, concerns brought up by patients or caregivers, and the transition from pediatrics to adult medicine.

Procedures

The survey was sent to health care providers, staggered by specialty, through the KPNC email system between April and June 2013. Following usual practices at Kaiser Permanente for delivering brief surveys to health care providers, eligible participants first received an email from their department chief encouraging them to complete an upcoming survey about adults with autism. Shortly after, each provider received a survey recruitment email from their chief with an individual link to the survey and a concise note with consenting language emphasizing voluntary participation and confidentiality. To maximize response rates, the survey was intentionally very brief, and e-mail reminders were sent to those who had not completed the survey after 2 and 4 weeks of receiving it. Survey completion times ranged from 3 to 5 min.

Primary care physicians were invited to participate in the follow-up interview via email. Given the wide geographical spread of Kaiser Permanente facilities in Northern California, and the physicians’ limited availability, all interviews were conducted by the anthropologist (MLM) over the telephone. Each interview began with obtaining verbal consent to participate and permission to record the session. After being asked about medical specialty and ASD training in medical school, physicians were invited to provide a detailed example of an office visit with one of their patients who was diagnosed with, or suspected of having autism. Once details about physician-patient interactions emerged, comfort level in caring for patients with ASD was discussed. The final questions were about resources and training that would serve physician needs in caring for adult patients with ASD. All interviews lasted 30–60 min. They were recorded, transcribed verbatim, and analyzed by the anthropologist who also wrote notes with additional information for data interpretation. The anthropologist presented preliminary findings to the workgroup and revised the analysis incorporating feedback from its members.

Data Analysis

To determine adult healthcare providers’ general knowledge about autism and to assess their comfort level treating patients with ASD, survey responses among the three types of providers were compared using a Chi square test with two degrees of freedom. To determine the accuracy of providers’ responses regarding the number of patients with ASD in their panel, survey responses were compared to the

actual number of patients in their panel according to information recorded in the KPNC electronic administrative databases.

Content analysis was used to summarize open-ended responses to question 2 of the survey. Rather than starting from an a priori theoretical approach to identify themes from the semi-structured interviews, content analysis was also used. Using a within-case and across-case analytic strategy described in Ayres et al. (2003), the anthropologist transcribed and read each interview a number of times to obtain full immersion in the data and identify significant statements in each interview (within-case strategy). This was followed by a comparison of significant statements across interviews to detect categories of statements describing experiences common to all participants (across-case strategy), which were organized by themes. The interviews were analyzed through an inductive, or “bottom-up,” process (Braun and Clarke 2006). Meaning from both explicit (e.g., directly stated) and implicit statements (e.g., those that presented contradictions, ambiguities, or inconsistencies) was used to develop themes (Ayres et al. 2003). The first level of analysis was carried out by the anthropologist. Subsequently, the resulting themes were evaluated and finalized with feedback from the Workgroup members.

Results

Survey

Overall, 922 providers completed the online survey (response rate 25.3 %), and 852 (92.4 %) completed all survey questions. The average time to complete the survey was 3.8 min (with a standard deviation of 0.9 min). The majority of respondents were physicians ($n = 593$, 69.6 %), followed by psychologists ($n = 102$, 12 %), licensed clinical social workers ($n = 68$, 8 %), marriage and family therapists ($n = 31$, 3.6 %), and nurses ($n = 58$, 6.8 %). Approximately 50 % ($n = 429$) of respondents were internal and family medicine providers, 16 % ($n = 132$) were OBGYN providers, and 34 % ($n = 291$) were mental health providers.

More than 90 % of respondents indicated that they would explore the possibility of ASD in a patient with limited eye contact, and more than 80 % would suspect ASD in patients with an atypical communication style (Table 1). Less than 10 % would suspect ASD in a patient that easily volunteers information about him/herself, shows an interest in other people, expresses his/her emotions, or concentrates on the whole picture rather than on small details. Not surprisingly, mental health providers self-

identified as most knowledgeable about ASD characteristics compared with medicine and OBGYN, who had a similar level of knowledge (Table 1).

Question 2, which included a multiple choice menu and a free-text field, asked providers what they did when they suspected ASD in a patient. Sixty-five percent of respondents indicated that they probed about the patient’s developmental history, 40 % consulted with a colleague, and 29 % provided usual care. Most responses varied by department (Table 1). Mental health providers were most likely to probe about developmental history, consult with colleagues, schedule a follow-up appointment, and refer to case management. OBGYN providers were most likely to provide “usual care”, and least likely to make referrals to other departments or schedule follow-up appointments. Fifteen percent of survey respondents provided written comments in the free-text field of question 2. Most of the comments alluded to lack of knowledge, resources, and training, which led the researchers to focus on ASD training and knowledge as opening questions in the follow-up interviews. In addition, respondents included comments about severity of symptoms, referrals, and inclusion of the patient’s family members in decision making.

The majority of respondents rated their knowledge/skills in providing care to ASD patients as poor or fair (77 %). The response varied by type of provider, with 88 % of OBGYN providers rating their knowledge/skills as poor or fair, followed by 79 % of providers in adult medicine and 70 % of providers in mental health (Fig. 2). Only 13 % of all providers agreed or strongly agreed that they had adequate tools/referral resources/practice models to accommodate patients with ASD in their practice (Table 2). This proportion varied by type of provider, with the highest level of agreement indicated by providers in adult medicine and lowest level of agreement indicated by mental health and OBGYN providers (Fig. 3). Likewise, only ~25 % of all providers agreed or strongly agreed that their patients with ASD, or the caregivers of those patients, had adequate support and services to partner with them effectively. (Table 2)

In terms of training and resources, the majority of respondents indicated the usefulness of several resources, including a conference with description of ASD (66 %), a checklist of community resources for patients with ASD (77 %), training on effective communication strategies with ASD patients (71 %), and a special primary care clinic or service within KPNC to serve adults with developmental disabilities (64 %) (Table 2). Level of endorsement of each response category varied by type of provider (Fig. 4).

A high proportion of respondents under-reported the actual number of patients with ASD in their panel (Fig. 5). Finally, almost half ($n = 395$) of the survey respondents were willing to be contacted for a follow-up telephone

Table 1 Survey responses by adult healthcare providers regarding knowledge of autism spectrum disorder characteristics and care practices, Kaiser Permanente Northern California

	All participants (n ^a = 852) n (%)	Internal/family medicine (n = 429) n (%)	Obstetrics/gynecology (n = 132) n (%)	Mental health (n = 291) n (%)	Chi squared ^b p values
<i>Which of the following patient characteristics would lead you to explore the possibility of an autism spectrum disorder (ASD) (check all that apply)</i>					
Has limited eye contact ^d	778 (91.31)	387 (90.21)	121 (91.67)	270 (92.78)	0.47
Easily volunteers information about her/himself	36 (4.23)	22 (5.13)	2 (1.52)	12 (4.12)	0.19 ^e
Has a flat affect ^d	553 (64.91)	277 (64.57)	82 (62.12)	194 (66.67)	0.64
Shows an interest in you	12 (1.41)	3 (0.70)	1 (0.76)	8 (2.75)	0.07 ^e
Is sensitive to touch ^d	538 (63.15)	256 (59.67)	77 (58.33)	205 (70.45)	<0.006
Is sensitive to light/sound ^d	516 (60.56)	233 (54.31)	71 (53.79)	212 (72.85)	<0.0001
Expresses her/his emotions	14 (1.64)	8 (1.86)	2 (1.52)	4 (1.37)	0.06 ^e
Gives concrete responses/has literal communication style ^d	482 (56.57)	182 (42.42)	62 (46.97)	238 (81.79)	<0.0001
Has atypical communication style ^d	735 (86.27)	361 (84.15)	108 (81.82)	266 (91.41)	<0.006
Concentrates on the whole picture rather than on small details	17 (2.00)	8 (1.86)	2 (1.52)	7 (2.41)	0.80 ^e
Has a monologue style of communication ^d	549 (64.44)	264 (61.54)	72 (54.55)	213 (73.20)	<0.0001
Is unusually direct ^d	333 (39.08)	146 (34.03)	47 (35.61)	140 (48.11)	<0.0001
<i>When you suspect ASD in a patient, do you? (check all that apply)</i>					
Probe about developmental history	552 (64.79)	253 (58.97)	43 (32.58)	256 (87.97)	<0.0001
Consult with a colleague	344 (40.38)	120 (27.97)	31 (23.48)	193 (66.32)	<0.0001
Schedule a follow-up appointment	207 (24.30)	71 (16.55)	4 (3.03)	132 (45.36)	<0.0001^e
Refer patient to specialty care outside KP	36 (4.23)	5 (1.17)	0 (0.00)	31 (10.65)	<0.0001^e
Refer patient to KP behavioral medicine department	148 (17.37)	121 (28.21)	20 (15.15)	7 (2.41)	<0.0001
Refer patient to KP psychiatry department	321 (37.68)	238 (55.48)	21 (15.91)	62 (21.31)	<0.0001
Refer patient to KP neurology department	54 (6.34)	44 (10.26)	4 (3.03)	6 (2.06)	<0.0001
Refer patient to a case manager	53 (6.22)	10 (2.33)	1 (0.76)	42 (14.43)	<0.0001
Provide usual care	247 (28.99)	118 (27.51)	62 (46.97)	67 (23.02)	<0.0001
Other ^c	127 (14.9)	37 (8.62)	34 (25.75)	56 (19.24)	<0.01

Statistically significant values are given in bold (*p* values)

^a Analysis based on the number of people with 100 % response to all questions in the survey

^b All Chi square tests were 2 degrees of freedom

^c Participants endorsing this choice were asked to provide comments

^d Considered characteristics that can lead to suspect ASD in a patient

^e Based on Fisher exact test

interview to talk about their experience of caring for adult patients with ASD.

Interviews

Of the 9 primary care physicians who were interviewed, six were female, and three worked at Young Adult Clinics. Of

the three male physicians, one was certified in both pediatrics and internal medicine, and the other two were family physicians. In terms of experience, physicians ranged from having 10–25 years of medical practice.

The themes that emerged from the content analysis of the free text in question two include (1) lack of knowledge about ASD and resources, (2) no encounter with adult

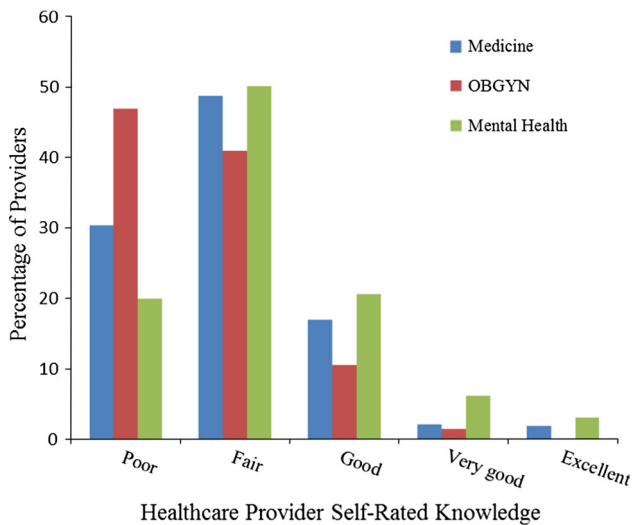


Fig. 2 Healthcare provider self-rated knowledge and/or skills in providing care to adults with autism spectrum disorder, Kaiser Permanente Northern California

patients with ASD, (3) assumption that ASD is a childhood condition, and (4) no treatment available. These themes were further explored in the interviews with primary care physicians and reorganized as follows: lack of ASD knowledge, need for training and resources, and need for accommodations during office visits.

Lack of ASD Knowledge

The lack of familiarity with autism among some primary care physicians was illustrated by confusion about the term ASD, not knowing if it included Asperger’s, the category they seemed to recognize more easily. None of the physicians had received formal training in the screening and diagnosis of ASD. Those who reported knowing something about autism had learned about it through self-training, or through presentations they attended, and often their interest arose from a personal connection to someone with the diagnosis.

Table 2 Survey responses by adult healthcare providers regarding adequacy of resources and training needs, Kaiser Permanente Northern California

	All participants (n ^a = 852) n (%)
<i>You have adequate tools/referral resources/practice models to accommodate people with ASD in your practice</i>	
Strongly disagree	162 (19.01)
Disagree	277 (32.51)
Neither agree nor disagree	300 (35.21)
Agree	107 (12.56)
Strongly agree	6 (0.70)
<i>Your patients with ASD have adequate support to partner with you effectively</i>	
Strongly disagree	47 (5.52)
Disagree	185 (21.71)
Neither agree nor disagree	427 (50.12)
Agree	180 (21.13)
Strongly agree	13 (1.53)
<i>The caregivers of your patients with ASD have adequate services and support to partner with you effectively</i>	
Strongly disagree	49 (5.75)
Disagree	176 (20.66)
Neither agree nor disagree	402 (47.18)
Agree	213 (25.00)
Strongly agree	12 (1.41)
<i>What kind of training or resources would be useful to you? (check all that apply)</i>	
Conference with description of ASD	559 (65.61)
Checklist of community resources for patients with ASD	656 (77.00)
Knowledge of psychotropic drugs to treat patients with ASD	373 (43.78)
Training on effective communication strategies with ASD patients	603 (70.77)
Special primary care clinic or service within KPNC that serves adults with developmental disabilities	543 (63.73)

^a Analysis based on the number of people with 100 % response to all questions in the survey

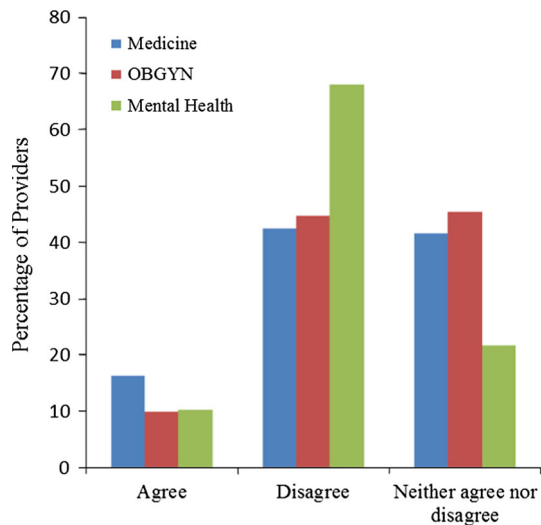


Fig. 3 Endorsement of the statement “You have adequate tools/referral resources/practice models to accommodate people with ASD in your practice” by Type of Providers. Kaiser Permanente Northern California

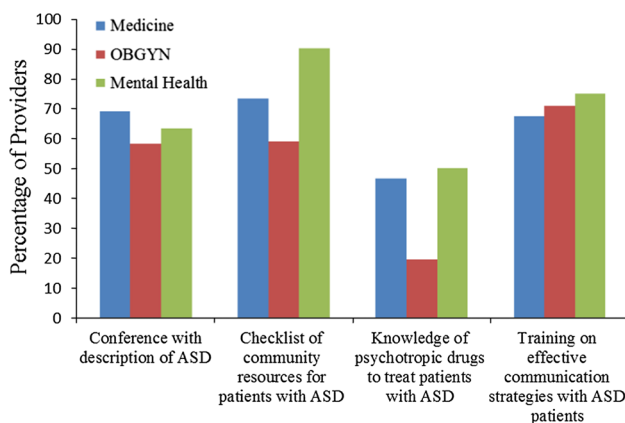


Fig. 4 Response to the question: “What kind of training or resources would be useful to you?” by Type of Providers. Kaiser Permanente Northern California

Need for Training and Resources

With the exception of one physician trained both in pediatrics and internal medicine, all others indicated that they had received little or no autism training during medical school or residency. A physician who had been practicing family medicine for over 25 years stated: “I think that ... we need education. I mean, autism was like “Rain Man” [reference to the 1988 film] when I was in medical school. There wasn’t anything else besides that: it was Rain Man or nothing.” Another physician, who was trained in pediatrics and internal medicine, made the distinction that while he knew about the diagnosis, he never learned about patient management for autism, “Boy...I don’t really recall...I

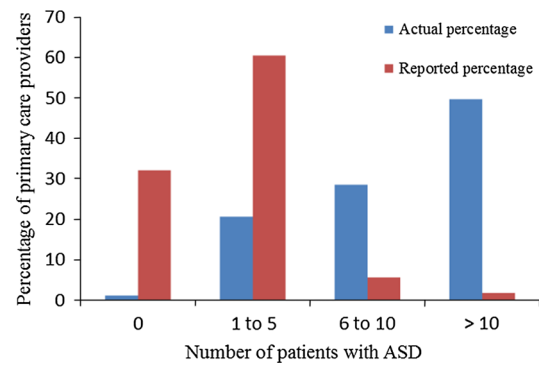


Fig. 5 Percentage of primary care providers reporting how many patients they have on their panel versus percentage of primary care providers with the actual number of patient with ASD that exist in their panel. Kaiser Permanente Northern California

mean certainly we knew about autism, and we may have learned about it in some of our classes, but from a training standpoint in managing patients or understanding it, I think very, very, little. I don’t recall any directed training in autism; you know, outside of the pathophysiology.”

Physicians experience many frustrations in treating patients with ASD. Difficulty communicating, primarily with patients with limited verbal abilities, was frequently attributed to lack of training. A family doctor who cares for two brothers with autism with intellectual disability, expressed her feelings as follows: “[I feel] Very uncomfortable, very. ... One of them, recently, ... fell and broke his hand and he could tell me that it hurt, but he must have a super high pain threshold because I was looking at his hand and it was just God awful... Normally someone would be crying, you know, he dislocated his thumb, and he was just sitting there. And if his hand wasn’t as swollen, I probably would have sent him home without having an X-ray... So it is really difficult because it is more like doing ... medicine for an infant, because he can’t tell me the severity of his feelings, and definitely he can’t tell me any history... For them, the biggest thing is communication.”

In some cases, difficulty with communication was a barrier to establishing rapport with the patient, leaving the physician at a loss. This is how a physician who, despite being quite knowledgeable about ASD, described a visit with a patient who comes by himself to the visit, “Um, he doesn’t seem to connect at all, you know, I don’t feel [he has] any ability to bond with me as a person, hum, and he seems to have, ... sort of limited communication skills... and yet, I don’t think he has, you know, limited intelligence. So, I sort of always wondered what’s going on.” Similarly, when discussing her lack of success in connecting with a new patient with ASD, another physician stated, “Well, I did try the way I make all patients [feel at

ease], you know, talk to them, chat with them, try to find things they are interested in, joke with them a little bit, encourage them, you know, it depends on their level and where they are, and what's happening. So, I mean, the very low functioning people there is no way to make them comfortable. You do the best you can."

Need for Accommodations During Office Visit

When invited to suggest changes and accommodations to better serve their patients with autism, more than half of the respondents brought up the need for improvements in the transfer of care between pediatrics and adult medicine. For instance, careful preparation of the young adult patient in pediatrics could avoid unpleasant experiences at the adult clinic, as this doctor described in an interview: "Well, you know, [I was] a complete stranger, and it's a different setting, because I was adult medicine and he was coming from pediatrics. He was 19 or so, 20, when he transferred. I think that was one challenge. It was an adult medicine clinic, it's a different setting and he was very uncomfortable with that.... Well he was ... almost he was heading for the door, like he was ready to leave." The physician reported that it took him a couple of years to get that patient to come to his office with a more trusting attitude. Some physicians discussed the value of creating clinics, similar to HIV or other specialty clinics dedicated to the care and management of patients with autism, and staffed by a multidisciplinary team of interested and knowledgeable physicians, psychologists, and social workers.

To establish better rapport with their patients with ASD accommodations for office visits are made by some physicians. One physician who cares for high-functioning professionals in the Information Technology industry described her experience greeting one of her patients, "Well, [conversation] is kind of focused on how are they doing today. How are you right now? Are you comfortable? I try to build rapport and set patients at ease, and try to be with them where they are. Whether it's more personal space or less personal space, sometimes I sit beside the patient, so I am not looking directly at them, I'm not facing them.... And then, I focus on what brought them in today." This physician also described working in a special clinic where physical accommodations had been made, such as exam rooms with low light, extra-large screen monitors that both doctor and patient look at together, and a serene waiting room with few people waiting. Another physician provided the following example, in this case, of how she incorporates the patient's mother in the visit: "So I would always start the visit by saying, 'Listen, let's have your mom here, I'd like to know if she has any concerns so I can hear those, then I will give you a chance to have your

privacy so you can talk to me too.' I would always start the visit that way ... So, you are an advocate for that person."

Office visits for patients with ASD were longer when there were parents, spouses, or caretakers present, although this is not unique to autism. One physician commented, "Are they longer visits? Sure they are. The explanation may take a little longer if you have a caregiver you have to interact with, [but] it's not that different [from] an elderly demented patient or even someone old who doesn't have the confidence ... We deal with that all the time. I don't know if I've looked at it as a huge obstacle in terms of my time."

Additional Topics that Emerged from Interviews

Issues regarding conservatorship and privacy were raised by physicians treating low-functioning patients who bring parents or caretakers to visits, and some physicians stated that they did not talk about sex, drugs and alcohol with their patients with autism as they do with non-ASD affected patients. When asked if he asked patients with ASD the same questions he asked non-ASD patients the same age, an internal medicine doctor responded, "I would say no, and that probably is a bias. I think we assume, oh this person, they probably don't smoke, they probably don't drink alcohol, they're probably not having sex. I mean, that's just wrong, but ... that's the reality!"

Many doctors raised the issue of comorbid conditions, and stated that their patients with autism had eating disorders (were overweight or obese), were sedentary, had diabetes, were socially isolated, and suffered from anxiety and depression among other diseases. A couple of physicians worried about their female patients being exposed to sexual abuse in group residencies. A family physician attributed her patient's obesity in part to that lack of social awareness. When asked if the patient's obesity could be due to medication or to a sedentary lifestyle, the physician responded, "... I think that it has to do more with the underlying cognitive condition, probably a little bit of a lack of ... in certain cases a lack of a self-awareness... a different adult might feel a little uncomfortable with their weight and want to change it, but the individuals I'm thinking about, they may not actually feel socially conscious about their weight".

Discussion

These findings, from the first study to use a quantitative survey enhanced by qualitative interviews to explore health care providers' knowledge and attitudes about ASD in adults, have significant implications for clinical care both for adults with autism, and for the growing population of

children with ASD who are transitioning from pediatrics to adult medicine. The main findings from the survey—that adult health care providers, despite recognizing autism characteristics, have insufficient skills and tools for providing healthcare to patients with ASD, and need additional training—were further supported through the details provided during the semi-structured follow-up interviews.

These results are consistent with findings from a previous survey of general pediatricians and family physicians who reported a lack of self-perceived competency in providing care to children with ASD (Golnik et al. 2009), and a survey of adult neurologists who reported feeling less comfortable treating adults with autism and other childhood onset neurodevelopmental disorders than adults with other neurological disorders (Oskoui and Wolfson 2012). As in previous surveys (Bruder et al. 2012; Golnik et al. 2009; Hartley-McAndrew et al. 2014), providers who participated in the present study expressed the need for additional training in order to provide the best care to adults with ASD. Lack of training of adult providers was also recognized in the Oskouri and Wofson (2012) study where pediatric neurologists reported that adult neurologists may not have adequate training to provide optimal care to adults with childhood onset neurodevelopmental disorders including ASD. While lack of training in medical school or residency is likely widespread across adult specialties, it may impact family and internal medicine physicians the most as patients with ASD come to them for primary care. The lack of training translated into lack of knowledge which led to misconception about ASD including symptoms and considering ASD as a childhood disorder only.

One of the most frequently endorsed training needs by survey respondents was training in effective communication strategies with patients with ASD. In several interviews physicians expressed frustration at not knowing how to communicate or establish rapport with these patients. Effective communication strategies suggested in previous studies include being concrete, asking direct questions, using specific language, and explicitly asking for the information needed (Prayson and Franco 2012). Additional considerations for the healthcare provider suggested by these authors include being calm and patient, confirming that the patient is engaged, and avoiding appearing pushy.

While nearly one-third of survey respondents reported that they provide “usual care” when they suspect autism in a patient, the vast majority of physicians interviewed stated that they did not ask questions about sex, drugs and alcohol with their patients with autism as they do routinely with their patients without autism. Usual care may be ineffective for this population given the significant communication challenges (American, Psychiatric, and Association 1994); high rates of medical and psychiatric comorbidities (Croen

et al. 2015); unusual sensory responses to environmental stimuli, such as hypersensitivity to touch during examinations and increased anxiety associated with entering new stimulating environments (Muskat et al. 2014), and lack of interest or awareness in social reputation (Izuma et al. 2011).

The considerable variability across the types of providers (medicine, OBGYN, mental health) in self-rated knowledge and skills in providing care to patients with ASD underscores the need for physician training tailored to provider type. Whereas the majority of mental health and OBGYN providers similarly rated their knowledge/skills in providing care to patients with ASD as poor to fair, OBGYN providers were substantially less likely to endorse the need for adequate tools/referral resources/practices models to care for this patient population. This suggests that OBGYN providers may not be aware of the special needs of this patient population. As a consequence, this may lead to suboptimal care for adult women with ASD, for example lower utilization of preventive health services such as Pap smears (Nicolaidis et al. 2013). Some interviewees described modifying their regular practice and implementing accommodations in the way they approach patients or include caregivers, congruent with adaptations suggested in recent studies (Kripke 2014; Nicolaidis et al. 2014; Prayson and Franco 2012). Others pointed out that adaptation of the physical space at the facility made it easier for providers to accommodate adult patients with ASD. For example, one family physician caring for high functioning professional adults with Asperger’s equipped her clinic with exam rooms with low light, extra-large screen monitors that both doctor and patient can look at together, and a serene, uncrowded waiting room. These adaptations improved her ability to engage with her patients. Future studies should evaluate the effectiveness of methods reported by the providers in our study.

More than half of the physicians interviewed mentioned the need for improvements in the transition from pediatrics to adult care. Better management of the transition would help prepare adult primary care physicians for new patients with ASD entering their practice and help patients and their families receive better care (Cheak-Zamora et al. 2013).

Limitations and Strengths

Although the intention was to send the survey to all providers in adult medicine, obstetrics-gynecology, and mental health, only those whose department chiefs shared their distribution lists were invited to complete the survey. The 25 % response rate in this study, while relatively low, was higher than that of previous similar studies, which ranged from 6 to 22 % (Bruder et al. 2012; Golnik et al. 2009; Khanna and Jariwala 2012), and in line with the reported

average 33 % response rate of online surveys (Nulty 2008). Nonetheless, those who completed the survey may not have been representative of the target population in terms of ASD knowledge, experience and resource needs.

The survey did not include questions about the demographic and professional characteristics of the healthcare providers, and therefore an examination of variability in survey responses by provider sex, age, race/ethnicity, or number of years of experience was not possible. Furthermore, the survey was not formally tested with cognitive interviews, and psychometric properties of individual questions were not assessed.

The study did not include direct observations of patient-provider interactions, review of care guidelines, and interviews with patients. These activities would have ensured a more robust and comprehensive study. However, the format of the interview, which did not constrain the conversation by a set of preconceived structured questions, allowed the physicians to provide details about a number of topics.

By interviewing physicians who volunteered information in question 2 of the survey and who indicated willingness to be interviewed, the authors anticipated encountering information-rich cases that would help characterize a variety of experiences of primary care physicians treating adult patients with ASD. However, this approach may have yielded an interview sample that was more representative of providers who did not like the categorical responses rather than providers who were most likely to provide rich information. The themes that emerged from these providers likely do not reflect the full range of experiences of all adult medical providers, including providers in other specialties (OB/GYN, mental health) who were not interviewed. Furthermore, the themes that emerged may not represent thoughts or perceptions of providers not residing in Northern California and/or without a Kaiser Permanente affiliation. Finally, the reliability of the findings may have been affected by having a single rater analyze all interviews. In order to obtain a more rounded picture of health care experiences for adults with ASD, future studies should include interviews with a larger number of physicians from multiple subspecialties, as well as interviews with patients and caregivers, observations of patient-provider interactions, and analyses of institutional policies.

Despite these limitations, this is the first comprehensive study to integrate quantitative and qualitative methods to explore adult healthcare providers' knowledge and comfort level in treating a growing population of adults with ASD. By conducting a survey followed by qualitative interviews, nuanced information about the challenges facing providers in treating adults with ASD was obtained. The study included providers from a single healthcare organization with the same policy of care for all patients. The availability of electronic medical record data allowed a novel

comparison of provider-reported number versus actual number of patients with ASD in each provider's panel. This analysis demonstrated that most providers were not aware of the volume of patients with ASD under their care.

Conclusion

While the majority of adult healthcare providers correctly recognized the core characteristics of ASD, some erroneously believed that autism was a disorder affecting only children and a large proportion were not aware of ASD in some of their adult patients. Providers across all departments reported having inadequate knowledge, skills and tools to care for adult patients with ASD. In order to accommodate the unique characteristics of this growing patient population, the study findings clearly support the need for provider training on effective communication strategies and management of their healthcare visits. Furthermore, given the increasing numbers of children with ASD approaching adulthood, improvements in the transition from pediatrics to adult medicine are urgently needed. Future research will be needed to evaluate the effectiveness of provider training and new transition processes in settings where they are implemented.

Acknowledgments The authors thank the members of the KPNC ASD in Adults Workgroup for their valuable insights and generous input regarding study design, data analysis, and interpretation of study results. No compensation was received for these contributions. The members include Lisa Croen, PhD, Stephen Rich, MD, Scott Rich, MA, Opal Thornton, MD, Clarissa Kripke, MD, Agnes Amistoso, MA, Elizabeth Dixon, LCSW, Chuck Trumble, MFT, Stephen Sidney, MD, Ousseny Zerbo, PhD, Maria Massolo, PhD, Carmen Ancinas-Gee, MFT and Neeraja Maramreddy, MD. The authors also appreciate the feedback received from Joe Gallo, MD, Meghan Davignon, MD, Thomas Weisner, PhD, and Britt Dalhberg, ABD.

Author contribution Drs. Croen, Massolo and Zerbo conceptualized the study, obtained funding, and drafted the initial and final manuscript. Dr. Qian provided data management.

Funding This study was funded by grants from the Special Hope Foundation.

Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

Informed consent Informed consent was obtained from all individual participants included in the study.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Appendix: Identifying Autism Spectrum Disorders in Adult Healthcare: Provider Survey

1. Which of the following patient characteristics would lead you to explore the possibility of an autism spectrum disorder (ASD) (check all that apply):
 - Has limited eye contact
 - Easily volunteers information about her/himself
 - Has a flat affect
 - Shows an interest in you
 - Is sensitive to touch
 - Is sensitive to light/sound
 - Expresses her/his emotions
 - Gives concrete responses/has literal communication style
 - Has atypical communication style
 - Concentrates on the whole picture rather than on small details
 - Has a monologue style of communication
 - Is unusually direct
2. When you suspect ASD in a patient, do you ... (check all that apply)
 - Probe about developmental history
 - Consult with a colleague
 - Schedule a follow-up appointment
 - Refer patient to specialty care outside KP
 - Refer patient to KP behavioral medicine department
 - Refer patient to KP psychiatry department
 - Refer patient to KP neurology department
 - Refer patient to a case manager
 - Provide usual care
 - Other (please specify)
3. How many patients in your current practice do you know are on the autism spectrum?
 - 0
 - 1–5
 - 6–10
 - More than 10
4. You have adequate tools/referral resources/practice models to accommodate people with ASD in your practice
 - Strongly disagree
 - Disagree
 - Neither agree nor disagree
 - Agree
 - Strongly agree
5. Your patients with ASD have adequate support to partner with you effectively (e.g. they have the support they need to ask for help when they are ill; provide an accurate history; attend and cooperate at appointments; provide informed consent; and follow through on their health care plan).
 - Strongly disagree
 - Disagree
 - Neither agree nor disagree
 - Agree
 - Strongly agree
6. The caregivers of your patients with autism spectrum disorder have adequate services and support to partner with you effectively.
 - Strongly disagree
 - Disagree
 - Neither agree nor disagree
 - Agree
 - Strongly agree
7. How would you rate your knowledge and/or skills in providing care to people with ASD
 - Poor
 - Fair
 - Good
 - Very good
 - Excellent
8. What kind of training or resources would be useful to you (check all that apply)?
 - Conference with description of ASD
 - Checklist of community resources for patients with ASD
 - Knowledge of psychotropic drugs to treat patients with ASD
 - Network of providers to consult with about ASD (within and outside KP)
 - Toolkit for screening and diagnosis of ASD
 - Training on effective communication strategies with ASD patients
 - Special Primary Care clinic or service within KPNC that serves adults with Developmental Disabilities
9. Are you a.....(Please check the appropriate box):
 - MD
 - Nurse
 - Psychologist
 - LCSW
 - MFT
 - Other (please specify)
10. What is your department?

- Adult and family medicine
 - Obstetrics/gynecology
 - Neurology
 - Psychiatry
 - Behavioral medicine
11. If you are willing to be contacted for a short follow up telephone interview, please provide the following information.
- Telephone number:
 - Best time to reach me: (format of day/time)
 - I am not interested

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