

Brief Report: The Medical Care of Adults with Autism Spectrum Disorders: Identifying the Needs

Mary Beth Bruder · Gerard Kerins ·
Cynthia Mazzarella · Jessica Sims ·
Neil Stein

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Abstract There is a lack of information concerning adults with autism spectrum disorder (ASD), especially with regards to their access to health care. A paper and electronic survey was sent to 1,580 primary care physicians in Connecticut. 346 respondents returned a survey and provided care to adults with an ASD. This physician survey provides data on adults with ASD such as: reasons for physician visits, living arrangements, employment status, and any services they are receiving. Responses revealed inadequate training in the care of adults with an ASD and physicians interest in obtaining additional training. The ability to provide a medical home for adults with autism will need to address effective strategies to train current and future physicians.

Keywords Adults with autism · Medical needs · Characteristics of adults with ASD · Training of physicians

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M. B. Bruder (✉) · G. Kerins · C. Mazzarella · J. Sims
A.J. Papanikou Center for Excellence in Developmental
Disabilities Education, Research, and Service, University of
Connecticut, 263 Farmington Avenue, MC6222, Farmington,
CT 06030-6222, USA
e-mail: bruder@nso1.uhc.edu

G. Kerins
Hospital of St. Raphael, New Haven, CT, USA

J. Sims
Child Care Aware of Missouri, St. Louis, MO, USA

N. Stein
University of Connecticut Health Center, Farmington, CT, USA

Adults with Autism Spectrum Disorders: Who is Providing Medical Care

According to the U.S. Census, there are 50 million Americans who have some type of disability including developmental disabilities. The provision of quality health care for this population is becoming recognized as a public health issue as adults with disabilities are living longer, and encountering the health issues of the typical aging population (Drum et al. 2009; Henry et al. 2011; Smith 2008). However, a number of studies have raised concerns that adults with developmental disabilities are not receiving appropriate health care services that include preventative practices, screenings, and dental services (Bruder et al. 2010; Kang and Harrington 2008; Lewis et al. 2002; Messinger-Rapport and Rapport 1997; Smith 2008; Sutherland et al. 2002). For example, the U.S. Department of Health and Human Services in 2005 reported that among women over the age of 40 with all types of disabilities, only 65% said they receive mammography as compared with 75% of women without disabilities, and among adults and children with disabilities only 37% reported that they have annual dental visits, compared with 46% of children and adults without disability. These and other studies have concluded that persons with disabilities have disparities in health outcomes, access, health promotion and health behaviors (Drum et al. 2009). There are many reasons for this, however physician training, comfort level and reimbursement for care may have been identified as contributing to the lack of quality care available to this population (Bond et al. 1997; Friedlander et al. 2006; Melville et al. 2005).

Adults with autism spectrum disorder (ASD) are a specific component of this population, and little is known about the parameters of health care needs for them; in particular their access to medical care and quality

outcomes. ASD is defined as a group of developmental disabilities that cause significant social, communication, and behavioral challenges. ASD include Asperger syndrome, autistic disorder (classical autism), and pervasive developmental disorder-not otherwise specified (PDD-NOS). Symptoms may be mild and difficult to discern or quite severe. Current estimates are that ASD occur in 1:110 children (Centers for Disease Control and Prevention 2010). The prevalence rate for adults with ASD is unclear though it has been suggested the prevalence is similar to that in the population of children (Ameson et al. 2009; Brugha et al. 2009). This prevalence will continue to grow as the prevalence of children diagnosed with ASD is increasing yearly (Centers for Disease Control and Prevention 2010), and children grow older. Therefore, the number of adults diagnosed with ASD will continue to grow nation-wide.

Most research to date on the special health care needs of those with ASD has focused on children and their access to quality health care, specifically through a medical home model (Brachlow et al. 2007; Golnik et al. 2009). A recent report in *Pediatrics* discusses the role of physicians in the chronic management of autism spectrum disorder in their patients with the ultimate goal being “functional independence and quality of life” (Myers et al. 2007, p. 1162). The authors suggest that children with ASD require the same basic medical care as children without ASD and may require additional medical care and support related to their diagnosis, and the medical home model is an appropriate context in which to address these needs (Myers et al. 2007). The medical home model is characterized by care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective (National Center for Medical Home Implementation n.d.). A recent national survey of pediatricians and family physicians on the care of children with ASD reported, however, that there are more barriers to providing quality care to this population than other populations of children with disabilities. These included a lack of available care coordination for families and current reimbursement models for extensive office visits and follow-up (Golnik et al. 2009). In addition these authors found that physicians report a need for additional training and education about children with ASD beyond the training available to children without other disabilities or special health care needs. Analyses of the National Survey of Children’s Health (2003–2004 telephone interview) also confirmed that families of children with ASD reported a lack of coordinated family-centered and comprehensive care (Brachlow et al. 2007).

There is also growing interest in the use of a medical home model for adults (Larson and Reid 2010; Reid et al. 2009), though little is known about the availability of medical homes for adults with ASD. Studies about the

health care status of adults with ASD have focused on the existence of co-morbid conditions (Koritsas and Iacono 2009), heart rate changes as a result of stress (Grodin et al. 2005) and quality of life for those with Asperger syndrome (Barnhill 2007). While there has been some information gathered on the availability of the medical home for adults with developmental disabilities (see Bruder et al. 2010) there is little to no information on the availability of comprehensive and coordinated medical care using a medical home model for adults with ASD. While it seems reasonable to assume that adult care physicians would report similar challenges to the delivery of primary care as pediatric physicians (Heidgerken et al. 2005), there is little empirical evidence of this in the literature. The purpose of this study was to conduct a needs assessment with primary care physicians in one north-eastern state on the prevalence and needs associated with caring for adults with ASD.

Method

Physicians in one state were contacted by mail to complete a brief survey about serving adults with autism spectrum disorder. The authors obtained a list of 1,580 physicians in the state through the WebMD National Physicians Data Source. The source originated from “the little blue book” which is a published reference of licensed physicians and others (nurse practitioners, physicians assistants, etc.) for a locality. Physicians on the list we received for Connecticut consisted of general practitioners, family practitioners, and internists.

Procedure

The survey was initially mailed to 600 randomly selected physicians from the total list in mid-September 2009. Due to a low response rate ($N = 94$ for a 15.6% return), the survey was mailed to all 1,580 physicians on the list in the beginning of January 2010. Because this was an anonymous survey, there was no way to determine who had already filled out the survey. However, survey instructions stated that it did not need to be filled out if a survey had been completed and mailed in the fall of 2009. Nineteen were “returned to sender” due to inaccurate addresses.

Each physician received a cover letter, survey, and self-addressed, stamped envelope for return of the survey. The cover letter included information on the purpose of the study and instructions for completion as well as a statement thanking those that already filled out the survey. Participants could opt to complete an online version of the survey and instructions were provided for this as well. The Survey Monkey link was closed at the end of February and any

surveys that were returned by mail after this date were filed, but not entered into the database.

Each paper survey was given an ID number and data was manually entered into SPSS. Twenty-four percent of the data entries were checked for accuracy and were found to be 99% accurate. For instances of disagreement, researchers met, reviewed the original data, and agreed on what should be entered. Data that was collected through Survey Monkey was downloaded into an excel file and then imported into SPSS. Each completed survey was also printed, labeled with an ID number, and filed.

Instrument

The survey consisted of 14 multiple-choice questions. Three questions allowed participants to choose more than one response option, and four questions provided participants with space for open-ended responses in addition to the response options. The first two questions established the type of population served by the physician, as we were interested in physicians who served adults with autism spectrum disorder. If the physician did not provide primary medical care for adults they were instructed to return the survey. This is because primary care physicians are presumed to have ongoing care with the patient, as opposed to a one time visit. The survey in the initial mailing requested that physicians who did not provide medical care for adults with ASD to stop and return the survey ($N = 54$). The survey in the second mailing requested that physicians who do not provide medical care for adults with ASD to skip to question 11 ($N = 152$). The next eight questions focused on the characteristics of the patients with ASD (living arrangements, typical health needs, employment, age, etc.). The final four questions were about the interest and need for training on caring for adults with ASD and other developmental disabilities. The survey was submitted to this university's Institutional Review Board (IRB) for approval. The IRB determined this survey was not human subject research (see "Appendix A" of supplementary material for a copy of the survey).

Data Analysis

Descriptive statistics were calculated for the data. Responses to open-ended questions were summarized. The results from the data analysis of the survey are presented in the following results section.

Results

The number of physicians who returned the survey was 376, which represented a 23.8% return rate. Thirty responses were discarded because the respondents indicated they did not

provide medical care for adults. Of the 346 physician respondents who did report they provided primary care for adults, 139 or 40.2% indicated they served adults with ASD. The vast majority of these physicians (81.3%) indicated they saw between 1 and 5 adults with ASD, while the rest saw more. These patients ranged in age from 18 to over 51, with the majority of the physicians (72%) serving patients aged 18–40, and most were male patients. The most common medical condition/medical need of these adult patients with ASD was reported to be a yearly health checkup (32.1%). Other conditions which necessitated care by the physician included mental health needs (21.9%), infectious diseases (14.6%) and metabolic needs (such as thyroid disease or diabetes) (13.9%). Other conditions requiring medical care included gastrointestinal issues, self-inflicted trauma and secondary skin infection, and cardiovascular issues including hypertension as other medical conditions under treatment.

The physicians reported the vast majority of their patients with ASD do not live independently. Further, 54.7% of their patients with ASD could not understand and follow medical recommendations, thus necessitating the active involvement of the patient's caregiver in the ongoing care plan. Only 36.3% of physicians reported that the majority of patients they care for are employed, while only 17.4% of physicians indicated that a majority of their patients are attending school. Physicians also reported other services their adult patients with ASD received. These included mental health services, job supports, transportation, and dental services. Table 1 contains the description of patient characteristics.

The survey responses of all 346 responding physicians were computed as a group on a number of variables addressing education and preparation to serve the adult population of persons with ASD. Thirty-six percent of all respondents reported receiving some training about caring for adults with ASD. For these 105 who did receive training, 52 physicians indicated training occurred during their ongoing professional education, 37 reported it occurred during residency, and 45 indicated training occurred during formal continuing medical education. Over half of the physicians state that they would like more training in caring for persons with ASD; and half would also like training on other developmental disabilities such as Down syndrome, cerebral palsy, and ADD/ADHD. Again, over half of the physicians indicated their preferred mode of training to be workshops/conferences. Other preferences included web-based, detailed reading material, and Grand Rounds. Not surprisingly, when comparing the responses of those physicians who did care for adults with ASD and those who did not, significant differences were found on all variables related to previous training, and identified needs for more training, favoring the group that already provided care to those with ASD. Table 2 contains this summary data.

Table 1 Summary of patient characteristics

	Number	%
The average age of the adults with ASD I care for is:		
18–40 years	97	71.9
41–50 years	22	16.3
51 years or older	12	8.9
The majority (>50%) of adults with ASD I care for are:		
Male	97	71.9
Female	37	27.4
The most common medical condition of adults with ASD I care for is:		
Infectious disease	20	14.6
Metabolic	19	13.9
Neurological	4	2.9
Gastrointestinal	1	0.7
Mental health related	30	21.9
Generally well, just yearly check-ups	44	32.1
Other	6	4.4
The majority of adults with ASD I care for are able to independently understand and follow recommendations		
Yes	62	45.3
No	75	54.7
The majority of adults with ASD I care for predominantly live:		
Independently	15	11.5
With family	63	48.5
In a supervised setting/group home	52	40.0
The majority of adults with ASD I care for are attending school		
Yes	24	17.4
No	114	82.6
The majority of adults with ASD I care for are employed		
Yes	49	36.3
No	86	63.7
My adult patients with ASD are also receiving the following services: (multiple responses)		
Mental health	100	80.0
Job support	61	48.8
Dental services	54	43.2
Transportation	61	48.8
Respite	16	12.8
Other	9	7.2

Discussion

The results of this survey suggest that there is a small cohort of physicians in the state that provide medical care for adults with ASD. However, the majority of those who responded as having patients with an ASD, actually serve very few. The majority of these patients had a need for supervision by caregivers for activities of daily living, as well as meaningful use of time. These patients were also reported to be unemployed at a higher rate than national

Table 2 Percentage of responses by group (only those who serve adults with ASD, and only those who serve adults, but none with ASD)

	Serve adults with ASD (N = 139)	Do not serve adults with ASD (N = 207)
My training in the care of adults with ASD occurred during (% selected):		
Professional education***	23.0	12.5
Residency*	19.4	5.9
Post-residency CME**	20.1	10.5
N/A Did not receive training**	55.4	72.4
I would like more training specific to caring for adults with ASD (% yes)*	67.2	43.4
I would like more training in caring for adults with other DD (% yes)**	63.9	45.4
My preferred mode(s) of receiving training include (% selected):		
Workshops/conferences**	52.9	38.2
Grand rounds	28.8	23.0
Web-based	41.7	32.2
Detailed reading material	34.5	30.9
Other	2.2	4.6

*Group differences significant at $p < 0.001$

**Group differences significant at $p < 0.01$

***Group differences significant at $p < 0.05$

statistics on employment of persons with disabilities would suggest (Butterworth et al. 2011). The living arrangements of the patients with ASD were reflective of national trends for adults with disabilities (Braddock et al. 2011), as the majority of the patients are living with their family. A well documented consequence of this living arrangement is the stress caused to caregivers over time, and the effects of this stress on family quality of life (Benson 2006; Blacher and McIntyre 2006; Eisenhower et al. 2005; Smith et al. 2010). This may suggest a need for caregiver supports for this group of patients (Benson 2010; Blacher and Hatton 2007), as well as the need to examine and expand the availability of postsecondary options for those with ASD transitioning into adulthood (Hart et al. 2010; Henry et al. 2011; Hetherington et al. 2010). Lastly, the data also suggest a need for an expansion and improvement in the availability of community based geriatric supports and services as this population ages (Kerins and Bruder 2003).

Other findings from the survey that warrant further evaluation are the reasons for which adults with ASD seek medical attention. Routine physical exams which may include certain preventive health strategies are a common reason, although further study is needed to separate out what exactly occurs during these encounters and the

standards of care which must be formulated to maximize the benefit from such encounters. Other services reported as being received by patients as reported by their physicians included mental health, job supports, transportation, dental and respite. In regard to the latter two, one would hope all patients would receive dental services, and the number of patients reported as living with family would suggest a higher need for respite.

The development of appropriate medical homes may be the best way to advocate and coordinate the multitude of services needed by adults with ASD. A medical home model would be one vehicle to maximize outcomes related to each service and to improve function and quality of life within this specific population. The medical home model continues to be supported and promoted for both children and adults (AAFP, AAP, ACP, & AOA 2007), though more research is needed for all populations and specifically for those with developmental disabilities (Bruder et al. 2010). A medical home contains the following elements: access to health care, usual source of care, personal doctor or nurse, referrals for specialty care, and person-centered care (Larson and Reid 2010). The implementation of a person-centered medical home model might be the most viable way to coordinate those services needed by adults with ASD.

The majority of all physician respondents (those who did and those who did not care for adults with ASD) reported having a lack of training in the care of adults with ASD, and those that reported having had training never totaled to more than 23% in any one type of training. However, these small numbers who reported having had training did demonstrate statistical differences between the two groups of physicians: those that cared for adults with ASD and those that did not. There were twice as many respondents who care for adults with ASD, than who did not, who reported having had professional education and post residency CMEs about the care of this population, and three times as many of this group who reported having training during residency. Of interest is that those who do serve this population indicated a significantly greater need for more training than those that do not serve this population, as well as wanting more training on caring for adults with other developmental disabilities (DDs). This most likely is because these physicians who are serving adults with ASD recognize their need for additional information and knowledge to better serve adults with DDs and ASD.

Both groups of physicians reported that workshops or conferences were their preferred way to receive training with significantly higher numbers of those who serve adults with ASD requesting this. The second highest preferred mode reported was online web-based, then reading materials and grand rounds being last. This last choice may have reflected the short time span of most grand rounds (<1 h).

These results are of concern when compared to the evidence on effective training models for adult learners (National Research Council 2000). Most research on adult learning does not regard workshops/conferences as effective strategies to build competence and changes in behavior (Knowles et al. 1998) and support more sustained practices with reflection and feedback as models that build mastery (National Research Council 2000). Certainly, the time constraints of physicians may limit access to certain types of continuing education and training, but the culture of continuing education must change to reflect evidence in effectiveness. Knowledge about the medical needs for a growing segment of the adult population deserves to be transmitted to physicians in the most effective way possible. This is an area that warrants further research and examination.

The results of this study have significant limitations. The survey was only administered in one state, therefore the prevalence and description of adults with ASD may be limited to this state. Additionally, the survey respondents represent a volunteer group who have interest in the population. Other physicians who chose not to respond to the survey may have reported differently to the survey than the sample who did. Lastly, the survey was an anonymous needs assessment, and as such it did not request information from the respondents that may have provided additional key data from which to draw conclusions about the care of adults with ASD. For example, type and location of physical practices, age and year of completion of medical and residency training, and prevalence of adults with other types of disabilities in their practice would have enabled more robust conclusions from the data collected. The anonymity may have also contributed to respondents completing the survey twice as the survey was sent out twice. Though the physicians were told to ignore the second request if they had previously responded, we do not have data to assure that.

Conclusion

This survey provides baseline knowledge related to the health care of adults with ASD. The data collected suggests that the 2005 *Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities* (U.S. Department of Health and Human Services 2005) continues to be a challenge for adults on the spectrum. Future research should obtain a broader national sample of physicians along with their demographic data, as well as an effort to gather information from adults with ASD to understand their perceptions and needs for health care. Finally, effective training models for physicians and other health care providers is needed to improve the quality of care and services for adults with ASD.

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