

Brief Report: Factors Influencing Healthcare Satisfaction in Adults with Autism Spectrum Disorder

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Abstract The current study investigated healthcare satisfaction and factors related to satisfaction in 92 adults with Autism Spectrum Disorder (ASD). Participants or their caregiver completed a survey about their experiences with primary care and specialty physicians. Respondents reported a high level of satisfaction with their healthcare. The only factor significantly associated with satisfaction was age, with participants under age 26 reporting significantly higher levels of satisfaction than participants above age 26. Participants under age 26 also were significantly more likely to live at home, have private health insurance, and have others making their healthcare decisions than participants above age 26. Results indicate that healthcare satisfaction can be high for adults with ASD that have good family and community support.

Keywords ASD · Autism · Adult · Healthcare · Satisfaction

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Introduction

Recent studies have demonstrated that adults with Autism Spectrum Disorders (ASD) have unique health care needs which may result in higher utilization of health care services (Croen et al. 2015; Jones et al. 2015; Kats et al. 2013; Kohane et al. 2012; Lever and Geurts 2016; Tyler et al. 2011). Indeed, medical care is among the highest costs of caring for adults with ASD in the United States, totaling more than all other categories except for housing (Buescher et al. 2014). As rates of ASD diagnosis among school age children have increased over the past decade (Baio 2014; Christensen et al. 2016), there will be a corresponding increase in the number of children with ASD transitioning from pediatric to adult systems of medical care. Thus, a greater understanding of how adults with ASD are utilizing and engaging with healthcare providers is essential to providing medical services for this at-risk population.

Adults with ASD are particularly vulnerable to health care disparities because services and medical treatments for individuals with ASD are largely child-focused (McDougle 2013; Shattuck et al. 2012). Recent research has begun to explore the significant barriers adults with ASD face when accessing and utilizing health care such as difficulties communicating medical needs to providers, sensory issues with physical examinations, and lack of training for adult medical providers in treating those with ASD (Bruder et al. 2012; Nicolaidis et al. 2015; Warfield et al. 2015; Zerbo et al. 2015).

Previous work indicates that caregivers of children with ASD report low satisfaction with healthcare delivery (Liptak et al. 2006; Zablotsky et al. 2014). However, limited data exist on the healthcare satisfaction of adults with ASD. One study that examined this topic found that adults with ASD were less satisfied with their healthcare than

typically developing adults (Nicolaidis et al. 2013). The results of this study are of note because data from the general population demonstrate that patient satisfaction is an important indicator of healthcare outcomes (Jha et al. 2008; Manary et al. 2013). The data reported by Nicolaidis et al. (2013) were collected via online survey, however, which may limit the generalizability of their results. An online study is likely to exclude participants who do not have internet access or who have significant functional impairments and cannot self-report. Additionally, the researchers could not validate an ASD diagnosis through standardized, in-person measures.

The current study examined healthcare satisfaction and factors contributing to satisfaction in adults with ASD. The goal of this study was to describe the level of healthcare satisfaction and to explore potential correlates of high and low levels of satisfaction in this vulnerable population. This is one of the first studies to quantitatively examine factors involved in healthcare satisfaction for adults with ASD.

Methods

Participants

Participants were a subset of the Rhode Island Consortium for Autism Research and Treatment's (RI-CART) statewide research registry (Gerber et al. 2014). RI-CART is a collaboration between basic and clinical research centers, clinicians and service providers, and family and patient organizations. Since 2013, RI-CART has been developing a statewide research registry in order to facilitate research participation for interested participants and their families.

The sample consisted of 92 adults with ASD, ranging in age from 18 to 64 years ($M=31.1$ years, $SD=12.6$). Inclusion criteria were chronological age ≥ 18 years and the presence of a community diagnosis of ASD and/or an above-threshold score on the Autism Diagnostic Observation Schedule, 2nd Edition (ADOS-2; Lord et al. 2012). Most participants met both criteria, however, there were five that had a community diagnosis but did not score above threshold on the ADOS-2. The majority of participants were male, white, and lived in a family home. For a full description of participant characteristics see Table 1.

Measures

Medical Health Questionnaire

Study participants or their parent/caregiver completed a questionnaire about the participant's medical history. The topics addressed included: medical health problems (e.g. gastrointestinal concerns, major illnesses), neurological

Table 1 Participant characteristics as a percentage of the sample

Characteristic	Adult participants (N = 92)
Age	
<26	46
≥ 26	54
Sex	
Male	78
Female	22
Ethnicity/Race	
Asian	1
Black or African American	2
White	96
Mixed ethnicity	1
Living situation	
Family home	68
Other residence	32
Insurance status	
Private insurance	61
Public insurance/uninsured	39
Referral source	
Clinician	46
Community/parent group	25
Self	29
Guardianship	
Self	60
Other guardian	40

problems (e.g. tics, seizures), and co-morbid psychiatric conditions (e.g. anxiety, depression). For the present study, we examined medical (including neurological) and mental health problems separately. Medical and mental health complexity scores were computed by summing the number of endorsed lifetime (past or present) health concerns for each category. The majority of participants (87%) had a completed Medical Health Questionnaire.

Healthcare Survey

Information about the participant's health care experiences was obtained through a six-page Healthcare Survey completed by participants or their parent/caregiver. Respondents provided information about the participant's clinician (e.g. specialty), details about their latest appointment (e.g. reason for appointment), and their overall satisfaction with that clinician. The survey addressed primary care, dental care, vision care, and mental health. Satisfaction with each practitioner was rated on a 1–5 scale (1 = very dissatisfied, 5 = very satisfied). All 92 participants had a completed Healthcare Survey.

Clinical Assessments

The ADOS-2 is a semi-structured interview that is used to assess social communication, reciprocal social interaction, and repetitive and stereotyped behaviors (Lord et al. 2012). There are four available modules depending on the participant's language, ranging from no words (Module 1) to fluent speech (Module 4). The ADOS-2 produces a classification of autism, autism spectrum disorder, or non-spectrum, as well as a standardized severity score (ADOS-2 comparison score) that is comparable across modules. The majority of participants (83%) completed this measure. The ADOS-2 has been independently validated for adults with and without co-occurring intellectual disability (ID) (Bastiaansen et al. 2011; Sappok et al. 2013). For participants who received a Module 4, this study utilized the recently revised algorithm (Hus and Lord 2014). The utility of the new algorithm has been independently validated for use with adults who have ASD (Bildt et al. 2016; Pugliese et al. 2015).

Parents/caregivers or other close relatives of the participant (e.g. spouse, adult child) completed the Vineland Adaptive Behaviors Scales, Second Edition (Vineland) using the parent/caregiver rating form (Sparrow et al. 2005). A significant percentage of participants (66%) had a relative or caregiver available to complete this measure. The Vineland assesses functional skills in the domains of communication, domestic living, and social skills. The Vineland generates standard scores for all three domains and a total adaptive behavior composite (ABC) standard score. Respondents are asked to rate how often the participant uses a particular adaptive skill such as "listens to instructions," or "brushes teeth," from never to usually.

Procedure

Study procedures were approved by the Bradley Hospital/Lifespan Institutional Review Board. Informed consent was obtained from all participants or their legal guardian prior to beginning the study. Study data were managed using Research Electronic Data Capture (REDCap) electronic data capture tools. REDCap is a secure, web-based application designed to support data management for research studies (Harris et al. 2009).

Participants in this study were recruited through brochures distributed at hospitals, clinics, and group homes within Rhode Island. Participants were co-enrolled in the RI-CART research registry. A full description of the research registry is forthcoming. Enrollment in this study typically involved a single visit to complete questionnaires and assessments. For individuals who lived in a group home and were not their own guardian, RI-CART staff members traveled to their guardian's home to complete

the consent and then scheduled an ADOS-2 assessment through the group home staff. All ADOS-2 assessments were completed by research-reliable examiners.

Results

Results from the Healthcare Survey are presented in Table 2. The majority of surveys (70%) were completed by a parent or caregiver on behalf of the participant. A healthcare decision-making variable was created by dividing participants into those who were their own sole decision-maker and individuals who either reported no involvement in healthcare decisions or required help from another person. While only 29% of participants were reported to be their own sole healthcare decision maker, the majority of participants (60%) were their own legal guardian.

Survey respondents who were seeing a primary care physician reported a variety of primary care providers: family medicine (49%), internal medicine (21%), pediatrics (21%), other (9%). A small number of participants (18.5%) were reported to have seen a neurologist. Participants who were receiving mental health care listed psychiatrists (60%), psychologists (17%), social workers (5%), and other health care professionals (18%) as their primary mental health care providers. Additional health care providers reported included dentists (84%) and vision care providers (ophthalmologists/optometrists; 71%).

There were no significant differences in satisfaction ratings between primary care providers, dentists, vision care providers, and mental health care providers, $F(3,129)=1.10$, $p=.35$; therefore, a total healthcare satisfaction score was computed by averaging across provider types. Overall, respondents indicated that they were highly satisfied with the healthcare that study participants were receiving ($M=4.39$, $SD=0.88$). Using the total healthcare satisfaction score, 84% of respondents reported an average score of a 4.00 ("Satisfied") or higher.

Stepwise multiple regression was used to investigate the relationship between participant and family level characteristics and healthcare satisfaction. In order to maximize the number of participants included in analyses, separate regressions were run for demographic characteristics and assessment scores. Demographic variables included: insurance status, living situation, healthcare survey respondent (participant or parent/caregiver), guardianship status, medical health complexity, mental health complexity, biological sex, healthcare coordinator, and age. Participants were divided into young adults (<26 years of age; 46%), and adults (≥ 26 years of age) for age analyses. This cut point was selected because in the US, recent regulations derived from the Affordable Care Act provide parental insurance coverage to individuals who are 26 years of age or younger.

Table 2 Participant and parent reported healthcare variables as a percentage of the sample

Characteristic	PCP	Dentist	Vision	Mental health
Do they see this practitioner?				
Yes	93	84	71	82
No	7	16	29	18
How appointments were made				
Phone	75	70	61	64
Email	0	0	0	0
Text	0	0	0	0
Other	2	3	5	1
Multiple	9	10	6	16
Did not provide	14	17	28	19
Number of months since last appointment, mean (SD)	4.8 (5.3)	4.0 (4.8)	10.5 (13.6)	1.3 (1.8)
Location of visit				
Provider office	79	78	76	77
Medical clinic	5	8	2	1
Agency site	2	1	2	7
Group home	0	0	0	3
Personal home	0	0	0	1
Other	0	0	2	0
Did not provide	14	13	18	11
Transportation to visit				
Private vehicle	79	82	72	74
Public transportation	1	0	2	5
Other	6	4	6	8
Multiple	1	2	2	1
Did not provide	13	12	18	12
Reason for appointment				
Routine check-up	75	74	75	86
Illness	12	3	0	1
Emergency care	0	4	3	1
Multiple	1	3	2	0
Did not provide	12	16	20	12
Method of payment				
Private insurance	31	34	25	24
Public insurance	26	19	21	28
Out-of-pocket	1	7	5	1
Multiple	13	9	11	13
Did not provide	29	31	38	34
Overall satisfaction, mean (SD)	4.3 (1.1)	4.5 (0.9)	4.4 (0.9)	4.5 (1.0)

At step 1 of the stepwise regression using demographic data, age entered into the regression equation and was a significant predictor of healthcare satisfaction, ($F(1,77)=5.31, p=.02, R^2=0.06$). Specifically, participants below 26 were significantly more satisfied with their healthcare than participants 26 and older. Insurance status ($t=0.47, p=.64$), living situation ($t=0.05, p=.96$), healthcare survey respondent ($t=0.89, p=.38$), guardianship status ($t=0.63, p=.53$), medical health complexity ($t=1.79, p=.08$), mental health complexity ($t=1.17, p=.25$),

biological sex ($t=0.89, p=.38$), and healthcare coordinator ($t=0.53, p=.60$) did not enter into the equation at step 2 of the analysis.

Assessment variables included the ADOS-2 comparison score and the Vineland composite score. The mean adaptive skills score of study participants ($M=52.3, SD=19.7$) was three standard deviations below average, indicating that a substantial portion of the sample had significant impairment in adaptive skills. Indeed, the majority of individuals (75%) had Vineland adaptive skill composite scores

<70. Overall, 11 participants received an ADOS-2 Module 1 assessment, six received a Module 2, and 59 received a Module 4; however, ADOS-2 comparison scores are currently only validated until age 14 for modules 1–2 and age 39 for module 4. In our study, 32 of the 76 completed ADOS-2 assessments produced an ADOS-2 comparison score that was considered out of age range. There were no significant differences between within-range ($M=7.09$, $SD=2.04$) and out-of-range Comparison Scores ($M=7.19$, $SD=1.99$), $t(74)=0.21$, $p=.84$. Therefore, in an effort to include as many participants as possible in the analysis, all scores were used. At step 1 of the stepwise regression utilizing assessment data neither ADOS-2 comparison score ($t=0.30$, $p=.77$) nor Vineland composite score ($t=0.93$, $p=.36$) significantly predicted healthcare satisfaction, thus, no variables were entered into the model.

Additional analyses were conducted comparing individuals above and below age 26 on all variables that had been entered into the prior regression analysis. In order to account for the number of comparisons made, we applied a Bonferroni correction to α for all statistical tests ($\alpha: 0.05/10$ comparisons= 0.005). Results are reported in Table 3. Chi square tests of independence demonstrated that participants under 26 were significantly more likely to live at home, $\chi^2(1)=31.24$, $p<.001$, have private health insurance, $\chi^2(1)=18.03$, $p<.001$, have someone else complete

the Healthcare Survey, $\chi^2(1)=11.34$, $p=.001$, and have others make their healthcare decisions, $\chi^2(1)=10.62$, $p=.001$, than participants 26 and above. No other variables were significantly different between participants above and below age 26.

Discussion

This study described healthcare satisfaction in a heterogeneous group of adults with ASD who were participants in the Rhode Island Consortium for Autism Research and Treatment (RI-CART) research registry. While prior work has found that adults with ASD report lower satisfaction with their healthcare in comparison to individuals with typical development (Nicolaidis et al. 2013), adults with ASD in the current sample were largely satisfied with their healthcare. This was true despite study participants' generally low level of adaptive functioning.

While the satisfaction ratings in our study are higher than prior research on healthcare satisfaction in adults with ASD (Nicolaidis et al. 2013), they are comparable to previous national surveys of general healthcare recipients (Wolosin 2005). Nicolaidis et al. (2013) reported lower satisfaction with healthcare providers in individuals with ASD than comparisons. Several methodological factors make

Table 3 Age-related differences in participant characteristics

Variable	<26 years	≥26 years	Statistic
Living situation			
Family home	41	21	$\chi^2(1)=31.24^{***}$
Other residence	1	28	
Insurance status			
Private insurance	34	19	$\chi^2(1)=18.03^{***}$
Public insurance/uninsured	6	28	
Individual completing healthcare survey			
Self	5	22	$\chi^2(1)=11.34^{**}$
Other	37	28	
Healthcare decision maker			
Self	5	21	$\chi^2(1)=10.62^{**}$
Other	37	28	
Guardianship			
Self	20	33	$\chi^2(1)=2.75$
Other	20	16	
Biological sex			
Male	35	37	$\chi^2(1)=1.17$
Female	7	13	
Medical health complexity, mean (SD)	4.03 (2.97)	4.32 (3.08)	$t(84)=0.45$
Mental health complexity, mean (SD)	2.13 (1.72)	1.64 (1.44)	$t(84)=1.44$
VAB-2 ABC score, mean (SD)	57.46 (17.54)	47.85 (20.54)	$t(59)=1.95$
ADOS-2 CSS, mean (SD)	7.03 (1.93)	7.22 (2.09)	$t(74)=0.41$

* $p<.05$, ** $p<.01$, *** $p<.001$

it difficult to directly compare our findings with the study by Nicolaidis and colleagues, but nonetheless are worthwhile considering and may help to explain the differences between these studies. Nicolaidis et al. utilized an internet-based survey with a specific focus on healthcare issues. This precluded diagnostic confirmation and may have resulted in ascertainment of participants who were specifically motivated to answer questions about healthcare satisfaction. In addition, the sample in the Nicolaidis study was comprised of a relatively high proportion of female participants and individuals with college or advanced degrees. As a result of these differences, participants in the Nicolaidis et al. study were likely to have different healthcare needs and attitudes towards healthcare providers than the sample reported in the current study.

Interestingly, prior research on a general patient population reported by Wolosin (2005) found overall levels of satisfaction similar to those reported here in the current results. Of note is that the current sample was predominantly male. In the Wolosin sample, males tended to report higher healthcare satisfaction than females. Thus in this way, and in comparison the Nicolaidis et al. sample that had proportionally more females, individuals with ASD in the current study reported levels of satisfaction with healthcare that are comparable to the general population.

Determining which factors drive differences in patient satisfaction is an important issue for future study. While overall satisfaction with healthcare was high in this sample, there was variability in ratings of satisfaction with provision of and access to healthcare. Regression analyses revealed that older individuals (>26 years) were less satisfied than younger participants (18–25 years). This age-related finding is in contrast to Wolosin (2005) who found that healthcare satisfaction increased with age in a general population. Follow up analyses in the current study found that younger participants with ASD were significantly more likely to live at home, have private health insurance, and have more parent involvement than older individuals. These findings raise the hypothesis that healthcare satisfaction may be higher for adults with good family involvement and adequate health insurance, and when supportive services are available. This conclusion is in line with recent work indicating that a positive healthcare experience often necessitates family involvement (Nicolaidis et al. 2015).

Given the association between family involvement and healthcare satisfaction, it is critical to understand the impact of providing care to adults with ASD. In our sample, 68% of adults lived in their family home, comparable to other published work (Woodman et al. 2016). While several studies have explored the correlates of elevated stress levels experienced by parents of children with ASD (Davis and Carter 2008; Estes et al. 2009), little is known about the effects of caring for an adult child with ASD. In one study,

mothers who lived with an adolescent or adult child with ASD reported experiencing significantly more stressful events than mothers who lived with a typically developing adolescent or adult child (Smith et al. 2010). The number of stressful events was related to higher levels of negative affect in mothers of adults with ASD. Future research needs to investigate the impact of caring for an adult with ASD on parents and their ability to sustainably provide care.

An additional notable observation from these data was the large number of participants who were their own legal guardian, despite the fact that less than one-third of participants reported being responsible for their own medical decision-making. Given other work emphasizing the importance of family involvement (Nicolaidis et al. 2015), more research needs to examine what happens when parents are unavailable or no longer able to help adults with ASD make healthcare related decisions. More generally, this dissociation between guardianship and decision-making highlights legal and ethical issues related to transition to adulthood in individuals with autism and developmental disabilities (Parsi and Elster 2015). Furthermore, when parents make decisions for their adult children without having obtained formal legal guardianship, it raises complicated ethical questions about how to support autonomy without overly restricting how individuals can provide informed consent for medical examinations and participation in research studies. These issues are also relevant to other legal arrangements, including medical powers of attorney and conservatorship, and should be addressed by future research and policy efforts.

Our study had several limitations that restrict the extent to which our findings can be generalized. First, the majority of participants in the study were recruited through referrals from clinicians, community agencies and through parent support groups. Thus, our sample may have been biased toward having links to existing support systems, including more ready access to healthcare providers and specialists. Second, by recruiting via this method, we likely enrolled more individuals with significant impairment and limited participation by higher-functioning adults. It is possible that there may be lower satisfaction and more difficulty accessing care in higher-functioning individuals with ASD who are less likely to be eligible for the same types of services available to many of the individuals included in this study. Third, perhaps due to the poor adaptive functioning of our sample, the majority of the Healthcare Surveys were filled out by parents/caregivers instead of the individual with ASD, so they may not reflect the opinions of the adults with ASD. Finally, due to the high level of overlap between many of the demographic variables we utilized (e.g. living situation, insurance status, guardianship, etc...), it is impossible to disentangle the individual effects of each factor from our data.

In conclusion, the large majority of adults with ASD who participated in this study were highly satisfied with their healthcare. The strongest predictor of higher satisfaction was being below age 26, which, in turn, was associated with indices of greater family involvement. This study expands our knowledge of healthcare satisfaction in ASD to include individuals who are unable to self-report and who may have been excluded from online methodology. Further research needs to expand this work to community-based samples to better define the context as well as the related factors associated with healthcare satisfaction in adults with ASD. Finally, future studies should explore the impact of caring for an adult child with ASD and the consequences for the adult child when parents are no longer able to help.

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Author Contributions AHG participated in the study design, collected study data, and drafted the manuscript; CM participated in the statistical analysis and interpretation of the data, and helped draft the manuscript; TL participated in the design and coordination of the study and helped draft the manuscript; EMM participated in the design of the study and supervised the study; TA conceived of the study, participated in its design and coordination and contributed to the writing of the manuscript; SJS participated in the design and coordination of the study, supervised the study, and helped to draft the manuscript. All authors read and approved the final manuscript.

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Compliance with Ethical Standards

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

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.

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

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