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Characteristics associated with healthcare independence among autistic adults

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Abstract

Background: Healthcare independence refers to someone's ability to assume responsibility for their own health and complete tasks like taking medication as prescribed or scheduling healthcare appointments. Prior studies have shown that autistic people tend to need more support with healthcare tasks than people with other chronic conditions. We sought to identify modifiable and non-modifiable factors linked with healthcare independence among autistic adults.

Method: We conducted a cross-sectional survey to examine how executive functioning skills, restrictive and repetitive behaviors, gender, education, and age were linked with healthcare independence among this population. Participants included: (a) autistic adults (n=19) who are their own legal guardian, who participated via self-report; and (b) family members of autistic adults with a legal guardian (n=11), who provided proxy-reports.

Results: Findings differed between self- and proxy-reports. Among autistic adults who self-reported, difficulties in executive functioning were strongly linked with less healthcare independence. Among proxy-reports, greater restrictive and repetitive behaviors were strongly linked with less healthcare independence. According to the proxy-reports, having not completed high school, being older during the healthcare transition, and being male were all independently linked with less healthcare independence.

Conclusions: Interventions aimed at supporting executive functioning, providing opportunities to increase independence with healthcare tasks, and reducing the extent to which restrictive and repetitive behaviors interfere with daily activities may be viable options for supporting healthcare independence among autistic adults. Our findings are an important first step for future initiatives

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Conflict of Interest

C.H. is the founder and medical director of CAST. To minimize this potential source of bias, he was not involved in data collection or analysis.

Ethical Approval

Our Institutional Review Board (IRB) reviewed and approved this study (Protocol Number: 2019B0436).

to better identify individuals who need additional care coordination, supports, or services to maximize healthcare independence.

Keywords

autism spectrum disorder; adults; healthcare independence; healthcare transition

Introduction

Autistic adults have complex healthcare needs and higher rates of physical and mental health conditions than non-autistic adults (Croen et al., 2015; Hand, Angell, et al., 2020). If unaddressed or under-addressed, these health conditions could lead to serious secondary complications and chronic conditions. As a result, there is a nationally-recognized need to better meet the healthcare needs of autistic people as they age into and through adulthood (Interagency Autism Coordinating Committee (IACC), 2017).

One particularly vulnerable time for autistic adults is the transition from pediatric to adult healthcare systems. This transition is hard for autistic people due to widely documented barriers to adult care at the individual, provider, and system levels (Mason et al., 2019). These barriers are exacerbated by the fact that autistic individuals often demonstrate less healthcare independence than individuals with other chronic conditions (Beal et al., 2016). Healthcare independence refers to the degree to which someone can use self-management and healthcare utilization skills to assume responsibility for their own health (Heath et al., 2017). For example, healthcare independence includes tasks like taking medications as prescribed, refilling prescriptions as needed, reporting pain, answering doctor's questions, and scheduling appointments. Difficulties with these types of tasks may lead to autistic adults experiencing disruptions in continuity of healthcare and underutilizing important preventive services (Benevides et al., 2017; Vohra et al., 2014).

Among other clinical populations, healthcare independence has been linked with various individual characteristics. For example, among young people with epilepsy and college students, executive functioning skills are positively correlated with healthcare independence (Gutierrez-Colina et al., 2020; Smith et al., 2021). Gender has also been linked with healthcare independence, with women and girls demonstrating greater independence among people with complex healthcare needs and congenital heart disease (Sawicki et al., 2011; Stewart et al., 2017). Among adolescents and young adults with chronic and complex medical conditions, those with better academic performance demonstrated greater healthcare independence (Beal et al., 2016; Haarbauer-Krupa et al., 2019). Age has also been found to be positively correlated with healthcare independence among young people with type one diabetes, irritable bowel syndrome, and spina bifida (Gumidyala et al., 2018; Kim et al., 2019; Roth et al., 2020).

To our knowledge, no studies to-date have examined factors associated with healthcare independence specifically among autistic adults. In this study, we will examine how executive functioning skills, gender, education, and age are linked with healthcare independence among this population. Within this study, executive functioning skills refer to the related cognitive processes that propel goal-directed behavior and the development

of self-management skills (Phung & Goldberg, 2019). We will also examine the extent to which restrictive and repetitive behaviors (e.g., repetitive movements, intense or restricted interests, insistence on sameness, or sensory processing differences) are linked with healthcare independence. Our objective for this study was to identify modifiable (executive functioning, restrictive and repetitive behaviors) and non-modifiable (age, gender, education) characteristics associated with healthcare independence among autistic adults. Consistent with studies among other populations, we hypothesized that executive functioning skills, female gender, age, and education would be positively correlated with healthcare independence among autistic adults. We also hypothesized greater restrictive and repetitive behaviors would be linked with less healthcare independence.

Methods

Study Design

We conducted an observational study using self- and proxy-report data collection methods. Participants included autistic adults and family members of autistic adults. Participants completed an online survey in person while at the clinic using a provided iPad or were given a link to complete the online survey at a later time.

Study Setting

Participants consisted of a convenience sample of incoming patients and family members of incoming patients at a specialized primary care clinic designed for autistic adults. The primary care clinic was founded in 2014, is located in a suburban area of a Midwestern United States capital city, and is part of a larger university-based hospital system. This clinic was designed in partnership with autistic adults and their family members to minimize barriers to healthcare access and healthcare delivery (Saqr et al., 2018). The clinic provides an initial intake appointment prior to the patients' first medical visit to identify needed accommodations to the standard patient workflow. For example, patients with sensory sensitivity may bypass the waiting room when coming in for medical visits. Also, patients receive medical care from designated primary care physicians with extensive experience working specifically with autistic youth and adults.

Participants and Procedures

All autistic adults who were at least 18 years of age, were new patients at the clinic, and could understand study goals and provide informed consent were eligible for inclusion in this study. All patients had a community diagnosis of autism from a previous healthcare provider or school psychologist. Whenever possible, we recruited the patient to participate in the study themselves. Family members were given the option of participating only if they were the legal guardian of an autistic adult (age 18+ years) who was a new patient at the clinic.

Data for this study were collected between August 2020 and June 2021. We recruited participants by providing study information during an initial telephone intake with the clinic nurse and in-person during clinic appointments. For in-person recruitment, a study team member (not a clinician at the clinic) approached potential participants in the exam room

upon completion of their medical visit with a healthcare provider. Potential participants were given a brief verbal description of the study. Study team members explicitly stated to all potential participants that participation was voluntary, could be stopped at any time, and would not impact the patient's care at the clinic in any way. Individuals interested in participating had the option of completing the survey at a later time using a link on provided flier or completing the survey in the exam room on a provided iPad. Recruitment materials (e.g., study flier and brief study description) were reviewed and approved by a group of autistic adults and family members of autistic adults. Participants received a \$50 Amazon gift code for participation.

Measures

Transition Readiness Assessment Questionnaire (TRAQ). (Wood et al., 2014)—

The TRAQ is a 20-item assessment of independence with healthcare self-management and utilization skills designed and validated in a population of adolescents and young adults with special healthcare needs, including autism and other developmental disabilities (Sawicki et al., 2011). The TRAQ has five domains: (1) managing medications; (2) appointment keeping; (3) tracking health issues; (4) talking with providers; and (5) managing daily activities. The factor structure for the TRAQ is supported by EFA and CFA on independent samples of adolescents and young adults with special healthcare needs and demonstrates good internal reliability and criterion validity (Wood et al., 2014). Items on this self-report measure are rated on a 5-point scale where higher scores indicate greater independence with the task. Domain scores are calculated as the average score of completed items, resulting in five domain scores also ranging from 1 to 5. The TRAQ demonstrates good to excellent internal consistency (Cronbach's $\alpha=0.82-0.92$) among samples of people with complex healthcare needs (Sawicki et al., 2011).

The TRAQ was designed as a self-report assessment. However, because our intent was to recruit both patients and family members, before data collection, we created a modified version of the TRAQ for family members. For the family member version, we changed the instructions on the self-report assessment from *“Please check the box that best describes your skill level in the following areas that are important for transition to adult health care”* to *“When answering the following questions, please think about the autistic adult (patient) for whom you provide care. Please check the box that best describes the patient's skill level in the following areas that are important for transition to adult health care.”* We changed the wording of questions from second person (e.g., “Do you fill a prescription if you need to?”) to third person (e.g., “Do they fill a prescription if they need to?”). Also, we changed response scale options from first person (e.g., “Yes I always do this when I need to”) to third person (e.g., “Yes, they always do this when they need to”).

The Adult Repetitive Behaviour Questionnaire-2A (RBQ-2A). (Barrett et al., 2015)—

The RBQ-2A is a 20-item self-report assessment of restrictive and repetitive behaviors. Restrictive and repetitive behaviors include: (1) repetitive movements, use of objects, or speech; (2) insistence on sameness, inflexible adherence to routines, or ritualistic behavior; (3) intense or restricted interests; and (4) sensory processing differences (Turner-Brown & Frisch, 2020). This assessment looked at these behaviors in two domains: (1)

repetitive motor behaviors, and (2) insistence on sameness. Scores on the RBQ-2A are calculated by averaging item responses within each domain, and across all items for a total score. Scores range from 1-3, where higher scores indicate more restrictive and repetitive behaviors. This measure was developed from the Repetitive Behaviour Questionnaire-2 (RBQ-2), a parent-report measure of restrictive and repetitive behaviors in children (Leekam et al., 2007). The RBQ-2A demonstrates acceptable internal consistency (repetitive motor behaviors Cronbach's $\alpha=0.70$; insistence on sameness Cronbach's $\alpha=0.81$) and convergent validity with the Autism-Spectrum Quotient (Barrett et al., 2018).

Repetitive Behavior Scale – Revised (RBS-R).(Bodfish et al., 2000)—The RBS-R is a 44-item proxy-report questionnaire that is used to measure restrictive and repetitive behaviors among autistic children, adolescents, and adults in five domains (Lam & Aman, 2007): (1) stereotypic behavior; (2) self-injurious behavior; (3) compulsive behavior; (4) ritualistic/ sameness behavior; and (5) restricted interests. Items are scored on a four-point scale, where higher scores indicate more problematic restrictive and repetitive behaviors. Domain scores are calculated by summing the scores on individual items within each domain. Since each domain has a different number of items, the possible range of scores varies by domain. Stereotypic behavior scores range from 0-27, self-injurious behavior scores range from 0-24, compulsive behavior scores range from 0-18, ritualistic behavior scores range from 0-36, and restricted interest scores range from 0-9.

Behavior Rating Inventory of Executive Function – Adult Version (BRIEF-A). (Roth et al., 2005)—The BRIEF-A is a 75-item measure of behavioral regulation and metacognition. The behavioral regulation index captures the ability to maintain appropriate regulatory control of one's own behavior and emotional responses. This index is comprised of four sub-scales: (1) inhibit, which assesses inhibitory control and impulsivity; (2) shift, which assesses the ability to transition easily between different situations or activities as needed; (3) emotional control, which assesses the ability to modulate their emotional responses; and (4) self-monitor, which assesses social and interpersonal awareness. The metacognition index measures the ability to initiate activities, generate problem-solving ideas, sustain working memory, plan and organize problem-solving approaches, to monitor success and failure in problem solving, and to organize one's environment. This index is comprised of five sub-scales: (1) initiate, which assesses the ability to start a task or activity and independently generate ideas or problem-solving strategies; (2) working memory, which assesses the ability to hold information in the mind to complete a task; (3) plan/organize, which assesses ability to manage current and future task demands; (4) task monitor, which assesses the ability to monitor one's own successes and failures and correct mistakes; and (5) organization of materials, which measures organization of work, living, and storage spaces. Items are rated on a three-point scale, where higher scores indicate more difficulty with executive functioning. Two version of the BRIEF-A were used in this study. Patients completed the BRIEF-A Self-Report form and family members completed the BRIEF-A Informant Report form. The BRIEF-A has been validated for use with adults from 18 to 90 years old with a range of developmental and neurological conditions. Both forms have high internal consistency reliability (Informant Report form Cronbach's $\alpha= 0.80-0.98$; Self-Report form Cronbach's $\alpha= 0.80-0.94$), test-retest reliability (Informant Report form r

= 0.91-0.94; Self-Report form $r = 0.82-0.93$), and convergent validity with other measures of executive function (Roth et al., 2005).

Data analysis

Descriptive statistics were used to characterize participant characteristics. Continuous variables are presented as means and standard deviations, while categorical variables are presented as frequencies and percentages. Spearman's correlation coefficients, a type of effect size, were calculated to estimate the strength, direction, and relative importance of associations between participant characteristics and TRAQ domains. Based on previously published and validated thresholds for assessing strength of associations, correlation coefficients of less than |0.30| represent a weak association, coefficients between |0.30 and 0.49| represent a moderate association, and coefficients of |0.50| and above represent a strong association (Cohen, 2013). Based on current best practices in statistical reporting, all statistical analyses were reported using effect sizes (Kraemer, 2019; Amrhein et al., 2019; Nuzzo, 2014; Chavalarias et al., 2016; Livingston, 2014). Further, given the exploratory nature of this study, statistical significance testing was not performed in accordance with best practices (Kraemer, 2019). Statistical analyses were completed in SAS statistical software, version 9.4.

Results

Participant characteristics

Participants included 19 autistic adults who are their own legal guardians and 11 family members who reported on behalf of an autistic adult. Demographic information about participants is provided in Table 1. Most autistic adults who participated via self-report were male (68.4%), white (84.2%), non-Hispanic (94.7%), had completed high school or higher levels of education (52.6%), were not employed (73.7%), and lived with family (89.5%). All family members were female and identified as the parent or grandparent of the autistic adult for whom they provide care. Most family members were white (81.8%), had completed an associates degree or higher (54.5%), and were employed full time (54.5%). Family members also provided some demographic information about the autistic adult for whom they provide care. Among autistic adults whose family members completed the survey, most were male (72.7%), white non-Hispanic (72.7%), and had not yet attained a high-school diploma or equivalent (54.5%; includes those currently pursuing and those not pursuing diploma or equivalent).

Descriptive information about self- and proxy-report measures are provided in Table 2. With regard to the TRAQ, where higher scores indicate more healthcare independence, the mean domain-level scores for autistic adults who participated via self-report ranged from 2.7-4.4. The lowest mean domain-level score was observed for "appointment keeping" and the highest was for "talking with providers," followed by "managing daily activities." Among autistic adults whose family members completed the questionnaire, the TRAQ mean domain-level scores ranged from 1.2 to 2.7. The lowest mean domain-level scores were observed for "appointment keeping" and the highest for "managing daily activities," followed by "talking with providers."

For the BRIEF-A, where higher scores indicate more difficulties with executive functioning, higher scores were observed on the Metacognition Index (self-report mean=77.8; proxy report mean=85.2) than the Behavioral Regulation Index (self-report mean=57.9; proxy report mean=62.4) among both groups. Within the Behavioral Regulation Index domains, both groups scored highest in “emotional control,” and scored lowest in the domains of “shift” and “self-monitor.” Within the Metacognition Index domains, autistic adults who participated via self-report had relatively consistent scores (ranging from 15.3-15.9) on all domains except “task monitor” (mean score=11.9). Among autistic adults whose family members completed the questionnaire, the highest Metacognition Index domain scores were observed for “plan/organize,” indicating more difficulty in this area, and the lowest scores for “task monitor.”

Characteristics associated with healthcare independence

Among autistic adults who participated via self-report (Table 3), gender, age, and education were weakly correlated with all TRAQ domains. Difficulties with task monitoring were strongly correlated with poorer skills in managing medications, appointment keeping, tracking health issues, and managing daily activities. Also, greater difficulties in the BRIEF-A domains of inhibit, initiate, and organization of materials were strongly correlated with poorer skills in managing daily activities.

Among autistic adults whose family members completed the questionnaires (Table 4), male gender was strongly correlated with poorer skills in appointment keeping. All RBS-R domains were strongly correlated with at least one TRAQ domain, such that greater difficulty with: (a) stereotypic behavior was strongly correlated with poorer skills in tracking health issues, talking with providers, and managing daily activities; (b) compulsive behavior was strongly correlated with poorer healthcare independence in all domains except tracking health issues; (c) ritualistic/ sameness behavior and restricted interests were strongly correlated with poorer skills in managing daily activities. Interestingly, greater difficulty with self-monitoring, planning/organizing, and organization of materials were strongly associated with greater skills in talking to providers. Also, greater difficulty with self-monitoring and planning/organizing were strongly associated with better skills in managing medications and tracking health issues, respectively.

Discussion and Implications

As autistic individuals age into adulthood, they often experience steep declines in healthcare service use and discontinuities in care (Benevides et al., 2017; Vohra et al., 2014), leading to high unmet healthcare needs. Therefore, it is especially important to support autistic people before, during, and after transitioning to adult healthcare systems. Our study offers an important first step by describing modifiable and non-modifiable factors linked with healthcare independence among autistic adults establishing care at a specialized primary care clinic. Findings from this study may help providers better identify individuals who need additional care coordination or services to increase their healthcare independence.

Non-modifiable characteristics and healthcare independence

None of the non-modifiable characteristics we examined were strongly associated (i.e., $r > 0.50$) with healthcare independence among autistic adults who participated via self-report. However, among autistic adults who participated via proxy report, male gender was strongly associated with poorer skills in appointment keeping and moderately associated (i.e., $r = 0.30$ to 0.49) with poorer skills in talking to providers. Also, having at least a high school education or equivalent (vs. not completing high school) was moderately associated with better medication management and age was moderately negatively associated with skills in tracking health issues. These findings suggest that having a legal guardian, being male, having not completed high school or equivalent, and being older at the time of healthcare transition were all independent factors that may indicate a higher need for support.

Modifiable characteristics and healthcare independence

Consistent with the findings of studies among other populations (Gutierrez-Colina et al., 2020; Smith et al., 2021), difficulties in executive functioning were moderately to strongly associated with less healthcare independence among autistic adults who participated through self-report. Specifically, most BRIEF-A domain scores were moderately to strongly linked with TRAQ total scores, managing medications, tracking health issues, and managing daily activities. This may suggest that interventions aimed at improving or supporting executive functioning among autistic individuals may be viable targets to improve healthcare self-management and utilization skills. Examples of potential interventions for autistic adults may include mixed martial arts training and computerized attention training systems, which have been shown to improve executive functioning for this population (Chen et al., 2020; Phung & Goldberg, 2019). Future work would be needed to determine the extent to which interventions aimed at improving underlying executive functioning skills yield improvements in healthcare independence.

Interestingly, the direction of the association between executive functioning and healthcare independence differed for proxy-report participants. That is, family members reported higher levels of independence among autistic adults who had more difficulties with executive functioning. Prior studies found that family members report difficulty quantifying their autistic adolescents' potential for healthcare independence and may not provide adequate opportunities for the autistic individuals to independently complete healthcare tasks like scheduling appointments or managing medications (Cheak-Zamora et al., 2017). As a result, family members in our study may have struggled to accurately rate the autistic adults' healthcare independence, in part because the autistic adult may not have had opportunities to attempt healthcare tasks independently. We recommend that family members, autistic adults, and healthcare providers work together to facilitate opportunities for the autistic adult to increase their independence with healthcare tasks, as appropriate. Increasing independence with healthcare tasks could also be a valuable goal to add to an adolescents' Individualized Education Plans (IEP) as they prepare for the transition to adulthood (Heron et al., 2020).

While restrictive and repetitive behaviors were strongly associated with many domains of healthcare independence among those who participated via proxy-report, there were weak to moderate associations among autistic adults who self-reported. This finding may be due to

differences in question wording between the measures of restrictive and repetitive behaviors used for proxy-report (RBS-R) and self-report (RBQ-2A). For example, the RBQ-2A asks respondents to rate the frequency of behaviors (Barrett et al., 2015), while RBS-R asks respondents to rate how much of a problem the behavior causes (Bodfish et al., 2000). Therefore, this finding may indicate that healthcare independence is strongly associated with how much restrictive and repetitive behaviors interfere with daily activities, and less strongly associated with how frequently the behaviors occur. Possible options to explore to reduce the extent to which restrictive and repetitive behaviors interfere with daily activities may include self-management interventions and behavior replacement therapy (Chezan et al., 2017; Southall & Gast, 2011).

Limitations and future directions

There are some limitations to consider regarding the sample used in this study. Due to the limited sample size (n=19 autistic adults, n=11 family members of autistic adults), the correlation coefficients presented here may not be stable estimates of the true population values (Schönbrodt & Perugini, 2013). Therefore, the findings of this study should be interpreted as preliminary and exploratory. Our study involves a small convenience sample from a single specialized primary care clinic in the Midwestern United States. Some subgroups were not well-represented in this sample; for example, only 3 of the 11 family members included in this study provided care for a female autistic adult. Therefore, larger studies with expanded samples and greater stakeholder representation are an important future direction. The sample only includes people who transitioned to an adult healthcare clinic designed for autistic people. Our results may not generalize to those who do not establish care with an adult provider, or those who transition to adult general primary care.

Another important limitation to consider is related to the questionnaires used in this study. For example, we recognize that other unmeasured factors may also contribute to healthcare independence. While the surveys used in this study cover a wide variety of behaviors, emotional responses, and management strategies, there may be other factors that should be considered in work on this topic going forward, such as co-occurring conditions or receptive and expressive language skills. Also, while the TRAQ was developed and validated using a sample that included autistic people and people with other complex healthcare needs (Sawicki et al., 2011), the psychometric properties of this questionnaire among samples consisting exclusively of autistic adults have not been established. Additionally, our modified version of the TRAQ for family members has not been psychometrically evaluated; due to our limited sample size, psychometric evaluation of this modified questionnaire was not possible in this study. Since we initiated data collection for this study, a new version of the TRAQ and a tool to measure health-related independence specifically for autistic people were published (Cheak-Zamora et al., 2021; Johnson et al., 2021). In future work, these updated measures should be used to capture the most valid data on healthcare independence. Exploring why the self- and proxy-reports yielded different results was beyond the scope of the present study, but is an important consideration for future work.

Finally, we examined only characteristics of autistic adults associated with healthcare independence. Examining the links between healthcare systems, family member

characteristics, or provider-level characteristics with autistic adults' healthcare independence was beyond the scope of this study, but is an important consideration for future work.

Conclusion

This study is the first, to our knowledge, to examine the modifiable and non-modifiable characteristics associated with healthcare independence among autistic adults. Our findings highlight that having a legal guardian, being male, having not completed high school, and being older at the time of healthcare transition were all independent factors that may indicate a higher need for support among autistic adults. Interventions aimed at supporting executive functioning, providing opportunities to increase independence with healthcare tasks, and reducing the extent to which restrictive and repetitive behaviors interfere with daily activities may be viable options for supporting healthcare independence among autistic adults. Our findings are an important first step for future initiatives to better identify individuals who need additional care coordination, supports, or services to maximize healthcare independence.

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Highlights

- We examined factors linked with healthcare independence among autistic adults
- Factors linked with healthcare independence differed between self- and proxy-report
- Self-management skills may be a viable target to improve healthcare independence
- Having a legal guardian, being male, not having completed high school, and being older at time of healthcare transition were independent factors that may indicate a higher need for support

Table 1:

Participant demographic characteristics

	Autistic Adults (self-report) n=19	Autistic Adults (proxy-report) n=11	Caregivers n=11
Gender, n (%)			
Female	4 (21.1)	3 (27.3)	11 (100)
Male	13 (68.4)	8 (72.7)	0 (0.0)
Non-binary	2 (10.5)	0 (0.0)	0 (0.0)
Years of Age, Mean \pm SD	21.9 \pm 7.1	20.1 \pm 1.8	55.7 \pm 6.3
Race, n (%)			
Asian	1 (5.3)	0 (0.0)	0 (0.0)
Black/African American	2 (10.5)	1 (9.1)	1 (9.1)
White	16 (84.2)	8 (72.7)	9 (81.8)
> 1 race	0 (0.0)	1 (9.1)	1 (9.1)
Other	0 (0.0)	1 (9.1)	0 (0.0)
Hispanic	1 (5.3)	2 (18.2)	0 (0.0)
Highest level of education, n (%)			
Less than high school diploma or equivalent (not currently pursuing)	1 (5.3)	2 (18.2)	0 (0.0)
Pursuing high school diploma or equivalent	3 (15.8)	4 (36.4)	0 (0.0)
High school diploma or equivalent	6 (31.6)	5 (45.5)	4 (36.4)
Some college	6 (31.6)	0 (0.0)	1 (9.1)
Associate's degree	1 (5.3)	0 (0.0)	1 (9.1)
Bachelor's degree	1 (5.3)	0 (0.0)	1 (9.1)
Some graduate school	0 (0.0)	0 (0.0)	1 (9.1)
Graduate degree or higher	1 (5.3)	0 (0.0)	3 (27.3)
Annual Household Income, n (%)			
<\$25,000	4 (21.0)	--	2 (18.2)
\$25,000-49,999	1 (5.3)	--	2 (18.2)
\$50,000-74,999	0 (0.0)	--	1 (9.1)
\$75,000-99,999	2 (10.5)	--	0 (0.0)
\$100,000+	4 (21.0)	--	6 (54.5)
Not reported	8 (42.0)	--	0 (0.0)
Marital status			
Single	17 (89.5)	--	1 (9.1)
Married/partnered	2 (10.5)	--	7 (63.6)
Divorced	0 (0.0)	--	3 (27.3)
Employment		--	
Not employed	14 (73.7)		1 (9.1)
Retired	0 (0.0)	--	1 (9.1)
Employed part time	3 (15.8)	--	3 (27.3)
Employed full time	2 (10.5)	--	6 (54.5)

	Autistic Adults (self-report) n=19	Autistic Adults (proxy-report) n=11	Caregivers n=11
Living arrangement			
With family	17 (89.5)	--	--
Independently	1 (5.3)	--	--
With partner/significant other	1 (5.3)	--	--

SD = Standard deviation

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Table 2:

Self- and proxy-report measures of repetitive behaviors, executive functioning, and healthcare transition readiness

	Autistic Adults (self-report) n=19	Autistic Adults (proxy-report) n=11
RBQ-2A, Mean ± SD		
Repetitive motor behaviors	1.9 ± 0.4	--
Insistence on sameness	1.8 ± 0.5	--
RBS-R, Mean ± SD		
Stereotypic behavior	--	7.3 ± 5.6
Self-injurious behavior	--	2.4 ± 3.0
Compulsive behavior	--	3.0 ± 2.3
Ritualistic/ sameness behavior	--	12.1 ± 9.1
Restricted interests	--	5.1 ± 3.7
BRIEF-A, Mean ± SD		
Behavioral Regulation Index	57.9 ± 14.9	62.4 ± 15.1
Inhibit	14.3 ± 3.9	15.5 ± 3.3
Shift	12.6 ± 3.4	13.2 ± 3.3
Emotional control	19.6 ± 6.0	20.7 ± 6.1
Self-monitor	11.4 ± 3.5	13.0 ± 3.7
Metacognition Index	77.8 ± 19.9	85.2 ± 26.0
Initiate	15.9 ± 3.7	17.2 ± 5.3
Working memory	15.8 ± 4.9	18.3 ± 4.7
Plan/organize	15.8 ± 5.1	20.7 ± 7.1
Task monitor	11.9 ± 2.8	12.6 ± 4.1
Organization of materials	15.3 ± 4.8	16.4 ± 6.2
TRAQ, Mean ± SD		
Managing medications	3.1 ± 0.9	1.7 ± 0.7
Appointment keeping	3.1 ± 1.1	1.7 ± 0.9
Appointment keeping	2.7 ± 1.0	1.2 ± 0.5
Tracking health issues	2.8 ± 1.1	1.6 ± 0.8
Talking with providers	4.4 ± 0.8	2.5 ± 1.4
Managing daily activities	3.6 ± 0.8	2.7 ± 1.6

RBQ-2A = Adult Repetitive Behaviour Questionnaire-2A; SD = Standard deviation; RBS-R = Repetitive Behavior Scale – Revised; BRIEF-A = Behavior Rating Inventory of Executive Function – Adult Version; TRAQ = Transition Readiness Assessment Questionnaire

Table 3:

Spearman's correlations between participant characteristics and TRAQ scores among autistic adults who participated via self-report (n=19)

	Total Score	TRAQ Domain				
		Managing medications	Appointment keeping	Tracking health issues	Talking with providers	Managing daily activities
Male Gender (vs. Female or Non-Binary)	-0.20	-0.21	-0.16	-0.24	0.03	0.02
Age	-0.07	-0.10	-0.11	0.06	-0.17	-0.27
High school education or greater	-0.07	-0.28	0.06	0.02	0.14	0.13
RBQ-2A						
Repetitive motor behaviors	-0.01	-0.06	0.00	-0.12	-0.16	0.04
Insistence on sameness	0.04	0.16	0.02	-0.03	-0.36*	-0.19
BRIEF-A						
Behavioral Regulation Index	-0.07	-0.02	-0.07	-0.07	-0.32*	-0.26
Inhibit	-0.33*	-0.31*	-0.30*	-0.36*	-0.12	-0.53**
Shift	-0.01	0.06	0.01	-0.07	-0.41*	-0.13
Emotional control	0.13	0.16	0.10	0.14	-0.21	-0.11
Self-monitor	-0.26	-0.35*	-0.19	-0.19	-0.23	-0.29
Metacognition Index	-0.37*	-0.42*	-0.25	-0.36*	-0.16	-0.44*
Initiate	-0.38*	-0.37*	-0.26	-0.39*	0.03	-0.55**
Working memory	-0.31*	-0.41*	-0.22	-0.28	-0.27	-0.39*
Plan/organize	-0.35*	-0.37*	-0.26	-0.38*	-0.23	-0.33*
Task monitor	-0.59*	-0.51**	-0.50**	-0.59**	-0.24	-0.50**
Organization of materials	-0.26	-0.36*	-0.12	-0.20	0.04	-0.54**

An asterisk (*) indicates a moderate correlation ($r=0.30$ or higher) and two asterisks (**) indicates a strong correlation (i.e., $r=0.50$ or higher) as defined by Cohen, 2013. Statistical significance testing was not performed. RBQ-2A = Adult Repetitive Behaviour Questionnaire-2A; BRIEF-A = Behavior Rating Inventory of Executive Function – Adult Version; TRAQ = Transition Readiness Assessment Questionnaire. Higher RBQ-2A scores indicate greater difficulty with restrictive and repetitive behaviors; Higher BRIEF-A scores indicate more difficulty with executive functioning; Higher TRAQ domain scores indicate more healthcare transition readiness.

Table 4:

Spearman's correlations between participant characteristics and TRAQ scores among autistic adults whose caregivers completed the assessments (n=11)

	Total Score	TRAQ Domains				
		Managing medications	Appointment keeping	Tracking health issues	Talking with providers	Managing daily activities
Male Gender (vs. Female)	-0.33	-0.13	-0.75 **	-0.07	-0.33 *	-0.23
Age	-0.08	0.27	0.29	-0.46 *	-0.27	0.02
High school education or greater	0.00	0.42 *	0.13	-0.47 *	-0.18	0.03
RBS-R						
Stereotypic behavior	-0.70 **	-0.46 *	-0.30 *	-0.56 **	-0.55 **	-0.62 **
Self-injurious behavior	-0.47 *	-0.29	-0.18	-0.49 *	-0.37 *	-0.45 *
Compulsive behavior	-0.73 **	-0.53 **	-0.67 **	-0.46 *	-0.59 **	-0.60 **
Ritualistic/ sameness behavior	-0.59 **	-0.26	-0.30 *	-0.30 *	-0.40 *	-0.58 **
Restricted interests	-0.63 **	-0.40 *	-0.25	-0.35 *	-0.31 *	-0.67 **
BRIEF-A						
Behavioral Regulation Index	0.13	0.23	0.29	0.39	0.38 *	-0.03
Inhibit	-0.03	0.33	0.34 *	0.10	0.19	-0.03
Shift	0.19	0.24	0.32 *	0.42	0.40 *	0.01
Emotional control	-0.04	0.06	0.09	0.22	0.15	-0.21
Self-monitor	0.34 *	0.60 **	0.49 *	0.40 *	0.55 **	0.18
Metacognition Index	0.33 *	0.22	0.40 *	0.46 *	0.55 **	0.11
Initiate	0.14	-0.10	0.32 *	0.49 *	0.45 *	-0.06
Working memory	0.10	-0.12	0.31 *	0.44 *	0.44 *	-0.13
Plan/organize	0.31 *	0.15	0.37 *	0.50 **	0.62 **	0.03
Task monitor	0.26	0.20	0.38 *	0.22	0.43 *	0.11
Organization of materials	0.45 *	0.37 *	0.33 *	0.39 *	0.58 **	0.12

An asterisk (*) indicates a moderate correlation ($r=0.30$ or higher) and two asterisks (**) indicates a strong correlation (i.e., $r=0.50$ or higher) as defined by Cohen, 2013. Statistical significance testing was not performed. RBS-R = Repetitive Behavior Scale – Revised; BRIEF-A = Behavior Rating Inventory of Executive Function – Adult Version; TRAQ = Transition Readiness Assessment Questionnaire. Higher RBS-R scores indicate greater difficulty with restrictive and repetitive behaviors; Higher BRIEF-A scores indicate more difficulty with executive functioning; Higher TRAQ domain scores indicate more healthcare transition readiness.