

Title: Perspectives of Adults with Autism on Healthcare Experiences

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Introduction: As rates of autism spectrum disorder (ASD) increase, more adults with autism⁴ are transitioning from pediatric to adult healthcare (Nevison et al., 2018). However, adult healthcare providers are generally ill-equipped to meet the healthcare needs of adults with autism (Bruder et al., 2012; Kuhlthau et al., 2015; Zerbo et al., 2015) and there is often a lack of transition services (Cheak-Zamora et al., 2013). Additionally, many individuals with autism have increased healthcare needs, and are less likely to have those needs met (Croen et al., 2015; Schott et al., 2020; Weiss et al., 2018). However, despite an increased need, few studies have examined the perspectives of adults with autism regarding their healthcare experiences. The aim of this study was to gain a deeper and more nuanced insight into the healthcare experiences of adults with autism.

Method: A mixed method approach was used. The sample included 20 adults with autism (Age M = 25.6, SD = 5.1, range 18-35 years, 13 male, 6 female, 1 trans female). Participants completed questionnaires including a demographic survey, Patient-Provider Communication Self-Report, and Barriers to Healthcare Checklist – Short Form. Participants also completed qualitative semi-structured interviews via the Zoom videoconferencing platform. Interviews asked about satisfaction with primary care services, positive and negative experiences with healthcare providers, how much their providers knew about ASD, and suggestions for providers to provide better care and accommodations. Recorded interviews were transcribed and thematic analysis was conducted using Dedoose, a qualitative and mixed methods data analysis platform. Good coding reliability was established between the two coders (Pooled Cohen's Kappa = .83), and 100% agreement was reached during consensus coding.

Results: Descriptive statistics indicated that of those receiving primary care, 88% of respondents indicated that quality of their health care was either "excellent" or "very good," 12% reported that their healthcare quality was "good," and none of the participants reported "fair" or "poor" quality of healthcare. The most common healthcare barriers reported by the participants included trouble following up on care; fear, anxiety, embarrassment, or frustration; and problems filling out paperwork. Four primary themes were identified in the qualitative analysis: (1) Access to care, (2) clinic environment, (3) provider factors, and (4) patient-provider partnership. Several subthemes were identified within each theme. Regarding access to care (Theme 1), adults with autism identified that getting an appointment, costs and insurance coverage, location and transportation, and continuity of care were important. For example, one individual identified that he had to drive "about a hour and a half to two hours" just to see the providers that met his needs and accepted his insurance. Subthemes identified under clinic environment (Theme 2) included accommodating sensory needs, managing anxiety and pain, and wait time and visit length (e.g., "if you gotta wait a long time and the waiting room's crowded, it makes you just wanna leave or go home"). Provider-related (Theme 3) subthemes included provider knowledge of ASD (e.g., "one doctor was... 'You don't seem autistic, you seem fine.'), provider rapport (e.g., "he asks me some questions, and he listens to me, and he jokes with me a lot") and provider communication (e.g., "there's some slight disconnect on what I'm trying to communicate and what they're sort of picking up on"). Finally, the patient-provider partnership theme (Theme 4) included subthemes on healthcare independence and caregiver involvement (e.g., "They let my mom come in the room with me...it makes me more comfortable") and promoting treatment plan adherence (e.g., "summarizing appointments with written language that people can look back over").

Discussion: Quantitative findings indicated that overall, adults with autism in the study were satisfied with their healthcare quality but had some significant barriers to healthcare access as well. The qualitative findings support themes that have been identified in previous literature. These include patient-level factors such as communication, sensory difficulties, and appointment anxiety; provider-level factors such as knowledge of ASD and accommodations; and system-level factors such as barriers to healthcare access (Bradshaw et al., 2019; Dern & Sappok, 2016; Nicolaidis et al., 2015). These findings have a number of implications including a need to for better provider training on ASD, heterogeneity of ASD, and individualized accommodations for adults with autism. Additionally, these findings bring to light the barriers to healthcare access for many adults with autism, particularly insurance coverage and physical access to appointments.

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⁴ Regarding autism-specific terminology, there is not current consensus across the autism community regarding the use of person-first or identity-first language. Some individuals prefer person-first language, such as “person with autism,” “person on the autism spectrum,” while others prefer disability- or identity-first language, such as “autistic person” or “Aspie.” (Kenny et al., 2016; Vivanti, 2020). In the current abstract, we use the specific language preferred by the participants in this study. We asked each participant to let us know which terminology they preferred in order to use the autism-specific language most comfortable to them. The majority (75%) said that they had no preference. Of those with a preference, most preferred person-first language (e.g. person “with autism” or who “has autism”), while only one participant preferred identity-first language. As such, person-first language will be used in the current abstract.