

Understanding Adults with Autism Spectrum Disorder in the Clinical Encounter

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ASD

- Challenges with social competencies such as communication, collaboration, and relationships, ¹⁻⁵ even for those without an intellectual disability (i.e., the participants in this study)^{1,2}



Healthcare Research and Adults with ASD

- Patient-Centred Care (PCC) emphasizes healthcare relationships, collaboration and communication⁶⁻¹⁰, all of which adults with ASD may struggle with
- Adults with ASD are largely excluded from research for many reasons¹¹⁻¹³
- This contributes to adults with ASD feeling unsupported, and healthcare practitioners feeling ill-equipped in treating adults with ASD¹²

Method

- Participants:** 32 North-American adults with ASD age 20+, who were able to navigate healthcare independently
- Data Collection:** Online (Qualtrics)
 - AQ-10 Screen¹⁴; Demographic Q's
 - 4 open-ended study Q's/Theoretical Sampling Q's
- Analysis:** Constant Comparison Analysis (Grounded Theory)



Purpose: To understand how adults with ASD experience their healthcare communication and healthcare relationships by asking them directly and exclusively

Main Finding: Overall, healthcare providers (HCPs) were portrayed as either adversaries or allies

Adversaries were perceived as:

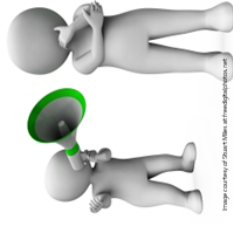
- Dismissive of intelligence:** Telling them [HCP's] that a parent or friend has suggested a certain test or treatment will get monumentally better results than saying it was your own idea. [...] Bonus points for bringing someone else to the appointment to say it for you. (Stephanie)
- Dismissive due to a lack of knowledge about ASD and social competencies:** Don't see my gaze aversion or flat monotone as annoying, or disinterest. I matter! (Diana)
- Dismissive of patient strengths (e.g., written communication skills):** The specialist refused to even look at the information or drawing. In one instance the papers were grabbed from my hand and discarded. As you can imagine these were not successful encounters. (Kate)
- Dismissive of ASD:** I have been told many times that I did not "look" autistic, therefore I must not be. (Elaine)

Allies were perceived as:

- Supportive of patient strength:** Sometimes my voice fails, but a list helps. Making a list is a strength. It helped me get an important rheumatologist referral. (Diana)
- Supportive of patient struggles:** I am not always up for talking, she shows warmth and acceptance [...] rather than investigating me with questions. [Sometimes] I just sat there... she did not give up on me. And neither did I. (Anne)
- Treating the patient like a person, not a condition:** I am not one for small talk. For him to take the time to ask me questions about how school goes and how my volunteer work goes shows me he has a genuine interest. (Emanuel)
- Caring:** I am fortunate to have a great GP, and two great orthopedists. I feel at home talking to them. I feel like I am talking to someone who really cares. (Francois)

Discussion

- Positive and negative reported experiences of healthcare were often determined by HCPs' knowledge about ASD and its impact on the individual patient experience.
- Important knowledge for HCPs to have includes:
 - Adults with ASD may appear rude/disengaged despite putting in full effort to engage with their HCP.
 - Communication challenges are not necessarily indicative of intellectual delay.
 - Although social anxiety is common in individuals with ASD, it is distinct from social competence (i.e., social anxiety vs social skills), and must be addressed in terms of its impact on communication.
 - Adults with ASD are highly diverse; HCPs must find ways to foster relationships and communication to gain an understanding of each individual in order to make healthcare truly patient centred.



Strengths

- Data from ASD adults directly
- Novel investigation, addresses literature gap
- Stakeholder & member checks

Limitations

- Potential recruitment bias - those with more extreme experiences are more likely to sign up
- Does not include HCP view

References

11. Williams, T., Johnson, J., & Johnson, J. (2020). Healthcare access in people with autism spectrum disorder: A review of the literature. *Journal of Autism and Developmental Disorders*, 50(1), 1-15.

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