

KEY POINT SUMMARY

OBJECTIVES

An online survey was administered to identify problematic patterns of sensory and communication experiences for autistic adults.

Experiences of sensory overload and communication barriers by autistic adults in health care settings

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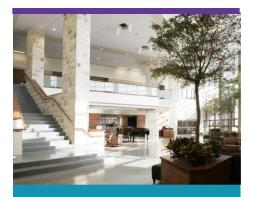
Key Concepts/Context

Autistic adults have an elevated risk for health problems that can be further exacerbated by stressful and inefficient healthcare experiences. The goal of this study was to identify problematic patterns of sensory and communication experiences for autistic adults. Intense, unpredictable, and uncontrollable environments present barriers to communication and contribute to overstimulation. These results suggest that removing barriers and improving healthcare environments can improve both communication and sensory experiences for autistic adults.

Methods

The researchers conducted an online survey in Sweden between May and September 2019 designed to "help improve environments, communication and knowledge in health care situations" from the perspective of autistic patients. The study used a snowball recruitment strategy of women, men, and transgender people, with and without neurodevelopmental diagnoses via social media platforms. An anonymous online questionnaire was used for data collection. It included questions about demographics, a 10-item Autism Quotient section for autistic characteristics, questions about the number and type of psychiatric and somatic conditions that were used to estimate individual health burden, sensory questions that were rated using a 5-point Likert response scale, and six open-ended healthcare questions — four about the environment and two about communication. The settings that questions pertained to included waiting rooms, examination rooms, common rooms, and patient rooms in outpatient and inpatient somatic and psychiatric healthcare clinics. The response sample consisted of 98 respondents, 62 of whom were diagnosed with autism; individuals self-identifying as autistic without being diagnosed were excluded from analysis. Most respondents were born in





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Sweden, young (m=36), well-educated (graduated at least high school), and female or gender diverse. Statistical logistic regression and thematic analysis was used to evaluate and compare responses provided by individuals with and without autism. Analysis revealed that the most common co-occurring conditions with autism were anxiety disorders (p<0.01), ADHD (p=0.02), depressive disorders (p<0.01), and exhaustion (p<0.09). The association of autism (as well as autism adjusted for age, age+ADHD, and age+ADHD+anxiety+depression) with measures of sensory discomfort in healthcare settings was analyzed using odds ratios and 95% confidence intervals.

Findings

Questions relating to communication revealed a desire to feel safe and stress free. Suggestions for improved personal interactions related to clinicians communicating in writing, by reframing, and through repeating information. Environmental stressors that impeded communication related to the effects of sensory unpredictability and the inability to exercise control over the immediate environment, including odors, movement, wayfinding, and the proximity of other people. Questions relating to sensory processing gave rise to the intensity of a variety of stimuli. Background sounds were perceived to be particularly stressful and exhausting to autistic respondents. Olfactory and tactile stimuli were also a source of sensory overstimulation in autistic respondents.

Bright, flickering, and non-diffused lights, clutter, unpleasant colors, temperature, and ventilation were mentioned by respondents with and without autism.

Limitations

The small sample of individuals with and without autism may have been subject to selection bias and was not matched on health status or exposure to health settings. The internet-based recruiting strategy did enable researchers to effectively reach representation of marginalized populations, including females, gender-diverse, and older adults that are generally absent within the autism literature.

Design Implications

The architecture, interior design, and resulting environmental stimuli of healthcare settings should support vulnerable patients to interact with their surroundings and effectively communicate with healthcare providers. Auditory control should be



exercised in relation to TVs, alarms, phones, clicking tocks, and between-room sound transmission. Bright, non-diffused, flickering, fluorescent, sharp, and pointed lighting should be avoided. Items usually regarded as positive distractions, such as artwork and views to nature, can also be distracting to individuals with autism.

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