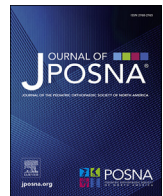




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Original Research

The Healthcare Experience of Autistic Patients in Orthopaedic Surgery: A Survey Study of Autistic Patients' Parents, Caregivers, and Orthopaedic Providers



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ABSTRACT

Background: Autistic patients can have different communication and sensory needs, potentially making orthopaedic visits stressful. This study evaluated which factors play the greatest role in autistic patients' comfort and overall experience in orthopaedic settings by surveying the parents, caregivers, and orthopaedic providers of these patients.

Methods: We developed two online surveys focused on the experience of autistic patients in orthopaedic settings: one for parents/caregivers and another for orthopaedic surgeons. Parents/caregivers of patients under 26 years of age with a diagnosis of autism spectrum disorder (ASD) and an orthopaedic visit at a single pediatric institution between 2017 and 2022 were eligible. The provider survey was sent via email to members of the Pediatric Orthopaedic Society of North America (POSNA).

Results: Parent/caregiver survey: In total, 83 parents/caregivers (mean patient age: 12, 77% male) provided complete responses. The most anxiety-provoking situations included blood draws (49% of patients beyond neutral anxiety level), loud/unfamiliar noises (42%), getting imaging (38%), casting (35%), and cast removal (34%). Parents/caregivers noted that purposeful eye contact, explanations in advance, and use of technology helped improve patient comfort.

Provider survey: In total, 61 orthopaedic surgeons responded. The majority of providers reported being aware of an ASD diagnosis in their patients some (48%) or most (40%) of the time. Situations that make autistic patients more anxious/uncomfortable than nonautistic patients included cast removal (80% of respondents), loud/unexpected sounds (77%), imaging (70%), and the physical exam (62%). The most common accommodations in place included child life specialists (53%) and ear plugs/headphones (51%); 18% reported no accommodations. Most providers changed their approach to visits with autistic patients, including discussions with parent/caregiver about patient's preferences (66%) and more time in the room (54%).

Conclusions: Orthopaedic practices looking to improve autistic patient experience can prioritize interventions that lower the sensory demands of cast removal, brace fitting, and radiologic imaging. Orthopaedic surgeons are broadly cognizant of the challenges autistic patients face during clinical visits, but improved awareness and accommodations are necessary.

Key Concepts:

- (1) Autistic patients can have different communication and sensory needs, potentially making orthopaedic visits stressful and uncomfortable.
- (2) We surveyed parents/caregivers of autistic patients treated at a single pediatric institution, as well as a national sample of orthopaedic surgeons, regarding the experiences of autistic patients in orthopaedic settings and the factors that make the greatest impact on their experiences.
- (3) According to autistic patients' parents/caregivers, the most anxiety-provoking situations were those that involved high sensory loads and/or discomfort, though patient experience can be improved with purposeful eye contact, thorough explanations, and use of technology or distraction devices.

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- (4) According to orthopaedic providers, most practices used accommodations to improve autistic patient experience, though 18% of practices had no accommodations in place and provider approaches to visits with autistic patients were variable.
- (5) Orthopaedic practices looking to improve autistic patient experience can prioritize interventions that lower the sensory demands of clinical visits and expand baseline accommodations available.

Level of Evidence: IV

Introduction

The current healthcare system is not well equipped to accommodate individualized patient needs relating to communication, social interaction, and sensory processing commonly seen in autism spectrum disorder (ASD) conditions [1–5]. According to the American Psychiatric Association's Diagnostic and Statistical Manual, Fifth Edition (DSM-5), a diagnosis of ASD requires persistent deficits in social communication and social interaction, as well as multiple restricted, repetitive behaviors [6,7]. Throughout this article, we use identity-first language in reference to autistic individuals as a thorough review of the literature evaluating preferences for identity-first versus person-first language has demonstrated a consensus for using identity-first language [8–14]. Our foremost aim is to use language respectful to autistic individuals, and we recognize that preferences will differ among individuals.

The challenges faced by autistic patients can be exacerbated in healthcare specialties who routinely see high volumes of patients, utilize medical devices, and care for patients with painful injuries. These characteristics are common in orthopaedic surgery, and consequently, visits to orthopaedic providers can be profoundly stressful for autistic patients. Despite the relatively high prevalence of ASD (1.7%–2.5% of U.S. children) and the fact that autistic patients often have comorbidities that increase their risks of orthopaedic conditions, little attention has been paid to exploring autistic patients' experiences in orthopaedics [6,15–27].

To this point, no studies in the orthopaedics literature have directly sought to understand what aspects of orthopaedic care can be difficult for autistic patients [27]. Therefore, the field has relied on data collected from other specialties and settings to inform efforts to improve care for autistic patients in orthopaedics [28,29]. This study aimed to evaluate which factors play the greatest role in determining an autistic patient's comfort and overall experience in orthopaedic settings. Given the key aspects of ASD described earlier, situations requiring greater social demands and high sensory loads were expected to be the most challenging. We surveyed the parents and caregivers of autistic patients seen by orthopaedic providers at a single pediatric institution, as well as a national sample of orthopaedic providers. By capturing perspectives on autistic patient experience from both sides of the orthopaedic clinical visit—patient and provider—we sought to assess the issues of most concern to each, as well as identify where perspectives might align.

Materials and methods

Survey development

We developed two online surveys focused on the experience of autistic patients in orthopaedic clinical settings: the first to be completed by parents and caregivers of those patients, with assistance from the patients themselves when possible, and a second for orthopaedic providers. Question domains for the parent/caregiver survey included demographics, relevant clinical data, emotional dysregulation measures, and comfort levels with numerous situations common to orthopaedic visits. Question domains for the provider survey included practice characteristics, perceived challenges for autistic patients, changes in provider approach, and current accommodations for autistic patients. Questions and answer options were thoroughly reviewed and improved upon through an iterative process by a multidisciplinary team of professionals in orthopaedic surgery and physical medicine and rehabilitation.

Recruitment

This study was approved by the hospital's institutional review board. The parent/caregiver participant sample was identified by screening a clinical database at a single pediatric institution for patients under 26 years of age with a diagnosis of ASD and an orthopaedic visit within the period from 2017 to 2022. The age cut-off of 26 years was used because patients can continue to receive care up until this age at this pediatric hospital. Parents and caregivers were recruited using personalized survey links sent via email with up to two follow-up emails and a phone call. Responses were collected from April to June 2023.

For the provider portion of this study, we submitted our provider survey to the *Pediatric Orthopaedic Society of North America* (POSNA) for critical review by its evidence-based practice committee. Once approved, the survey was sent by POSNA administrators via email to the membership. Responses were collected from May to July 2023, with one reminder email.

Data capture and analysis

Deidentified responses for both surveys were collected and analyzed using Research Electronic Data Capture (REDCap) [30,31]. The provider survey did not require identifying information. Emotion dysregulation was evaluated in the parent/caregiver survey using the Emotion Dysregulation Inventory (EDI), which is a questionnaire answered by caregivers designed to capture emotional distress and problems with emotion regulation [32–34]. The form asks the caregiver to rate how much of a problem certain key behaviors or expressions of emotion are for the individual (e.g., “has explosive outbursts,” “cries or stays angry for 5 min or longer,” and “has trouble calming him/herself down”). The following scale is used—not at all = 0, mild = 1, moderate = 2, severe = 3, very severe = 4—to produce raw scores that are converted to t-scores using validated conversion tables, where scores >1 standard deviation above the general population norms are considered clinically elevated emotion dysregulation. Subgroup analysis was performed comparing patients with positive (clinically elevated) emotional dysregulation scores (indicating higher than average emotional distress) with those with negative scores. Descriptive statistics were calculated within REDCap, and the Mann–Whitney *U* test for statistical significance in nonparametric data was used to compare subgroups.

Results

Parent/caregiver survey results

In total, 805 unique recruitment emails were sent, 210 parents/caregivers were confirmed to have received the link (i.e., clicked on the link, responded to email, or answered phone call), and 83 provided complete responses. Mean patient age was 12 years (range: 4–25, 9 patients were >18 years of age), and 77% were male and 23% female (assigned at birth). The patient sample was 77% White, 18% Hispanic/Latinx, 11% Black, 6% Asian or Pacific Islander, <1% Native American/American Indian, and <1% other (multiple answers allowed). Using the EDI, respondents reported clinically elevated reactivity and dysphoria scores for their children in 35% and 40% of cases, respectively. Comorbid conditions included anxiety disorder (42%), gastrointestinal problems (39%), attention disorder (36%), disrupted sleep or sleep disorder (30%), and issues with eating (22%). Additional details on the patient sample

are provided in Table 1. Ninety-eight percent of the respondents were parents and 2% were grandparents, with all of them being the healthcare decision-maker for the patient.

Patients had regular annual visits with an orthopaedic provider in 43% of cases, with 23% of patients visiting orthopaedics two or more times per year; 34% of patients had no regular or recurring visits to an orthopaedic provider. Patients saw a physical, occupational, or behavioral therapist on a weekly basis in 63% of cases, with 22% having no regular therapy visits and 16% having therapy visits on a monthly or yearly basis. Patients commonly visited orthopaedics for follow-up visits (73%), new patient appointments (34%), and for a surgery or procedure

Table 1.

Autistic patients from parent/caregiver survey, n = 83.

Characteristic	N (%)
Age (years, range)	11.78 (4–25)
Sex assigned at birth (n = 82)	
Male	63 (76.8%)
Female	19 (23.2%)
Race/ethnicity*	
White	64 (77.1%)
Hispanic or Latinx	15 (18.1%)
Black	9 (10.8%)
Asian or Pacific Islander	5 (6.0%)
Highest level of education	
No formal education/schooling completed	20 (24.1%)
Elementary school (grades 1–5)	26 (31.3%)
Middle school (grades 6–8)	17 (20.5%)
High school (grades 9–12)	17 (20.5%)
Some college with no degree	1 (1.2%)
Associate's degree	1 (1.2%)
Trade/technical/vocational training	1 (1.2%)
Health insurance*	
Private insurance from employer	55 (66.3%)
State health plan/Medicaid	51 (61.4%)
Private insurance from an exchange (such as healthcare.gov)	6 (7.2%)
Civilian Health and Medical Program from Veterans Affairs (CHAMPVA)	1 (1.2%)
Children's Health Insurance Program	1 (1.2%)
Unsure	1 (1.2%)
Other	6 (7.2%)
Comorbid conditions*	
Anxiety or generalized anxiety disorder	35 (42.2%)
Gastrointestinal problems	32 (38.6%)
Attention-deficit hyperactive disorder or attention deficit disorder	30 (36.1%)
Disrupted sleep or sleep disorder	25 (30.1%)
Feeding problems or issues with eating	18 (21.7%)
Epilepsy	15 (18.1%)
Depression or depressive disorder	11 (13.3%)
Cerebral palsy	7 (8.4%)
Obsessive compulsive disorder	6 (7.2%)
Down syndrome (Trisomy 21)	3 (3.6%)
Bipolar disorder	1 (1.2%)
Schizophrenia	0 (0%)

* =multiple responses allowed.

(28%). The most common indications were pain in their limbs and/or joints (35%), muscle weakness (34%), difficulty walking or limping (28%), and injuries from sports or accidents (24%).

Factors affecting autistic patient experience

Parents/caregivers generally reported that their child was not anxious prior to the visit (58% calm; 17% mostly calm; 11% neutral, 8% quite a bit anxious, 6% very anxious), becoming slightly more anxious during the visit (31% calm; 30% mostly calm; 18% neutral, 13% quite a bit anxious, 7% very anxious). Parents/caregivers reported that the patient had trouble with their emotions during the visit in 43% of cases. In addition, 46% reported that it was moderately or very difficult for the patient to communicate with members of the team.

As for specific aspects of the visit that may have caused anxiety or worry, the most impactful situations included blood draws (49% of patients beyond neutral anxiety level), loud/unfamiliar noises (42%), getting imaging (38%), casting (35%), cast removal with a cast saw (34%), brace fitting (33%), and wearing clinic/hospital gown or shorts (29%). Several of these experiences were common occurrences among patients: loud/unfamiliar noises (61 of 75 respondents who answered this question experienced this situation, 81%), imaging (59/77, 77%), wearing a clinic/hospital gown or shorts (54/78, 69%), brace fitting (46/75, 61%), and blood draws (42/76, 55%). Fig. 1 shows average anxiety level for selected clinical situations, and Fig. 2 shows the percent of patients who reported at greater than neutral anxiety level by clinical visit situation.

In the subgroup analysis using EDI scores, there was no significant difference in anxiety levels between those with a positive emotional dysregulation score on the EDI and those with a negative score across the clinical scenarios. Anxiety levels were significantly higher for patients who did not have regular visits to orthopaedic providers during the following clinical scenarios (scale from 0 to 4, with 0 being “calm, not anxious” and 4 being “very, very anxious”): waiting in the exam room (median: 2.5 vs 1, $P = .029$), wearing a brace/orthotic (3 vs 1, $P = .010$), unusual/unexpected smells (2 vs 1, $P = .029$), bright rooms (2 vs 1, $P = .025$), and rooms that were too cold or too warm (2 vs 1, $P = .005$).

Parent/caregiver free responses

Parents/caregivers commonly noted that purposeful eye contact with the patient themselves, explanations in advance of any transitions or movements, providers watching for known cues of discomfort, and use of iPads or other technology were all helpful for improving patient comfort. Many parents/caregivers made mention of bringing their own toys or tablets to help reduce anxiety.

Parents/caregivers noted several communication and environmental challenges. Instances where the provider seemed rushed, providers speaking only to parents, and staff seeming untrained in working with autistic patients led to poorer experiences. Additionally, failing to adequately prepare patients for different parts of their visit (e.g., exams, casting, imaging) contributed to higher anxiety levels. Regarding the clinic environment, unpredictable wait times, busy waiting rooms, and anxiety regarding the physical exam heightened the strain on autistic patients.

Orthopaedic provider survey results

In total, 61 orthopaedic surgeons responded. Most respondents had been in practice for 15+ years (59%), worked in an academic hospital (82%), and cared for pediatric patients only (90%). The most common subspecialties included trauma (61%), lower extremity/foot and ankle (51%), general/no subspecialty (41%), spine (38%), and neurologic conditions (36%). One-third of respondents indicated they specialized in caring for patients with ASD. Additional demographic information for the providers is summarized in Table 2.

On average, respondents estimated that 11% of their monthly patient panel has ASD. The majority of providers reported being aware of an ASD

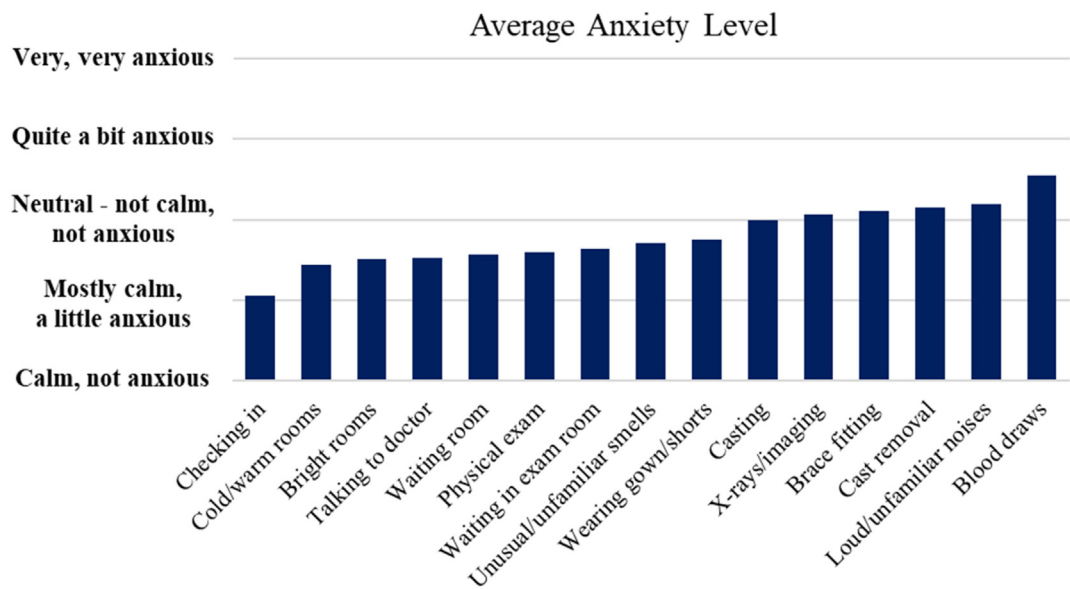


Figure 1. Average anxiety level by clinical visit situation, reported by caregivers.

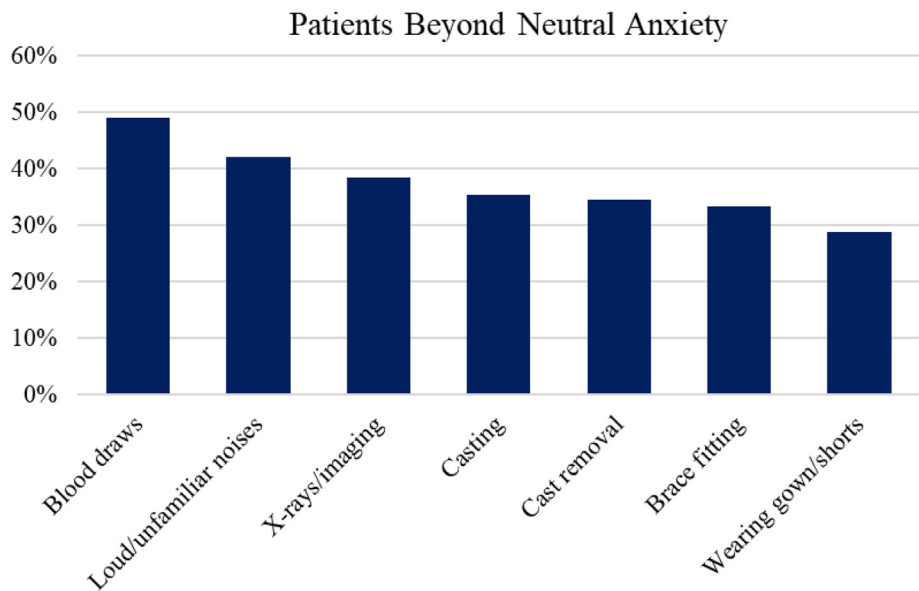


Figure 2. Percentage of patients reported at greater than neutral anxiety level by clinical visit situation, reported by caregivers.

diagnosis in their patients some (48%) or most (40%) of the time; 71% reported the electronic medical record does not notify them a patient has ASD.

Perspectives on visits with autistic patients

Situations that providers perceived to make autistic patients feel more anxious than nonautistic patients included cast removal (80% of respondents), loud/unexpected sounds (77%), imaging (70%), the physical exam (62%), and cast application (58%) (Fig. 3). The most common accommodations in place were assistance of child life specialists (53%), ear plugs/headphones (51%), games/toys (49%), tablets/smartphones (33%), and sensory devices (25%); 18% reported no accommodations. Most providers changed their approach to visits with autistic patients, including discussions with parent/caregiver about patient's preferences (66%), more time in the clinic room (54%), discussions with patients about preferences (46%), and a more focused physical exam (34%).

Providers reported that both autistic and nonautistic patients struggle with their emotions/behaviors in at least some visits, but only autistic patients were reported to struggle in most visits (24% of providers). Specifically, providers reported that anxiety (85% of respondents), fear (67%), impulsiveness (60%), uncertainty (42%), and nonverbal communication (38%) have been the most challenging for autistic patients to manage during visits. Strategies for managing autistic patients with behavior/emotional control challenges included behavioral-based strategies (55%), parent training/education (43%), technology (35%), pictures/visual aids (31%), and sensory processing integration (22%).

Provider free responses

Providers stressed the heterogeneity of their patients with ASD and that there is no single approach or adjustment that works for everyone. Involving parents/caregivers or child life specialists in aspects of the

Table 2.

Orthopaedic surgeons from provider survey, n = 61.

Characteristic	N (%)
Gender	
Male	42 (68.9%)
Female	19 (31.1%)
Race/ethnicity* (n = 59)	
White	50 (84.7%)
Hispanic or Latinx	3 (5.1%)
Black	1 (1.7%)
Asian or Pacific Islander	5 (8.5%)
Other	1 (1.7%)
Prefer not to answer	2 (3.4%)
Years of practice (postresidency)	
<5 years	6 (9.8%)
5–10 years	11 (18.0%)
10–15 years	8 (13.1%)
15+ years	36 (59.0%)
Patient population (n = 60)	
Pediatrics only	54 (90.0%)
Adult only	0 (0%)
Pediatrics and adults	6 (10.0%)
Specialize in the care of autistic patients	
Yes	20 (32.8%)
No	41 (67.2%)
Subspecialty*	
Trauma	37 (60.7%)
Lower extremity/foot and ankle	31 (50.8%)
General/no subspecialty	25 (41.0%)
Spine	23 (37.7%)
Neurologic conditions	22 (36.1%)
Sports medicine	10 (16.4%)
Upper extremity	7 (11.5%)
Joint/arthritis	3 (4.9%)
Oncology/cancer	2 (3.3%)
Other	5 (8.2%)
Practice setting*	
Academic hospital	50 (82.0%)
Community hospital	10 (16.4%)
Multispecialty group practice	5 (8.2%)
Urban solo practice	1 (1.6%)
Other	1 (1.6%)

* =multiple responses allowed.

visit that may be more uncomfortable (i.e., physical exam, casting/bracing) can be helpful. Many providers stressed the need for changing their typical approach to visits to accommodate patient preferences once known and providing different levels of patient-specific friendly gestures. The most commonly cited part of the visit autistic patients enjoyed the most was when it was time to leave the clinic. Patients most disliked situations that made them feel anxious and providers also noted that discussions about needing surgery were difficult for patients.

Discussion

This survey of parents/caregivers and orthopaedic providers of autistic patients showed that many clinical situations more common in orthopaedics may induce anxiety in autistic patients—casting and bracing, imaging, and the orthopaedic physical exam. Other situations not unique to orthopaedics, including blood draws and busy waiting rooms, were also disruptive to autistic patients. Providers often make accommodations for autistic patients' preferences, though responses for how to do so were variable.

According to parents/caregivers, clinical scenarios with high sensory demands led to the most severe anxiety in autistic patients in the quantitative portion of the survey, whereas communication difficulties bore high importance in the free responses. To accommodate autistic patients, orthopaedic practices can prioritize interventions targeting the sensory demands of cast removal with cast saws, brace fitting, radiologic imaging, and donning gowns/shorts for the exam. Patients without regular orthopaedic visits were more anxious in the clinic than those who have regular visits with regard to waiting in exam rooms, amount of light, specific smells, and room temperature. This finding underscores the importance of preparing new patients for their clinical encounter with descriptive/instructional materials and setting expectations for the visit. Nearly half of patients reported having difficulty communicating with their care team, making efforts to improve communication and situational awareness with autistic patients an important goal for orthopaedic practices.

Similar to parents/caregivers, orthopaedic providers reported cast removal, loud/unexpected noises, imaging, and the physical exam made autistic patients feel anxious. Notably, accommodations for autistic patients were varied and not always available clinic wide. More advanced accommodations, such as having behavioral-based interventions or child life specialists, may be difficult for all clinics to implement. However, clinics should be equipped with a basic set of accommodations for autistic patients. Reasonable low-cost options include investments in parent training/education, pictures/visual aids, and technology for patient use. With time to leave being the favorite part of the visit for autistic patients, orthopaedic clinics should strive to have prompt rooming and clear expectations for what the steps of the visit will entail. While it may not be feasible to fully accommodate each patient's individual needs, awareness of pain points noted in our study can help inform a clinic-wide plan that can benefit many autistic patients.

Orthopaedic practices can utilize existing interventions from other specialties to improve experience. For blood draws, orthopaedics clinics could use social stories or other descriptive/instructional materials about blood draws, written schedules and instructions, and distraction methods [35–37]. Separate, soothing sensory spaces, improving wait-time estimates, and visual schedules for autistic patients can assist with busy/loud waiting rooms [1,37]. Interventions to reduce patient anxiety in orthopaedics for allcomers could also help in autistic patients. The use of virtual reality and other visual technologies has been effective in reducing anxiety in pediatric procedural settings, including cast room procedures [38,39]. Instructional videos, social stories, and calming audio therapies have also shown improved patient satisfaction with casting [40]. Similar strategies can be extended to the physical exam and while getting imaging. However, these interventions have not been studied in autistic patients, so feasibility studies to assess how autistic patients may tolerate such strategies should be pursued.

This study has limitations. Since we surveyed the parents/caregivers and providers of autistic patients, we were not able to receive direct feedback from patients themselves. Although this is common practice in pediatric populations, we recognize the importance of including the voices of autistic patients themselves, which should be a focus of future projects. The overall parent/caregiver survey response rate was 10%, which limits our study's representation of the entire patient sample—this possibly reflects limitations in using email-first contact methods and accurate email documentation in medical records. Response rate of those

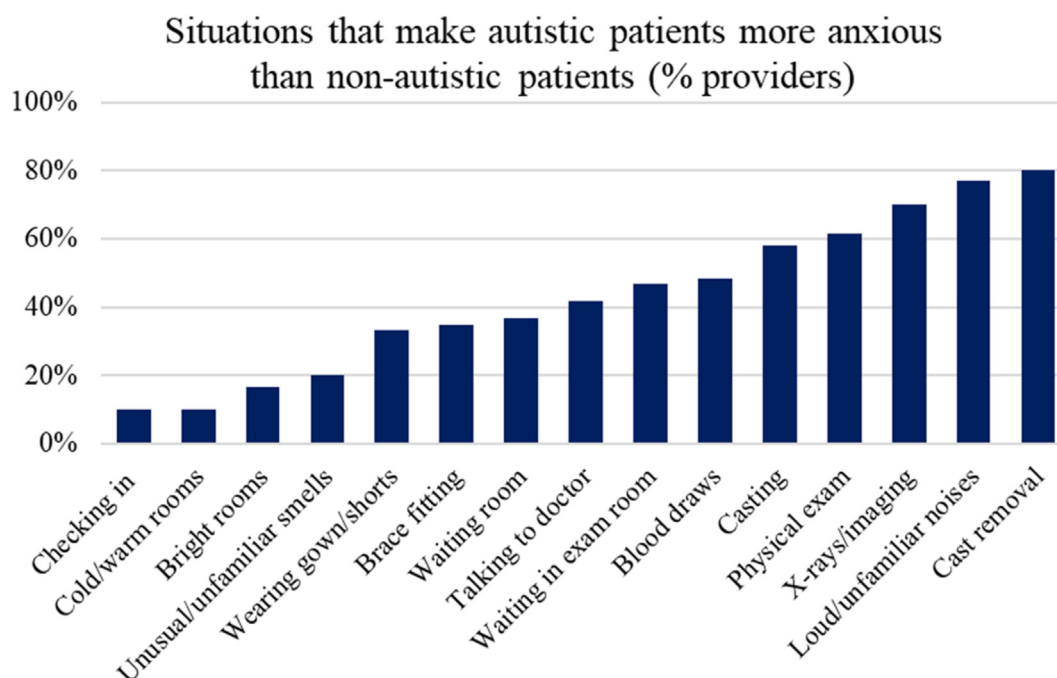


Figure 3. Situations that make autistic patients feel more anxious than nonautistic patients, by percent of providers who agreed.

confirmed to have received the survey was 40%. Our parent/caregiver participant sample was recruited from a single institution, which may limit the generalizability of our results to other institutions where fewer or greater resources may be available. We did not survey a control group of nonautistic patients for comparison as our objective was to perform a scoping analysis of how autistic patients experience orthopaedic care to both bring attention to this issue and identify preliminary areas for improvement. Finally, since our surveys required respondents to answer based on past experiences, our study may be limited by recall bias.

Through surveys of autistic patients' parents/caregivers and orthopaedic providers, this study identified the aspects of orthopaedic care that are perceived to be the most impactful for autistic patients. Orthopaedic practices looking to improve autistic patient experience can prioritize interventions that lower the sensory demands in clinic. While orthopaedists are broadly cognizant of the challenges autistic patients face during visits, improved awareness and accommodations are necessary. Future studies should include focus groups of autistic patients and their caregivers to further explore challenges with orthopaedic visits and potential solutions.

Additional links

- CDC: [Data and Statistics on Autism Spectrum Disorder](#)
- CDC: [Information on Autism Spectrum Disorder for Healthcare Providers](#)
- [Association for Autism and Neurodiversity](#)
- [Autistic Society](#)
- British Journal of Hospital Medicine: [Autistic SPACE: a novel framework for meeting the needs of autistic people in healthcare settings](#)

Consent for publication

The author(s) declare that no patient consent was necessary as no images or identifying information is included in the article.

Ethics approval and consent

This study was approved by the Boston Children's Hospital Institutional Review Board (IRB-P00043534).

Author contributions

Steven D. Criss: Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Maya Fajardo:** Writing – review & editing, Writing – original draft, Project administration, Methodology, Investigation, Formal analysis, Data curation. **Sang Won Lee:** Writing – review & editing, Writing – original draft, Validation, Project administration, Methodology, Investigation, Formal analysis, Data curation. **Mary Dubon:** Writing – review & editing, Validation, Supervision, Resources, Methodology, Investigation. **Collin J. May:** Writing – review & editing, Writing – original draft, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Formal analysis, Conceptualization.

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Declarations of competing interests

The authors declare no conflicts of interest related to this study.

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References

- [1] Straus J, Coburn S, Maskell S, Pappagianopoulos J, Cantrell K. Medical encounters for youth with autism spectrum disorder: a comprehensive review of environmental considerations and interventions. *Clin Med Insights Pediatr* 2019;13: 1179556519842816. <https://doi.org/10.1177/1179556519842816>.
- [2] Hall T, Kriz D, Duvall S, Nguyen-Driver M, Duffield T. Healthcare transition challenges faced by young adults with autism spectrum disorder. *Clin Pharmacol Ther* 2015;98(6):573–5. <https://doi.org/10.1002/cpt.254>.
- [3] Enner S, Ahmad S, Morse AM, Kothare SV. Autism: considerations for transitions of care into adulthood. *Curr Opin Pediatr* 2020;32(3):446–52. <https://doi.org/10.1097/MOP.0000000000000882>.

- [4] Taghizadeh N, Heard G, Davidson A, Williams K, Story D. The experiences of children with autism spectrum disorder, their caregivers and health care providers during day procedure: a mixed methods study. *Paediatr Anaesth* 2019;29(9): 927–37. <https://doi.org/10.1111/pan.13689>.
- [5] Nicolaidis C, Raymaker DM, Ashkenazy E, McDonald KE, Dern S, Baggs AE, et al. Respect the way I need to communicate with you”: healthcare experiences of adults on the autism spectrum. *Autism Int J Res Pract* 2015;19(7):824–31. <https://doi.org/10.1177/1362361315576221>.
- [6] American Psychiatric Association. In: *Diagnostic and Statistical Manual of Mental Disorders: DSM-5-TR*. Fifth edition, text revision. American Psychiatric Association Publishing; 2022.
- [7] Clinical testing and diagnosis for autism spectrum disorder. US Centers for Disease Control and Prevention (CDC); 2024. <https://www.cdc.gov/autism/hcp/diagnosis/index.html>.
- [8] Terminology guidance. <https://journals.sagepub.com/pb-assets/cmscontent/AUT/Autism-terminology-guidance-2021-1626860796.pdf>; 2022.
- [9] Vivanti G. Ask the editor: what is the most appropriate way to talk about individuals with a diagnosis of autism? *J Autism Dev Disord* 2020;50(2):691–3. <https://doi.org/10.1007/s10803-019-04280-x>.
- [10] Botha M, Hanlon J, Williams GL. Does Language matter? Identity-first versus person-first language use in autism research: a response to vivanti. *J Autism Dev Disord* 2023;53(2):870–8. <https://doi.org/10.1007/s10803-020-04858-w>.
- [11] Kenny L, Hattersley C, Molins B, Buckley C, Povey C, Pellicano E. Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism Int J Res Pract* 2016;20(4):442–62. <https://doi.org/10.1177/1362361315588200>.
- [12] Lei J, Jones L, Brosnan M. Exploring an e-learning community's response to the language and terminology use in autism from two massive open online courses on autism education and technology use. *Autism* 2021;25(5):1349–67. <https://doi.org/10.1177/1362361320987963>.
- [13] Zajic MC, Gudknecht J. Person- and identity-first language in autism research: a systematic analysis of abstracts from 11 autism journals. *Autism* 2024;28(10): 2445–61. <https://doi.org/10.1177/13623613241241202>.
- [14] Taboas A, Doepke K, Zimmerman C. Preferences for identity-first versus person-first language in a US sample of autism stakeholders. *Autism Int J Res Pract* 2023;27(2): 565–70. <https://doi.org/10.1177/13623613221130845>.
- [15] Lai MC, Lombardo MV, Baron-Cohen S. Autism. *Lancet Lond Engl* 2014;383(9920): 896–910. [https://doi.org/10.1016/S0140-6736\(13\)61539-1](https://doi.org/10.1016/S0140-6736(13)61539-1).
- [16] Boucher J. Research review: structural language in autistic spectrum disorder - characteristics and causes. *J Child Psychol Psychiatry* 2012;53(3):219–33. <https://doi.org/10.1111/j.1469-7610.2011.02508.x>.
- [17] Fournier KA, Hass CJ, Naik SK, Lodha N, Cauraugh JH. Motor coordination in autism spectrum disorders: a synthesis and meta-analysis. *J Autism Dev Disord* 2010;40(10):1227–40. <https://doi.org/10.1007/s10803-010-0981-3>.
- [18] Maski KP, Jeste SS, Spence SJ. Common neurological co-morbidities in autism spectrum disorders. *Curr Opin Pediatr* 2011;23(6):609–15. <https://doi.org/10.1097/MOP.0b013e32834c9282>.
- [19] Simonoff E, Pickles A, Charman T, Chandler S, Loucas T, Baird G. Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. *J Am Acad Child Adolesc Psychiatry* 2008;47(8):921–9. <https://doi.org/10.1097/CHI.0b013e328179964f>.
- [20] Hofvander B, Delorme R, Chaste P, Nydén A, Wentz E, Ståhlberg O, et al. Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC Psychiatr* 2009;9(1):35. <https://doi.org/10.1186/1471-244X-9-35>.
- [21] Hofvander B, Delorme R, Chaste P, Nydén A, Wentz E, Ståhlberg O, et al. Clinical practice pathways for evaluation and medication choice for attention-deficit/hyperactivity disorder symptoms in autism spectrum disorders. *Pediatrics* 2012; 130(Suppl 2):S125–38. <https://doi.org/10.1542/peds.2012-0900J>.
- [22] Lee BH, Smith T, Paciorkowski AR. Autism spectrum disorder and epilepsy: disorders with a shared biology. *Epilepsy Behav* 2015;47:191–201. <https://doi.org/10.1016/j.yebeh.2015.03.017>.
- [23] Buie T, Campbell DB, Fuchs GJ, Furuta GT, Levy J, VandeWater J, et al. Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report. *Pediatrics* 2010;125(Supplement_1):S1–18. <https://doi.org/10.1542/peds.2009-1878C>.
- [24] Adamiak T, Plati KF. Pediatric esophageal disorders: diagnosis and treatment of reflux and eosinophilic esophagitis. *Pediatr Rev* 2018;39(8):392–402. <https://doi.org/10.1542/pir.2017-0266>.
- [25] Davignon MN, Qian Y, Massolo M, Croen LA. Psychiatric and medical conditions in transition-aged individuals with ASD. *Pediatrics* 2018;141(Supplement_4): S335–45. <https://doi.org/10.1542/peds.2016-4300K>.
- [26] Katzman DK, Guimond T, Spettigue W, Agostino H, Couturier J, Norris ML. Classification of children and adolescents with avoidant/restrictive food intake disorder. *Pediatrics* 2022;150(3):e2022057494. <https://doi.org/10.1542/peds.2022-057494>.
- [27] Criss SD, Kakulamari S, Xu RF, Fajardo M, Keeney T, Tolchin DW, et al. The healthcare experience of autistic patients in orthopaedic surgery and closely related fields: a scoping review. *Children* 2023;10(5):906. <https://doi.org/10.3390/children10050906>.
- [28] Deon Kidd V, De Claro AMO. Preparing for autistic patients in orthopaedic surgery: tips for a successful health-care interaction. *J Bone Jt Surg* 2018;100(20):e132. <https://doi.org/10.2106/JBJS.18.00252>.
- [29] Maloy GC, Kaszuba SV, Stoeckel M, Mariotti EC, Frumberg DB. A practical guide for improving orthopaedic care in children with autism spectrum disorder: current concept review. *J Pediatr Orthop Soc N Am* 2023;5(1). <https://doi.org/10.55275/JPOSNA-2023-640>.
- [30] Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inf* 2009;42(2): 377–81. <https://doi.org/10.1016/j.jbi.2008.08.010>.
- [31] Harris PA, Taylor R, Minor BL, Harris PA, Taylor R, Minor BL, Elliott V, Fernandez M, O'Neal L, et al. The REDCap consortium: building an international community of software platform partners. *J Biomed Inf* 2019;95:103208. <https://doi.org/10.1016/j.jbi.2019.103208>.
- [32] For The Autism and Developmental Disabilities Inpatient Research Collaborative (ADDIRC), Mazefsky CA, Day TN. Development of the emotion dysregulation inventory: a PROMIS®ing method for creating sensitive and unbiased questionnaires for autism spectrum disorder. *J Autism Dev Disord* 2018;48(11): 3736–46. <https://doi.org/10.1007/s10803-016-2907-1>. et al.
- [33] Mazefsky CA, Yu L, White SW, Siegel M, Pilkonis PA. The emotion dysregulation inventory: psychometric properties and item response theory calibration in an autism spectrum disorder sample: emotion dysregulation inventory. *Autism Res* 2018;11(6):928–41. <https://doi.org/10.1002/aur.1947>.
- [34] Mazefsky CA, Yu L, Pilkonis PA. Psychometric properties of the emotion dysregulation inventory in a nationally representative sample of youth. *J Clin Child Adolesc Psychol* 2021;50(5):596–608. <https://doi.org/10.1080/15374416.2019.1703710>.
- [35] Parent's guide to blood draws for children with autism. <https://www.autismspeak.org/tool-kit/atnair-p-parents-guide-blood-draws>. [Accessed 9 July 2023].
- [36] Davit CJ, Hundley RJ, Bacic JD, Hanson EM. A pilot study to improve venipuncture compliance in children and adolescents with autism spectrum disorders. *J Dev Behav Pediatr* 2011;32(7):521–5. <https://doi.org/10.1097/DBP.0b013e3282245b09>.
- [37] Health Care for Adults with Intellectual and Developmental Disabilities. Developmental Disabilities Primary Care Program. Communicate CARE May 2023: 1–4. <https://iddtoolkit.vksites.org/>.
- [38] Richey AE, Khoury M, Segovia NA, Hastings KG, Caruso TJ, Frick S, et al. Use of bedside entertainment and relaxation theater (BERT) to reduce fear and anxiety associated with outpatient procedures in pediatric orthopaedics. *J Pediatr Orthop* 2022;42(1):30–4. <https://doi.org/10.1097/BPO.0000000000002005>.
- [39] Richey AE, Khoury M, Segovia NA, Hastings KG, Caruso TJ, Frick S, et al. Virtual reality reduces fear and anxiety during pediatric orthopaedic cast room procedures: a randomized controlled trial. *J Pediatr Orthop* 2022. <https://doi.org/10.1097/BPO.0000000000002250>. Published online August 30.
- [40] Burkhart RJ, Hecht CJ, McNassor R, Mistovich RJ. Interventions to reduce pediatric anxiety during orthopaedic cast room procedures: a systematic and critical analysis review. *JBJS Rev* 2023;11(2). <https://doi.org/10.2106/JBJS.RVW.22.00181>.