Through the Eyes of Autism: Eye Care for these Special Patients

Participants:


Purpose / Relevance

“Autism Spectrum Disorder” (ASD) is a lifetime neurodevelopmental disability that is usually first recognized in early childhood. Autism is characterized by impairments in social interaction and communication, and a restricted range of behaviors and/or interests.

Prevalence has increased from approximately 1 in 10,000 in the 1990s to 1 in 100 by 2010. Increase likely due both to increased recognition, and real increase in ASD. ASD is frequently co-morbid with strabismus, amblyopia, infantile cataract, and glaucoma.

Pediatric ophthalmologists are inevitably encountering more and more patients with ASD. The ability to work effectively with children with ASD and detect subtle signs of undiagnosed ASD is critical to providing ophthalmic care to these children.

I. What is Autism?

A. Operational Definitions

**Autism** - developmental disorder that appears in the first 3 years of life, and affects development of social and communication skills.

**Asperger syndrome** - a high functioning autism. Characterized by difficulty interacting socially, repetitive behaviors, and often clumsiness.

B. New proposed changes to Autism Spectrum Disorder Classifications (DSM V)

Must meet criteria C, D, E, and F:

C. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:

1. Deficits in social-emotional reciprocity; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction,

2. Deficits in nonverbal communicative behaviors used for social interaction; ranging from poorly integrated- verbal and nonverbal communication, through
abnormalities in eye contact and body-language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures.

3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people

D. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:

1. Stereotyped or repetitive speech, motor movements, or use of objects; (such as simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases).
2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change; (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes).
3. Highly restricted, fixated interests that are abnormal in intensity or focus; (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
4. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment; (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects).

E. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)

F. Symptoms together limit and impair everyday functioning.

II. Some Autistic Behaviors

1. Anxiety with changes in environment, and in social situations
2. Intense interest in an unusual subject
3. Compulsions
4. Scripting – repetition of words or phrases.
5. Rocking
6. Hand flapping
7. Toe walking
8. Echolalia – repetition of what has just been said by another
<table>
<thead>
<tr>
<th>Autism Spectrum Disorder Severity Level</th>
<th>Social Communication</th>
<th>Restricted Interests &amp; Repetitive Behaviors (RRBs)</th>
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<tbody>
<tr>
<td>Level 3</td>
<td>Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning; very limited initiation of social interactions and minimal response to social overtures from others.</td>
<td>Preoccupations, fixated rituals and/or repetitive behaviors markedly interfere with functioning in all spheres. Marked distress when rituals or routines are interrupted; very difficult to redirect from fixated interest or returns to it quickly.</td>
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<td>Level 2</td>
<td>Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions and reduced or abnormal response to social overtures from others.</td>
<td>RRBs and/or preoccupations or fixated interests appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress or frustration is apparent when RRB’s are interrupted; difficult to redirect from fixated interest.</td>
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<td>Level 1</td>
<td>Without supports in place, deficits in social communication cause noticeable impairments. Has difficulty initiating social interactions and demonstrates atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions.</td>
<td>Rituals and repetitive behaviors (RRB’s) cause significant interference with functioning in one or more contexts. Resists attempts by others to interrupt RRB’s or to be redirected from fixated interest.</td>
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III. Prevalence of Autism

A. 1:110 children
B. 1:70 boys

IV. Social Impact of Autism

A. Autistic patients
B. Families of autistic patients
C. Schools
D. Society

V. Co-morbidities of Autism

A. Anxiety. Prevalence of anxiety disorder in ASD 11 - 84%.
B. Bipolar disorder
C. Bowel disease. Up to fifty percent have persistent GI problems. Constipation, often with overflow, or encopresis.
D. Depression and other psychopathological disorders
E. Fragile X syndrome
F. ADHD
G. Mental retardation. 25% to 70%, a wide variation illustrating the difficulty of assessing autistic intelligence. By definition, diagnosis of Asperger's excludes retardation.
H. Nonverbal learning disorder
I. Motor clumsiness and stereotypic behaviors. Poorly coordinated, or have an odd or bouncy gait or posture, toe walking, poor handwriting, problems with visual-motor integration, visual-perceptual skills, and conceptual learning, apraxia (motor planning disorder), poor balance, tandem gait, and finger-thumb apposition.
J. Obsessive-compulsive disorder (OCD). Characterized by recurrent obsessional thoughts or compulsive acts, repetitive stereotyped.
K. Tourette syndrome – in 6.5% with autism, higher than the 2% to 3% prevalence in general population.
L. Seizures. 25% develop seizures, often starting in early childhood or adolescence.

M. Tuberous sclerosis (TS) - in 1–4% of ASD. 25 - 61% of patients with TS have ASD.

VI. Strategies for Dealing with the Autistic Patient in the Ophthalmology Office

A. Recognize autism early in the encounter
   1. Ask about developmental disorders in history
   2. Alternatively, ask about regional center involvement as indirect query.

B. Immediately adapt to recognition of the condition.
   1. Reassure the parents that you are familiar with ASD.
   2. Be calm and predictable.
   3. Be patient.
   4. These approaches also work for mental retardation, multi-handicapped cerebral palsy, or visual loss (cerebral visual impairment, optic nerve hypoplasia, etc.).

C. Gradual examination progress, during one visit, and from one visit to the next.

D. Avoid direct eye contact, at least initially
   1. Arm’s length retinoscopy.
   2. Avoid phoropter and slit lamp.
   3. Eyedrops: after anesthetic, last part of examination, and administrated by someone else.

E. Avoid crowds in the exam and waiting rooms.

E. Behavior modification.

F. Distinguish ASD from other causes of visual loss
   1. Aversion to eye contact in ASD may be mistaken for visual loss.
   2. Cerebral or retinal visual loss may be confused with ASD.
   3. Be specific about the clinical evidence for visual loss

F. Parental behavior
VII. Treating the Whole Family

A. Empathy for the family.
B. Remember: specific diagnosis makes the patient and family eligible for services.
C. Refer to schools and Regional Center evaluation.
D. Discourage quackery. There is an immense amount of it out there.

VIII. Scenarios for Panel Discussion

A. “Difficult” first child, age 3 years, with strabismus.
B. Precocious 6 year old with amblyopia but also with behavior problems and tantrums
C. Strong, anxious 13 year old male with aphakic glaucoma.
D. Deaf 18 year old female with high myopia, retinopathy, and nystagmus.

Current Outcomes

Untrained intuition typically suggests counterproductive approaches to interactions with children with ASD that may reinforce anxiety and phobic reactions, diminish cooperation during examinations, and reduce compliance with therapies. Behavior modification techniques are highly effective but must be tailored to specific situations. No systematic training has heretofore been offered to pediatric ophthalmic ophthalmologists to enable them to work with ASD in clinical situations.

Results: Describe what the attendees will be able to do better or improve upon at the end of this workshop

At the conclusion of this presentation, the attendees will be able to identify the impairments in ASD. Attendees will be aware of the resources available for diagnosis and intervention for children with ASD. They will more readily recognize subtle autistic behaviors and understand appropriate ways to conduct effective eye examinations of children with ASD, and how to discuss this disability with the parents of their patients.
References


American Psychiatric Association Proposed Revisions DSM V
http://www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=94#