Autism Spectrum Disorder Care Collaborative

Taking Care of the Autistic Inpatient Adult: What Every Clinician Should Know

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Clinical Education Leads
What is the Autism Collaborative?

Multi disciplinary team developed to create resources for providers taking care of adult patients with Autism Spectrum Disorder/ (ASD)

- Clinical Units of Expertise
- Provider tool kits
- Patient/family navigator
Global Aims

• Create a patient centered care experience for patients with Autism Spectrum Disorder (ASD) admitted to MGH.

• Develop and disseminate best practices for caring for individuals with ASD with health care colleagues locally, nationally and internationally.
Why the Autism Collaborative?

• 1% of adults worldwide\(^1\) meet criteria for ASD
• Autism is the fastest growing developmental disorder with increasing adult populations
• Hospitalized ASD adults have worse outcomes compared to hospitalized patients without ASD
• Cognitive/communication challenges in ASD adults may be successfully optimized via best practices

\(^1\) [http://www.cdc.gov/ncbddd/autism/data.html](http://www.cdc.gov/ncbddd/autism/data.html)
Case Study

21 yr old non-verbal patient with autism spectrum disorder presented to ED with abdominal pain, nausea and vomiting:

Days 1-2:
- In ED found to have UTI, IV antibiotics initiated.
- In the ED hallway for 8 hours waiting for a bed
- Arrived to the floor agitated, pulled out IV twice
- Soft restraint was placed to preserve IV access for antibiotic
- Parent very upset at restraint and a near altercation erupted with the parent and the nursing staff
- Multiple nursing reassignments were made due the parent displeasure with nursing resulting in disorder and delayed care
Case Study

Days 2-6:
-Nurse with personal connection to autism was assigned and care improved. Vitals and monitoring were minimized.

-Medical team gave the parent 24 hour notice of pt readiness for discharge back to the group home on hospital day 6.

-On day of discharge, the group home director arrived and completed his own assessment. Group home director asked that all new prescriptions, follow-up appointments and discharge instructions be written out on the group home forms.

-The patient was left the floor at 3pm; approximately 5 hours after all discharge paperwork had been completed.

How could we have done this better?
What is ASD?

• Primarily a social communication disorder characterized by differences in information processing. Encompasses Asperger’s disorder, childhood disintegrative disorder, and pervasive disorder otherwise not specified²

• Main features
  • Persistent deficits in social communication and social interaction across multiple contexts
  • Restricted, repetitive patterns of behavior

What is ASD?

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Details</th>
<th>Clinical Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deficits in social communication and social interaction</td>
<td>Deficits in: social emotional reciprocity, nonverbal communication, developing relationships</td>
<td>• Difficulty in initiating or sustaining conversation, tendency to monologue</td>
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<tr>
<td></td>
<td></td>
<td>• Lack of eye contact, unusual tone of voice</td>
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<td></td>
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<td>• Challenges adapting to different environments with reliance on routines</td>
</tr>
<tr>
<td>Restricted or repetitive patterns of behavior, interests or activities</td>
<td>Stereotyped movements/speech, insistence on sameness, highly restricted fixated interests, hyper or hypo-reactivity to sensory input</td>
<td>• Repetitive movements</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Distress with change in routine</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Intense special interests</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Hypo or hyperactive response to environment</td>
</tr>
</tbody>
</table>

Adapted from Nicolaidis C, Kripke C and Raymaker D, Primary Care for Adults on the Autism Spectrum. Med Clin N Am 98 (2014) 1169-1191
Autism vs. Intellectual Disabilities

Autistic Patients:
- May have intact IQ
- Struggle with communication pragmatics (interpreting ambiguity or nuance, understanding context)
- Higher level of education
- Impacted by atypical sensory experiences
- Less likely to have support through disability services

1 Nicolaidis C, Kripke C and Raymaker D, Primary Care for Adults on the Autism Spectrum. Med Clin N Am 98 (2014) 1169-1191
ASD & Common Medical Conditions

- Depression, Anxiety, PTSD, and other mental illnesses are seen more commonly in patients with ASD\(^3\)
- 20-30% may have concurrent epilepsy
- 2-3 X higher incidence of death
- Increased prevalence of:
  - GI disorders
  - Feeding and nutritional disorders
  - Metabolic syndrome
  - Exposure to violence and abuse

## ASD & Common Medical Conditions

<table>
<thead>
<tr>
<th>System</th>
<th>Complaints</th>
</tr>
</thead>
<tbody>
<tr>
<td>General</td>
<td>Difficulty expressing and interpreting symptoms</td>
</tr>
<tr>
<td>GI</td>
<td>Constipation, food intolerance, GERD, dysphagia, esophgitis</td>
</tr>
<tr>
<td>Sleep Disturbance</td>
<td>May be exacerbated by medications</td>
</tr>
<tr>
<td>Feeding and Nutrition</td>
<td>Sensory sensitivity to flavors, textures or smells difficulty identifying hunger</td>
</tr>
</tbody>
</table>

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ASD Patient in the hospital

- Emotional outbursts
- Loss of communication abilities
- Increased somatic complaints

Stress of hospitalization and medical illness

Disruption to routine and sensory stimulation
- Emotional outbursts
- Refusal of tests
- Primary provider unavailable

Increased LOS
Missed dx
Inappropriate dx
Patient and family dissatisfaction

Poor medical outcomes

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## Optimizing Care of the Inpatient with ASD

<table>
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<tr>
<th>Step</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify diagnosis</td>
<td>Look for ASD icon*</td>
</tr>
<tr>
<td>Establish spectrum of presentation, communication needs and proxy providers</td>
<td>Autism Inpatient Questionnaire*, ASD clinical care algorithm*</td>
</tr>
<tr>
<td>Provide family with resources</td>
<td>What to expect guide*</td>
</tr>
<tr>
<td>Open communication plans with family/HCP</td>
<td>When and where is family available, Establish consistent time to discuss treatment plans</td>
</tr>
<tr>
<td>Anticipate necessary testing and eliminate unnecessary</td>
<td>Plan ahead and early</td>
</tr>
<tr>
<td>Provide resources matched to communication/behavioral needs</td>
<td>Communication tools, OT/PT consult if appropriate, Autism order set*</td>
</tr>
<tr>
<td>Minimize sensory environment</td>
<td>Single room if possible, minimize blood draws</td>
</tr>
<tr>
<td>Early discharge planning</td>
<td>Case management resource guide*</td>
</tr>
</tbody>
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* Resources developed by Autism Care Collaborative, can be found at XXXX
ASD Admission Process 101

- Establish in pass off if patient has ASD
- Ask for completion of autism questionnaire
- Confirm room assignment is compatible with pt needs

- Care team huddle to determine care needs
- Early establishment of treatment plan with family
- Consider cot for caretaker
- Inquire about dietary preferences
- Autism order sets: PT/OT, limited lab draws

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Case Study: Let’s Do Better

Patient triaged to low sensory ED room for assessment

MD/ RN encounters, with intake, exams, vitals, labs, diagnostics optimized per ACP/Guardian and clinician collaboration

Timely construction of clinical assessment, and transition to inpatient floor, discussion with patient/guardian and assignment to low sensory room/unit

ED to floor pass-off with discussion of clinical assessment as well as Autism Questionnaire (AQ) patient/guardian preferences

Use of low sensory environments

Minimized lab draws and testing

Timely transition out of ED
Case Study: Let’s Do Better

Preparation for arrival of patient to medical unit: low sensory single room, cot for family

Arrival of patient to unit with review of Autism Questionnaire (AQ) or completion of AQ on the unit.

Care team discussion with patient/guardian to create consensus around preferences listed in AQ and other logistics during stay

Patient/Care giver preferences guide pt-centered care
Autism Questionnaire use creates consensus
Case Study: Let’s Do Better

Patient/Guardian centered care delivery with nursing led check-ins for **early identification of unmet needs or new requests**

**Early discharge planning in coordination with patient/guardian and case management**
- PCP follow-up appt
- Clear post-discharge plan
- Group home discharge requires group home assessment

**Timely discharge after clear post-discharge plan communicated with patient and guardian**

**Frequent care team check-ins are critical**
**Early discharge planning to avoid delays and readmission**

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Safer Systems for ASD Patients

• Resources for common clinical scenarios
  – Autism for Adults Guide to Clinical Care on Sharepoint Site
  – Units of Expertise; RNs on Bigelow 9, Ell 19, PH20

• A way to partner with patients to optimize communication
  – Autism Care Profile on Sharepoint Site

• Case management resources
  – Case Management Resources on Sharepoint Site/CManager

• Resources for ASD patients/families
  – What to expect narrative on Sharepoint Site
  – What to expect pictorial on Disabilities Website
Autism Care Collaborative

Additional Resources:
MGH Disabilities website
Share point:
http://sharepoint.partners.org/mgh/autismcollaborative
MGH Lurie Center website

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