Getting an “A” in Inpatient Autism Care

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Disclosures

- We have no financial relationships to disclose.
Objectives

- “At the end of this plenary we want you to…”

1) Understand the Unique Challenges in providing High Quality Inpatient Care to Children with Autism Spectrum Disorder

2) Know the current Best Practices in Inpatient Care of Children with Autism Spectrum Disorder

3) Obtain strategies to leverage the Electronic Health Record in standardizing and improving Inpatient Care of Children with Autism Spectrum Disorder

4) Get a glimpse into the state of research and the future of Inpatient Autism Care.

Patient M

- 8 y.o. 10 m.o. male with a history of ASD, ADHD, anxiety/mood disorder (s/p 3 inpatient admissions; managed with clonidine, trazodone, amitriptyline), nocturnal, and severe chronic constipation, who presented with worsening constipation, progressive abdominal distension and irritability.

- Over the last few months prior to admission, his anxiety around stooling intensified and he was very violent towards his parents and younger sister. He would not go near a toilet or even talk about the bathroom. At the time of admission, he had not stooled in 20 days.
The Parent Perspective

- Video of Anne F. Parent of child w/ Autism

Disruptive Aspects of Hospitalization

Hospitalization is uniquely disruptive for persons with ASD which may result in increased stress, anxiety and inability to cope.

Illustration from Rebecca Burgess “Understanding the Spectrum”
http://theoraah.tumblr.com/post/142300214156/understanding-the-spectrum
Unfamiliar Hospital Physical Environment

Illustration from Rebecca Burgess “Understanding the Spectrum”
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Unfamiliar Hospital Social Environment

Illustration from Rebecca Burgess “Understanding the Spectrum”
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Unfamiliar Hospital Routine

- Meals
- Self care
- Wake/Sleep
- Medication
- Unstructured time

- Tests and procedures
- Inconsistent or unexpected people and events
  - Vital signs, examinations

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Hospital Procedures

- Vital signs taken regularly
- Lying on a stretcher
- Wearing hospital clothing
- IV and blood draw
- Wearing ID band

*Rebecca Burgess “Understanding the Spectrum” http://theoraah.tumblr.com/post/142300214156/understanding-the-spectrum*
Medical Co-Morbidity in ASD

Head: Headache, seizure, sleep
Eyes: Allergy, poor vision
Ears: Ear infections, foreign body, noise supersensitivity
Nose/sinuses: Allergies, sinus infections
Mouth/Throat: Cavities, abscess, strep infection, tonsillitis
GI: Reflux, ulcer, constipation, diarrhea, food allergy/intolerance
Abdominal: Appendicitis, hemia
Genitourinary: menstrual problems, kidney problems
Musculoskeletal: Fractures, reduced bone density
Cutaneous: Skin-picking (lesions/infection)
Impact Beyond Volume

- 2013 hospital self-assessment reflected the following concerns:
  - Patient and family experiences
  - Patient safety concerns
  - Inconsistent staff knowledge
  - Staff discomfort in providing care
  - Pediatric family-centered care versus adult care models
  - Hospital administrative systems challenges
    - Admissions, check-in, wait times
    - Communication challenges

Patient Experience of Hospitalization

- Video of patient describing hospitalization
“BEST PRACTICES”

Strategies are Possible for All Areas

- Individual with ASD
- Environment
- Procedures
Strategies for Optimizing Comfort

- Individual
  - Pro-actively learn about a person's needs and what may trigger anxiety and discomfort
  - Prepare the person for demands with the methods that work best for him or her
  - Supports: Closely involve the individuals who know the person best (family, caregivers, outpatient team)

- Environment
  - Physical environment: Modify the environment to minimize sensory overload
  - Social environment: Collaborate with staff to provide consistent interaction approach

- Procedures
  - Modifications: Determine what procedures can be modified to meet the person’s needs
  - Ease anxiety or discomfort by allowing the person to participate in procedures using the methods that work best for him or her

What Can Help

- Extra time when transitioning to a different activity/demand
- Wear personal clothing
- First-then visual schedule for the day
- Place the blood pressure cuff on nurse first
- Presence of a family member or caregiver
- No or dimmed fluorescent lights
- Private room/space
- Physical space and time
- Communicate with my iPad
- No more than 2-3 doctors or nurse in the room at once

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Autism Care Questionnaire

- Lists the non-medical needs of individuals with ASD within acute care settings
  - Methods of communication
  - Tolerance of hospital visit and examination
  - Unique sensory needs
  - Dietary needs and preferences
  - Safety concerns and preferred coping mechanisms
- Recommend ACQ is updated a minimum of every 2 years or as needed

Autism Care Questionnaire (ACQ)

- Developed to improve the experiences of individuals with ASD when receiving medical services
- Helps medical staff better interact with individuals with ASD in order to deliver quality medical care
## Autism Care Questionnaire

- **Flexibility**
  - Patient driven ➔ Completed by patients, families, or caregivers
  - Clinician driven ➔ Completed with patient and/or family upon admission or in outpatient office

- **Relevant Across Settings**
  - Outpatient offices
  - Procedural areas
  - Inpatient settings
  - Emergency department

## Behavior Support Plan (BSP)

- **Clinician Driven**
- Integrates multiple sources of data from multidisciplinary team, patient and family
  - ACQ, OT/SLP Evaluations, Plan for Hospital Course, Modifications to Hospital Environment and Routine
- Goal to provide access to most relevant information ‘at a glance’
Creation of Behavior Support Plan

- Brief
- Practical
- Highly Individualized
- Remain “live” as challenges arise
- Multidisciplinary

- Includes triggers, warning signs, strategies for calming, strategies for communicating geared toward caregivers

Patient Navigator for Autism

- Creation/hiring of Patient Navigator for Autism
  - Resource and advocate for individual patients
  - Development of staff ‘champions’ across departments
  - Electronic Medical Record
  - Staff education
  - Systems development
  - Help guide future initiatives
**Navigator Priorities**

- **Direct Clinical Care and Coordination**
  - Advocacy and support for parents
  - Support for nursing and other hospital staff

- **Education**
  - Needs of patients with ASD
  - Connection of outpatient and inpatient

- **Systems Development**
  - "Every patient with ASD is NOT really unique" for developing hospital systems
  - ASD patient care can be applied to other disabilities

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**Role of Inpatient Occupational Therapy**

- Assess a patient’s prior and current level of function
  - Cognition, sensory, functional communication, emotion regulation, physical abilities

- Determine how the changes in environment and context (i.e. disruption in daily routine) will affect a person with autism in the hospital setting

- Provide interventions to facilitate:
  - Participation in medical care (i.e. procedures, vitals)
  - Tolerance of environment (i.e. physical environment, social environment of staff)
  - Adjustment to changes (i.e. new routine, unexpected events)
When OT Can Help

- Difficulty with communication, expressing basic needs, pain
- Difficulty tolerating necessary nursing and medical care
  - Dressing changes
  - Tests
  - Self care/hygiene
- Difficulty managing hospital routines
- Difficulty tolerating hospital environment
  - Social and physical
- Most successful when **proactive**
  - Coping when weaning from sedation

![Diagram of OT resources and support for employees](image_url)
Outcomes from ACQ

- Parents who used the Autism Care Questionnaire reported a better hospital experienced and staff attention to their child’s ASD-specific needs (Broder-Fingert et al., 2016)

Family Feedback

“We were treated with respect.”

“The attending this morning said ‘I'm glad you came.’ So many times we've felt that they [other hospitals] didn't want us there - this was the first time someone ever said that to us - many people think that would be a little thing, but it's not so little.”

“The doctors spoke without being in a hurry to get out. They were receptive to hearing what I had to say. It was one of the few times I've ever had a chance to have an MD hear me and be open to what I had to say…”
Physician Feedback

“Our entire service would look so different to us and to our patients if we had people in your role for other conditions, as well.”

USING THE EHR
Autism Add-on Order Set for Pedi and Adult

Best Practice Advisory
Patient Care Coordination Note

Karen T., 08/16/20, 11:56 AM

By: Lauren Congrove, OT

Special needs: K. is a 7-year-old girl who was seen for a follow-up developmental behavioral pediatrics consultation in the Lane Center due to a history of obsessive-compulsive disorder (OCD) and social anxiety. He was seen previously for a consultation, and his behavior has improved since then. His mother states that he is able to attend school and to participate in social activities. He often has difficulty with anxiety and hyperactivity in the classroom, but he appears to be doing well overall. He has some difficulty with transitions and routine, and he may have some difficulty with social anxiety and social skills. He is currently on medication for anxiety and hyperactivity.

Strategies for Caring:

- Provide a quiet, relaxed environment.
- Offer him a favorite object or toy to hold.
- Encourage him to take deep breaths.
- Provide aToken chart to help him stay on task.
- Offer him a visual schedule to help him understand what is expected, and allow choices if appropriate.

Communication:

- Strategies: Briefly explains interventions prior to doing them to minimize anxiety. Requires increased time for processing of verbal information. May be helpful to use pictures. First, then words. Positive reinforcement. May benefit from picture board or daily schedule, will continue to follow.
- Language: English.

Sensory Needs:

- Movement: K. reports he likes movement. He also enjoys physical activity and playing video games, playing with stuffed animals, and taking rough-and-tumble play.
- Sensory sensitivities: He may benefit from wearing noise-canceling headphones.

Further recommendations (in collaboration with Karen T., Patient Navigator from Lane Center):

- Offer music therapy sessions.
- Offer art therapy sessions when available.
- Offer him a visual schedule to help him understand what is expected, and allow choices if appropriate.

Other:

- Medications:
  - K. is currently on medication for anxiety and hyperactivity. He may benefit from additional medication for attention-deficit/hyperactivity disorder (ADHD).

Tailoring strategies for K:

- Social story in a quiet environment.
- K. will benefit from being read a social story as a visual cue and a warning that he is expected to be in the classroom.
- Try to have a quiet, calm space when he is to go to the bathroom.
- Encourage him to take deep breaths after stressful events, after dinner.
- K. will benefit from being read about the need to sit on the toilet for a certain amount of time (this will require ongoing monitoring for how long). Initial start time 3 minutes.
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Mass General Hospital for Children
... including De-Escalation plan

DE-ESCALATION PLAN
If pt is in ROOM:
- Back away and give him space as soon as he begins to escalate
- Mom will give space/leave the room
- Security - call to be present on standby (out of view from pt but present if he continues to escalate)
- Minimize talking to pt until he begins to settle (communication abilities deteriorate). If you must talk, only 1 person should speak to pt
- Allow him to roll over if possible and bring his head against pillow
- Once begins to settle, try distraction with an activity vs. asking him questions
- PRN medication

If pt is in HALLWAY/PLAYROOM:
- Call security
- Encourage pt to return to his room to his "safe space"
- Only physically intervene if pt is affecting the safety of other patients (attempting to enter another patient's room) before security is present
- PRN medication

Activities for Calming/Setting:
- Safe space (bed being ordered for trial)
- Playing video games, playing with stuffed animal
- Coloring
- Mine craft on youtube

Deadpool:
It is OK for patient to talk 1:1 activity about Deadpool. Trying to redirect from Deadpool has triggered agitation. Mom has given OK.

ONGOING INITIATIVES AND AREAS OF INNOVATION
Current Initiatives

- Boston Children’s Hospital has a team of child life specialists, resource specialists, and an Autism specialist who provide ASD training for staff throughout the hospital.

- Nemours ER in Florida has a program called REACH that is added to each child’s hospital chart and is hung outside their exam room to alert doctors of their diagnosis. The ER also has a separate waiting room that includes: toys, sensory brushes, iPads, headphones, music boxes, and projectors with soothing colors and stars.

- Capital Health ER in New Jersey trains their staff to recognize behaviors that are characteristic of autism, provide a calm setting, and better communicate with patients. The pediatric emergency nurses use iPads to communicate with patients, to get a better sense of their pain, discomfort, fears, and preferences.

Current Initiatives (continued)

- Royal Manchester Children’s Hospital in the UK has developed a resource called “My Traffic Light” that indicates important information that providers need to know about their patients including: allergies, medical issues, eating habits, communication tools, medication, and bathroom usage.

- The National Autistic Society created “My Hospital Passport” which includes information about the patient that providers should be reading before examining them, especially about how they experience pain and triggers.

- Indiana University developed a training manual and DVD called A Guide for Emergency Department Personnel: Assessing and Treating Individuals With Autism. Aims to educate emergency medical personnel on how to assess, communicate with, and treat the autistic patient.
Autism Friendly Initiative at Boston Medical Center

- "The Autism Friendly Initiative will address systemic change on a hospital wide level including staff training, environmental adaptation, and protocol adjustment to best meet the needs of patients with ASD and their families."
- To launch the Autism Friendly Initiative, three key phases have been outlined:
  - Preliminary phase: develop, implement, and evaluate a comprehensive needs assessment to determine best practices and define Boston Medical Center (BMC) as an Autism Friendly hospital.
  - Second phase: implementation of the best practices at 1-year into the project. Grant funding will be used to implement sensory changes, develop resources, and provide comprehensive staff training to best serve our patients.
  - Final phase: develop a certification process that enables one to be Autism Friendly. The vision is for other hospitals to adopt and implement Autism Friendly.

MGHfC Collaborative Initiatives

<table>
<thead>
<tr>
<th>Autism Care Questionnaire (ACQ)</th>
<th>Resource Guide for Case Management</th>
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</thead>
<tbody>
<tr>
<td>Training Videos</td>
<td>Internal Website Resources</td>
</tr>
<tr>
<td>3 Designated Inpatient Units</td>
<td>Office Visits for Adults Tip Sheet</td>
</tr>
<tr>
<td>Navigator Position Creation</td>
<td>First-Then Handouts for Procedures</td>
</tr>
<tr>
<td>Inpatient Admissions Guidelines</td>
<td>Best Practice Alert for ACQ in EMR</td>
</tr>
<tr>
<td>Autism Order Sets in EMR</td>
<td>EMR Alert for patients with ASD</td>
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<td>Autism FYI Flag in EMR</td>
<td>OT &amp; SLP Inpatient Team</td>
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Patient M

- Manually disimpacted twice during the hospitalization (2 weeks apart)
- Began using the toilet while on an aggressive stool regimen.
- He had an autism care plan created.
- Psych was involved for medication recommendations and an agitation plan was created.
- He responded well to a daily schedule that included music therapy where he was the most expressive and engaged.
- He was then transitioned to Bradley Hospital in RI for continued care.
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<thead>
<tr>
<th>Patient Experience</th>
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<td>▪ <strong>Video of Patient M dancing</strong></td>
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