CENTER FOR DEVELOPMENT & DISABILITY

UNIVERSITY CENTER FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES EDUCATION, RESEARCH AND SERVICE

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NMHealth

PREPARING NEURODIVERSE YOUTH FOR INPATIENT HOSPITALIZATION

TIPS FOR FAMILIES AND OUTPATIENT TEAMS

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Disclosure Statement

The presenter has no disclosures.

Objectives

- Describe increased risk for hospitalization in neurodiverse youth
- Discuss common challenges that may occur during medical hospitalization
- Plan for successful medical hospitalizations
- Apply communication, crisis and de-escalation plans for neurodiverse youth in the hospital setting

Increased Risk of Hospitalization

Neurodiverse kids are more likely to be hospitalized than peers

Children with ASD have high rates of medical comorbidity→ more likely to be medically hospitalized (Thom et al)

Children with ASD are six times more likely to be psychiatrically hospitalized

Medical hospitalizations for kids with ASD longer and more difficult

Inpatient admissions are more than two days longer (6.5 vs 4.2 days) for children with ASD (Lokhandwala et al)

Caregivers report decreased satisfaction with their care and increased unmet needs (Kogan et al)

Avoidance of Outpatient Clinics

Lack of regular outpatient care lead to delay in preventative care, which may in turn increase emergencies

- Lack of appropriate referrals
- Incomplete outpatient team
- Increased risk of infection/ complications from routine medical concerns

Common Challenges During Hospitalization

Discussion

What are some common challenges your neuroatypical patients or family members have experienced in the hospital setting?

Medical visits and hospitalizations are a big stressor

Patients may have had multiple negative experiences in a clinic or ED

At the same time, some kids may develop interest or fixation on medical tools→ may lead to increased excitement

More hospitals implementing strategies to address needs of youth on the spectrum

Challenges for neuroatypical patients

Long wait times → sensory overload

Physical spaces that are not ideal → sensory overload

Unpredictability, lots of transitions→ inability to use coping skill, increased anxiety

Alternative communication styles→ communication challenges

Challenges for medical teams

Lack of appropriate training to care for neurodiverse patients

Large patient volumes

High turnover of inpatient care teams

Lack of clear treatment guidelines for patients with ASD

A stressed child may become agitated

According to one study, ~20% of pediatric patients with ASD had an episode of agitation during medical hospitalization

Risk factors for agitation

- Prior episodes of agitation in medical setting
- Significant sensory sensitivities

"Psychiatric comorbidity, intellectual disability, acute pain on admission, number of preadmission psychotropic medications, Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition ASD diagnosis, age, and sex were not significantly associated with increased risk." (Hazen et al)

Planning Ahead

Discussion

What advanced planning strategies have supported your neuroatypical patients or family members in medical settings?

Ask providers for as much information as possible

Learn as much as you can about planned admissions

Where is the hospital? Do they offer a pre-admission tour?

What are goals of hospitalization?

Anticipated length of stay

Possible adverse events or factors that could prolong hospitalization

→ Relay to youth using appropriate communication strategies

Common Reasons for Pediatric Medical Admissions in patients with ASD

Constipation/Bowel clean-out

Respiratory difficulties (viral respiratory infection, bronchiolitis, asthma, pneumonia)

Uncontrolled seizures/ EEG, monitoring

Identify appropriate psychiatric treatment or placement

Prepare ASD-specific patient information sheet for medical team

Baseline core ASD symptoms

- Social and communication characteristics
- Sensory needs
- Restricted and repetitive behaviors

Medication list and list of medications with negative side effects

If medical providers do not ask for this, offer the information during admission process or request interdisciplinary meeting

Autism Care Questionnaire-
MGH Lurie Center

Communication

1. How do you/the patient like to communicate needs/wants?
2. What other ways will the patient tell us what he/she needs/wants?
3. How does the patient communicate “yes” or “no” when asked a question?
4. How does the patient learn new information or instructions?
5. How does the patient know that time is passing?

Communication

6. What is the best way for us to prepare the patient for tests (i.e. how lon g the wait will be for a test or how long the test will take)?
7. How will the patient tell us that he/she has to go to the bathroom?
8. How will the patient tell us that he/she is hungry or thirsty?
9. How will the patient let us know if he/she is in pain?
10. Are there other ways the patient will let us know that he/she is in
11. pain?

Hospital Visit and Physical Examination

1. How should we greet the patient?
2. What is the best way for us to examine the patient?
3. Is there a part of the exam that may especially bother the patient?
4. Will the patient wear a hospital gown?
5. Will the patient wear a hospital ID band on their wrist?

The Physical Exam can be a very stressful time for children on the spectrum- occurs at least daily during medical admissions

Comfort and Safety

1. Is the patient sensitive to: Loud noises Unexpected noises Bright lights Specific colors Fragrances/smells Textures Touch Specific types of touch Other:
2. How long does the patient usually sleep at night?
3. Will a family member or caregiver be staying with the patient? If yes: What hours will the caregiver be at the hospital?
4. Are there special ways to make mealtimes easier?
5. Is the patient on a special diet?
6. Are there special times of the day that the patient eats snacks or meals?

Comfort and Safety

7. Does the patient prefer that different foods in a meal not touch, or to have separate plates for each type of food?
8. Are there any words, phrases or actions that will upset the patient?
9. How will the patient let us know if he/she is upset/anxious?
10. What comforts the patient when he/she gets upset or anxious?
11. What may help decrease the patient's anxiety?
12. Are there any other safety concerns we should know about?
13. Is there anything else we should know about so we can make the patient's visit as positive as possible?

Communication, behavior and crisis planning

Behavior as Communication

All behavior is communication, and sometimes only form of communication available to kids

Caregivers are the experts in their child's behavior and most able to recognize a change

- With changes in behavior, may need to advocate for assessment for pain, change in medical condition etc

Communication Plan

Bring assistive communication devices from home

Be prepared to advocate for appropriate use of communication tools

If communication with medical team is not effective, consider requesting speech/language, occupational therapy, child life, behavioral response team or psychiatry team consult

Top 3 Communication Strategies for Medical Settings

First/ Then

Goal

- Increase motivation and compliance in completing task

How

- Identify motivating item for pt
- Only provide motivating item AFTER pt has completed task.

Context

- Can be used at ANY point throughout a day/item/request
- Replace a demand with a First/Then statement

SCAN ME

Easy, Easy, Hard

Goal

- Increase pt compliance

How

- Present two easy tasks before the more difficult task.

Context

- Can be used to turn electronics off
- Used access all settings

SCAN ME

Choices

Goal

- More choices = More Compliance

How

- Provide choices related to the task
- Pt will feel in control/ownership of situation

Context

- Order of tasks to be completed
- Materials to use
- Person to work with

SCAN ME

Addressing sensory needs

Sensory Kit

- Sunglasses
- Headphones/Ear protection
- Sensory toys
- Bites
- Weighted blanket/vest
- Compression clothing

Request Child Life consult

Addressing behavioral needs

Work with bedside nurse to remove items that are challenging in patient's space

Find ways to incorporate movement in a small space

May need to be creative

Crises

The goal is to prevent crises, but they may be unavoidable

Crisis Plan- De-escalation

What works for your child?

Consider (some of) 10 domains of de-escalation:
- Personal space
- Avoid provocation
- Be consise
- Identify wants and feelings
- Set clear limits and expectations
- Offer choices

Crisis Response Plan:

- Use of 2-3 words
- Remember the importance of **Wait Time**
- One directive at a time
- One communication partner

Slide credit: Felicia Nevarez, Kayla Lopez et al

Crisis Response Flow sheet

Remember that behavior is communication, so before going immediately to PRN, think of what changes can be made immediately through either communication or environment.

SCAN ME

Slide credit: Felicia Nevarez, Kayla Lopez et al

Crisis Plan- Medication Management

As needed medications can be helpful

- Aka PRN (*Pro Re Nata)*

Neuroatypical patients at higher risk of side effect, paradoxical reaction and lack of benefit

- Note PRN trials and outcome

PRN Medication Options

- Patients on the spectrum have idiosyncratic medication response
- More likely to have paradoxical reactions to typical first line medications such as diphenhydramine, hydroxyzine and benzodiazepines
- More likely to have side effects of all kinds
- Also less likely to have medications work
- BEHAVIORAL STRATEGIES ARE ESPECIALLY IMPORTANT IN THIS POPULATION
- First choice should be extra dose of patients standing medication
- **Start low and go slow**
- Avoid IM unless absolutely necessary for safety
- Autism genetics a growing area of research that may guide medication management in the future

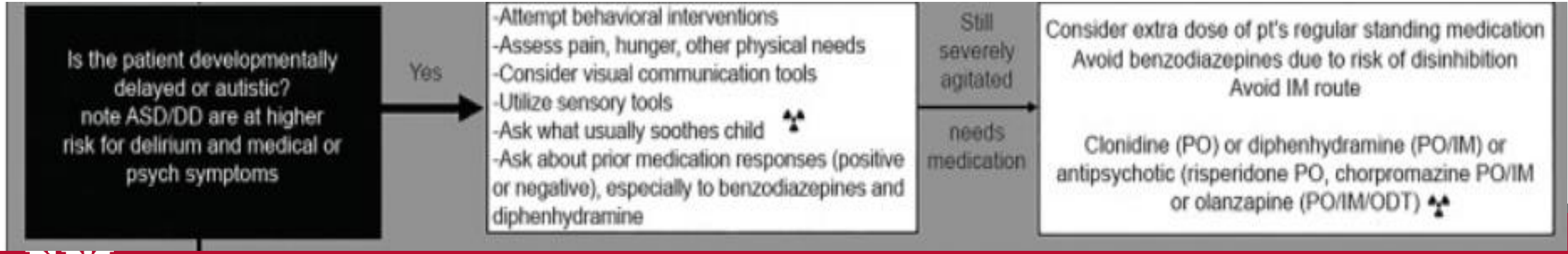
Best Practices for Evaluation and Treatment of Agitated Children and Adolescents (BETA) in the Emergency Department: Consensus Statement of the American Association for Emergency Psychiatry

Seminal guideline on medication management for agitation, based on “diagnosis”

Recommends behavioral interventions first

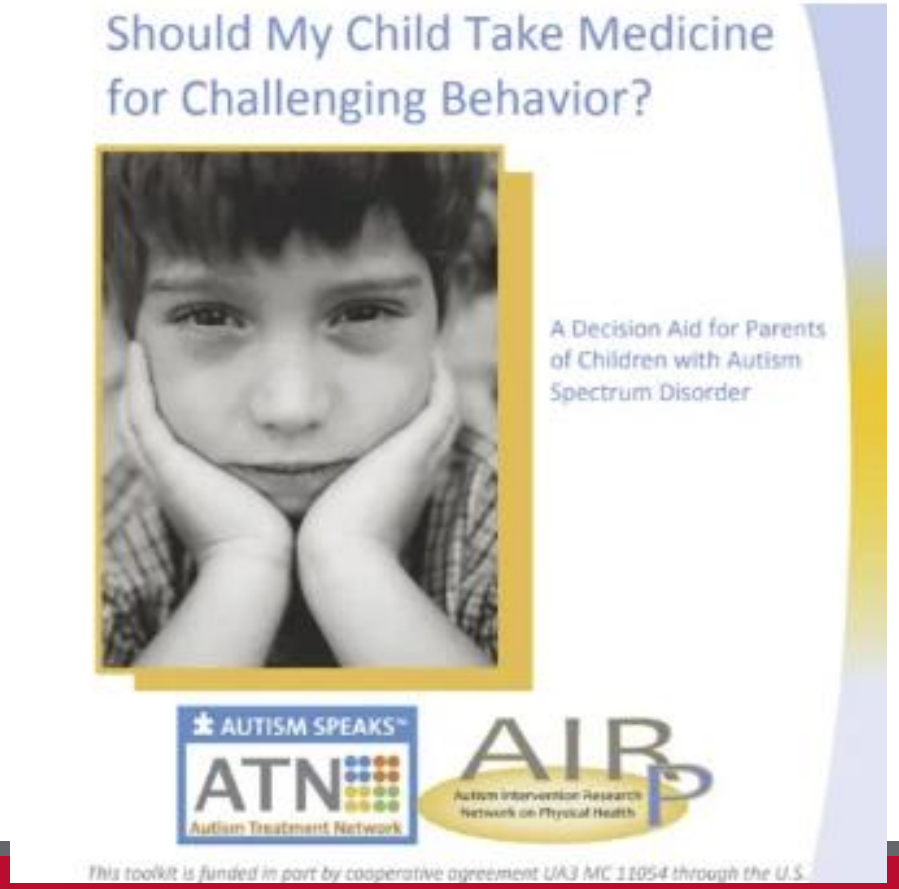
Extra dose of patient’s standing medication

Clonidine, diphenhydramine, or antipsychotic medication

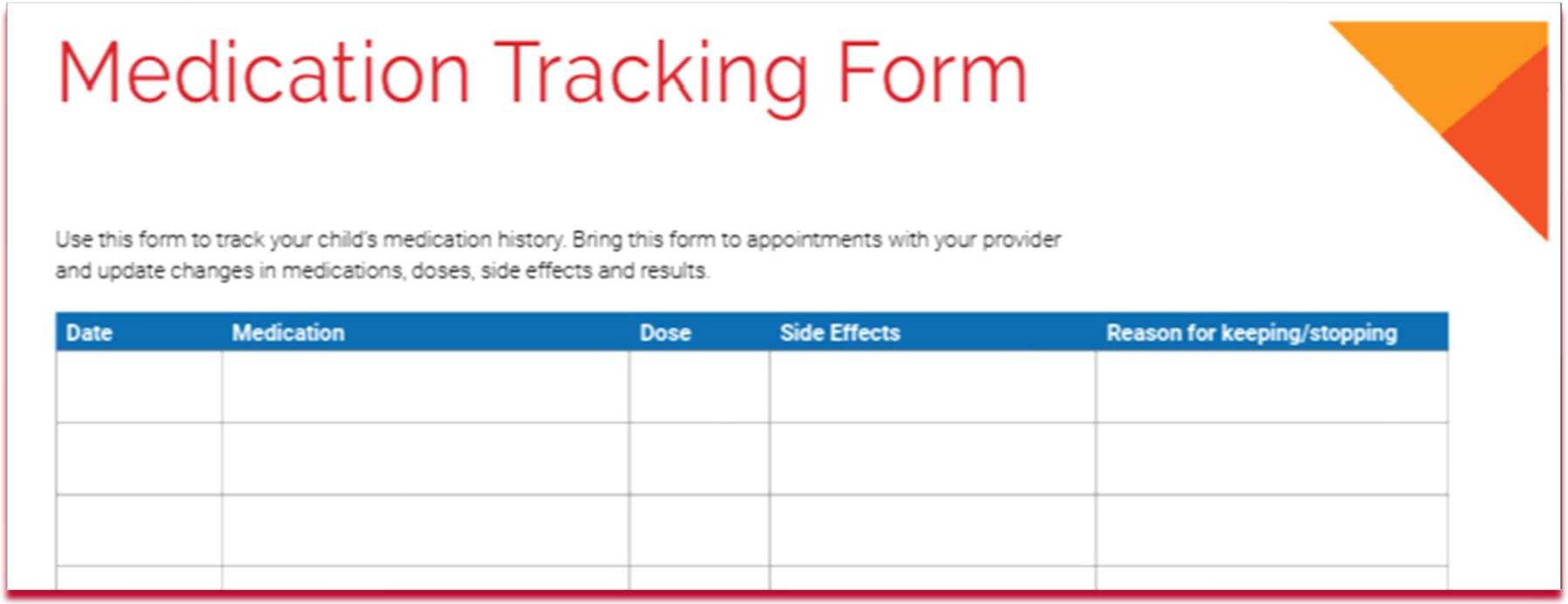


Standing medications in ASD

- Only risperidone and aripiprazole have FDA approval, several other medications families are commonly used
  - Address co-occurring diagnoses such as ADHD, insomnia, anxiety, depression, etc



Keeping Track of Medications



Medication Tracking Form

Use this form to track your child's medication history. Bring this form to appointments with your provider and update changes in medications, doses, side effects and results.

Date	Medication	Dose	Side Effects	Reason for keeping/stopping

Debriefing after challenging medical visit

Address with youth when calm

Discuss with outpatient team

- Reassess services available to patient
- Discuss communication strategies and behavioral approaches
  - What worked and what did not
- Revisit standing medication management plan, if applicable

Discussion

What are your take-aways from today?

Conclusions

Neurodiverse youth are more likely to have a medical hospitalization than peers, and it may be a challenging experience.

There are tools to support planning and preparation for inpatient admissions.

Crises may occur, be prepared to advocate for youth and debrief afterward.

Resources

Autism Speaks

- ATN/AIR-P Medication Decision Aid (access free after submitting email address)

American Association of Child and Adolescent Psychiatry (AACAP)

- https://www.aacap.org/AACAP/Families_and_Youth/Family_Resources/Parents_Medication_Guides.aspx

Mass General Lurie Center Autism Care Questionnaire and Resources:

- https://www.massgeneral.org/children/autism/lurie-center/autism-care-questionnaire
- https://www.massgeneral.org/children/autism/lurie-center/autism-patient-resources

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NM-ABC = New Mexico's Resource

Supporting Providers Who Support Children's Mental Health

✓ CASE CONSULTS

NM-ABC supports providers and professionals with questions related to medications, treatment recommendations, differential diagnosis and more.

✓ TRAININGS

Free CME trainings for healthcare providers and other professionals working with children and youth. Offering a wide variety of topics related to pediatric mental health.

✓ RESOURCES

Need assistance locating resources for a child or youth with mental health needs? NM-ABC staff can assist in identifying appropriate resources.

There is never any charge for NM-ABC services; NM-ABC is a federally funded partnership of the ***UNM Center for Development and Disability*** *and the* ***NM Dept of Health***

NM-ABC Case Consults

- talk to UNM specialists
  (child and adolescent psychiatrists, psychologists, social workers, specialists in neurodevelopmental disorders, autism spectrum disorder, FASD, substance use)
- quick questions or longer conversations;
- patient identifying info not requested;

Frequent consult questions….

- ✓ ***Medication hasn't helped—now what?***
- ✓ ***Medication helps but problematic side effects?***
- ✓ ***Managing sleep (or appetite) problems?***
- ✓ ***Managing aggressive or self-harming behaviors?***
- ✓ ***Help finding appropriate therapy resources?***

Training Topics

(**Free** CEU/CME trainings for practices, schools, clinics, hospitals, etc.)

- **Infant and Early Childhood Mental Health**

- **Autism Spectrum Disorder:** Screening and Interventions

- **Youth Suicide:** Screening and Safety Planning

- **Non-Suicidal Self Injury:** Screening and Interventions

- Helping Children and Youth Cope with **Loss and Grief**

- **Adolescent Substance Use:** Screening and Interventions

- **Anxiety Disorders** in Children and Adolescents

- **Depressive Disorders** in Children and Adolescents

- **Trauma and Trauma-Informed Care** with Children and Youth

- **Brief Intervention Techniques** with Children and Youth

- **ADHD** Diagnosis and Management

- **SSRIs and Pediatric Patients:** Best Practices

- **Youth Returning Home from Inpatient and Residential Stays:** Bridging the Transition

- **Tips from a Child and Adolescent Psychiatrist:** What Providers Need to Know

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