Emergencies in Medically Complex Children: Tip & Tools

ANGIE CUNNINGHAM, BSN, RN, CCRN-K, C-NPT
TRANSPORT OUTREACH AND EMS RELATIONS COORDINATOR
CHILDREN’S MERCY CRITICAL CARE TRANSPORT
KANSAS CITY, MO

Disclosures

I have no relevant financial or nonfinancial relationships in the products or services described, reviewed, evaluated or compared in this presentation.

Children with Special Healthcare Needs (CSHCN)

Children with special health care needs (CSHCN) represent the most rapidly growing subset of pediatric patients, constituting 16–18% of children in the United States.

(Sacchetti, et al 2000)
Children with Special Healthcare Needs (CSHCN)

- Those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

Complex Medical Needs

- Among this group are a smaller number of medically complex, or medically fragile, children including those with intense medical needs that result from multisystem disease states, technology dependence, or complex medication regimens.

Medical

- Asthma
- Cardiac conditions
- Cancer
- Cerebral Palsy
- Congenital anomalies
- Cystic Fibrosis
- Diabetes Mellitus
- Hemophilia
- Renal disease
- Muscular Dystrophy
- Neurologic impairment
- Obesity
- Adrenal Insufficiency
- Pulmonary-BPD, trachs
- Seizure disorder
- Syndromes
Behavioral/ Mental Health

- ADD
- Anxiety
- Autism spectrum disorders
- Cognitive impairment
- Depression
- Developmental delays
- Fetal Alcohol Spectrum Disorder
- Learning disorders
- Psychiatric illness
- Tourette syndrome

Epidemiology- Gender

Race/ Hispanic Origin
Spectrum of Providers

- Medical and technological advances have increased the number of children with special health care needs (CSHCN) in the community.
- With great advancement comes a need for the community to be able to provide specialized medical care in the event of an emergency.
- Includes EMS, not just PCPs, specialists, ED and pediatric tertiary center staff.

Is Your Service Prepared?

- Do your protocols have special considerations for medically fragile or complex children?
- Do your crews know who to contact if they encounter such a child and caregiver instructions conflict with current pediatric protocols?
- Will crews contact appropriate Medical Control in this situation?
- Do crews feel legally and organizationally supported in giving home medications in emergency situations?
- Are current training opportunities provided for these situations?
Resources

Do you and your crews know what your resources are locally? Regionally? Nationally?
- Parents/Caregivers
- Organizations with programs in place
- EMSC
- Health Department/Emergency Preparedness
- Pediatric tertiary or quaternary facilities
- Community physicians
- Educational resources online or print
- Legislative representatives

Increased Risk for Suboptimal Care

- Even with advanced training for healthcare providers, CSHCN are at risk for suboptimal care during an emergent event.
  - Occult medical problem
  - Recognizable problem with atypical management
  - Unknown baseline status in a known medical condition
  - Rare condition
  - Technology-dependent child

Emergency Information Form (EIF)

- The emergency information form (EIF) was proposed as a means to provide rapid access to a health summary for children with special health care needs in a 1999 joint policy statement (reaffirmed in 2002) by the American Academy of Pediatrics (AAP) and the American College of Emergency Physicians (ACEP).
A summary describing their medical condition(s), medications, and special health care needs is necessary to reduce delays in diagnosis and treatment and facilitate greater efficiency in the provision of emergency care to children with special health needs.

This important document will assure prompt and appropriate care for Children with Special Health Care Needs (CSHCN). Now, when these patients present to emergency departments or health care professionals with an acute illness or injury, physicians, parents, EMS professionals, and nurses will be able to use the EIF as a tool to transfer critical information.

Varied Faces of EIF

- Provider and Parent/caregiver communication
- CAD integration
- Disaster Preparedness integration
- Programs differ by region/state
  - Minnesota
  - Delaware
  - Kansas City, MO
  - St. Louis, MO
  - Alaska
Provider and parent/caregiver communication

- Deficits in care have been linked to lack of communication of child specific health information
- Provides documentation for EMS providers to follow parent instructions
- Survey completed one year into PEF program at Children’s Mercy Kansas City.

Feedback-Parents and EMS

- Parents
  - "Thank you guys for that paper. My daughter passed away but it helped them to try to save her."
  - "I’m THANKFUL we have it & even more THANKFUL that we haven’t had to use it. I have given a copy of it to the local EMS department & they have given a copy of it to the local ambulance & hospital too."
  - "I like the peace of mind of having the info with me if ever in a critical situation, excellent idea."
  - "Helpful"

- EMS
  - "Very helpful to take the guesswork out of what’s best for these kids in an emergency situation."
  - "I feel so much more confident taking care of these complex kids in the field with this form."
  - "Can we get one for every kid?"
  - Already asking for the form on kids they bring into the ED that don’t have one.

CAD Integration

- Delaware Emergency Preparedness Voluntary Registry
- Minnesota Emergency Medical Services for Children Information System
- Missouri (Eastern Region) Special Needs Tracking & Response System
- Kansas & Missouri (Western Region) Pediatric Emergency Form
**EIF- Minnesota**

- The Midwest Emergency Medical Services for Children Information System ([www.memscis.org](http://www.memscis.org)) is an EIF central repository program in Minnesota that uses a "break-the-glass" entity for emergency access to EIF information. This terminology clearly distinguishes routine EIF maintenance activities from emergency information access. Emergency access via the "glass breaker" is obtained by entering the requestor's identifying information.

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**EIF in Disaster Preparedness**

- Ideally, EIFs should be reviewed periodically by local emergency care providers to confirm that the recommendations are clear and that the necessary specialized equipment, medications, and services are available at the emergency care center.
- Disaster-management plans must include medical care for children with special health care needs. If a disaster compromises the availability of health records, an EIF would be beneficial in providing useful information such as medication doses.
Additional Resources

- Educational resources
  - Pediatric tertiary and quaternary referral centers specialists
  - Chronic illness in pediatric population
  - Online training for autism awareness: [www.prevent-educate.org](http://www.prevent-educate.org)
  - Aiming to reach all first responders—be they firefighters, EMTs, paramedics, police officers or emergency room personnel—how to effectively interact with individuals with autism.
  - The non-profit organization offers training which gives providers the tools needed to effectively communicate with autistic individuals, as well as help reduce or eliminate dangerous behaviors.
  - The training includes a pre-test and participants can earn up to 5 CEUs in most states.

www.prevent-educate.org

Additional considerations

- Conservative medication administration
- Glucose in ketogenic diet patients
- Oxygen and fluids in cyanotic heart conditions
- Extended scene times with ASD patients
- Blankets vs restraints
- Passive interaction vs intervention
- Seizure alert dogs
- Policy to allow in ambulance
- Trach care
- Troubleshooting equipment, airway and ability to oxygenate/ventilate
- Home medication administration
- Hydrocortisone
- Factor
Questions?

References