Emergencies in Medically Complex Children: Tip & Tools

ANGIE CUNNINGHAM, BSN, RN, CCRN
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.

We have no special needs children. Just children...with special needs.

-Uwe Maurer
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.

Federal Maternal and Child Health Bureau's Division of Services for Children With Special Health Care Needs (DSCSHCN) 1998

Medical

- Cardiac conditions
- Cancer
- Cerebral Palsy
- Congenital anomalies
- Cystic Fibrosis
- Diabetes Mellitus
- Hemophilia
- Renal disease
- Muscular Dystrophy
- Neurologic impairment
- Adrenal Insufficiency
- Pulmonary- Asthma, trachs
- Seizure disorder
- Syndromes
Epidemiology: Gender

Who meets the definition?

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

Who meets the definition?

Epidemiology: Gender
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.

(References: Burns, K., et al. 2010)
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.
- EMS, PCPs, specialists, ED & pediatric tertiary center staff.

(American Academy of Pediatrics, 2010)

Is Your Service Prepared?

- Do your protocols have special considerations for medically fragile or complex children?

Is Your Service Prepared?

- 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?
Is Your Service Prepared?

- Do crews feel legally and organizationally supported in giving home medications in emergency situations?

- Are current training opportunities provided for these situations?
  - Simulation
  - Didactic
  - Skill specific training
  - Formal classes (PEPP, PEARLS, PALS, EPC, etc)

Resources

- Pediatric tertiary and quaternary referral center staff
- EMS for Children grant programs
  - High risk/low volume acute illness
  - Chronic illness in pediatric population
  - Specific treatment protocols
Online training for autism awareness

www.prevent-educate.org

- Aiming to teach all first responders how to effectively interact with individuals with autism.
- A non-profit offering training to give providers tools needed to effectively communicate with autistic individuals & help reduce or eliminate dangerous behaviors.
- Includes a pre-test with up to 5 CEUs in most states.

Do you have a protocol for that?

- Conservative medication administration
- Glucose in ketogenic diet patients
- Oxygen and fluids in cyanotic heart conditions
- Trach care
- Troubleshooting equipment, airway and ability to oxygenate/ventilate
- Home medication administration
- Hydrocortisone
- Factor
Do you have a protocol for THAT?

- Extended scene times with ASD patients
- Blankets vs restraints
- Passive interaction vs intervention
- Communication with non-verbal patients
- Seizure & PTSD dogs
- Policy to allow in ambulance

EMS use in pediatric cases

- National Hospital Ambulatory Medical Care Survey used to analyze transportation mode and acuity of more than 250,000 patients—representative of 914 million ED visits.
- Was EMS being over-used for transportation of pediatric patients who don’t need EMS care?
- Comparison of adult use of EMS with pediatrics and proportionately compared the acuity of each.

Richards and Zwehl-Burke 2011 descriptive study review in JEMS

EMS use in pediatric cases

- Pediatric cases account for less than 10% of EMS call volumes, and often are not life-threatening.
- Out of the greater than 90% of pediatric patients that arrive by POV, 34% had critical complaints.
EMS vs POV

- Pediatric patients with critical conditions that could potentially benefit from EMS are transported by POV much more often than adults.
- Why isn’t EMS called for the sickest patients?
- Previous studies that show parents may not recognize that their child is very sick, may not understand appropriate use of 9-1-1.

EMS use in pediatric cases

- Previous studies have identified that some physicians and families have low confidence in EMS’ ability to care for sick children.
- It’s even more alarming to think perhaps it is best to avoid ambulances in some cases.
- The authors point out lack of outcome data so can’t conclude if those transported by ambulance fared better.

Increased Risk for Suboptimal Care

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

(Sacchetti et al., 2000)
Your Toolbox

- Have you identified your resources locally? Regionally? Nationally?
  - Parents/ Caregivers
  - Organizations with programs in place
    - EMSC
    - Health Department/ Emergency Preparedness plans
    - Pediatric tertiary or quaternary facilities
    - Community physicians
  - Educational resources online or print
  - Legislative and regulatory representatives

Community Integration

- Scientific evidence shows that EMS is under-used for kids, and the community of healthcare providers & parents may need education about the role of EMS in pediatric emergency care.

Emergency Information Form (EIF)

- The emergency information form (EIF) was proposed to provide rapid access to a health summary for children with special needs in a 1999 joint policy statement by the American Academy of Pediatrics (AAP) and the American College of Emergency Physicians (ACEP).
  - Reaffirmed in 2002
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 EDs or health care professionals with acute illness or injury, physicians, parents, EMS professionals & 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
- Regional/ State plans
- Pediatric facility, physician’s offices, community hospitals and EMS integration
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/Caregivers

► Thank you guys for that paper. My daughter passed away but it helped them try to save her.

Feedback - Parents/Caregivers

► 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 [fire] department & they have given a copy of it to the local ambulance & hospital too.
Feedback - Parents/Caregivers

- I like the peace of mind of having the info with me if ever in a critical situation, excellent idea.
- Helpful.

Feedback - EMS Professionals

- Very helpful to take the guesswork out of what’s best for these kids in an emergency situation.

Feedback - EMS Professionals

- I feel so much more confident taking care of these complex kids in the field with this form.
Feedback - EMS Professionals

▶ Can we get one for every kid?

Feedback - EMS Professionals

▶ Already asking for the form on kids they bring into the ED that don’t have one.
▶ Contacted by EMS professionals for their own children with special needs to have a PEF written.

Programs for CSHCN

▶ Programs differ by region/state
  ▶ Examples
    ▶ Minnesota
    ▶ Delaware
    ▶ Kansas City, MO
    ▶ St. Louis, MO
    ▶ Alaska
  ▶ Process owned by
    ▶ Emergency preparedness planners
    ▶ PCP
    ▶ Specialties/ Medical Home
    ▶ EMS Services
CAD Integration

- Delaware Emergency Preparedness Voluntary Registry
  - For citizens with special needs
- Minnesota Emergency Medical Services for Children Information System
- Missouri (Eastern Region) Special Needs Tracking & Response System
  - Given STARS tracking number by EMS region
- Kansas & Missouri (Western Region) Pediatric Emergency Form
  - Primary EMS service alerted that patient has PEF in place
  - Premise Notes can be accessed by crew
- Individualized Care Plan for EMS

EIF - Minnesota

- The Midwest Emergency Medical Services for Children Information System (www.memens.org) is an EIF central repository program in Minnesota that uses a “break-the-glass” entry 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.

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.

Regulatory/Legislative Partnerships

- MO State Advisory Council to Bureau of EMS
- Legislative & State Medical Directors Advisory Committee
  - Regional Medical Directors may develop protocols for patients with special needs that may cross boundaries within a region
  - May serve as medical direction for EMS professionals when caring for patients with special needs
  - Includes home medication administration

Pediatric Subcommittee
- Tasked to develop a minimum list of requirements for an EIF
- All programs to adhere
- Pediatric centers staff, EMS professionals, EIF program administrators and community health care facility staff at the table
Key Takeaways

- Building relationships between patients, parents, and health care professionals is integral to improvements in patient outcomes.
- Having a plan in place for children with special needs is a necessary step in maintaining patient safety from accidental harm.
- Ongoing training for EMS professionals in pediatric emergency care is essential.
- All levels of healthcare providers must work together to develop a plan to support these patients and each other.
- Resources for pediatric education and training exist - tap into them!

Questions?

Email me at: adcunningham1@cmh.edu
References