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NEONATAL BRAIN DAMAGES, CHILDRENS WITH SPECIAL HEALTH CARE NEEDS & PRE-HOSPITAL EMERGENCY SERVICES: AN INTERESTING CONNECTION?

...Alberto, 12 years old: serious brain damage due to perinatal anoxia; carrier of PEG, infusional device for drugs, PM & DAE implanted for QT-long syndrome;

Lorena, 5 years old, post-natal asphyxia, born 28-weeks gestation; tracheostomy placed at 4 months of age; pressure-simv at home;

Andrea, 2 years old, spastic cerebral paralysis due to perinatal suffering; PEG, permanent IV-line;

Alessio, 4 years old, carrier of liquor shunt (VP shunt) due to congenital brain damage;

...just some of our little patients, in their homes, in our city.

AIMS

Purpose of this presentation is to show the interconnections between the care and the study of the cerebral suffering in the newborn, children with special care needs and pre-hospital emergency services.

Our observations started from some, by now, consolidate realities:

- With advances in medical care, children who would not have survived in the past are being discharged from hospitals into the community.
- New technology, life sustaining devices, and an explosion in the development of new drugs have led to significant changes in the care of patients with chronic illnesses such as diabetes, sickle cell disease, chronic pulmonary diseases, and childhood cancers.
- The survival of extremely premature newborns has also led to an increasing number of children with a variety of special needs being cared for at home.
- When EMS is called for a child with special health care needs, the prehospital professional must anticipate dealing with a medically complex patient.

METHODS

Children With Special HealthCare Needs (CSHCN) are a group of young population with chronic physical, developmental, behavioral, or emotional condition and required health related services of a type or amount beyond that required by children generally. This estimate includes children with existing special health care needs but excludes the at-risk population. These children often require suitable evaluation and treatment, at home or in ED.

Technology Assisted Childrens (TAC) usually depend on medical devices for their survival. Common of these devices are tracheostomic tubes, ventilators, IV-lines, feeding tubes, pacemakers, VP-shunts. (*From Commentary in Pediatrics, Vol. 102, No. 1 July 1998*)

Today, these children survive for a long time; they live at home and needs much more medical intervention than children of the same age.

The baseline of these children is often abnormal, and a correct assessment may be an important challenge for each pre-hospital professionalist.

Pre-Hospital professionalists must know the most common CSHCN and TAC features and problems, so that they don't become a threat for them.

RESULTS

FORMULATION OF KEY CONCEPTS FOR THESE PATIENTS:

CORRECT ASSESSMENT:

- Describe the anxiety and attentions during the initial assessment and the clinical stabilization of every CSHCN;
- Describe the single steps during treatment of medical devices complications;
- Outline all the priorities during each evaluation, management and transport for CSHCN;
- Parents, brothers/sisters or caregivers
 - Are well-trained about medical priority of their ill households
 - They know the normal baseline of the children
 - They are familiar with medical devices
 - Are trained to solving problems related with the children's baseline
 - They are very involved in CSHCN's medical care

TREAT YOUR LITTLE PATIENT, NOT THE MEDICAL DEVICES!!!

- Don't think that an ill children, with an important physical disability, has also an important cognitive handicap! Many children with cerebral spasticity, for example, don't have any cognitive handicap!
- When a technology-dependent child has an acute clinical deterioration, the possibility of device failure or mechanical malfunction must be addressed.
- In the case of a ventilator-dependent child with a tracheostomy, obstruction of the tracheostomy tube is the most likely cause of acute deterioration.

CHILDREN'S BASELINE

- Ask to the caregivers what is normal for this child, and what, apparently, is abnormal;
- Establishing a medical and functional baseline is critical in making treatment decisions about CSHCN.
- Caregivers can generally provide this critical information and define "normal" for their child. At times, a caregiver's "gut feeling" about a subtle alteration in the child's level of consciousness or degree of respiratory distress may be the tip-off about a serious change in status.
- Without the help of the caregiver, interpreting the children's assessment can be difficult. Use this important resource to determine just how far from baseline the child is.

Baseline health status of children:

- CSHCN can be "abnormal" at your assessment although with *their* baseline status is normal! Vital signs (HR, RR, BP) can be apparently abnormal but normal for *this* child.
- Decisions about transport must be directed on *what is usually normal* for *this* child;
- Parents and caregivers can be helpful for many important clinical and medical information: ask:
 - What is the **normal** work of breathing?
 - What is the **usual** pulseoximetry?
 - What is the normal mental/physical status of the child?
- Do you need further information about transport?
- Do continue assessment during transport

REMEMBER: VITAL SIGNS IN CSHCN CAN APPEAR "ABNORMAL" AT YOUR PRIMARY ASSESSMENT BUT CAN, ACTUALLY, BE IN A NORMAL RANGE FOR THESE CHILDREN!

INFORMATIONS/MEDICAL FORMS:

- Wisconsin's Child Alert 10-33, New Mexico's ChUMS (Children's Updated Medical Summary),
- New Hampshire's SKIPS (Special Kids Information Program)

IN THE U.S.A: EVERY STATE/COUNTY HAVE SPECIFIC PROGRAMS FOR CSHCN!!!

Emergency Information Form for Children With Special Needs		
 		Date form completed by: _____ Revised by: _____
Name: _____		Birth date: _____ Nickname: _____
Home Address: _____		Home/Work Phone: _____
Parent/Guardian: _____		Emergency Contact Names & Relationship: _____
Signature/Consent: _____		Phone Number(s): _____
Primary Language: _____		_____
Physicians:		
Primary care physician: _____		Emergency Phone: _____ Fax: _____
Current Specialty physician: _____ Specialty: _____		Emergency Phone: _____ Fax: _____
Current Specialty physician: _____ Specialty: _____		Emergency Phone: _____ Fax: _____
Anticipated Primary ED: _____		Pharmacy: _____
Anticipated Tertiary Care Center: _____		
Diagnoses/Past Procedures/Physical Exam:		
1. _____		Baseline physical findings: _____
2. _____		_____
3. _____		Baseline vital signs: _____
4. _____		_____
Synopsis: _____		Baseline neurological status: _____
_____		_____
_____		_____

THINK OF PAIN AS THE “5TH VITAL SIGN.” – (“Biscuits”)

Can pain be measured in newborn? Really, we have some systems to do it. Some are easy, but too poor in reliability (HR, duration and characteristic of weeping), and more than 30 different step-methods for acute pain evaluation. These methods however are not often applied in practical approach because they're very complicated.

- Complete the assessment to determine the cause of pain
- Treat pain with the most appropriate drug, and with the right dosage

WHAT ABOUT TRANSPORT? SOME TIPS

- Bring all medical equipment (such as a home ventilator) with the patient to the ED. Medical records or Emergency Information Form (EIF on page 290 of the PEPP textbook) are also of great help in facilitating care in these complex patients. Bring all available documentation to the ED.
- Although most hospitals should be able to provide supportive care, there are few facilities that specialize in the care of the complex chronically ill child. You can expedite definitive care by transporting to the facility that provides regular services to the child. He is likely to have extensive records there, as well as specialty providers who are familiar with his needs.
- Ask this question: “What special transport considerations might you face?”
- CSHCN are often quite fragile and do not tolerate stress well. Even seemingly mild illnesses may result in decompensation and critical physiologic compromise.
- Monitor CSHCN closely during transport. Changes can occur quickly.

BEWARE FOR:

- Tracheostomy
- Latex, allergies
- Shunts devices
- Permanent iv-lines
- Feeding tubes
- Infections
- Past medical problems

SEARCH AND TREAT HYPOGLICEMIA!!!

CONCLUSIONS

- Children with “reliance on technology” play an important challenge for all pre-hospital professionals and for all the emergency medical services;
- Acute illness or problems, with important change of status of a CSHCN may be carefully evaluated!
- Establish a medical and functional baseline, in according to parents and caregiver’s information and of knowledge
- As medical care advances, more CSHCN survive beyond infancy.
- With trends toward home care, EMS must be ready to manage children with severe and complex chronic disease.
- Collaboration with caregivers and consultation with medical oversight are keypoints in treating this special population.

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