The Emergency Information Form: A focused clinical summary for emergency preparedness for Children with Special Healthcare Needs

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Abstract:

Background: Pediatric patients with special health care needs present unique challenges in emergency care. A generalized definition of children with special healthcare needs (CSHCN) refers to patients who require, or potentially may require, increased resources compared to a typical pediatric patient. These complex healthcare needs pose unique challenges for first responders and emergency practitioners. Therefore, these patients may benefit from a concise summary of important health-related information that is easily accessible during emergency settings.

Methods: Key sections of Emergency Information Forms (EIFs) outline demographic information, physician contact information (primary and specialty care), diagnoses, past medical and procedural history, allergies, medications, and immunizations. In addition to these elements, the sample EIF from the American College of Emergency Physicians and the American Academy of Pediatrics added components such as "Procedures to be avoided" and "Common presenting problems" with suggested approaches to management.

Results: This EIF format was subsequently implemented in an electronic format to facilitate instant access and was analyzed in various emergency or disaster settings and simulations. A review of these studies demonstrated subjective and objective benefits for both parents of CSHCN and emergency providers.

Conclusions: There are numerous barriers to widespread implementation of EIFs: privacy and security concerns, interoperability, and integration into different practice patterns and electronic medical records. However, there is increasing opinion-based and data-driven support of the concept and utility of emergency-focused clinical summaries. The EIF can also be used for complex adults with rare or congenital medical diagnoses to enhance emergency preparedness. The push for enhanced, instant access to integrated health information has created an environment in the post-EHR era to facilitate broader EIF utilization and implementation. Additional studies and analysis of larger scale use of EIFs are needed to further elaborate their specific benefits for patients with complex health care needs.

Keywords: emergency information form; children with special health care needs; electronic medical record

Section 1: Background

1.1 Overview

Pediatric patients with special health care needs present unique challenges in emergency care. A generalized definition of children with special health care needs (CSHCN) refers to patients who require, or potentially may require, increased resources compared to a typical pediatric patient. The American Academy of Pediatrics (AAP) defines CSHCN as patients who are at risk for or currently have chronic physical, developmental, behavioral or emotional conditions and, as a result, require health services not usually required by normally developing children.1

These complex healthcare needs pose unique challenges for first responders and emergency practitioners. These providers report that they are more uncomfortable at baseline in life-threatening pediatric emergencies.2 Although additional training and certification, specialization, and clinical experience can ameliorate this, these factors cannot make up for lack of information regarding particular risks for CSHCN.3,4 Given improvements in medical care, patients with chronic childhood illnesses are living longer. Therefore, the principles of emergency preparedness for CSHCN become applicable to many adults with congenital conditions and other uncommon diseases. Their problem may be rare, complex and unfamiliar to emergency or disaster providers.

CSHCN have more complex health conditions and may benefit from a concise summary of important health related information and baseline health status, which includes neurologic status, communication methods, special precautions, and medications.1 This information can streamline providers' diagnostic and treatment approaches, especially in emergency settings.5 Providers in busy emergency care or disaster settings do not have access to or the time to review complex medical charts. Moreover, they may be unable to access required pediatric subspecialists. This makes CSHCN particularly prone to medical errors or poor outcomes given their increased reliance on medications and medical devices and their propensity for acute deterioration.5 Therefore, medically complex children and adults require unique treatment approaches in emergency situations. These scenarios may be rare in rural or general Emergency Departments (ED) and providers may benefit from succinct emergency-focused health summaries.

1.2 Case Presentation

A real case scenario provides an example of the need for an easily accessible emergency health information tool for CSHCN. A 10-year old patient with cyanotic congenital heart disease with single-ventricle physiology (tricuspid valve atresia status post Fontan Operation) presented at a rural ED with a first episode of atrial flutter. The mother was not aware of the details of her child's prior operations or pathophysiology. She asked the physician to call the child's pediatric cardiologist but the ED physician reassured the mother that this is not necessary and that this is a commonly encountered arrhythmia.

The mother became concerned and contacted the cardiologist, who facilitated transfer of the patient to a higher level of care. The mother and the pediatric cardiologist realized the need for an emergency-focused clinical summary. This could address anticipated problems that are common for this child's unique healthcare history, list treatments to avoid (for example, certain antiarrhythmic agents that are typically used in other patients), and suggest treatment pathways.

In order to standardize the approach to these patients, the Emergency Information

Form (EIF) was developed to provide and organize health-related information for families and health care providers in emergency settings. A mechanism is needed to quickly identify CSHCN when they present for emergency care and access the relevant aspects of their past medical history.6 This relies on both entities identifying at-risk children, filling in the data sets, and utilizing the form when needed. Disaster care presents an additional need to communicate the baseline overall status of patients to avoid over-triage that could result in exhaustion of limited resources. The EIF presents the information in a concise, standardized template that is limited to a two-sided, single sheet of paper.

Section 2: The Development of the Emergency Information Form

2.1 Precursors to the EIF

The Red Alert Program for children with life-threatening asthma was one of the early examples of systematic formulation of a network that aimed to enhance emergency care for a specific subset of CSHCN.7 The investigators tracked usage and outcomes data to demonstrate the utility of an emergency treatment plan aimed to reduce morbidity and mortality in an at-risk pediatric group. Moreover, they reported parental survey results to see the impact of the program on families and the setbacks and areas for improvement that can be applied to other similar programs. For example, they identified a need for enhanced, early communication with pediatric subspecialists after emergent presentation of children with asthma.

Patient-driven data capture was a hallmark of another asthma-based study, the Asthma Kiosk, which served as an example of real-time data collection for emergency use.8 Authors collected granular data (such as patient medications) to facilitate guideline-driven care for children with asthma in a timely fashion. Pediatric asthma served as a platform to implement a patient-centered electronic tool to facilitate care in the ED environment. The study identified several key components, including providing education for emergency medical caregivers and patients' families.

2.2 EIF Origins

The 1998 American College of Emergency Physicians (ACEP) EIF policy statement and the 1999 American Academy of Pediatrics (AAP) EIF statement both emphasized the importance of emergency-based healthcare information forms and laid the foundation for development of future electronic EIF forms. These collaborative efforts and task forces identified essential components of an emergency care plan for CSHCN: identification of children with special healthcare needs; a standardized form or template to facilitate completion by healthcare providers and parents; 24-hour access; patient confidentiality; and family education.[1]

Different means of conveying health information included wallet cards, passports, window stickers for homes of CSHCN, or one-page summaries. Different sections in the forms concisely outlined demographic information, physician contact information (primary and specialty care), diagnoses, past medical and procedural history, allergies, medications, and immunizations. Figure 1 (on the next two pages) shows a sample of a two-sided, single-sheet EIF.

One notable section was "Procedures to be avoided". This was a critical portion because it allowed providers to outline what procedures, which may typically be safe and routinely performed in most patients, could be potentially detrimental or even fatal in CSHCN. Another crucial subsection outlines common presenting problems, clinical findings, and suggested approaches for management specific to the patient's unique medical conditions.

This information must be updated regularly and maintained in an accessible and usable format. Other important elements included emergency telephone numbers and involving schools and child care facilities. With the advent of and improvements in electronic

medical records, future statements transitioned to electronic forms and improved ease of access.

Emergency Information Form for Children With Special Needs

Last name:

American College of Emergency Physicians® American Academy of Pediatrics

Date form completed 1/1/97 By Whom J. Heart, MD
Revised 5/15/98 Initials JH
Revised Initials

Name: Blue, Little B. Birth date: 7/4/96 Nickname: LB

Home Address: 1313 Mockingbird Lane, Anytown, USA, 11111 Home/Work Phone: 900-555-1212 (home) 777-8899 (work)

Parent/Guardian: Sandra Blue, mother Emergency Contact Names & Relationship: Beatrice Blue, grandmother

Signature/Consent*: Sandra Blue

Primary Language: English Phone Number(s): 900-444-5566

Physicians:

Primary care physician: Marcus Welby, MD
Emergency Phone: 1-800-KIDS-RUS
Fax: 000-000-0000

Current Specialty physician: P. Card. Jime Heart, MD
Specialty:
Emergency Phone: 000-000-0000
Fax: 000-000-0000

Current Specialty physician: P. Neuro. Joe Neuro, MD
Specialty:
Emergency Phone: 000-000-0000
Fax: 000-000-0000

Anticipated Primary ED: Smallville Hospital Pharmacy:

Anticipated Tertiary Care Center: Childrens All Star Regional Med Center

Diagnoses/Past Procedures/Physical Exam:

1. tetralogy of Fallot with pulmonary atresia; RV to PA conduit 2/97 VSD left, ductus and collaterals ligated
2. Asplenia syndrome
3. thrombosed bilat femoral, iliac veins and inferior vena cava
4. Seizure disorder: generalized tonic-clonic

Synopsis: Asymptomatic, mildly cyanotic nb. Asplenia syndrome noted. Surgery of RV to PA conduit at 8 mos. of age. Post-op seizures-mild R CVA, hemiparesis resolved.

Baseline physical findings: gr III harsh murmur, few crackles at base of left lung, liver down 5 cm.

Baseline vital signs: P 90 BP 100/50 R 24, O_2 Sat 85%
Weight: 12 kg Date: 5/15/98

Baseline neurological status: Awake, age appropriate, interactive. Mild increased tone L>R. EEG 5/97: Mild assymetry with right-sided slowing

*Consent for release of this form to health care providers

Figure 1: Sample EIF (front side) printed with permission from the AAP.[1]

Last name:

Diagnoses/Past Procedures/Physical Exam continued:

Medications:

1. Digoxin 50 mcg=1cc BID
2. Lasix 10 mg BID
3. Amoxil 200 mg BID
4. Phenobarb 40 mg BID
5.
6.

Significant baseline ancillary findings (lab, x-ray, ECG):

moderate cardiomegaly on cxr
chronic LLL atelectasis on cxr
RVH on EKG

Prostheses/Appliances/Advanced Technology Devices: homograft conduit RV to MPA — no extra precautions. Sternal wires and clips on vessels — no MRI until 6 mos post-op

Management Data:

Allergies: Medications/Foods to be avoided	and why:
1. Betadine	rash
2.	
3.	
Procedures to be avoided	**and why:**
1. femoral venous puncture	no fem veins
2. instillation of air into venous catheters	R to L intracardiac shunt
3.	

Immunizations

Dates	9/4/96	11/4/96	1/4/97	1/10/98	
DPT	X	X	X	X	
OPV	X	X	X	X	
MMR				X	
HIB	X	X	X		

Dates	9/4/96	11/4/96	1/4/97	1/10/98	
Hep B		X			
Varicella					
TB status					
Other				Pneumovax	

Antibiotic prophylaxis: Indication: Asplenia, SBE Prophylaxis Medication and dose: Amoxil 200 mg BID, Amoxil 50 mg/kg one hour prior to procedure

Common Presenting Problems/Findings With Specific Suggested Managements

Problem	Suggested Diagnostic Studies	Treatment Considerations
Worsened CHF	cxr	increase lasix
Status Epilepticus	check electrolytes-Na check phenobarbitol level	midazolam, correct lytes
Fever	sepsis w/u	broad spectrum atbx for asplenic individual

Comments on child, family, or other specific medical issues: Mother is an excellent caregiver a nd knows when LB is blue.

Physician/Provider Signature: Jime Heart MD **Print Name:** Jime Heart, MD

Figure 1 (continued): Sample EIF (back side) with permission from the AAP.[1]

Section 3: EIF Use

3.1 Electronic Implementation

In emergency or disaster settings, a paper form may not be readily available or may have been destroyed. Therefore, immediate electronic access to this information can be invaluable and may be the only way to obtain critical information for initial management in these complex patients. The platform needs to facilitate family and provider updates of information and emergency access at any care facility with internet access.[9]

In 2005, the MEMSCIS website (Minnesota Emergency Medical Services for Children Information System) was developed to securely house the EIF developed by the AAP and ACEP.[9] The electronic platform, compared to paper forms, was designed to enhance the ability to update the information and access it in emergency situations when parents may not have the necessary information. The database used the standardized, approved EIF template and allowed for role-specific access and authorship privileges.

It maintained compliance with the Health Insurance Portability and Accountability Act by protecting the data with encrypted internet transmission and password-regulated access in emergency settings.[9] A special "break the glass" setting was created to allow for instant access by emergency medical providers. The accessing practitioner's license information and method of access (e.g. computer URL and IP address) were recorded. In addition, the family and primary and specialty providers were notified of the event via email.

This website emphasized the role of parents as the key stakeholders and the only consistent factor involved in emergency care of CSHCN. Continual updating of the data housed in the EIF was essential to the utility and accuracy of potentially lifesaving information. However, one advantage of MEMSCIS compared to other proprietary medical alert systems was the additional contribution of information by medical professionals.

3.2 EIF Utilization

A 2010 study delved into the effect of the availability and use of MEMSCIS on parents of children less than two years of age with significant cardiac disease.[10] Surveys compared 94 parents who had children with EIFs in the database with a control group of 76 with no EIFs. Overall, parents felt that prehospital and in-hospital providers were better prepared for and had increased perceived comfort levels while treating patients in emergent situations when compared to parents who did not participate in the program. The authors speculated that the program also facilitated feelings of "normalization" for parents enrolled in MEMSCIS based on survey results. This effect was seen in parents even if they had not actually utilized the EIF in an emergency setting during the study period.

This further reinforced the MEMSCIS project's goal of "establishing a culturally sensitive, family-centered methodology for the emergency planning process for the CSHCN with cardiac disease and measuring effectiveness of this process".[9] The program emphasized the process of normalization, which encompassed improved family resilience due to enhanced preparation and availability of health information. The EIF was meant to augment other measures initiated at discharge such as patient/parent education and CPR training.

A recent study evaluating the utility of EIFs during a simulation activity highlights the effects on providers. Abraham et al created a simulation exercise involving medically complex children with scenario-specific checklists of critical actions and related pathways.[11] They randomized junior and more experienced providers to groups with or without access to EIFs. The group with access to EIFs, independent of provider experience, scored far higher on the scenarios with shorter times to completion and significantly lower complication rates. All providers "strongly agreed that EIFs can improve clinical outcomes" for CSHCN. This study went beyond parental and provider impressions of the tool by using experimental methodology and data-driven means to demonstrate the hypothesized utility of EIFs in emergency care.

3.3 Barriers to Implementation

A commentary on this simulation further analyzes the utility of EIFs and potential barriers of use despite purported benefits.[12] First, it was

noted that very little objective data are available in this area. The literature predominantly contains expert opinions, consensus statements, or data elements from involved organizations such as the AAP, ACEP or American Medical Association (AMA). In addition, they author stated that a "critical mass of EIF users" hasn't been assembled to drive universal adoption. The previously discussed MEMSCIS pilot project revealed important lessons such as the need for updates and accessibility but is no longer operational in Minnesota.

Although a website-platform addressed the challenges associated with a paper copy or flash drive, emergency providers involved in the MEMSCIS project had reservations regarding the stand-alone website. Privacy and security issues, interoperability, and integration into different practice patterns and electronic medical records continue to hinder widespread implementation. More simulations and studies with larger sample sizes are needed to enhance the understanding of how EIFs can improve care and outcomes in emergency scenarios for CSHCN. This can then be extended to disaster scenarios and medically-complex adult patients. It would also be valuable to explore the utility of EIFs for subsets of CSHCN with specific communication barriers, such as those with deafness, blindness, autistic spectrum disorders, speech impairment, or developmental delay.

Section 4: Health Information Management in Disasters

Natural or man-made disasters can present a significant challenge to communities and health systems that need to assemble an emergency medical response in the face of escalating needs and scarce resources. As previously mentioned, CSHCN can be at particular risk during these hectic times, given their medical complexity and need for additional resources. Irmiter and coworkers in the AMA Disaster Preparedness Department created a framework for a disaster medical record using a combination of literature review and focus groups.[13] They identified seven key domains: identification, emergency contacts, healthcare contacts, past medical history, medications, allergies/dietary restrictions, and family information. Experts in this study deemed these as the minimum health information elements that first responders and emergency providers must have available to provide appropriate care. They also emphasized the importance of automatically updating and validating these data elements during clinical encounters.

An AMA Task Force conducted a disaster drill during a grant meeting to demonstrate the usefulness of a disaster medical record. The AMA group did not incorporate the ACEP-AAP concept of an "advice" section to address frequent known emergencies of a patient based on their diagnoses. Given the subjective benefit provided to simulation providers, future drills and simulations should evaluate the effect of this type of information being available for managing CSHCN in a timely manner despite limited resources.

Section 5: Conclusion

The ACEP-AAP Emergency Information Form provides a concise summary of a medically complex patient's medical and social history. It also outlines potential emergencies and patient-centered recommendations for immediate evaluation and treatment driven by specific chief complaints. There is increasing opinion-based and data-driven support of the concept and utility of emergency-focused clinical summaries. The push for enhanced, instant access to integrated health information has created an environment in the post-EHR era to facilitate broader EIF utilization and implementation. Additional studies and analysis of larger scale use of EIFs are needed to further investigate specific benefits for patients with complex health care needs.

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Reference List

1. Committee on Pediatric Emergency Medicine. Emergency Preparedness for Children With Special Health Care Needs. *Pediatrics*. 1999;104(4):e53-e53.

2. Simon HK, Sullivan F. Confidence in performance of pediatric emergency medicine procedures by community emergency practitioners. *Pediatr Emerg Care*. 1996;12(5):336-339.

3. Spaite DW, Karriker KJ, Seng M, et al. Increasing paramedics' comfort and knowledge about children with special health care needs. *Am J Emerg Med*. 2000;18(7):747-752.

4. Smith GA, Thompson JD, Shields BJ, Manley LK, Haley KJ. Evaluation of a model for improving emergency medical and trauma services for children in rural areas. *Ann Emerg Med*. 1997;29(4):504-510.

5. Committee on Pediatric Emergency Medicine and Council on Clinical Information Technology, American College of Emergency Physicians, Pediatric Emergency Medicine Committee. Emergency Information Forms and Emergency Preparedness for Children With Special Health Care Needs. *Pediatrics*. 2010;125(4):829-837.

6. Emergency Information Form for Children With Special Health Care Needs. *Ann Emerg Med*. 2010;56(3):315-316.

7. Sherman JM, Capen CL. The Red Alert Program for life-threatening asthma. *Pediatrics*. 1997;100(2 Pt 1):187-191.

8. Porter SC, Cai Z, Gribbons W, Goldmann DA, Kohane IS. The Asthma Kiosk: A Patient-centered Technology for Collaborative Decision Support in the Emergency Department. *J Am Med Inform Assoc*. 2004;11(6):458-467.

9. Pyles LA. Development of a Web-Based Database to Manage American College of Emergency Physicians/American Academy of Pediatrics Emergency Information Forms. *Acad Emerg Med*. 2005;12(3):257-261.

10. Pyles LA, Scheid M, McBrady MP, et al. Parent and emergency physician comfort with a system of on-line emergency-focused medical summaries for infants with significant cardiac disease. *Matern Child Health J*. 2011;15(4):534-541.

11. Abraham G, Fehr J, Ahmad F, et al. Emergency Information Forms for Children With Medical Complexity: A Simulation Study. *Pediatrics*. 2016;138(2). doi:10.1542/peds.2016-0847.

12. Pyles LA. Testing the Consensus-Based Emergency Information Form. *Pediatrics*. 2016;138(2). doi:10.1542/peds.2016-1715.

13. Irmiter C, Subbarao I, Shah JN, Sokol P, James JJ. Personal derived health information: a foundation to preparing the United States for disasters and public health emergencies. *Disaster Med Public Health Prep*. 2012;6(3):303-310.