



Open Journal of Pediatrics & Neonatal Care

Research Article

Disaster Drill to Induce Awareness of an Emergency Information form Program for Children with Special Health Care Needs -

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Submitted: 07 February 2018; **Approved:** 16 April 2018; **Published:** 18 April 2018

Citation this article: Pyles LA, Hemmati P, Hellmich TR, Elsbecker S, Bentler K, et al. Disaster Drill to
Induce Awareness of an Emergency Information form Program for Children with Special Health
Care Needs. Open J Pediatr Neonatal Care. 2018;3(1): 003-008.

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ABSTRACT

Objective: Disasters represent a challenge to child health care delivery, especially for Children with Special Health Care Needs (CSHCN) at least in part from the information deficit that accompanies the disruption in healthcare networks. The Emergency Information Form (EIF) is an emergency and disaster focused health summary for CSHCN. We conducted a disaster simulation for groups of children with cardiac and genetic diagnoses to analyze disaster preparedness by families and providers, identify barriers and evaluate parent and provider impressions of the simulation.

Methods: After a simulated tornado strike, parents and children reported to an emergency department or care center with a scripted scenario of psychosocial and medical problems based on their actual health history. Providers reviewed histories and made an initial assessment. Some children had emergency summaries available and some not.

Results: Participants included 34 CSHCN from 26 families plus 13 health care professionals. Parents' impressions significantly improved. All participants responded with similar attitudinal changes regarding provider disaster preparedness. Debriefings suggested that MyEIF.org would improve a disaster response.

Conclusions: A disaster simulation for cardiac and genetic CSHCN produced a teachable moment that resulted in a transformative experience for parents and potential disaster providers. This is the first reported simulation to use actual parents and CSHCN as participants in a disaster drill.

Keywords: Disaster preparedness; Emergency preparedness; Children with Special Health Care Needs; Patient simulation; Disaster drill; Emergency Information Form (EIF); Delivery of health care

ABBREVIATIONS

CSHCN: Children with Special Health Care Needs; AAP: American Academy of Pediatrics; ACEP: American College of Emergency Physicians; EIF: American College of Emergency Physicians-American Academy of Pediatrics Emergency Information Form

INTRODUCTION

Disaster drills can train health care providers in mass casualty care and are usually focused on the general adult and pediatric populations [1]. Children can be inordinately affected by disasters as a result of dependence upon adults who have additional responsibilities and priorities aside from the children. Children with Special Health Care Needs (CSHCN), who require greater medical services and resources than the general pediatric population, are further affected during disasters when compared to healthy children [1]. Reports of experience with children in disasters focus on increased resource utilization by CSHCN and the unique medical requirements to care for these children in emergency settings have been addressed by national pediatric and emergency care organizations. In 1999, the American Academy of Pediatrics (AAP) and the American College of Emergency Physicians (ACEP) jointly formulated a policy to advocate for preparation of emergency plans for CSHCN [2,3]. The policy established a standardized format, dataset, and implementation plan for CSHCN based on the ACEP-AAP Emergency Information Form (EIF). And has been recently updated and reaffirmed by AAP, including a recommendation for disaster drills and planning [4]. The Federal Maternal and Child Bureau Emergency Medical Services for Children Program, in its 2001-2005 Five-Year Plan, advocated for formation of model emergency care plans for CSHCN [5]. The AAP has offered recommendations for school disaster preparedness that include completion of an EIF for any students considered to have special health care needs [6]. The AMA has recently proposed a set of disaster data elements, similar to the EIF data elements as a part of a CDC disaster preparedness grant [7].

Disaster drills have been proposed in a 2010 AAP Policy Statement ("Emergency Information Forms and Emergency Preparedness for Children with Special Health Care Needs") as a way to help ensure

that CSHCN receive appropriate care during a natural disaster or act of terrorism [5]. Significant barriers to health care and health information dissemination in a disaster include displacement of the patient away from the medical home or usual site for receiving health care; unavailability of family members familiar with the past medical history; disruption of electrical power, computers and electronic health records; and sudden escalation of need for health services exhausting available resources.

The extraordinary demand for resources in a disaster could result in health care rationing that could adversely affect CSHCN, especially if their complex needs are not well-delineated or understood. For example, without an emergency-focused health summary, a child with a diagnosis such as medium-chain acyl-CoA dehydrogenase deficiency might experience an inadvertent but potentially adverse rationing of care, or an inappropriate triage decision. In the absence of a concise emergency-focused clinical summary that explains the child's diagnoses and special precautions, a disaster provider may be more likely to limit or delay timely delivery of sufficient medical care and resources. The EIF has demonstrated the capability to address the emergency information deficit for CSHCN [8]. With this study, we sought to demonstrate that this readily available electronic EIF could help address the information deficit for CSHCN during a disaster. A disaster simulation could increase provider and family awareness of the EIF, train them to use the tool, and enhance EIF utilization in times of need [9].

METHODS

EIF and MyEIF.org

The Emergency Information Form (EIF) is an emergency and disaster-focused clinical summary formulated in a consensus-driven process by the Committee on Pediatric Emergency Medicine of the AAP, and the Pediatric Emergency Medicine Committee of the ACEP [3]. The paper-format EIF was first published in national policy statements by the two organizations in 1999. The EIF includes sections on demographics, diagnoses, past procedures, medications, allergies, baseline physical and neurobehavioral findings, and anticipated problems with suggested evaluations and solutions. The anticipated problems and suggested solutions section makes the EIF



unique among suggested formats for personal health records.

MyEIF.org hosted online electronic EIFs for CSHCN. The MyEIF application is a web-linked database developed as part of a Department of Health and Human Services Maternal and Child Health Bureau Emergency Medical Services for Children Targeted Issues grant, hosted on an MS-SQL platform employing ColdFusion and Crystal Reports utilities, as well as web editor and security software developed by the programmers from Image Trend, Inc of Lakeville, MN. Image Trend programmed the MyEIF.org website under our direction and hosted and provided technical support for the site since inception in August 2002. Initial start-up of the website, originally named Midwest Emergency Medical Services for Children Information System (MEMSCIS), has been previously reported [9]. The site is now inactive.

Study population

The study population consisted of children with cardiac and genetic diseases and their parents and other caregivers, in addition to disaster-oriented care providers (emergency and critical care nurses, advanced practice nurses and physicians). Child and family participants were recruited during clinic visits, by telephone and email from cardiac and genetics clinic directories, and MyEIF.org registries. Additionally, an email flyer was sent to MyEIF.org members that invited them to participate in the disaster drill. Approximately half of the child and family participants were enrolled in MyEIF.org (with a completed on-line EIF). The remaining patients were children with similar cardiac and genetic diagnoses, not enrolled in MyEIF.org. None of the families had created a different personal health record. Some possessed an informational letter from a pediatric sub-specialist. Parents gave informed consent for participation in the drill and assent was obtained from eligible older children using a protocol approved by the University of Minnesota Committee for the Protection of Human Subjects. Disaster care providers also gave informed consent to complete surveys and tests.

The disaster drill was conducted at the University of Minnesota Amplatz Children's Hospital and consisted of the following steps: A written disaster scenario was given to family participants and providers after they signed informed consent on the day of the event. Families of CSHCN were separated from providers until the drill started. Briefings designed to provide "Just-in-Time" factual information of basic disaster preparedness were separately delivered to the families and providers immediately prior to the drill. The simulation included two sites of care: a special needs shelter and an emergency department. MyEIF.org members and non-members with cardiac and genetic conditions were each randomly assigned to both areas. An individualized scenario was crafted for each child based on his or her actual past medical history and the assigned site of care. Examples included pacemaker failure due to crush injury, lack of specialty feeding formula for a child with an inborn error of metabolism, and requirement for refills of various prescription medicines.

Disaster scenario

It has been a sunny steamy day in the Twin Cities Metro. At 5 pm the skies begin to dim and storm clouds are gathering. Some are concerned due to a nearby possible tornado sighting. Rain and hail are followed by a deathly still and a string of tornadoes is generated along a line through the Minneapolis metro area. Winds to 70 mph are noted and power and telephone are out to 25,000 homes along the

front line. The hospital is operating under emergency power but EHR systems are down.

Drill parameters

The children were presented to the care areas every 60 minutes in three cohorts of 10-12 children, each by family with a random sample of the four cohorts described previously. No family had partial MyEIF.org participation if they had multiple CSHCN. Care providers were asked to work in teams to perform initial triage on the patients. The individual scenarios included simulated vital signs in some cases. Children were given a red scarf to place over an area of simulated laceration, a Sponge-Bob Band-Aid® for a minor laceration, and a tan scarf to denote a crush injury. Not all children had simulated injuries. Parents were not portrayed as injured and no children were separated from their parents. A \$50 gift certificate from a national discount chain was given to the family for each participating child. Parking and lunch were provided for families and these items were included in the IRB protocol and recruitment flyers.

Data collection and analysis

Providers completed multiple-choice knowledge inventory surveys before and after the drill. Additional survey items included questions that explored knowledge, attitudes and beliefs regarding childhood disaster preparedness and the simulation. Parents were surveyed for knowledge of and attitudes towards disaster management and their beliefs and impressions of availability of emergency-focused health information's impact on the providers. A post-simulation debriefing with the patient families and the professional staff was conducted, focusing on determination of satisfaction with the drill, family and provider attitude changes, and lessons learned as a result of the simulation.

Data were analyzed using JMP® Statistical Software (SAS Institute, Cary, NC). Comparisons of Likert evaluations were tested with Wilcoxon Rank Sum distributions. The parent survey was based on that of a previous study and was developed using guidelines suggested by Demeris et al. [9,10] Parents responded on a Likert Scale of 1-5, in which 5 was the favorable answer (strongly agree) and 1 was the unfavorable answer (strongly disagree). The parents were questioned regarding previous emergency experiences and their attitudes towards them. Endpoints for the investigation included the incremental increase in knowledge of disaster management by the participants and changes in attitude towards the need for specialized health information for CSHCN. The University of Minnesota Human Subjects Institutional Review Board reviewed and approved this study including consent.

RESULTS

Participants comprised of 32 Children With Special Health Care Needs (CSHCN) from 26 different families, each with at least one parent or caregiver. The children were divided into four groups: children with inborn errors of metabolism possessing an EIF on MyEIF.org (n = 10), children with inborn errors without an EIF (n = 6), children with cardiac diseases possessing an electronic EIF on MyEIF.org (n = 10) and children with cardiac disease without an EIF (n = 6). No parent or child presented with a different electronic or printed personal health record. Table 1 lists the children's medical diagnoses and acute problems. Five physicians and eight nurses and advance practice providers participated in the drill. Two physician investigators and two staff from the Fairview Health System simulation team participated as observers.

The professional and family responses to the attitudinal surveys are presented in tables 2,3. Six of 13 professionals felt that lack of knowledge of medication prescription dosing was the major barrier to delivery of adequate care. Professionals noted safety of their own family was a valid disaster concern (13 responses with Likert score 4.6 of 5.0) and felt that hospitals should prepare for any possible disaster as opposed to disasters considered likely for their specific area. Many of the professionals initially incorrectly chose ESPN.com as a reliable source of disaster education information. Seven of 13 professionals were unfamiliar with disaster immunization recommendations for children.

Figures 1,2 present parent responses to two questions asked both pre- and post-drill that focused on parental assessment of provider attitudes. Family survey responses included significant changes in Likert Scale responses for questions that measure the family comfort level for emergency care and the family perception of the professional's comfort level for emergency care related to the presence of an EIF for the special needs child. Figure 1 presents the significant improvement in families' impressions of the helpfulness of an EIF for health care providers. Figure 2 presents the change in parents' perception of comfort level of the professional volunteers with caring for CSHCN. Table 3 presents the professionals' impressions of the importance of the various types of data in an EIF history for CSHCN. The most desirable categories were medications, diagnoses, and

Table 1: Patient Chronic Diagnoses and Acute Problems.

Diagnosis Type	EIF	Destination	Underlying Diagnosis	
Cardiac	EIF	6 ED 4 Clinic	CAVC, Coarct, PA-IVS, PS, VSD (3), TAPVC, TOF, Corrected Transposition	Crushed in house; Pacemaker failure, HR 40; Multiple trauma: Head Bonk, compound fracture of right arm (2); chest trauma, crush injury, sat 75%; (baseline 85%); Displaced from home (6) some with minor abrasions, lost meds, minor head trauma.
Cardiac	no EIF	3 ED 4 Clinic	AS, MR, TOF, TOF-PA, TGA, Truncus (2)	Arm laceration, minor head trauma; Displaced from home (6), some with lost meds, minor abrasions, minor head trauma.
Genetic/ Metabolic	EIF	8 ED 1 Clinic	3-MCC Deficiency, Argininosuccinic Aciduria (3), MCAD Deficiency (2), Cobalamin C, OTC Deficiency(2)	Several sets of siblings with inborn errors; ill, sleepy after not eating for 12 hours (3), out of medicines (4), unrelenting vomiting (1), healthy but inborn error (1)
Genetic/ Metabolic	No EIF	0 ED 6 Clinic	Biotinidase Intake (2), Congenital Disorder of Glycosylation 1A, Septo-Optic Dysplasia, Spinal Muscular Atrophy, Wolff-Hirschhorn Syndrome	Displaced from home with no medicines (5), tracheostomy requiring electricity for suctioning.

CAVC: Complete Atrioventricular Canal Defect; Coarct: Coarctation of the Aorta; PA-IVS: Pulmonary Atresia with Intact Ventricular Septum; VSD: Ventricular Septal Defect; PS: Pulmonary Valve Stenosis; TOF: Tetralogy of Fallot; TAPVC: Total Anomalous Pulmonary Venous Connection; MS: Mitral Valve Stenosis; TGA: Transposition of the Great Arteries; Truncus: Truncus Arteriosus; 3-MCC: 3-Methylcrotonyl Coa Hydroxylase Deficiency; MCAD: Medium Chain Acyl Coa Dehydrogenase Deficiency; OTC: Ornithine Transcarbamylase Deficiency.

Table 2: Provider Feedback to the question: What barriers did you face if the patient participant was not enrolled in MyEIF?

Response Area	Number of Responses
Medication questions	6
General information deficit	5
Diagnosis	1
Foreseeable barrier: in availability of parents	3

Table 3: Professional Preference for Importance of Information Provided.

Information Type	Professional's Choice Number			
	#1	#2	#3	#4
Medication List	12	0	0	0
Health Providers	1	3	3	0
Diagnosis List	0	7	5	0
Special Precautions	0	0	2	8
Past Procedures	0	1	1	2
Other	0	0	0	0

Disaster care providers' post-drill impression of data found to be most important from the EIF during the disaster drill. Choices included medication list, diagnosis list, provider list, past procedures, special precautions and other (only choices 1-4 are shown).

primary care provider's contact information. Special precautions, the unique feature of the AAP-ACEP EIF, was picked as third most important by two people and fourth by nine providers.

Nine families reported that they had family disaster plans while 17 had no plan. Post-simulation, 14 of 17 said that they would create a plan. All 26 families reported that they knew the preferred emergency department they should use. Thirteen families reported MyEIF utilization. Seven had a paper emergency health summary (although these were not brought to the drill) and six had no emergency summary of any sort.

Family responses to questions about barriers and challenges are presented in table 4. Recurrent themes in narrative responses included concern for rarity of the child's disorder and a new appreciation of how a care provider might utilize their child's emergency summary. The families seemed to gain an appreciation of the importance of practicing the disaster response. In actual usage, 11 parents reported that they always gave an emergency provider access to an electronic or paper EIF and three families sometimes gave the access. Seven families reported that they had previously updated their EIF's (average duration of time needed to update was reported as 16 minutes) while seven had not done so. All families reported that they would use the EIF again, although one family reported dissatisfaction because they did not want to personally update the document.

DISCUSSION

This is the first special needs-focused disaster drill to use actual parents and children with special health care needs as participants in the simulation. We found that families of CSHCN and health care professionals were significantly more confident of the quality of care during this disaster drill if the child's medical history was available via EIF, based on parent input from survey and provider impression from the debriefing. Parent and provider participants experienced a significant attitudinal change regarding emergency and disaster

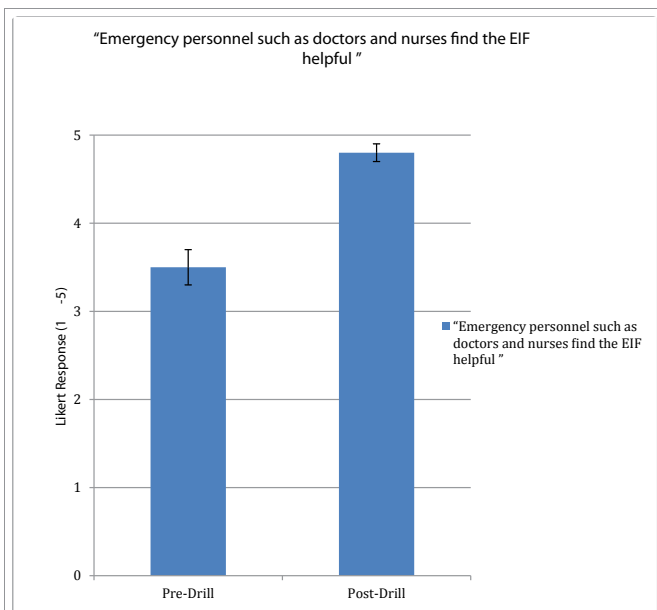


Figure 1: Family responses to the statement “Emergency personnel such as doctors and nurses find the EIF helpful” pre and post disaster drill. The change in Likert scale response was highly significant (Wilcoxon rank sum distribution $p < 0.0001$). Parental impression that an EIF would be helpful to the professionals increased from 3.5 ± 0.2 (mean \pm SE) of 5 on a Likert Scale to 4.8 ± 0.1 ($p < 0.0001$) where 1 = strongly disagree 5 = strongly agree. Median Likert response increased from 3 to 5.

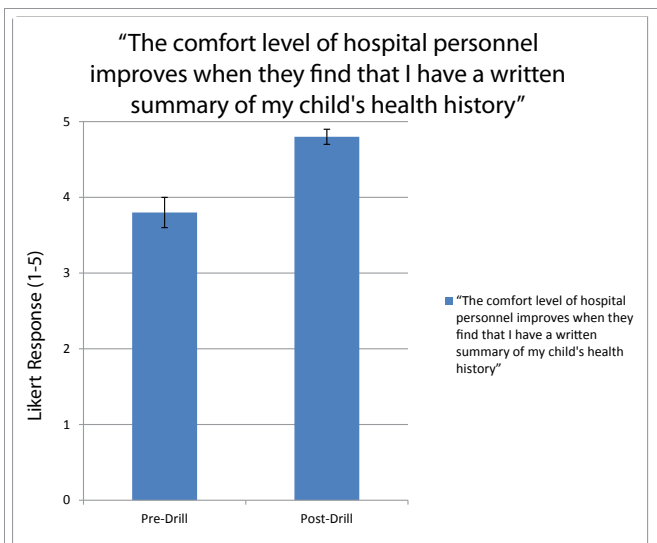


Figure 2: Responses from patient families pre and post disaster drill to the statement: “I find that the comfort level of hospital personnel improves when they find that I have a written summary of my child's health history”. Likert response increased from 3.8 ± 0.2 to 4.8 ± 0.1 of 5 (Wilcoxon rank sum distribution $p < 0.0001$) where 5 = strongly agree and 1 = strongly disagree. Median Likert response increased from 4 to 5.

preparedness for CSHCN as a result of this drill.

Parents who were not enrolled in MyEIF.org expressed an interest in joining after the simulation. Debriefing with parents and professionals exhibited an impression that emergency care plans would improve a disaster response. Debriefing discussions with the families underscored their increased understanding of the importance of EIFs for the disaster care professionals that were meeting their

CSHCN for the first time. The family debriefings and professional participants’ and observers’ reports did not reveal any instances of child participant anxiety. Overall, the discussions and the survey responses indicated that the families had experienced a significant change in attitude regarding the need for emergency and disaster preparedness. The disaster drill created a model for a teachable moment for professionals and parents, engendering a positive feeling for use of the EIF for CSHCN to prepare before a disaster. It also motivated parents to consider use of the MyEIF.org website to maintain emergency and disaster-focused clinical summaries for their CSHCN.

This simulation presented a unique opportunity to alter attitudes of involved families and professionals. Of note, families and actual medically fragile children were involved in the drill with factual health histories used as the point of embarkation to create the individual disaster scenarios. The drill created an increased awareness of the issues of CSHCN in disaster settings for both families and providers. The emergency and critical care professionals were made aware of the utility of an emergency-focused health summary when they contemplated the need to assemble critical supplies for a medically fragile child displaced from his or her home with limited access to medical history and for trauma care for such a child. The parents became aware of the critical health information that providers would need in a disaster setting. The knowledge expansion for parents was an added bonus that could not be obtained using simulation with manikins or actors, as advocated by other reports. [11,12] This group of exercises, each lasting 20 minutes, could serve as a model for subsequent learning activities that could be designed to produce a similar change in attitudes and behaviors for the families and professionals.

Despite an intuitive grass-roots belief in the effectiveness of EIFs and promising initial evidence, efficacy of emergency care plans has not been proven. [9,10] Also, no description of a large experience in dealing with CSHCN in a disaster is available. Rath and coworkers reported results of surveys of children (39% with pre-existing conditions) presenting for emergency care in New Orleans after Hurricane Katrina [2]. Of these subjects, 58% of CSHCN vs. 34% of children with no pre-existing conditions experienced some disruption in health care. The authors stated that “Children and adolescents with chronic conditions are at increased risk of adverse outcomes following a natural disaster. Providers may be able to reduce negative effects on this population by developing condition-specific preparedness care mechanisms.” [2] Condition-specific instruments may not be necessary if the EIF is used to create a patient-specific instrument that follows the general template in the ACEP-AAP form. After Hurricane Katrina, easy portability of immunization records of Louisiana children to other locales was reported, but newborn screening for inborn errors of metabolism was disrupted [13,14].

This study is limited in its ability to show that EIFs or the MyEIF.org website specifically produced the attitudinal transformation since all groups of the parent participants equally and dramatically changed their survey responses regarding the providers. We did not segregate EIF owners from non-owners in the simulations and the debriefings. In fact, this lack of separation may be an important part of the experience for both groups of families because the experiences of the opposite groups of families reinforced the importance of, or need for an EIF. In addition, it does not appear to be necessary to separate CSHCN by disease categories for these simulations. In future studies, a larger group of family participants could elucidate a difference in



attitudes at the start of the exercise in prior MyEIF.org participants compared with other CSHCN families.

In summary, we demonstrated the feasibility of a disaster simulation involving children with special health care needs as advocated in the 2011 AAP Policy Reaffirmation. No child anxiety was observed in the course of the scenarios but the role-playing resulted in an important learning experience for families and providers. The CSHCN were highly engaged in the process. Our disaster simulation is the first to report a focus of assessment of preparedness for disasters of CSHCN. The changes in parental assessment of provider comfort parallels the attitudinal changes observed after one to two years of participation in MyEIF.org by families with CSHCN [9]. Similar disaster drills or computer-based simulations can conceivably produce the same attitudinal changes for other groups of participants in the future.

FUNDING/SUPPORT

University of Minnesota USEEE Pilot Research award, Centers for Disease Control and prevention (CDC) as part of the Preparedness and Emergency Response Research Centers (PERRC) program. US DHHS Maternal and Child Health Bureau Grant U22MC03963 to Michigan Public Health Institute for the Region 4 HRSA Regional Genetics and Newborn Screening Service Collaborative "Improving Access to Genetic Services for Children with Heritable Disorders". University of Minnesota Health Informatics ARRA Training Grant #1T15OC000073-01 Dr. Pyles was a University Partnership for Health Informatics Scholar in the UM Health Informatics MS Program.

Role of Sponsors

The funding sources had no role in the design and conduct of the study; collection, management, analysis, or interpretation of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication.

Additional Contributions

Fat Lorenzo's Restaurant in Minneapolis, MN provided lunch for the disaster drill.

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