RESEARCH ARTICLE

Preparing Families of Technology-Dependent Children for Emergencies

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ABSTRACT

OBJECTIVES: To characterize the baseline level of emergency preparedness among families of technology-dependent children admitted to our PICU and to determine if an ICU-based planning intervention can sustainably improve families' disaster preparedness.

METHODS: A single-arm, survey-based study used to assess participants' preparedness to handle a 72-hour home power outage on the basis of a novel 8-point checklist. Parents of patients in the study completed the survey questions when their child was admitted to the PICU, discharged, or transferred from the PICU, after at least 2 weeks at home, and after at least 6 months at home. This study included a cohort of 50 children younger than18 years old who required daily use of at least 1 piece of qualifying electronic medical equipment at home and their custodial parents. The checklist surveyed was designed with the goals of maximizing care capacity at home during a power outage and planning for evacuation. Counseling and other resources were provided on the basis of item completion at admission assessment.

RESULTS: Patients' families completed a median of 3 items (range: 0–8; $N = 50$) at admission, 4 items (range: 1–8; $n = 45$) at discharge, and 7 items (range: 3–8; $n = 37$) at the 2-week follow-up and retained 7 items (range: 5–8; $n = 29$) at the 6-month follow-up. Completion rates were significantly higher at each follow-up time point compared with baseline ($P < .001$).

CONCLUSIONS: Families of technology-dependent children admitted to our PICU have significant disaster-preparedness needs, which can be addressed with an inpatient intervention.

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Estimates of the prevalence of children with special health care needs (CSHCN) includes up to 20% of households.[1] Children with medical complexity, a subset of CSHCN, make up a much smaller portion of the population but account for a larger portion of the health care cost, most of which occurs during inpatient admission. Coller et al[2] found that complications associated with the technology used by this population were frequently related to potentially preventable admissions. This population is underrepresented in disaster-preparedness literature.[3] All children are known to be more vulnerable than adults in times of emergencies or disasters because of physiologic, psychological, and developmental differences.[4] Families of children with medical complexity often rely on medical technology dependent on electricity, which may be unavailable in the event of an emergency, heightening the vulnerability of those children.

Data reveal that families of children who are technology dependent are insufficiently prepared to manage their children's health care needs during prolonged power failures. After the 2003 New York City blackout, 11 children dependent on home respiratory support were admitted to a local PICU solely because of respiratory-device failure.[5] Similarly, after the 2011 earthquake in eastern Japan, 55% of all pediatric patients in the area who were technology dependent and 89% of patients requiring a ventilator were admitted to a hospital.[6] These hospitalizations represent a preventable surge of admissions after disaster events.

Studies conducted in the outpatient or emergency department setting have identified specific gaps in disaster preparedness among families of children who are technology dependent. Baker and Baker[1] studied families of CSHCN and found that they often lacked an emergency kit and communication plan and that this population's preparedness level was also significantly lower than that found in similar studies of the general population. A subsequent study revealed a similar result for similar cohorts in different geographic locations.[7] A third study revealed that an educational intervention led to improvement in preparedness when assessed 30 days later.[8] Sakashita et al[9] found that only 19 of 35 families of children using a ventilator, oxygen concentrator, or feeding pump could identify whether that machine had a back-up battery and that only 22 of 50 families of children reliant on electricity-powered technology had a prolonged power failure plan.

Hospital admission provides a unique opportunity to identify and address preparedness gaps. Technology-dependent children admitted to a PICU likely represent a particularly vulnerable population. We conducted a single-arm study to characterize the baseline level of emergency preparedness among families of technology-dependent children admitted to our PICU and to determine if an ICU-based planning intervention could sustainably improve families' disaster preparedness.

METHODS

Study Population

Study subjects included a cohort of 50 children admitted to an urban PICU and their custodial parents. A power calculation was completed before the start of the study by using the results of the Sakashita et al[9] trial as the estimate for baseline preparedness in this population because that study population was the most closely matched in the literature. To show an increase in preparedness from ∼50% of subjects in that trial to 75% in this trial (an increased considered by the authors of this trial to be a significant difference), at least 38 subjects would need to be enrolled. Eligibility criteria included child age <18 years and daily use of at least 1 piece of qualifying electronic medical equipment at home before admission. Qualifying equipment was defined as a device without which the patient would likely require medical intervention within 24 hours. For this reason, exclusion criteria included exclusive use of mobility devices or respiratory adjunct devices such as nebulizers or humidifiers. Non–English speaking parents were also excluded. Verbal consent was obtained from the custodial parent before enrollment, and when appropriate, verbal assent was obtained from the child if over the age of 7 years and able to answer questions at the time of the initial interview. Of note, of families approached, only 1 family declined to participate; no children declined to assent.

Study Design

A quantitative and qualitative survey was designed to characterize the child's technology dependence and to assess the extent to which families would be prepared to care for their technology-dependent child during a 72-hour power failure. The first author acted as the sole surveyor throughout the study period. Study subjects were selected on the basis of daily review of the PICU census during periods when the first author was not responsible for caring for patients in the unit, although families were informed that the surveyor was in the rotation of hospital staff who cared for patients in that unit. Families of patients who met study criteria and were expected to have a PICU length of stay >48 hours were approached by the surveyor after introduction by a member of the care team as soon as practically possible after admission. Completion of the phase 1 survey took 15 to 30 minutes; subsequent phases took <10 minutes. Families were informed of the time commitment and the 3 subsequent surveys at the first visit. Phone numbers for follow-up were obtained at that time directly from the families. They were also given a written information sheet about the project, which contained this information. Surveys were completed verbally by the person who identified as being primarily responsible for caring for the child. If both parents were present and wished to complete the questionnaire together, then the recorded answer represented a consensus between the 2. Responses to open-ended questions were transcribed verbatim by the surveyor.

Preparedness was assessed by using an 8-item checklist used to evaluate strategies to maximize care capacity at home as well as plans for evacuation if needed. Checklist items were chosen on the basis of a review of disaster-preparedness literature and discussions with parents of technology-dependent children who were members of

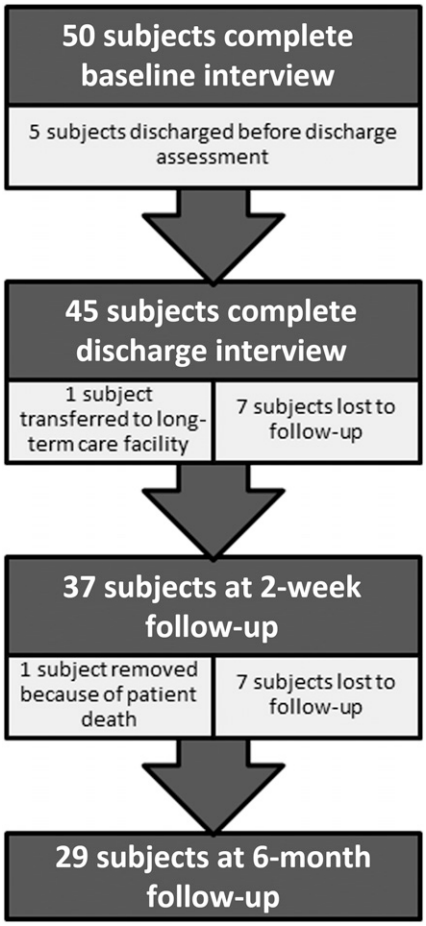

FIGURE 1 Flow of subjects through the study.

our hospital's Family Advisory Council. Please see Supplemental Table 4 for a list of the checklist items, the rationale for including each (with references to the articles in which each has been reported previously in the literature), the requirement for completion of each item, and interventions if the item was not completed at the baseline interview. Face validity of the survey tool was assessed before enrollment of subjects by reviewing the questions with the parents of 2 patients in the PICU who were technology dependent. The parents were asked to read the questions and restate each item in their own words. Minor adjustments to item language were made in response.

Preparedness was assessed at baseline (as soon as practicable after the child's admission), at PICU discharge, and 2 weeks and 6 months after hospital discharge. After collection of baseline data, a targeted educational intervention was performed, specifically addressing each deficiency identified by the preparedness checklist; interventions provided for each specific item are listed in Supplemental Table 4. Follow-up preparedness assessments were conducted at PICU discharge, and after ≥2 weeks and ≥6 months spent at home.

Initial and discharge surveys were completed in person, whereas the 2-week and 6-month follow-up surveys were completed over the phone. Up to 3 attempts were made to contact the caregiver, and only those caregivers who completed the 2-week follow-up were contacted at 6 months. The study was approved by our institutional review board.

Preparedness Checklist Items and Educational Intervention

The study intervention was the provision of information and materials to parents of children who were technology dependent to improve their ability to care for their children in the case of a prolonged power failure on the basis of any deficiencies noted in the baseline assessment. The materials and education were provided by a study investigator immediately after the baseline survey and preparedness assessment. The education and materials were designed to address 8 preparedness items selected from a review of disaster-preparedness literature (see Supplemental Table 4 for specific references). Checklist items are described in detail in Supplemental Table 4.

Statistical Analysis

The median number of checklist items complete at each time point was compared by using the Friedman test for nonparametric data with multiple repeated samples. Comparisons of the overall checklist at each individual time point were then performed by using Wilcoxon rank tests. Completion of individual items at specific time points was assessed by using the McNemar test for paired samples.

RESULTS

Fifty baseline assessments were completed between February 2016 and December 2016. The flow of subjects through the study is shown in Fig 1. Children in the study used a median of 4 (range: 1–5) qualifying devices daily, with a median daily duration of use of 15.5 hours (range: 1–24 hours). Twenty subjects reported continuous use of at least 1 device. Subject demographics are detailed in Table 1.

Twenty-three of 50 parents (46%) reported that they had called 9-1-1 or taken their child to a hospital simply because of a past power outage or that they would expect to do so if they experienced a prolonged power failure in the future.

TABLE 1 Subject Demographics

Demographic	Value (N = 50)
Child's age, y, median (range)	3.5 (0.4–17)
Total length of stay in the PICU, d, median (range)	3 (1–35)
No. devices used at home, median (range)	4 (1–5)
Individual devices, *n* (%)	
Feeding pump	46 (92)
Suction	43 (86)
Oxygen monitor	37 (74)
Oxygen concentrator	22 (44)
Mechanical vent	14 (24)
BiPAP	10 (20)
CPAP	2 (4)
Device-use duration, median (range)	2 y (3 d–15 y)
Hours per d for most-used device, median (range)	15.5 (1–24)

BiPAP, bilevel positive airway pressure; CPAP, continuous positive airway pressure.

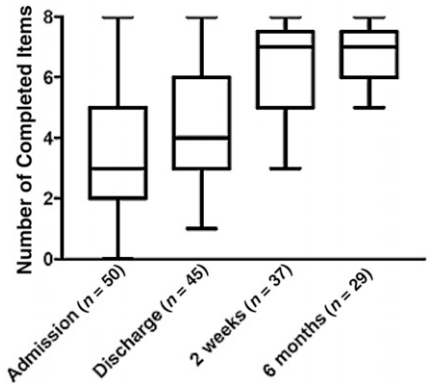

FIGURE 2 Checklist-item completion for all subjects available at each interview phase. Paired checklist-item completion at each phase for 29 subjects managed through 6 months can be found in Supplemental Fig 3.

Thirteen parents reported they had experienced a power failure lasting at least 6 hours since the child had been at home using electronic medical equipment, and 11 of those parents used an alternate power source or left home during that time. Of the 2 remaining subjects in this category, 1 was preparing to leave when the power came back on at ~6 hours. Twenty-four of the 50 subjects surveyed reported having access to a generator or other alternate power source.

The 8-item preparedness assessment was evaluated on admission ($N = 50$), at discharge ($n = 45$), 2 weeks after discharge ($n = 37$), and 6 months after discharge ($n = 29$). Overall, subjects completed a median of 3 items (range: 0–8) at admission, 4 items (range: 1–8) at discharge, and 7 items (range: 3–8) at the 2-week follow-up and retained 7 items (range: 5–8) at the 6-month follow-up (Fig 2). Completion rates were significantly higher at each follow-up time point compared with baseline ($P < .001$). This finding was unchanged when only the 29 families with complete data sets were included. Supplemental Figure 3 reveals the median and interquartile range at each phase for the subgroup of subjects who completed all phases; these numbers were not significantly different when compared with the entire cohort.

The impact of the intervention on each individual checkpoint item was also assessed. Significant improvement was seen in the proportion of families who had successfully completed 5 of the 8 checklist items at discharge compared with admission. At 6 months, significant improvement was seen in 7 of the 8 items (Tables 2 and 3).

During the 18-month study period, 19 children from the original cohort of 50 were readmitted to our PICU at least once (32 total readmissions); 1 has remained in a subacute care facility, and 1 has died. The subgroup that required readmission represents a large portion of the cohort. They were not resurveyed on readmission, although additional resources were provided if they were requested by the family. In the subgroup analysis, those 19 families had a median completion of 3 items (range: 1–6) on admission, 4 items (range: 1–6) on initial discharge, 6 items (range: 3–8) 2 weeks after discharge from initial admission, and 7 items[5–8] 6 months after discharge from initial admission. Despite repeat exposure to our PICU, the results from this group did not reveal a significant difference from the analysis of the entire cohort.

TABLE 2 Proportion of Subjects Who Completed Each Checklist Item at Each Interview Phase for All Available Subjects

Checklist Item	Admission ($N = 50$)	Discharge ($n = 45$)		2-wk Follow-up ($n = 37$)		6-mo Follow-up ($n = 29$)	
	n (%)	*n* (%)	*P*	*n* (%)	*P*	*n* (%)	*P*
Phone list	15 (30)	19 (42)	.041	31 (84)	<.001	24 (83)	<.001
Emergency form	25 (50)	28 (62)	.041	35 (95)	<.001	26 (90)	<.001
3 days of supplies	38 (76)	37 (82)	.248	36 (97)	.008	25 (86)	.289
Go bag	20 (40)	20 (44)	.248	27 (73)	<.001	26 (90)	<.001
Machine backup	31 (62)	35 (78)	.023	31 (84)	.023	27 (93)	.026
Evacuation plan	11 (22)	15 (33)	.041	20 (54)	<.001	22 (76)	<.001
Neighborhood resources	22 (44)	23 (51)	.134	24 (65)	.003	19 (66)	.016
Utility company	19 (38)	28 (62)	.003	31 (84)	<.001	24 (83)	.002

P values indicate results of the McNemar test, used to compare a paired sample of only subjects when complete data were available for a given interview phase.

DISCUSSION

We found that a simple inpatient educational intervention can significantly and lastingly improve the level of disaster preparedness for families of children who are technology dependent. The American Thoracic Society has recommended that emergency preparedness be part of discharge planning for children on home ventilator support.[10] We agree that an inpatient admission offers a valuable opportunity to identify and address gaps in family's disaster preparedness. Inpatient intervention also allowed for introduction of resources at a time when the subject is a captive audience with access to medical care and care management teams.

Although we conducted this intervention in a PICU, all of the information and education we provided could, and should, be provided to eligible families during all hospital admissions. We suggest that the 8-item checklist we developed for this study serve as a tool for assessing and improving family's preparedness. The use of the checklist in the PICU setting allowed for a cohort of patients who had dependence on more machines for a greater portion of the day than previously reported,[9] but the intervention would likely benefit all levels of technology dependence.

In our cohort, drawn largely from New York City, a high proportion of families did not have access to alternate power sources such as generators. For this population, ensuring that families are registered with the local utility company as having an individual who requires life-sustaining equipment in the home and ensuring that families are fully familiar with the use of

TABLE 3 Proportion of Subjects Available for All 4 Study Phases Who Completed Each Checklist Item at Each Phase

Checklist Item	Admission (n = 29)	Discharge (n = 29)		2-wk Follow-up (n = 29)		6-mo Follow-up (n = 29)	
	n (%)	*n* (%)	*P*	*n* (%)	*P*	*n* (%)	*P*
Phone list	7 (24)	11 (38)	.134	23 (79)	<.001	24 (83)	<.001
Emergency form	9 (31)	14 (48)	.074	27 (93)	<.001	26 (90)	<.001
3 days of supplies	21 (72)	24 (83)	.248	28 (96)	.023	25 (86)	.289
Go bag	10 (34)	13 (45)	.248	21 (72)	.003	26 (90)	<.001
Machine backup	18 (62)	23 (79)	.074	24 (83)	.041	27 (93)	.026
Evacuation plan	5 (17)	10 (34)	.074	15 (52)	.004	22 (76)	<.001
Neighborhood resources	9 (31)	12 (41)	.248	18 (62)	.008	19 (66)	.016
Utility company	11 (38)	21 (72)	.004	25 (86)	<.001	24 (83)	.002

P values indicate results of the McNemar test.

back-up batteries are items of particular importance. Hospitals serving different regions of the country will likely encounter different needs specific to their populations.

The reported level of disaster preparedness significantly increased for the study cohort, with a lasting effect that carried through 6 months. The biggest gains were seen in completion of the written phone list, the emergency health information form, and the utility company registration. In this study, the checklist was administered by a PICU fellow who was not on the care team at the time, but it could be accomplished by a variety of care planning team members with the help of the primary care team. Further work is needed to determine how best to incorporate this education and provide families with needed materials as part of routine discharge planning. This approach will allow for the maximum potential impact, with the least burden on the medical care team.

This study was limited primarily by reliance on parent report of item completion. Further limitations include the exclusion of non–English speaking subjects, incomplete follow-up, and lack of conclusive evidence that completion of the items on our checklist will meaningfully impact family behaviors during an actual disaster. Although a significant number of families did not complete all 4 phases, Table 3 and Supplemental Fig 3 reveal that the 29 families who did complete them did not have significantly different results from baseline when compared with the entire cohort. There is also possible concern about power differential on follow-up given that the surveyor was also sometimes responsible for the health care of the subjects. Each family was told that the survey was not a test and that their answers would not impact when their child would be able to leave the ICU. The surveyor was in training at the time, and all final decisions regarding discharge were made by the supervising attending physician on service, who was not involved with the study.

CONCLUSIONS

Families of technology-dependent children admitted to our PICU have significant disaster-preparedness needs, which can be addressed with an inpatient intervention. Further research is needed to determine if planning for a large disaster can help families become more resilient in the face of smaller emergencies at home and if this can decrease the readmission rate. A comprehensive, team-based approach that includes both inpatient and outpatient interventions will likely have the greatest effect on reducing the vulnerability of this population.

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