

Disaster Preparedness and Families of Children with Special Needs: A Geographic Comparison

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Abstract Over eleven million children in the United States have special health care needs. These unique needs can burden community and emergency responders after a disaster, complicating rescue and recovery efforts and generating reunification needs. Family disaster preparedness can help to moderate the extent that community resources are utilized by preparing families to be self-sustaining after a disaster and streamline access to medical care when needed. This study explored differences in two populations of families of children with special health care needs to determine if geographic differences exist in preparedness levels and whether a brief education intervention would prove successful in increasing baseline preparedness levels across both populations. A brief education intervention was delivered by trained community health educators to 210 families of children with special health care needs. A quasiexperimental pre-posttest design was used to compare baseline preparedness levels and 1 month follow-up levels. Although there was no difference in preparedness levels based on geographic location, both populations demonstrated a statistically significant increase in preparedness levels post-intervention. This study provides additional evidence that a brief education intervention

helps to increase preparedness levels among families of children with special health care needs.

Keywords Disaster preparedness · Children · Special needs · Education

Introduction

The number of families with special needs children is alarming. Estimates suggest that 15–20 % of U.S. households, over eleven million children, have special needs with complex care, and their care is complex (American College of Emergency Physicians [1], NSCSHCN [19]). The 2009/2010 National Survey of Children with Special Health Care Needs reported that nationwide, 90 % of special needs children (over nine million) require between two and seven specific health care services or needs for specialized equipment. Caring for children with special needs during a disaster can present difficulties for rescue and recovery efforts by complicating triage and stressing resources, as well as generating unique reunification needs (Chung and Shannon [6]). Local and community health resources can be easily depleted in the absence of family preparedness. However despite the gravity of the problem, little empirical research has been conducted on families with special needs children. In this article, we address the problem of deficiencies in disaster preparedness in the vulnerable population of families with special needs children. The purpose of the study is twofold. First, we sought to determine whether geographic differences exist in levels of preparedness of families with special needs children. Geographic differences reflect the type of disaster a family is more likely to experience. Second, we investigated the effectiveness of a brief educational intervention with pre-test/post-test interviews.

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Background

The US Department of Health and Human Services (DHHS) defines children with special health care needs as “those who have or are at increased risk for a chronic physical, developmental, behavioral or emotion condition and who require health and related services of a type or amount beyond that required by children generally” (McPherson et al. [16]). Disaster preparedness for families with special needs children is of critical importance, but it is a symptom of the broader problem of lack of preparedness across populations. The National Center for Disaster Preparedness [18] found that less than half the general public has an emergency plan and that only one-third felt prepared for a disaster. A similar study conducted by [7] also found low levels of preparedness. It is also notable that despite public health education efforts and mass media communication coverage of disasters such as Hurricane Katrina, levels of disaster preparedness appear to have changed little over time. Redlener and Berman’s [22] review of the literature from 1940 to 2005 found no significant difference in disaster preparedness in the general public.

Perhaps the most vital piece of educational information across all populations is the understanding that help may not be immediately available when a disaster strikes. FEMA [10] recommends that families devise a disaster plan to prepare to sustain themselves for a minimum of 3 days, because it may take up to 72 h for emergency personnel to reach a disaster site. According to [18], two-thirds of the general public believes that help will arrive within hours of a disaster. This is a dangerous assumption, particularly for vulnerable populations such as children, the elderly, and individuals with medical or other special needs.

According to [11], one additional piece of key information needed for personal disaster preparedness is understanding how to best prepare for specific types of disaster likely to occur in one’s geographic location (FEMA and ARC [11]). Natural disasters are not entirely unpredictable and research suggests that the general public is aware of the type of disaster that is more likely to affect their region (Viscusi and Zeckhauser [25]). However, immediate warnings for an impending natural disaster can vary considerably. For example, the approximate location for a hurricane strike may be known a week in advance, but a tornado warning may have only 15 min advance warning (Gad-el-Hak [12]). In addition, the magnitude, duration, and scope also vary for diverse natural disasters such as hurricanes, tornados, wildfires, floods, snowstorms, earthquakes, etc.

Among vulnerable populations, the evidence suggests that personal planning for disasters of any type requires not

only stockpiling resources but also maintaining multiple communication plans (Baker and Baker [2], Eisenman et al. [9], Murphy et al. [17]). For example, medical plans may require frequent updating, which is more time consuming than storing basic supplies such as food, water, and batteries. If an up-to-date medical plan is not available, first responders may need to treat and diagnose children with limited information which both restricts the ability to provide optimal care and consumes significant time, energy, and resources from relief and recovery efforts. The consequences of failure to prepare reach beyond the effects to vulnerable populations themselves, for the extra time and care they require creates an additional burden on emergency response efforts, delaying provision of services to all (Callaghan et al. [5], Nick et al. [21], Uscher-Pines et al. [24]).

Children are particularly vulnerable in disasters for a variety of reasons. As several researchers have noted, disasters may occur far from pediatric hospitals and first responders and general hospital staff may not be adequately trained or staffed to care for children (Kanter [14], Johnston and Redlener [15]). Children can add an extra burden to a crisis if they need to be transferred to specialty hospitals. In the chaos of a disaster, children may be separated from the parents. Young children in particular may be unable to communicate special medical problems or even identify who they are. In 2011, after an F4 tornado struck the small city of Tuscaloosa, Alabama (population approx. 90,000), dozens of unaccompanied children presented to their regional medical center (Kanter [15]). When Hurricane Katrina hit the New Orleans over 5,000 children were reported missing or separated from their families (Broughton et al. [4]).

A recent meta-analysis of the available literature on public health emergency preparedness literature found little empirical data on pediatric care in major disasters (Yeager et al. [26]). Even less is known about disaster preparedness for children with special needs even though they comprise a significant proportion of the pediatric population and are especially vulnerable in the event of a disaster (Dolan and Krug [8]). Addressing families with special needs is critical for disaster response due to the sheer raw numbers of those affected, the potential life-threatening consequences of lapses in health care, and the secondary burdening of relief and recovery efforts. Our current study is built upon previous findings of the lead author conducted at Children’s Hospital of Alabama which demonstrated that families with special needs children were not sufficiently prepared for a disaster (Baker and Baker [2]). In brief, it was found that over 88 % of the families surveyed did not have a personal disaster kit and 90 % had no family communication plan even though 50 % of the families had a child that had multiple health care needs. In this study,

we sought to understand the extent to which the types of disaster likely to affect a region made a difference in levels of preparedness.

We assessed differences in disaster preparedness in two Southeastern U.S. populations of families with children with special healthcare needs. One population was located in Birmingham, Alabama and the other in Ft. Lauderdale, Florida. Alabama, along with Mississippi, Arkansas, and Louisiana are the southeastern states having the highest frequency of strong (F/EF-2 to F/EF-3) and violent tornadoes (F/EF-4 to F/EF-5) and is where the greatest number of casualties occur (Southeast Regional Climate Center [23]). Historically, Fort Lauderdale (in South Florida) averages a direct hit from a hurricane (i.e. Atlantic tropical cyclone) every 5.6 years and is affected by a neighboring hurricane every 2.2 years (Hurricane City Database [13]).

Present Study

Based on the review of literature and results of prior studies on preparedness we explored two specific hypotheses. First, we hypothesized that families of children with special healthcare needs who are living in geographic areas with a high likelihood of a significant, large scale disaster will exhibit a higher level of baseline preparedness than those living in a more moderate risk area. Second, we hypothesized that a brief psycho-educational intervention will result in higher levels of preparedness on quantitative assessment of preparedness at 30 days post-intervention than levels prior to intervention, regardless of geographic area. The second hypothesis was set forth to confirm results from an earlier study on preparedness interventions (Baker and Baker [2]). In addition, the authors wanted to explore mediating variables for baseline levels of preparedness among the combined population that included (1) whether or not the family has been affected by a large scale disaster, (2) the level of concern that a family has about specific types of disasters, and (3) the healthcare needs of the child.

Method

Participants and Population Comparisons

A convenience sample of families of children with special healthcare needs was recruited from two different geographic locations over a consecutive 3 month period in 2010–2011. The first location included three specialty care clinics in a large, inland urban children's hospital in Alabama. Participating clinics included the specialties of Pulmonary, Endocrine and Neurological services. The second location was a large pediatric clinic located in South Florida that provided specialty and primary care

services for families living in a coastal, urban community. The geographic area surrounding the Florida clinic has a significant history of natural disasters including direct impacts from large scale hurricanes over the past 5 years. Community educators, trained in research methods and intervention delivery, approached families in clinic waiting rooms and provided information about the study. Families needed to identify an English speaking parent or guardian willing to participate. The identified parent or guardian was provided with Informed Consent prior to initiation of the survey and intervention. After obtaining consent, educators utilized a guided interview to direct families through a self-report quantitative measure of individual preparedness (such as Blessman et al. [3]) that covers multiple aspects of preparedness activities, as well as a brief demographic questionnaire, prior to receiving the intervention (pre-test). Participants were then contacted by phone approximately 30–45 days after the initial contact to complete an identical survey (post-test). A minimum of three attempts were made to conduct the follow-up survey. This study received approval from the Institutional Review Board at the University of Alabama at Birmingham and Broward Health Care of Florida.

In total, 210 parents provided consent to participate; 114 from the Alabama region (AL) and 96 from the Florida region (FL). The majority of respondents from the Alabama region were married (64 %) as opposed to single (15 %). Respondents in the Florida region were more likely to be single, never married (43 %) than married (27 %). Additional demographic information of the two populations is outlined in Table 1. Information collected on the children's healthcare status indicated significant needs across both populations, including 75.9 % of children needing daily medication, 29.7 % needing a nebulizer, 4.1 % needing a home ventilator, and 69.1 % having multiple healthcare needs.

Sample characteristics for both populations were also explored in order to evaluate potential differences that may influence outcomes, based on the above hypothesis that preparedness may vary by geographic location. In addition to demographic variables, participants were asked to rate their level of concern about the likelihood of a disaster occurring in

Table 1 Demographic characteristics

	Minimum	Maximum	Mean	SD
Alabama				
Respondent age (n = 104)	21	64	39.36	8.40
Children in household	0	6	2.18	1.14
Florida (N = 93)				
Respondent age (n = 93)	19	71	38.08	11.59
Children in household	0	7	2.26	1.38

their area in the next 2 years. Ratings were recorded on a 5-point Likert scale ranging from 1 (extremely unlikely) to 5 (extremely likely). There were no significant differences in the level of concern about likelihood between the two populations for power outage, $t(206) = 1.178$, $p < .240$, or outbreak of disease, $t(207) = -.083$, $p < .935$. However there were significant differences by population for likelihood of terrorism, $t(207) = -2.698$, $p < .008$, and severe weather, $t(207) = 3.492$, $p < .001$ with the FL population indicating higher levels of likelihood about terrorism ($M = 2.42$, $SD = 1.285$) than the AL population ($M = 2.0$, $SD = .892$), and the AL population indicating higher levels of likelihood about severe weather ($M = 3.81$, $SD = 1.136$) than the FL population ($M = 3.22$, $SD = 1.290$).

Research Design

A one-group pretest–posttest design $O_1 X_1 O_2$ with a 1-month follow-up was selected to evaluate the effectiveness of the education intervention. This design is commonly utilized in social science research when a control group is not available or is not deemed to be necessary (Neuman [20]). In the present study the researchers elected to not include a control group since general population data is available on baseline levels of personal preparedness. This design allows for comparison of pretest scores to posttest scores to determine if there has been an increase in the baseline level of preparedness as measured by the preparedness checklist.

Intervention

The brief intervention (10–20 min) was provided by one of the trained health educators. Educators used the preparedness survey as a guide to provide information on the effects of disasters, as well the three key elements of preparedness which include (1) being informed about potential disasters, (2) completing an emergency preparedness plan with family members, and (3) compiling a home disaster kit. Participants were provided with information handouts from the Federal Emergency Management Agency (FEMA), the American Red Cross (ARC) and the Department of Homeland Security (DHS) on disaster preparedness, as well as a *Family Emergency Plan* form from DHS and the *Emergency Information Form for Children with Special Needs* from the American Academy of Pediatrics (AAP). Specifically the intervention included an in-depth review of the preparedness information handouts, discussion of potential barriers that may inhibit completion of preparedness tasks and guidance for completing the health care forms with their care provided. Participants were encouraged to keep hard copies of the information for future reference.

Measures

Level of family preparedness was determined by use of an adapted version of the Family Preparedness Survey (Blessman 2007). The original survey is a 21-item paper and pencil survey that gathers information about preparedness based on the completion of indicators of preparedness, such as “Do you have a 3-day supply of water?”. The current study utilized a modified version that evaluates 16 preparedness indicators that are applicable to families of children with special healthcare needs (Fig. 1). Since the original survey has been altered the authors evaluated the internal consistency of the measure with the study population ($N = 210$) and found an adequate Cronbach’s $\alpha = .78$. This finding is similar to the alpha obtained in an earlier study by the authors using the 16-item scale in a sample of 149 where Cronbach’s $\alpha = .78$ (Baker and Baker [2]).

Results

Hypothesis Testing

Hypothesis #1: Families living in a high risk area will exhibit a higher level of baseline preparedness than those living in a lower risk area. The mean baseline preparedness score for the Florida sample (high risk) was 7.40 ($N = 114$) while the mean baseline for the Alabama sample ($N = 96$) was 7.14. There was no significant differences in preparedness scores between the two populations $t(175) = .518$, $p < .605$. The range of possible scores is 0–16, with 16 indicating that all preparedness indicators have been met. This sample included participants that only completed the pre-test ($N = 210$) as opposed to participants that completed both pre and post tests ($N = 102$).

Hypothesis #2: A brief psycho-educational intervention will result in higher levels of preparedness on quantitative assessment at 30 days post-intervention than levels prior to intervention, regardless of geographic area. There were significant differences in pre and post preparedness scores in both groups. The Alabama sample demonstrated a higher change in the mean scores from pre ($M = 7.58$) to post scores ($M = 9.37$) with the results reaching a level of significance $t(61) = -5.077$, $p < .000$. The Florida group also experienced a significant increase scores from pre ($M = 8.15$) to post ($M = 9.15$), $t(39) = -2.161$, $p < .037$.

Mediating Variables

The authors wanted to explore whether or not there were variables that influenced baseline preparedness scores. To this end, three specific variables were selected that the authors believed may mediate preparedness behaviors. The

Fig. 1 Family preparedness survey

Instructions: For the following set of questions, please indicate “Yes” if you have *completed* the following tasks at your home.

		Yes	No	N/A
1	Does your family have a written Family Emergency Communication Plan in case you are separated during a disaster?			
2	Does your family have a designated emergency meeting place outside of your <i>home</i> ?			
3	Does your family have a designated place to meet outside of your <i>neighborhood</i> ?			
4	Does your family have an Emergency Supply Kit that can last for 3 days?			
5	Does your family have a fire escape plan for your home?			
6	Does your family keep emergency supplies in each of your vehicles (blankets, flashlights)?			
7	Does your family have stored 3 gallons of water for each person in your household (3 day supply)?			
8	Does your family have enough stored food that does not need refrigeration or preparation that can sustain your family for 3 days?			
9	Is the food separated from your regular food supply?			
10	Do you have a working flashlight with an extra set of batteries in your home?			
11	Do you have a packaged first aid kit in your home?			
12	Do you have a container that is both fireproof and waterproof for storing important papers in your home?			
13	Do all family members over 14-years old know how to turn off the power, gas and water to your household in case of an emergency?			
14	Do you have a copy of your child's Medical Emergency Plan completed by his or her doctor?			
15	Do all children over 5 years old in your house know how to state their full name, address and phone number?			
16	Do you have an extra supply of medication on hand for family member requiring daily medication? How many days? _____			
	Total Score			

first variable was whether or not the family had been affected by a large scale disaster. Approximately 22 % of the sample population reported experiencing a large scale disaster ($N = 38$) as opposed to 78 % of the population that did not have such an experience ($N = 167$). The mean pre scores for those experiencing a disaster ($M = 7.37$) were not much higher than pre scores for those without

disaster experience ($M = 7.28$) and not surprisingly did not result in a statistically significant difference, $t(203) = .133$, $p < .894$. The authors also wanted to explore whether or not a family's level of concern about likelihood of specific disasters would influence baseline preparedness scores. Since initial analysis indicated no significant differences in the level of likelihood between

the two populations for power outage, or outbreak of disease, the entire study population was utilized to determine if there was a significant relationship among preparedness scores (0–16 scale) and concern about likelihood of these two categories of disasters (1–5 scale). There was not a significant correlation between preparedness scores and likelihood of power outage ($r = .112$, $p = .108$) or outbreak of disease ($r = -.07$, $p = .316$).

Since there *were* significant differences by population for concern about likelihood of terrorism and severe weather the Florida and Alabama populations were additionally explored as separate groups for these variables. In the Florida population there was not a significant correlation between preparedness scores and likelihood of terrorism ($r = .107$, $p = .300$) or preparedness scores and likelihood of severe weather ($r = .020$, $p = .845$). The same held true for the Alabama population as there were not significant correlations between preparedness scores and likelihood of terrorism ($r = -.135$, $p = .153$) and preparedness scores and likelihood of severe weather ($r = .019$, $p = .838$).

Discussion

We anticipated that differences would exist in preparedness between the Birmingham and Fort Lauderdale populations due to the types of disasters experienced in the past. Birmingham is located in a tornado-prone area, with a history of violent tornados, but which most often inflict only localized damage. Fort Lauderdale is located in a hurricane-prone area, with a history of causing widespread damage. However, there were no significant differences in the two populations in their levels of baseline preparedness. If we had found differences, it would have suggested that educational materials might be most effective if tailored to address the specific types of disasters occurring in given geographic regions. Although the hypothesis was not supported, it did provide valuable information, suggesting that the model of “all hazards” preparation may remain an effective educational tool. Our findings are also consistent with nation-wide studies that indicate that lack of preparedness is generalized problem across populations.

A positive finding was that administration of a brief educational tool improved levels of preparedness in both populations. While this outcome is encouraging, one limitation in determining the effectiveness of the intervention is that our follow-up assessment was conducted at a relatively brief time interval after the education, at 30 days. Further study is needed to determine if such an intervention is able to sustain improved levels of preparedness over the long-term. It will be important to determine how long such an educational intervention can maintain changes in

preparedness behavior in order to plan time and cost effective strategies for educational interventions.

Disaster preparedness is of vital importance for all populations. As previously described, national studies have revealed two disturbing generalizations. First, most of the general public is not prepared for a disaster and second, most hold the erroneous belief that help will arrive within a few hours after an event occurs. This is a dangerous combination, and even more so for families with children with special needs. The minimal level of readiness recommended by agencies such as FEMA and the American Red Cross of preparing a three-day survival kit are insufficient for families with special needs children; many have complex medical problems that may require refrigerated medications or specialized equipment needing a power source. Disaster preparedness in families with special needs children remains understudied even though one in five families have children with at least one special need. Effective interventions will not only serve to improve the health and survival of special needs children, but will also aid in the general effectiveness of disaster response. Greater efficiency in caring for special needs children will improve the overall ability for emergency personnel to respond to all people affected by a disaster.

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