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Impact of the 2021 north american winter storms on children with epilepsy

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ABSTRACT

Purpose: In February 2021 a series of winter storms caused power outages for nearly 10 million people in the United States, Northern Mexico and Canada. In Texas, the storms caused the worst energy infrastructure failure in state history, leading to shortages of water, food and heat for nearly a week. Impacts on health and well-being from natural disasters are greater in vulnerable populations such as individuals with chronic illnesses, for example due to supply chain disruptions. We aimed to determine the impact of the winter storm on our patient population of children with epilepsy (CWE).
Methods: We conducted a survey of families with CWE that are being followed at Dell Children's Medical Center in Austin, Texas.
Results: Of the 101 families who completed the survey, 62% were negatively affected by the storm. Twenty-five percent had to refill antiseizure medications during the week of disruptions, and of those needing refills, 68% had difficulties obtaining the medications, leading to nine patients—or 36% of those needing a refill—running out of medications and two emergency room visits because of seizures and lack of medications.
Conclusions: Our results demonstrate that close to 10% of all patients included in the survey completely ran out of antiseizure medications, and many more were affected by lack of water, heat, power and food. This infrastructure failure emphasizes the need for adequate disaster preparation for vulnerable populations such as children with epilepsy for the future.

Introduction

> *"For if medicine is really to accomplish its great task, it must intervene in political and social life. It must point out the hindrances that impede the normal social functioning of vital processes, and effect their removal."*
>
> Rudolf Virchow (1849).

In February 2021 a series of winter storms caused power outages for nearly 10 million people in the United States, Northern Mexico and Canada. In Texas, the storms caused the worst energy infrastructure failure in state history (known as the "2021 Texas power crisis"), leading to shortages of water, food, power and heat for days with an impact on the majority of the state's population [1]. Power outages affected 69 % of residents statewide, and up to 75 % of residents reported difficulties in procuring food. The reported death toll in Texas was 246, although some sources estimate over 700 fatalities related directly or indirectly to the storm [2,3]. Ten percent of deaths were attributed to exacerbated preexisting illnesses[3]. Pharmacies and physician offices were closed for days, and hospitals struggled with deliveries of medical supplies and low water pressure.

Increases in seizure frequency have been observed on several occasions after natural disasters such as earthquakes, possibly as a combination of increased stress and restricted access to medications and medical care[4,5]. Children with epilepsy (CWE) are particularly vulnerable to running out of medications due to disruptions in the supply chain. In addition, altered sleep patterns, temperature changes and stress are known seizure precipitants [6,7]. After the storm, many parents of CWE reported running out of antiseizure medications. We aimed to better quantify the impact of the winter storm infrastructure failure on our patient population of CWE using a survey. This could help guide development of interventions to improve preparedness for future events.

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Methods

We performed a language-concordant cross-sectional survey of families with CWE about the impact of the 2021 winter storm. Study data were collected using REDCap (Research Electronic Data Capture) tools hosted at Ascension. Families of children with epilepsy treated at Dell Children's Medical Center in 2020 and 2021 were contacted via phone or text message in English or Spanish, based on their preferred language. All questions were multiple choice except for one open-ended question ("What additional concerns would you like to share?", see supplemental figure). Survey responses were de-identified, multiple entries were avoided by phone number identification. This study was determined to be exempt by the UT IRB.

Results

Two-hundred and eighty-six families were contacted, of which 257 (90 %) were English-speaking and 29 (10 %) Spanish-speaking families. One hundred and one surveys were included in the analysis (response rate 35 %). Of all respondents, 95 % were English speakers, and 5 % were Spanish speakers. Thirty-seven percent of English-speaking families and 17 % of Spanish-speaking families completed the survey (for survey questions, see supplemental figure).

The age distribution of CWE was 0–2 years at 7 %, 3–5 years at 19 %, 6–10 years at 28 % and 11 years and older at 46 %. For all ages, 24 % had daily seizures, 11 % had weekly seizures, 13 % had monthly seizures and 52 % had less than monthly seizures (Table 1).

A total of 62 % of families stated that they had been negatively affected by the storm. Of those affected, 73 % lost power and 68 % were without heating, with the majority losing power and heat for>24 h. In comparison, the state average duration of power outage was 42 h and average water disruption time 52 h[8]. Forty-three percent of families reported disruption in water supplies. Twenty-seven percent of our respondents did not have access to drinking water, and 30 % did not have enough food (Fig. 1a). During the week of weather disruptions, 25 % of CWE needed refills of their antiseizure medications (ASMs). Of those needing refills, 68 % reported difficulties refilling ASMs. Another 5 % reported difficulties refilling other medications. Reasons for inability to refill medications were dangerous road conditions (65 %), closed pharmacies (65 %) and/or delayed shipments (53 %) (multiple answers were permitted). A total of 23 % reported difficulties reaching the neurologist's office when trying to call with questions or to get a refill, and 18 % reported not getting calls back. Seventy-three percent of families trying to reach the neurology after-hours paging service with questions were unable to get through. Nine patients completely ran out of ASMs as a result of not being able to refill (9 % of all and 36 % of those needing a refill), five had an increase in seizure frequency or duration, and two went to the emergency room as a result of increased seizures after running out of medications (Fig. 1b). Several families reported an increase in seizure frequency or changes in behaviors despite having adequate supply of antiseizure medications, and many reported overall increased stress on parents because of worries about their children's condition (open question in the survey). Because of low responder rates from Spanish speaking families, we decided to combine results from both questionnaires rather than reporting them separately. Briefly, 40 % (2/5) Spanish-speaking responders had no power, heat and electricity, and 60 % (3/5) had difficulties procuring food. One family who called our office reported difficulties reaching us. No Spanish-speaking family in the survey needed a medication refill.

Table 1
Characteristics (language, age, seizure frequency) of our cohort. The majority of responders were English speaking; 46 % were over the age of 10 years and 54 % were under 10. Forty-eight percent had a seizure frequency of monthly or more, and 52 % less than monthly. Table 1**. Patient characteristics.**

Language Contacted / responded (%)	Age (years) n (%)	Seizure frequency n (%)
English 260 / 96 (37)	0–2 7 (7)	Daily 24 (24)
Spanish 29 / 5 (17)	3–5 19 (19)	Weekly 11 (11)
Total 289 / 101 (35)	6–10 28 (28)	Monthly 13 (13)
	>10 47 (46)	Less than monthly 53 (52)

Discussion

Almost 90 % of the Texas population depends on the Electric Reliability Council of Texas (ERCOT) for electricity, making energy supply in Texas particularly vulnerable to natural disaster disruptions[8]. In February 2021, a combination of multiple factors, including lack of winterization of the power generators, underestimated peak demand and misjudged severity of the storm, caused widespread power outages across the state, narrowly avoiding a complete statewide blackout[8]. Power outages caused supply chain disruptions in many areas of the state, thereby worsening access to medications and medical care.

Children with chronic illness are at higher risk for negative outcomes after disasters[9], and environmental disasters can cause major health impacts and worsen structural disparities[10]. We had a lower response rate to our survey from Spanish-speaking families compared to English-speaking families despite providing language-concordant surveys and sending out links to the survey via text messages to avoid phone calls. Underrepresentation of Spanish-speaking individuals in surveys is likely multifactorial [11]. Overall, Spanish-speaking families reported similar issues on the survey compared to English-speaking families, but because of the low response rate we were unable to assess for language-based disparities. Although we cannot rule out skewed results due to selection bias—a common problem with surveys—the overall rate of families negatively affected by the storm in our survey (62 %) matches statewide estimates of 60 %-70 %, suggesting that our results could be representative.

We showed that two-thirds of families had difficulties refilling their children's ASMs, and almost 10 percent of children included in the survey ran out of medications completely, resulting in increases in seizure frequency and emergency room visits. In any given week, the expected percentage of patients needing to refill medications will be around 25 %, consistent with our observations. When we asked families to comment about their situation that week, many emphasized the stress caused by worries about their child's health, and several reported an increase in seizure frequency despite having adequate medication supplies. Although we did not address the effect of stress directly in this survey, it might have contributed to worsening of seizures and certainly contributed to the overall impact the storm had on families.

Possible interventions to lessen the impact of future natural disasters could include automated reminders to families to refill their medications and stock up on supplies prior to forecasted weather changes, as well as working with insurances to provide individual emergency supply containing antiseizure medications, medical supplies and rescue medications for storage at home to bridge supply chain disruptions. And last, discussing these events during clinic appointments and offering referrals for counseling, if needed, could help with trauma management and increase preparedness for future events.

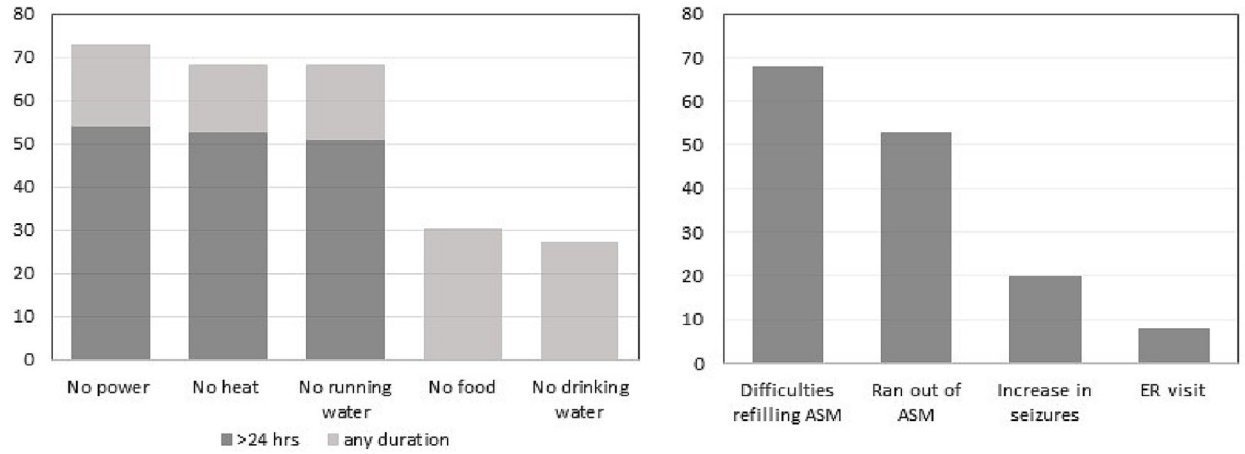

Fig. 1. Disruptions caused by the storms. Fig. 1: a) Basic needs disruptions caused by the storm. Y-axis shows percentage of families who experienced lack of power, heat, running water, food and/or drinking water for > 24 h (dark bars) or any duration (dark plus light bars) during the winter storm. b) Effect on epilepsy management on patients needing medication refills. Y-axis shows percentage of CWE who had difficulties refilling ASM, ran out of antiseizure medications, had an increase in seizure frequency as a result of running out of ASM or needed to go to the emergency room due to seizures during the winter storm week. ER emergency room, ASM antiseizure medication.

Conclusions

Climate change is regarded as one of the main causes for increases in frequency and severity of environmental disasters [12]. Major electric grid failures due to natural disasters have already occurred in Texas in 2011 and 2021. Our survey results from the 2021 winter storm demonstrate the vulnerability of CWE to supply chain disruptions and hindered access to medical care during severe weather conditions and infrastructure failures. Communities around the globe will increasingly experience environmental injustice and be disproportionally affected by climate change, likely worsening existing disparities. Disaster preparedness and emergency response require action. The specific needs of vulnerable populations such as children with epilepsy will require appropriate disaster preparations for consistent health care delivery to support their future well-being.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ebr.2023.100592.

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