

Experiences of Families with Children/Youth With Special Health Care Needs in a Focused Emergency Preparedness Intervention

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Introduction: Families with children and youth with special health care needs (CYSHCN) have enhanced requirements for staying safe in disasters and emergencies but tend to have low levels of household preparedness. Our goal was to explore associations between participant sociodemographic factors and experiences in a virtual home preparedness intervention (VHPI)—especially those related to preparedness barriers. Our interdisciplinary research team recently found improved preparedness metrics in a diverse sample of 170 family-caregivers of CYSHCN recruited from medical homes across Pennsylvania who participated in the VHPI. The VHPI included (1) CYSHCN-centered pre/post interviews on preparedness, the child's medical needs, and social determinants of health; (2) tailored preparedness information and a gift card; and (3) as-needed referrals to professionals in the medical home and community partners for resources. It culminated in semi-structured interviews (SSIs) (Table 1) in which participants provided feedback.

Methods: Approval for the project was obtained from the Drexel University College of Medicine Institutional Review Board (protocol no. 2305009880). The SSIs were audio recorded and transcribed verbatim. Using NVivo, conventional content analysis was applied to assign codes and identify sample-wide themes. Using cross-tabulations in NVivo and review of excerpts, the team then assessed whether participants with certain sociodemographic factors were disproportionately represented within certain themes.

Results: The participants (n = 143) had CYSHCN with reliance on medical equipment (64%), physical mobility needs (48%), intellectual or communication challenges (80%), and/or vision/hearing loss (39%) (Table 2). Emergent themes included (1) preparedness as a missing piece of health care, (2) expertise and action (3) self-efficacy, and (4) compassion and flexibility (Table 3). Prevailing preparedness barriers were limited financial resources, time constraints, communication with the CYSHCN/family, and access and functional needs of household members (Table 3). Whereas quantitative analysis of this sample (data not shown) demonstrated that living with an individual with a disability/functional need, in addition to the CYSHCN of focus, was associated with higher preparedness scores, the qualitative analyses indicated that these individuals were less likely to say that they felt confident in their preparedness or had no remaining preparedness barriers.

Conclusion: Participants generally felt that the VHPI was effective, attributing this to its delivery by an activated, supportive team. Future work should address incorporating elements of the VHPI into preventive care visits for CYSHCN in the medical home.

Table 1. Semi-structured interview given to participants after completing the virtual home preparedness intervention (VHPI)

Item	Prompt
1	Has this study changed your level of emergency preparedness for your family?
2	Is there any information you didn't know prior to the study that stood out to you?
3	Since the last time we met, have you made any changes with disaster and or emergency preparedness?
4	What are the remaining barriers you face when getting ready for different types of emergencies considering both your family and specifically [CYSHCN's name]?
5	What was it like to go through this process with our team?
6	Would you recommend that other caregivers of children with special medical needs (ie, parents/guardians), such as yourself, go through this process?
7	Is there anything our home assessment team did not cover that you would have liked us to cover? What could we have done better or differently?
8	<i>[Regarding component (2) of the VHPI: tailored preparedness information and gift card]</i> You should have received a packet of handouts from our study team. Do you remember receiving these? Did you get a chance to go over them? Were they easy to use, did you find them to be useful and did you consult anyone else while filling them out? Did any of the documents stand out to you, or were any documents particularly helpful for you?
9	Please tell us anything else you would like to share or feel you need more support with.

Table 2. Sociodemographic characteristics of the study sample (n = 143)

Characteristic	No. of Participants (%)
<i>Caregiver-specific items</i>	
Relationship of caregiver to CYSHCN	
Mother	115 (80.4)
Father	7 (4.9)
Grandmother	5 (3.5)
Foster parent	4 (2.8)
Other ^a	12 (8.4)
Race of primary caregiver	
White	58 (40.6)
Black or African American	47 (32.9)
Asian	5 (3.5)
American Indian or Alaskan Native	1 (0.7)
Other ^b	29 (20.3)
Did not specify	3 (2.1)
Ethnicity of primary caregiver	
Not Hispanic or Latino	90 (62.9)
Hispanic or Latino	53 (37.1)
Preferred language of primary caregiver^c	
English	125 (87.4)
Spanish	15 (10.5)
Other ^d	3 (2.1)
Employment status of primary caregiver	
Not employed	76 (53.1)
Employed full-time	41 (28.7)
Employed part-time	23 (16.1)
Multiple employment	3 (2.1)
<i>CYSHCN-specific items</i>	
Mean age (SD) of CYSHCN, years	9.1 (6.5)
Median age (range) of CYSHCN, years	7.6 (0.2 – 26.2)
Gender of CYSHCN	
Male	92 (64.3)
Female	51 (35.7)
Race of CYSHCN	
Black or African American	51 (35.7)
White	53 (37.1)
Asian	5 (3.5)
Other ^e	31 (21.7)
Did not specify	3 (2.1)
Ethnicity of CYSHCN	
Not Hispanic or Latino	78 (54.5)

Hispanic or Latino	65 (45.5)
Diagnostic category of CYSHCN^f	
Intellectual/cognitive challenges	115 (80.4)
Reliance on medical equipment/utility	92 (64.3)
Physical mobility impairment	68 (47.6)
Vision/hearing impairment	56 (39.2)
No. of diagnostic categories into which CYSHCN falls^f	
1	44 (30.8)
2	37 (25.9)
3	35 (24.5)
4	27 (18.9)
Use of home nursing/home health aide services	
No	76 (53.1)
Yes	67 (46.9)
Household-specific items	
Household income (annual, pretax)	
Less than \$15,000/year	28 (19.6)
\$15,000-24,999/year	16 (11.2)
\$25,000-34,999/year	14 (9.8)
\$35,000-49,999/year	17 (11.9)
\$50,000-74,999/year	11 (7.7)
\$75,000-\$99,999/year	6 (4.2)
\$100,000-149,999/year	2 (1.4)
\$150,000-199,999/year	1 (0.7)
Prefer not to answer	10 (7.0)
Unknown	38 (26.6)
Homeownership status	
Caregiver owns home, pays mortgage	55 (38.5)
Caregiver rents home	82 (57.3)
Other	6 (4.2)
Geographic area of residence^g	
Urban	126 (88.1)
Rural	17 (11.9)
Other individual(s) in the home with disability/functional need	
No	83 (58.0)
Yes	60 (42.0)

CYSHCN, children/youth with special health care needs; SD, standard deviation.

^aAdoptive mother (n = 4), mother and father (n = 2), grandfather's spouse (n = 1), legal guardian (n = 1), mother and foster parent (n = 4).

^bCaregivers who selected "Other" self-reported race as Hispanic (n = 21), Puerto Rican (or PR) (n = 2), Greek (n = 1), Brazilian (n = 1), American descendent of slaves (n = 1), and prefer not to answer (n = 2). One caregiver indicated both Black/African American and American Indian/Alaskan Native.

^cSemi-structured interviews were given in the caregiver's preferred language.

^dEnglish and Spanish (n = 2), Portuguese (Brazilian) (n = 1).

^eHispanic (n = 22), PR (n = 1), Puerto Rican and Peruvian (n = 1), White/Black (Brazilian) (n = 1), Greek (n = 1), American descendent of slaves (n = 1), prefers not to answer (n = 2). Two caregivers selected multiple race responses: Black or African American and White (n = 1), White and Asian (n = 1).

^fDiagnostic categories were assessed by medical record review.

^gUsing the county definition of rurality developed by the Center for Rural Pennsylvania and based on a population density of <291 people per square mile.

Table 3. Themes identified in the qualitative analysis and illustrative quotations.

Sample-wide Theme	Illustrative Quotation
Preparedness as a missing piece of health care	<ul style="list-style-type: none"> • “Who would you ever talk to about it? Your family doctor is not going to bring this stuff up...Other than from school, maybe you get a flyer saying, ‘Are you prepared for an emergency...?’ ...I think it's something that needs to be out there...parents of special needs kids get inundated with so many things, but it's like, “Who owns this piece? Nobody.”
Expertise and action of the research team centered on the CYSHCN	<ul style="list-style-type: none"> • “It was nice ‘cause...[DME provider] understood what I was trying to talk about, so it was obvious that he was knowledgeable in talking about that stuff. It wasn’t like, you know, he had no idea what a g-tube was.”
Building self-efficacy	<ul style="list-style-type: none"> • “Before, if his G tube comes out, I’ll be like, ‘All right, we’ll have to run around and grab this and this.’ And by the time we left the house and got to the hospital, a lot of times, it’s hard for them to put it back in. But now we even prepared for that like, ‘Oh, G tube is out? We got what we need, let’s go.’”
Compassion and flexibility from the research team	<ul style="list-style-type: none"> • “I’ve had so many true emergencies here, so I had to [reschedule the VHPI visit]...You really were very helpful and very compassionate...that is very appreciated because sometimes if you don't know a special needs child, or you haven't worked with one, or you don't have one, you don't know the challenges that one goes through.”
Preparedness Barrier	Illustrative Quotation
Limited financial resources	<ul style="list-style-type: none"> • “Well sometimes money is needed because there are things that needs money to be done and if you don't have it, well, you cannot do anything.”
Time constraints	<ul style="list-style-type: none"> • “Every day is a busy time...I do mostly like all the like... therapies for the whole day...So I am working and trying but...there are things, more pressing things, that get in the way sometimes.”
Communication with the CYSHCN/others	<ul style="list-style-type: none"> • “I guess the one of the biggest barriers is the fact that he's nonverbal...You know, he can't tell, you know, an EMT or whatever what his name is, and this and that” • “That's my concern is he's gonna fall off task because when you're talking to a child with autism, because they have so much going on in their heads, sometimes, it's like overwhelming for them.”

Living in a household with another individual with a disability or functional need (other than the CYSHCN of focus)

- “My...asthma might become a challenge. I tend to panic about it...and panic leads to asthma attacks, so that’s one thing.”
- “I have two kids with conditions...get them out of bed, and the machines. Yes, it is difficult with two kids.”
- “My biggest concerns would be... being able to help... if I'm stuck and I have to either choose. Because there could be an emergency where you have to choose... whether to help my mother or to help CYSHCN.”

CYSHCN, child/youth with special health care needs; DME, durable medical equipment; VHPI, virtual home preparedness intervention