

Original Research

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Addressing Health-Care Disparities in Pediatric Disaster Planning: A Qualitative Study

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Abstract

Objective: The Western Regional Alliance for Pediatric Emergency Medicine (WRAP-EM) is a multi-state, Administration for Strategic Preparedness and Response (ASPR) funded pediatric disaster center of excellence. WRAP-EM set out to determine the impact of health disparities on its 11 core areas.

Methods: We conducted 11 focus groups during April 2021. Discussions were led by an experienced facilitator, and participants could also include their thoughts on a Padlet throughout the discussion. Data were analyzed to determine overarching themes.

Results: Responses focused on health literacy, health disparities, resource opportunities, addressing obstacles, and resilience building. Health literacy data highlighted the need for development of readiness and preparedness plans, community engagement in cultural and language appropriate means, and increasing diversity in training. Obstacles faced included funding; inequitable distribution of research, resources, and supplies; lack of prioritization of pediatric needs; and fear of retribution from the system. Multiple already existing resources and programs were referenced highlighting the importance of best practice sharing and networking. A stronger commitment to mental health-care delivery, empowerment of individuals and communities, use of telemedicine, and ongoing cultural and diverse education were recurring themes.

Conclusions: Results of the focus groups can be used to prioritize efforts to address and improve health disparities in pediatric disaster preparedness.

A broad array of factors within the health-care system drive disparities in achieving health and accessing health care. Research reveals the role multiple factors, such as underlying genetics, health choices, social and environmental factors, and accessibility to health care integrally play in obtaining healthy outcomes.¹ The current severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) pandemic identified already pre-existing disparities in health care while also highlighting the inadequacies and shortfall of disaster preparedness for emergency health-care needs related to children.^{2–4}

Children's disparities occur across the spectrum of health care, including mortality, access to care, use of services, prevention, and quality of care.⁵ Children are often overlooked in plans for disaster management, and it is common to see generalizations occur in the management of pediatric populations during disasters.^{6,7} Pediatric patients are often treated as young adults, which thereby ignores the specific needs of a unique subset of the overall population. Furthermore, pediatric patients commonly arrive at adult hospitals during disaster scenarios and these facilities may not be prepared to receive influxes of children.⁸ Therefore, a critical component of any disaster planning program needs to address the specific needs and distinct vulnerabilities of the pediatric population.

With funding provided by the Assistant Secretary of Preparedness and Response (ASPR), WRAP-EM (Western Regional Alliance for Pediatric Emergency Management) was established as a Pediatric Disaster Care Center of Excellence (<https://wrap-em.org/>) comprised of six western states. Its goal is to provide leadership in pediatric disaster preparedness and to address the serious gaps in pediatric disaster management. WRAP-EM aims to serve as a trusted hub for resources and potential solutions to address the ongoing problem of health disparities among children as well as other critical disaster preparedness challenges for the pediatric population. In researching and studying disparities in health care for children during the SARS-CoV-2 pandemic, WRAP-EM intends to further delineate the nature of the health disparities and establish a framework for data review, information sharing and the provision of recommendations for pediatric patients.

Methods

Study Population and Recruitment

WRAP-EM is comprised of 11 focus groups which include Burns, Countermeasures, Deployable Assets, Evacuations, Mental Health, Obstetrics/Neonatal Intensive Care Unit, Patient Movement, Patients Tracking, Supply Chain, Surge and Telemedicine. Each group holds regularly scheduled meetings. Focus group discussions were conducted with each of these 11 groups during April 2021 during their designated meeting time.

Analytical Methods

Focus group discussions were led by experienced facilitators (I.N. and D.M.) using a structured focus group guide that was created to explore members' perspectives on health disparities in pediatric disaster preparedness, how it can be or has been successfully addressed in their respective domains, gaps in health literacy and preparedness, perceived challenges to addressing health disparities in pediatric disaster preparedness, and barriers and promoters of resilience. Participants were also able to add their comments using a Padlet during the focus group discussion. The Padlet is a cloud-based tool which allows for real-time collaboration in a virtual bulletin board format. Each group covered a specific topic area, but the Padlet questions were all standardized for consistency. Data from each group were downloaded into Microsoft Excel® and analyzed using preidentified themes and sub-themes. Conventional content analysis was used to assimilate the rich qualitative data of the focus groups. A set of codes was developed, the criteria for assigning a specific code to a block of text was systematically developed by A.S. The coding scheme was refined and expanded upon to reflect and incorporate emerging insights throughout the coding process.

Results

The following table (Table 1) categorizes the common themes identified in focus group discussions for each of the three areas of health literacy, health disparity, and resilience. Briefly, responses focused on health literacy, health disparities, resource opportunities, addressing obstacles, and resilience building. Health literacy data highlighted the need for development of readiness and preparedness plans, community engagement in cultural and language appropriate means, and increasing diversity in training. Obstacles faced included funding; inequitable distribution of research, resources, and supplies; lack of prioritization of pediatric needs; and fear of retribution from the system. Multiple existing resources and programs were referenced highlighting the importance of best practice sharing and networking. A stronger commitment to mental health-care delivery, empowerment of individuals and communities, use of telemedicine, and ongoing cultural and diverse education were recurring themes throughout all focus groups discussing resilience. All groups noted ongoing progress but also the need to continue to expand to meet the needs of the pediatric population. Resource gaps and possible solutions to filling those gaps were identified.

Discussion

Focus group responses centered on health disparities, health literacy, resource opportunities, addressing obstacles, and resilience building. All groups noted ongoing progress in the area of pediatric

disaster management but also the need to continue to expand to meet the needs of the pediatric population. Natural or man-made disasters present a tremendous threat to regions already suffering from limited resources and minimal access to care.⁹ Both of these factors, among other determinants of health, act as precursors to health-care disparities.¹⁰ Such health-care disparities are not usually explicitly accounted for in surge capacity modeling. While the field of disaster management gains more attention due to recent events, the impact of health-care and health-care disparities on disaster management remains out of the spotlight of discussion. Our focus groups broadly discussed health-care disparities but also aimed to highlight gaps and find opportunities for improvement within already established disaster models. Engaged conversation and discussion among the focus groups led to identification of not only unique themes individual to each focus group but common threads among all focus groups as well. The discussions provided valuable insight, knowledge, and understanding regarding disparities in pediatric disaster management. Throughout the discussions, the need to recognize the distinct vulnerabilities of the pediatric patient and unique requirements of various communities based on pre-existing medical, social, and economic conditions or region were cited as critical to effective disaster planning.

No direct association has been found in the literature between health literacy as related to health disparities¹¹; however, health literacy as related to healthy outcomes in children has been shown to have a strong association.¹² Furthermore, although dissemination of useful and practical information to the public has certainly advanced in the past two decades with ongoing research and assessments in health literacy,¹³ our focus groups highlighted multiple recurring themes regarding health literacy relating the importance of the public's understanding in times of emergencies. The group identified both the paucity of useful and practical disaster and safety information along with the complexity of some of the available material resulting in unnecessary difficulties for the public during an already stressful situation. Risk communication studies have previously shown that in high-concern, high-stress situations, the ability to process information diminishes and even more so if literacy rates are low or if there are language barriers.¹⁴ Within health literacy, the focus groups identified the need to address language barriers, provide children's resources, and establish best practices to share across common networks. Solutions included making available care instructions in multiple languages, the need to create and utilize resources for younger age groups, and providing education to hospital personnel. Focusing on community-centered care and establishing community leaders as disaster planning advocates were critical elements to expanding health literacy.

A majority of participants also identified gaps in care accessibility and delivery in rural areas. Research into health disparities in rural regions less resourced and less accessed have begun to inform an emerging literature highlighting just how under addressed the topic is.⁹ The need for plans for mobilization of care from more urban resourced areas into the rural communities as well as establishing predisaster care coordination networks and protocols were opportunities identified to improve care. The SARS-CoV-2 pandemic resulted in rapid and large-scale expansion of telemedicine providing lessons which can be used in disaster management. Similar innovative use of technology, whether to provide telemedicine, training, or communications, were all cited as methods to consider in addressing care disparities. Furthermore, the need to provide predisaster training and education to health-care personnel in rural areas confirms what Hsu *et al.* found in a cross-

Table 1. Themes and selected ideas and solutions addressing health literacy and health disparities

Theme (subthemes)	Ideas/solutions
<i>Health literacy</i>	
Addressing language barriers	<ul style="list-style-type: none"> • Provide discharge and after care instructions in primary language • Address fears of deportation if health care is sought
Children's resources	<ul style="list-style-type: none"> • Address the educational process starting at a younger age by creating age-appropriate material.
Best practice sharing and networking	<ul style="list-style-type: none"> • Promote assistance and education based resources such as Poison Control Centers, Doctors Without Borders, Pillowcase Project, Just In Time, state foster care programs
Providing white paper report	<ul style="list-style-type: none"> • Advocate for decision making in health literacy as a tool for Disaster Management
Establishing MOUs and disaster literacy programs	<ul style="list-style-type: none"> • Provide education for hospitals, EMS, transport systems, surrounding hospital facilities regarding best use of personnel and systems during disasters
Family education	<ul style="list-style-type: none"> • Create and disseminate language appropriate literature and education to families regarding disaster management
Engaging community organizations	<ul style="list-style-type: none"> • Enlist schools, school districts, PTAs to assist in disaster preparation • Enlist religious leaders, community leaders and organizers to encourage and assist with disaster preparation
Translation capabilities	<ul style="list-style-type: none"> • Arrange available translators in multiple languages
Family centered care model	<ul style="list-style-type: none"> • Encourage family centered care to empower groups to make choices toward better health outcomes
<i>Health disparities</i>	
Addressing specific populations	<ul style="list-style-type: none"> • Promote and encourage research related to specific socio-economic groups and special populations such as pediatrics
Telemedicine	<ul style="list-style-type: none"> • Utilize technology such as telemedicine to reach rural populations or tribal populations • Focus on specific critical needs such as mental health
Opportunities to add to current programs	<ul style="list-style-type: none"> • Recommend to CDC and SNS to specifically address pediatric population (ie, converting medications to pediatric doses); promote use of Psy-START
Utilization of current resources	<ul style="list-style-type: none"> • Adapt existing resources such as the COVID19 Fact sheet and create templates to address disparate populations regarding disaster responses • Support processes and national programs already in place addressing resilience
Developing supply chain, emergency teams, resources specifically geared for disparate populations	<ul style="list-style-type: none"> • Work with current working agencies and systems to adapt to address specific population such as pediatrics
Drills and exercises	<ul style="list-style-type: none"> • Re-design drills, triage, and exercises to address disparities • Develop objective criteria for assessment and avoiding subjective criteria
Ethics	<ul style="list-style-type: none"> • Involve Ethics committees in development of programs and exercises
Resource sharing and networking	<ul style="list-style-type: none"> • Collaborate with pre-established networks such as larger hospitals systems who more often have capacity to address surge management, disparities in health care, and fewer limitation in resources.
Gaps in mental health service	<ul style="list-style-type: none"> • Identify the critical need to address gaps in mental health care and services pre- and post-disaster events • Need to develop networks with current existing programs to address mental health needs
Limited funding	<ul style="list-style-type: none"> • Prevents development of programs, securing resources, supply establishment, and providing education – need to explore alternative sources of funding at national and regional level
Heightened awareness and recognition of at-risk populations	<ul style="list-style-type: none"> • Promote a culture of heightened awareness for at risk populations – children, certain socio-economic groups, elderly
Mobilizing care	<ul style="list-style-type: none"> • Explore opportunities and ideas to reach populations instead of assuming populations will seek health care when needed
<i>Resource opportunities</i>	
Telemedicine	<ul style="list-style-type: none"> • Improve infrastructure to support telemedicine via programs such as Regional Resiliency Assessment Program • Identify and apply for government funding available for telehealth support • Establish policies promoting and permitting telehealth
Virtual training	<ul style="list-style-type: none"> • Establish virtual programs to allow for broader reach in education and training (ie, Stop the Bleed program).
Funding from agencies geared toward disaster management and recovery	<ul style="list-style-type: none"> • Apply for funding from agencies providing support for disaster management and recovery: <ul style="list-style-type: none"> ○ American Rescue Plan Act ○ CDC ○ Regional Pediatric Pandemic Network Program ○ Non-profit organizations focused on relief ○ Robert Wood Johnson Foundation ○ National Institute of Health ○ Pediatric Disaster Coalition Grants ○ Local government funds ○ Rural Health Grants

(Continued)

Table 1. (Continued)

Theme (subthemes)	Ideas/solutions
Checklists and toolkits	<ul style="list-style-type: none"> • Use established toolkits such as: <ul style="list-style-type: none"> ○ National Pediatric Readiness Project Toolkit ○ TRAIN tool- provides equitable and medically based decision making for patient movement solutions
Network and best practice sharing	<ul style="list-style-type: none"> • Develop collaboratives and networks to share best practices and resources such as among emergency managers and emergency departments • Establish national and regional collaboratives to address key issues facing pediatric disaster management
Addressing Obstacles	
Limited transportation	<ul style="list-style-type: none"> • Consider alternative means of health-care delivery such as mobile clinics or telehealth
Scarce resources	<ul style="list-style-type: none"> • Establish collaborative networks for more equitable supply distribution
Care coordination	<ul style="list-style-type: none"> • Establish care coordinator with training to provide more global approach to health-care delivery for individuals
Difficulty obtaining follow-through with patients	<ul style="list-style-type: none"> • Establish additional means of communicating with patients either via telehealth, through arranged transportation, mobile clinics
Lack of pediatric representation	<ul style="list-style-type: none"> • Implement drills, protocols, programs, policies, space planning to consider pediatric population in development
Telecommunication limitations	<ul style="list-style-type: none"> • Need to address reimbursement challenges and state boundary limitations
Lack of championship	<ul style="list-style-type: none"> • Need to establish leadership and champion around pediatric disaster management
Funding	<ul style="list-style-type: none"> • Explore grants, programs, research, networks to overcome funding barriers
Language barriers	<ul style="list-style-type: none"> • Identify and understand language needs of the community to establish appropriate resources for communities
Protected data	<ul style="list-style-type: none"> • Need for centralized or sharing networks to develop protocols, best practices, legal processes to permit sharing of data
Cultural understandings and pre-established notions	<ul style="list-style-type: none"> • Need to understand and address cultural barriers, embrace and address skepticism
Cost of care	<ul style="list-style-type: none"> • Need to establish more equitable delivery and negotiations as related to cost of care as high healthcare costs preclude individuals from seeking care and health-care systems from delivering care;
Larger hospitals versus smaller hospitals and resource distribution	<ul style="list-style-type: none"> • Need to establish collaborative networks between those with greater resources to assist less resourced facilities
Shifting of focus due to COVID-19 pandemic	<ul style="list-style-type: none"> • Re-shift focus from more specific COVID management to more global disaster planning
Immigration concerns	<ul style="list-style-type: none"> • Develop policies that equitably deliver health care for all and address fear regarding deportation
Gap analysis	<ul style="list-style-type: none"> • Perform gap analysis specifically related to at risk populations and encourage public/community input
Public information coordination	<ul style="list-style-type: none"> • Establish uniform messaging across various information sources
Perceived value	<ul style="list-style-type: none"> • Educate and promote understanding among community regarding disaster preparedness and management
Political ideologies and bureaucracy	<ul style="list-style-type: none"> • Address and engage pre-conceived ideas and philosophies while advocating for more health-care delivery in disaster management
Resilience building	
5 Pillars of resilience	<ul style="list-style-type: none"> • Integrtae 5 Pillars of Resilience as part of the foundation for disaster planning
Using pre-established resilience models	<ul style="list-style-type: none"> • Use already existing models for resilience development: <ul style="list-style-type: none"> ○ FEMA- Resilience Building ○ Harvard Center for Developing Child Resilience Program Natural Hazards Center Resilience Program
Building upon current renewal of interest in health disparities given COVID-19 pandemic	<ul style="list-style-type: none"> • Use public pages, programs already in place and building upon them to address resiliency. • Support processes and national programs already in place addressing resilience
Quality and process improvement initiatives	<ul style="list-style-type: none"> • Develop indicators within already established quality and process improvement programs to address and assess resiliency programs
Focus on pre-planning	<ul style="list-style-type: none"> • Shift focus from a response mindset to a preparation mindset through preparation programs, screenings, resource distribution, etc.
Messaging through various mediums	<ul style="list-style-type: none"> • Use social media, written documents, person to person interaction, news reports, etc. to cast a broad messaging net and capture all methods of information gathering by individuals
Encouraging health-care providers (primary care) to take the lead	<ul style="list-style-type: none"> • Develop screening tools, educational sessions, trainings to address disaster preparation to be used in primary care offices

sectional study that assessed language, confidence, and training needs in responding to public health emergencies among rural medical providers in Texas.¹⁵ The study highlighted the fact that many physicians lack public health emergency awareness, knowledge, and expertise, confirming what our focused groups identified as an area of need.¹⁵

Even though data suggest that nearly one-third of disaster victims are children, system planning generally does not include a pediatric focus which leads to inherent inequities in disaster systems.¹⁶ The focus groups identified multiple disparities in disaster programs, resource distribution, community involvement, and acknowledgement of high-risk populations. Pre-established networks, planning and pre-disaster drills were all mentioned as crucial components to successful emergency management in the pediatric population. Yet, pre-disaster planning is not a novel concept in emergency preparedness; both man-made and natural disasters over the years have highlighted the necessity of preparation as the hallmark to effective disaster care. Kelly et al. referenced the more than 9,800 natural disasters that have occurred since 1900 which have affected more than 67 million children worldwide, concluding that the unique needs of the pediatric population merit preparation before, during, and after emergency events.⁶ Our focus groups further added to the understanding of preparation needs by discussing development of supply chains, identifying gaps in mental health services, mobilizing care to reach populations in need, and utilizing telemedicine for care opportunities.

As with most qualitative focus group studies, there are limitations inherent to our study including the reliance heavily on assisted discussions to produce results which can lead to bias toward certain topics. Additionally, the facilitation of the discussion and skills or bias of the moderator can lean the topics in certain directions. Large volumes of qualitative data are often difficult to analyze in broader topics such as emergency and disaster preparedness. Furthermore, while a focus group format prevents the risks of a nominal group process, outspoken individuals can potentially dominate a discussion with opinions. A further limitation inherent to the focus group format is its participant selection system—participants are self-selected and study results are, therefore, harder to generalize to the larger population. Last, we did not collect demographic data on our participants. However, all participants were members of WRAP-EM and experts in pediatric disaster preparedness.

Ongoing lessons learned from each disaster continue to reinforce the importance and urgency of connecting pediatric and public health leaders and improving pediatric public health emergency preparedness and response. Our focus groups were able to identify critical gap areas in already existing systems and programs while also presenting distinct areas for opportunities to improve health-care management and delivery for our pediatric community members. By identifying critical areas including health literacy, health disparities, resource opportunities, obstacles, and resilience building, our findings can be used to prioritize the

ongoing research, efforts, and resources to equitably address pediatric disaster management.

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