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INFORMATION CHALLENGES ASSOCIATED WITH ACCESSING AND SHARING OF PATIENT INFORMATION IN DISASTERS: A QUALITATIVE ANALYSIS

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As disasters increase in frequency and severity, so too does the health impact on affected populations. Disasters exacerbate the already challenging health information-sharing landscape. A reduced capacity to access and share patient information may have negative impacts on providers' ability to care for patients individually and to address disaster health outcomes at the population level. Between October 2018 and July 2019, we conducted 21 semistructured interviews with physicians experienced in providing healthcare during disasters to understand the challenges related to patient information sharing in disaster responses. Key informants noted challenges with patient information management—including accessing, sharing, and transferring information—and that it was a barrier to providing effective clinical care in disasters. Three major areas were identified as challenges: (1) lack of systematic mechanisms for patient information sharing during disaster handoffs, (2) lack of access to a patient's past medical history, and (3) population-level impacts of patient information-sharing breakdowns in disasters. Reducing barriers to effective patient information sharing is a critical need during disasters. Requirements generally fall to overburdened clinicians, and novel solutions that ease this responsibility and leverage existing infrastructure should be explored. Work conducted during the COVID-19 pandemic may inform new solutions. Integrated approaches that support information sharing in real time will improve patient care at the individual level and can support operational improvements to current and future disaster responses.

Keywords: Mass casualty care, Volunteers, Disaster responses, Electronic health records

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Introduction

Disasters have been increasing in severity and frequency over the last several decades, with much of this increase attributed to climate change and weather-related events.[1] Disasters are, by definition, events that overwhelm available resources[2] and disrupt the natural and built environments. Each year, hundreds of millions of people across the globe are affected by disasters.[3] For example, in 2014, almost 10 years after the catastrophic failure of the healthcare system during Hurricane Katrina, roughly 1,000 patients required evacuation from hospitals in downtown Manhattan during Hurricane Sandy.[2] In 2020, the second hottest year on record, 389 disasters (excluding the COVID-19 pandemic) killed over 15,000 people.[4] As of October 10, 2023, over 103.4 million confirmed cases of COVID-19 and over 1.1 million deaths from COVID-19 had been reported in the United States alone.[5]

As these examples highlight, during a disaster there is significant potential for patient care needs to far exceed available resources at the hospital or healthcare system level.[2,6] In these circumstances, information sharing about patients may occur outside of routine conduits (eg, electronic medical record [EMR], standardized provider-to-provider report out) or may not occur at all. The exigencies of disaster situations can lead to breakdowns in continuity of medical care, negative mental health impacts on providers and patients, and increased morbidity and mortality.[7-9] This suggests that outdated approaches to sharing and accessing patient information during disasters—such as paper forms, offline systems, and ad hoc verbal handoffs—must be reevaluated.

An increasing body of evidence supports the need for systematic and high-quality information sharing for safe and effective patient care during nondisaster times.[10-13] In the chaotic setting of a disaster and in protracted health emergencies, this need remains critically important but may be more challenging to accomplish. Potential for patient harm is introduced to varying degrees when the individual or facility receiving a patient is given inaccurate or incomplete information about a patient. Also, there may be several competing opportunities for information sharing and transfer during a patient's pathway to definitive care during a disaster.[14] Further, the call continues for improved information sharing in emergencies at the population level,[15,16] but population-level data begin with high-quality data from individual patient interactions.

In other examples of high-risk, high-precision contexts—such as among law enforcement[17,18] or air traffic control[19-21]—information-sharing skills are routinely and systematically practiced and evaluated, allowing for anticipation of risk or failure points and honing the skills necessary for effective communication. In medicine, however, extensive variability in how information is managed occurs at every point during a patient's care continuum, even during routine care.[22] This lack of standardization creates an environment of increased variability and unpredictability in the disaster setting. Critical elements of effective information management—such as precise, unambiguous communication, standardized information-sharing processes, and a consistent setting[23]—may be less likely to occur in a disaster.

The issues around sharing and accessing patient information were on full display during the COVID-19 pandemic. Early in the pandemic, data sharing was limited, sporadic, and hampered public health and clinical response efforts.[24] Patients moved through medical systems with data systems that did not always allow for sharing across the care continuum,[25] sometimes with incomplete information in their EMRs.[26,27] As time progressed, innovative approaches to data sharing were developed, largely facilitated by the declaration of a public health emergency,[28] but challenges around trust, misaligned sharing incentives, and technological barriers remained. While the research described here was conducted before the pandemic, it highlights a prescient need, even as we adapt our approaches to patient information management based on the lessons learned in the pandemic.

Based on challenges experienced with patient information sharing in standard care settings and in our collective lived experience of a 21st century pandemic, the documented risks experienced during routine care increase during the relative chaos of a disaster environment.[29-32] In this article, we explore the critical role of information sharing during patient care in disasters and how this may impact providers' perceived ability to appropriately and effectively care for disaster patients.

Methods

We sought to explore the landscape of provider perception of information-sharing challenges in patient care during disasters. Ideally, this would occur through observation of patient–provider and provider–provider interactions and overall patient management in real time; however, disaster events do not safely allow for such an approach. Disasters create chaotic, challenging, and often dangerous environments. Attempting to collect primary data by observation in this type of environment presents a significant risk for researchers and can negatively impact disaster patient care. It also could further burden providers and tax already limited resources.

Given these limitations, we conducted qualitative, in-depth, semistructured interviews. Although this type of analysis does not provide highly generalizable or statistically significant results, it allows for deep insight into the personal mechanisms by which providers from different demographics, backgrounds, and training adapt patient information sharing and practice patterns in an austere or stressful situation.

Participant Selection

Individuals selected as key informants (KIs) were physicians responsible for patient care during disasters who had experiential knowledge of the provision of medical care during a disaster, either as a physician actively responding (ie, deploying) to a disaster or working in a hospital and receiving disaster-related patients. Particular focus was given to individuals with US-based disaster patient care experience and especially to those with disaster experience working in facilities that treated vulnerable populations, such as impoverished communities, long-term care facilities, and rehabilitation hospitals. We limited our sample to physicians because they operate with a higher level of clinical autonomy than other members of a clinical care team. Participants were selected through purposive and snowball sampling.

KIs were identified from several professional networks of disaster response physicians as described in the next section. The primary focus was on individuals who participated in responses to US-based, federally declared disasters, as the legal and regulatory landscape of international disasters is highly variable and may significantly change a provider's assessment of risk. While having domestic disaster response experience was an inclusion criterion, we did not exclude providers with international response experience as long as they also had domestic disaster response experience.

Recruitment

KIs were identified through professional networks (eg, American College of Emergency Physicians, National Disaster Medical System [NDMS], World Association of Disaster and Emergency Medicine) and colleague recommendations. At the end of each interview, we asked initially identified KIs for recommendations of additional potential KIs. We continuously identified KIs using a snowball sampling approach until data saturation was attained. A total of 60 potential participants were identified. Interviews were concluded after 21 KIs were interviewed as data saturation was reached (ie, no new themes were emerging). Interviews were conducted during the 10-month period between October 2018 and July 2019. The goal of the recruitment process was to attain a variety of perspectives based on different types of patient care, provider specialty, role in a given response, and level of experience.

Interview Guide

Based on an initial literature review, an interview guide was developed a priori for guiding discussion. We piloted and then refined the interview guide after the first 3 interviews. The interview guide contained distinct questions and prompts related to each study aim. Information on the interview's structure and purpose was provided at the beginning of each interview, as well as in the interview invitation email. Interviews were recorded and transcribed, and transcribed data were reviewed in their entirety. A detailed summary of key points was developed shortly after each interview and sent to each KI for validation of accuracy. Verbal consent was obtained at the beginning of each interview.

The final interview guide (see Supplemental Material, www.liebertpub.com/doi/suppl/10.1089/hs.2023.0058) was organized into the following domains: experience and background information, provider definition and perception of risk, information needed for safe patient handoff, legal environment, vulnerable patient populations, and altered standards of care. Key areas of the interview guide included:

- Basic questions about the KI's background, education and training, and history of responding to disasters
- Experience taking care of patients in a disaster setting, barriers or challenges to patient care in this environment, and elements that impact their ability to safely take on or care for a patient in a disaster setting
- The way the KI considers "risk" in this environment, including risks to themselves and patients, medicolegal risks, and risks associated with not having enough information
- The legal issues associated with providing disaster patient care, including concepts of "duty to treat," laws that impact patient care requirements and legal liability, and past legal issues they have experienced associated with disaster patient care
- How providers determine whether a patient is "vulnerable" in the disaster setting and how that influences their care of these patients

Once the draft interview guide was refined and finalized, the final guide was then used with KIs and was further refined to better explore emerging themes. This process also allowed for addressing outlier cases (ie, individuals who had exceptionally different experiences or no perception of risk) and was used ultimately to assess data saturation.

Data Collection

KIs were interviewed in person or by phone between October 2018 and July 2019. A semistructured interview process was employed based on the interview guide. All interviews were conducted by the same interviewer, and the interviews were all audio recorded and transcribed by the interviewer.

Interviews ranged in length from 21 to 48 minutes and were conducted until data saturation was reached (ie, no new relevant information was being collected). Personal identifying information related to the KI or any potential patient they may have encountered and described was removed.

Data Analysis

Transcriptions were coded based on an initially developed and subsequently refined thematic framework that informed a codebook. The interviewer also took written notes during each interview, which were coded using the final codebook. Throughout the analysis, the codebook was treated as a living document, and codes could be changed, merged, or amended to be as reflective as possible of the raw data. The steps of data analysis were as follows:

Step 1: Refamiliarization of data through review – The transcribed interviews and associated notes were read and re-read multiple times, and initial/potential codes were informally noted during this process.

Step 2: Application of key themes – Data were collected from preliminary literature reviews, study objectives, and overarching research questions, and used to identify key themes for the initial development of a codebook.

Step 3: Preliminary coding and analysis – Codes set in Step 2 were applied to the transcriptions and associated interview notes. Coding of the data was organized into broad and granular substantive code types to address key themes and specific content areas and supportive code types that helped to apply attribution to a chunk of text or highlight important nontechnical information. Two transcripts were coded by both the primary coder and a secondary coder to ensure accuracy and validity of the codebook.

Step 4: Full coding – Coding of all data was performed in NVivo version 12 (QSR International, Burlington, MA). The coded dataset (interview transcripts and notes) was reviewed again and finalized to summarize data into key themes and tie data to the study objectives and the research questions associated with the study aims.

Ethical Considerations

Before initiating this research, the protocol, interview guide, and target population were reviewed and approved by the Johns Hopkins School of Medicine Institutional Review Board (IRB00189580). The interviewer obtained oral consent from all participants before beginning the interview or recording. A fundamental ethical challenge of this study is that disaster response can have a significant mental health impact on those experiencing the disaster, including providers. While we took particular care to avoid traumatization or retraumatization during the interview process, we prepared for this possibility. Before each interview, the scope and major thematic elements that may have emerged were articulated to the participants, and additional resources were readily available for any individual who might have been negatively emotionally impacted during the course of the interview. We also prepared early stopping rules for individuals who were at risk of traumatization or retraumatization during the interview. No interviewees required the use of trauma-related resources or the need for early stopping of an interview.

RESULTS

Over 10 months, we conducted 21 semistructured interviews with KIs (Table) from 7 subspecialties of medicine. Of note, approximately half of the respondents (n=10) were emergency medicine physicians by training, including 1 pediatric emergency medicine physician. Other subspecialties included internal or family medicine, preventive medicine, critical care medicine, surgery, and infectious disease medicine. KI ages ranged from 35 to 65 years, and they had participated in 1 to 24 disaster responses. KIs had been deployed via several different response mechanisms, including the Disaster Medical Assistance Teams of the NDMS and various nongovernmental organizations, as well as at their local hospitals, with most respondents responding through multiple entities. KIs reported responding to hurricanes, tsunamis, earthquakes, floods, outbreaks, and wildfires.

Table. Key Informant Demographics

Characteristic	*Value*
Specialty,[a] number	
Emergency medicine	10
Surgery	4
Anesthesiology/critical care medicine	3
Internal medicine	3
Infectious diseases	2
Pediatric emergency medicine	1
Preventive medicine	1
Gender, number	
Female	8
Male	13
Age (years), range	35 to 65
Years of service as a healthcare provider, range	4 to 31
Number of disaster responses, range	1 to 24

[a] More than 21 specialties noted due to some of the key informants being double board certified.

The following 3 key themes emerged regarding challenges in the management of patient information during disasters: (1) lack of systematic mechanisms for patient information sharing during disaster handoffs, (2) lack of access to a patient's past medical history, and (3) population-level impacts of patient information management breakdowns in disasters (Figure). These themes indicate the breadth of information-sharing challenges in disasters. They scale from the individual to the population level and can have a dramatic impact on how we protect the health of those affected.

Patient Information Management Challenges in Disasters

Across all interviews, patient information management was described as a challenge (n=21) and, in many cases, a specific barrier to providing effective clinical care (n=14). KIs consistently noted how little has changed relative to patient information sharing in disasters, regardless of their number of years in the field. As 1 KI with over 2 decades of disaster response experience noted, "[i]nformation transfer is one of the hardest things we do in a disaster." Barriers to information sharing impact the patient, the provider, and the

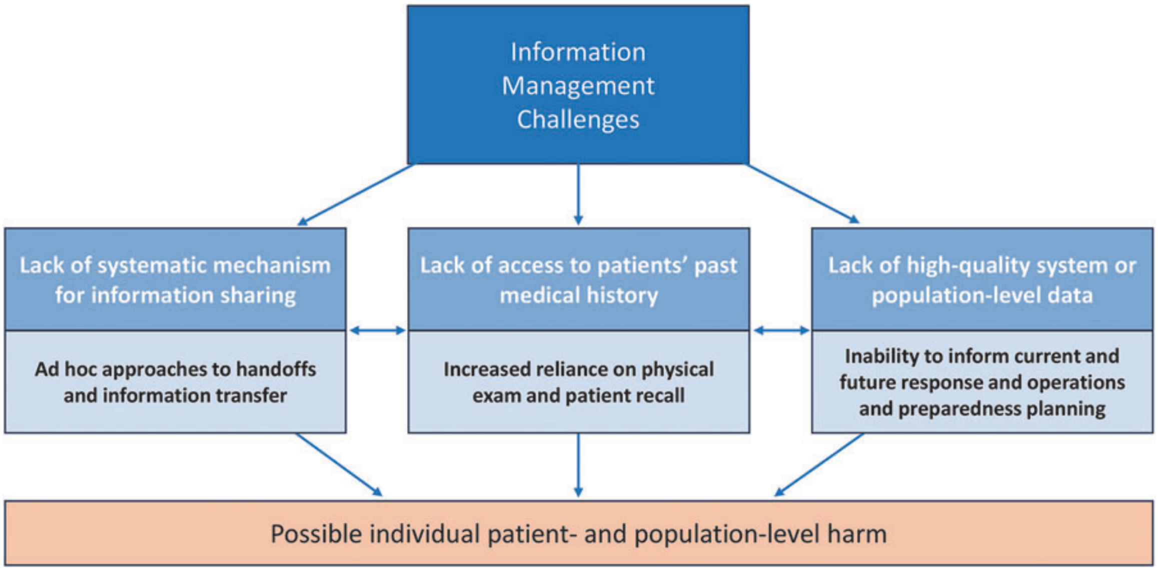

Figure. Patient care-related information management challenges in disasters.

system. These impacts are described in more detail by theme but they were especially well articulated by 1 KI:

> *Sometimes when you're in the thick of it you just wanna scream. I can't believe the lack of information that I can access sometimes. It's absolutely absurd. How can we not have fixed this? But then you recover. And you go back to treating the patients that are looking you in the face because they need care and there's nowhere else for them to go.* (KI 14)

Theme 1: Lack of Systematic Mechanisms for Information Sharing

The inability to obtain and share patient information—whether obtaining it at the onset of a patient interaction (either through a primary history taking or via an EMR), providing information about a patient to a new provider, or sending patients home with instructions—was consistently noted as an impediment to good clinical care in a disaster.

As 1 person poignantly reflected:

> *Good information, whether getting it or sending it, is just so hard. I've written a short synopsis on a piece of paper, a scribble on a 3x5 card and taped it to the patient. And you're just hoping for the best that the clinicians that take over for you know or understand what you were trying to communicate […] it's infuriating for both sides.* (KI 8)

Another KI similarly described the environment in a disaster and how it impacts the ability of emergency medical service teams to gather and share patient information:

> *In a chaotic disaster environment, there's not always time for first responders to gather that information for you. It's just not something you can rely on or plan on getting. They're not only trying to get information on the patient and take care of them, but they may be driving through dangerous, disaster affected environments.* (KI 1)

The mechanisms in place for sharing patient information in a disaster are often unreliable and disparate across different response organizations. KIs described several different ways of sharing patient information during handoffs in the disaster setting, including sending handwritten notes with a patient (n=11), giving verbal handoffs to emergency medical service or the next physician (n=10), writing on the patients themselves (n=4), and telling a patient's loved one or a person accompanying them (n=3).

Documentation of patient information is critical to the ongoing care of the individual but can be in tension with the challenges of providing care, documenting treatment, and sharing the information associated with that care. Many providers described the challenges of trying to share information during patient care in a disaster along with the impact these challenges may have on their patients in both the short and long term. Creating and sharing meaningful information about a patient encounter and ensuring that this information makes its way into the patient's EMR, where it can be used to inform future care, can be problematic. As 1 KI described:

> *If you're seeing 3 patients an hour, you can do that, you can write written notes. When you're seeing 200 patients yourself as a single physician in a day, there's just no way. You end up charting at the end of the day. We were charting at the end of the day and you try to remember as much as you could, but there's just no way. All of a sudden you have a patient in there, in that 200, that has a critical illness and you need to send them out to another place, you're scribbling it on a single piece of paper and handing it off to a medic and saying "go" […] that information is not meaningfully making its way to their next provider […] let alone into their record.* (KI 16)

Another KI described how a lack of documentation may leave a provider with a gap in awareness regarding what happens to a patient and how this may impact their care and can potentially cause harm:

> *Or maybe you get a patient who got decompressed [insertion of a needle into the pleural space to decompress a tension pneumothorax] and one of the questions could be—how long ago were they decompressed. This happened not too long ago. And in that situation, it was apparent that the intervention was performed because there was something sticking out of their chest. But you could easily imagine another intervention, a dose of pain medication or antibiotics let's say, and if it wasn't properly documented and that information wasn't shared, there could easily be an error there.* (KI 9)

Several KIs mentioned going into a disaster knowing that information sharing will be problematic, so they adjust their expectations based on this knowledge. As 1 KI noted:

> *Documentation is at the top of the list of barriers to providing good patient care in disasters. You know it was true the last time, and you just know it will be the next time.* (KI 21)

Theme 2: Lack of Access to a Patient's Past Medical History

A critical element of a patient's treatment is a review of their past medical history and pertinent health information during the initial exam. Even during routine care, patients' correct recall of their own medical information can be limited.[33] Pertinent patient information may include past diagnoses and current conditions, past and current prescriptions and their adherence to these medication regimens, and recent medical instructions. If this information is not readily available through an EMR, providers must rely on patients to recall this information, which can be problematic or potentially detrimental to the patient's outcome. KIs routinely noted the lack of access to a patient's past medical history during disasters and the impact it has on their ability to provide care.

As 1 person noted, even if the information is critical, it may be abbreviated or truncated due to the speed with which patients need to be moved through the system:

> *All I really want, and trust me sometimes it is still impossible to get at—but why they're there, past medical history, maybe a social history, medications and allergies [...] And I'll get their vital signs. And that probably gets truncated into three sentences based on what I can get out of the patient. Especially if I've got 50 patients who are all waiting to be seen at once.* (KI 13)

KIs throughout the interviews described barriers to obtaining information about patients, from patients, and how much of an impact those barriers can have. They noted that patients have recall challenges for many reasons, including their overreliance on their information being within an EMR, recall challenges due to the stress of the environment, and translation or language barriers.

Several KIs described an overreliance on information already being in the EMR. One KI with over 25 years of disaster response experience described the newer challenge of patients not having their information readily accessible:

> *Patients used to come in with a list of their medication or notes that they wanted to remember to tell the doc. That doesn't really happen anymore. They've gotten used to relying on their doctors to have all the information ready so they don't have to come in prepared with anything. This just doesn't work in disasters.* (KI 17)

Patients may also present with recall challenges due to the stressful and often overwhelming experience of needing healthcare in a disaster. As 1 KI noted:

> *Sometimes one of the hardest things is getting the patient to even just remember their medications or what they're allergic to. You wanna know if they're on blood thinners or they're allergic to a medication. You want to know if they're taking anything that might affect your ability to care for them safely. But oftentimes especially when they're stressed or overwhelmed by the situation, they don't have a great recollection, they don't have a good recall for what they've been taking or how they've been treated or even the conditions that they might have.* (KI 20)

Language barriers were described repeatedly as a challenge, and 1 KI described the challenges associated with not having access to translation services:

> *Another thing we just never seem to have enough of is translators. In the emergency department you can get a translation robot which helps with that initial impression if there's a language barrier. Not having any access to translation is a huge problem if you have a patient you can't communicate with. You're just sitting there with absolutely no information but what you can gather from your own examinations skills.* (KI 2)

One KI noted that the challenges associated with treating a patient with a language barrier are not unlike those experienced while treating a small child:

> *Yeah, I mean, it feels sort of like you're treating a kid with no parent, no one to say "this is the problem" or "this is what happened." You're just going on your exam skills and the way they react, and that's if they're conscious.* (KI 4)

Theme 3: Population-Level Impacts of Patient Information Management Breakdowns in Disasters

The effects of poor information sharing go beyond the impact on the patient, and these impacts were well recognized by our KIs. Many KIs described the challenges of charting and how that impacts their ability to make broader operational decisions and how the lack of quality information can potentially be detrimental to future disaster and public health emergency responses. As 1 KI described, the impact of poor or missing data can extend far beyond a specific disaster and can impact the system's responsiveness for the next disaster:

> *Charting at the end of the day serves a role to demonstrate that we're actually seeing each other. If I see 200 patients but I don't log 200 patients, then all they see is that I sat around on my butt all day. That's all that charting does. At the end of the*

> *day the administrators in [Washington,] DC look at those numbers […] and they do some rudimentary epidemiological stuff on it which then directly informs what physicians we recruit, what materials we buy, what equipment do we need. But bad data makes bad decisions in the end and that is certainly a problem with the system.* (KI 16)

KIs also described how a lack of available information from the community or local public health authorities or departments could impact their ability to respond and plan for the types of patients they will be caring for, especially those who need durable medical equipment or access to regular outpatient services such as dialysis:

> *One of the things we always see is that if we're not sharing good information about the community, with response planners, especially if you have power outages and transportation issues in a disaster, is the impact on patients who need things like dialysis or home oxygen. They don't often show up right away in your response, but if they can't get their dialysis or say they've run out of backup oxygen at home, they can show up days later really, really sick. If you don't have a good sense of the amount of patients like this there are in the area, you don't know what resources these patients might take up or need. You can't prep.* (KI 9)

Another KI noted the value of collected patient information for the affected community, which may be incorporated into postdisaster public health operations and planning:

> *Over time we gather information about local healthcare resources, and we become a conduit and we're able to provide that info to the populous about chronic medical conditions which can be very helpful for the affected community.* (KI 6)

Similarly, a KI described the need for information sharing for after-action review (AAR) and future response planning within their organization:

> *You know we always talk about the AAR. Sometimes it feels like we live and die by its creation—it's supposed to hold all the lessons learned to make us better. But if we have no data to inform the AAR, how can we get better? We are just guessing and using our hazy memories when actually if we did a better job of collecting data and tracking things, we could actually make evidence-based improvements to our approach, just like we do in medicine.* (KI 3)

These AARs often drive preparedness activities that inform future response planning and implementation. As the quote from KI 6 describes above, using "bad" data to inform decisionmaking will inevitably lead to poor decisions being made.

DISCUSSION

Challenges related to information management are widely known to be associated with patient care generally. Our interview data indicate that these challenges are substantially exacerbated during disasters, impacting not only patients but also the broader community and future patients. While emergency health information management has vastly improved—in many cases, due to innovation that occurred during the COVID-19 pandemic—there is still much work to be done. The US approach to patient information management and the sharing of health information in the face of 21st century health threats needs strengthening.[34]

As described in Theme 1, providers continue to be responsible for the appropriate transfer (both reception and onward transmission) of pertinent health information in disasters that may lead to critical gaps or breakdowns and that have downstream consequences on a patient's outcome. Further, it is important to note, as described by the KIs with NDMS experience, the substantive challenges of the NDMS electronic health records. The capabilities and lack of interoperability of the NDMS electronic health record exacerbate the information-sharing challenges experienced across hospital or health system EMRs. As discussed in Theme 2, without reliable access to information management systems that contain information about a patient before the disaster, providers must rely exclusively on a patient's recollection of their own medical information and a physical exam or family members with an understanding of the patient's medical information. Mechanisms for sharing patient health information and access to their past medical history are both critical elements of a patient's evaluation and care, but they are much stronger and more valuable when supported by linkages to ancillary and external systems, such as pharmacy and outpatient data and the extensive medical history maintained in a longitudinal medical record,[35-37] especially given the recent decline in provider physical examination skills.[38]

The COVID-19 pandemic amplified existing patient information management challenges, but it also provided opportunities to experiment with novel and flexible solutions under the federal public health emergency declaration. The value of the EMR and improved patient information sharing is well documented[39,40] and explored in all 3 themes identified in this study, as are the risks of reverting policies to the prepandemic status quo.[41] The imperative to improve information sharing for providers in disasters is clear. For physicians and their teams to provide the highest level of care to patients in disasters, an improved mechanism for documenting, reviewing, and sharing patient information is critical. This issue is reflected repeatedly in the literature; however, few solutions have effectively mitigated the problem to date.[42-44] The burden should not fall on patients or their family members to recall their critical (and detailed) health information during a disaster or emergency. Rather, state and federal governments, as well as EMR developers, should commit resources to developing and leveraging interoperable systems that work independently of a specific health facility. It is important to note that improvements have been made during the pandemic, with many systems having stronger capability to provide short-term EMR documentation access to providers from other health systems for individual patients. This is a step in the right direction to make a patient's documentation and information available to any provider who is providing care and would address the real-life concerns identified by KIs in Theme 2.

Interoperable systems are already being used across states and health systems at a regional level in nondisaster contexts.[45,46] Such systems could be further developed to facilitate and improve bedside care in disasters, as identified in Theme 3, with the benefit of informing improved ongoing, postdisaster patient care for disaster victims. Improved approaches to systematic information management at the individual and population levels will facilitate public health response to emergencies in myriad ways. Data can be used in real time, at an operational level, and retrospectively to inform planning and preparedness infrastructure and capacity building for future responses. Further, if large datasets from disasters can impact public health activities at the community level to improve health outcomes more broadly, community resilience can be strengthened to reduce the impact of a disaster from its onset.

Importantly, in the period since this research was conducted, the COVID-19 pandemic has led to developments that may improve patient information sharing and management during disasters. For example, during surges in the COVID-19 pandemic, exceptional circumstances required hospitals and health systems to work collaboratively with local public health agencies to facilitate patient care.[47,48] This was done through the widespread establishment and use of medical operations coordination cells (MOCCs).[49] While MOCCs are not new, the extent of their use during the pandemic is unprecedented. The goal of a MOCC is to optimize patient placement and distribution by coordinating healthcare capacity and load balancing at a regional level, which inherently requires improved information management.[50] An additional benefit of the use of MOCCs has been the ability to coordinate patient placement and load-balancing initiatives, which is facilitated by improved information sharing. During the COVID-19 pandemic, MOCCs often required a more systematic approach to sharing patient information for movement across health systems and thus created a requirement of standardization that had not previously existed at such scale.[51] While a pandemic is not directly akin to an acute disaster, the proliferation of MOCCs and other novel solutions to patient information sharing during the COVID-19 pandemic may provide insight on ways to systematically improve patient information management. The use of MOCCs during the pandemic demonstrates the value of prioritizing the development of novel solutions and systems for information sharing from the patient/provider level to the population level.

Interestingly, no KIs described the importance of patient documentation and information management for reimbursement purposes, even though it is essential for reimbursement from the federal government during a declared disaster.[52,53] This may be, at least in part, because many KIs noted being deployed through the NDMS (n=8) and nongovernmental organizations (n=11), which generally do not bill patients or do not involve volunteer physicians in the reimbursement process. Therefore, reimbursement may not be a consideration for this group.

Additionally, privacy and data breach concerns were not routinely addressed by KIs, perhaps because there are few "systems" that could potentially be breached or that privacy concerns are secondary to the immediate protection of life and limb. That being said, there are substantial threats to patient data in disasters and public health emergencies. Unauthorized access to patient information remains a threat. In the aftermath of a disaster, data may be accessed by unauthorized individuals who could misuse or exploit the information. Further, in the chaos and confusion of a disaster, there is an increased risk of data being entered incorrectly or patient records being misfiled or misplaced. To minimize these privacy concerns, it is important to have a robust disaster recovery plan in place that includes measures to protect patient data and ensure that it remains confidential, accurate, and secure.

Finally, the KIs did not address how novel threats, such as cyberattacks and warfare, may impact data and information sharing and, thus, patient care. While these issues were not explicitly discussed, information gleaned from this work may be applied to these scenarios given that the impact of not having access to information,[54] regardless of the reason or source, remains the same.

This study was designed to maximize strengths, minimize the likelihood of bias, and reduce limitations and weaknesses. The most significant limitation of this study is that the approach is retrospective. KI interviews were focused on historical events and subject to recall bias, particularly as it relates to highly stressful circumstances. Memory can be highly unreliable in 2 key ways: (1) details of an event or experience (including those that may be critical to one's understanding of an experience) may never be committed to memory by a participant; and (2) as memories are reviewed and "rehashed," information may be added or changed, evolving the story or perception. Another limitation is that the interviews and data collection occurred before the COVID-19 pandemic. Although they were conducted before the pandemic, clear and actionable gaps were identified that have not been resolved during the pandemic. Several of the themes mentioned by KIs arose during the pandemic response, and in some circumstances, preliminary solutions have been developed. A key strength of this study is the opportunity for in-depth analysis provided by the qualitative approach of the study design. Additionally, the use of purposive sampling to identify participants with variability in their disaster response and patient handoff experiences has provided a rich dataset for in-depth analysis.

Conclusion

Reducing or removing the challenges associated with information sharing is essential to protecting the physician–

patient relationship to enable the provider to focus on the patient and their care. As 1 KI noted, “There is no purer form of the practice of medicine that I’ve experienced than in a disaster. In a disaster setting, it is all about the clinician and the patient.” The need for high-fidelity patient information coupled with extensive provider responsibilities and consistent understaffing that occurs in disasters raises a critical opportunity for improvement. Developing and implementing a strategy that improves information sharing without the additive burden falling exclusively on the clinical care team will be crucial. Integrated solutions that allow providers to quickly and efficiently document in real time will improve patient care and our operational understanding of disaster medical response efforts. These improvements will carry the additional benefit of informing future responses.

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