National Center for Disaster Preparedness
Earth Institute | Columbia University

VULNERABLE POPULATIONS

CHRONIC DISEASE AFTER NATURAL DISASTERS:

PUBLIC HEALTH, POLICY, AND PROVIDER PERSPECTIVES

A Final Project Report

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About the National Center for Disaster Preparedness

Founded in 2003, the National Center for Disaster Preparedness (NCDP) is an academically-based resource center at Columbia University's Earth Institute dedicated to the study, analysis and enhancement of the nation's ability to prepare for, respond to, and recover from major disasters, including terrorism. The NCDP has a wide-ranging research, training and education, and advocacy agenda, with a special interest in megadisasters. NCDP staff and faculty have testified at Congressional hearings, conducted briefings for senior government officials, and have presented at numerous scientific conferences and meetings.

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"At first blush it might seem odd to rest the ethics of national health reform on a base of public health preparedness. After all, dozens of other nations far less wealthy than the United States have not justified reform as a matter of "preparedness". However, if the concept of preparedness will bring the nation to meaningful and lasting reform, then by all means, policy makers and health care leaders should proceed in that vein. The notion that the world's most powerful nation would continue to lurch from disaster to disaster, jury-rigging inadequate and temporary solutions, is simply untenable. Is it really necessary to wait for the next disaster to strike before taking the modest step of establishing a fallback public health insurance system in times of national crisis?"[1]

- Sara Rosenbaum, JD

EXECUTIVE SUMMARY

Individuals with chronic conditions require special attention in the planning, response, and recovery phases of disasters, given their unique needs for medication, medical equipment, continued medical care, and the potential for exacerbation of their conditions that require resource-intensive management.

In addition to exacerbating existing disease, disasters also contribute to the development of new chronic illnesses. The estimated cumulative cost of natural disasters in 2017 was over $300 billion.[2] With the expected increase in severity of natural disasters in the setting of climate change, understanding the post-disaster burden of these diseases and the approach by local, state, and federal agencies in preparing for and responding to them in disaster settings is as important as ever.[3]

Over 60% of Americans have at least one chronic condition, and over 40% have multiple.[4] Decades of research have characterized the post-disaster burden of chronic conditions, and authors have more recently begun to discuss how a more unified approach can be taken by public health practitioners and public officials in the disaster sphere to better address the needs of this population across the disaster lifecycle.[5, 6]

The purpose of this report is to provide public and private stakeholders, especially at the state and local levels, with a resource to help them better understand, and support, the needs of this subgroup. We achieve this by providing a review of key research addressing the burden of chronic diseases, their management, and broader solutions across the disaster life cycle followed by 15 interviews conducted with direct service providers, as well as public health and policy leaders working at the local, state, and federal level. Our interviews highlight the strengths and weaknesses that have been experienced or are anticipated in current approaches to this issue and provide direction for next steps in research, policy, and public health practice as more Americans develop chronic conditions.

We close by providing the following recommendations for stakeholders:

- Improve consistency in the definition of chronic disease
- Increase focus on the needs of these patients during the disaster recovery phase
- Integrate local and non-traditional partners into preparedness activities
- Conduct more operations and solutions-oriented research
- Advocate for and develop more tailored legal solutions
- Provide better support alongside the expanding duties of the existing public preparedness workforce to address the needs of this population

EXECUTIVE SUMMARY

- Better integration of non-traditional healthcare infrastructure-oriented stakeholders
- Improve knowledge on the effect of drills and exercises on personal preparedness
- Improve buy-in across healthcare, business, and infrastructure
- Leverage existing sources for disaster data to better understand this population
- Expand monitoring of the CMS Emergency Preparedness Rule to include specific impact on this population
- Clarify roles and responsibilities of direct service providers, especially related to improving personal preparedness
- Integrate personal and community preparedness
- Include non-traditional partners in the dissemination of preparedness and response-oriented information
- Improve mechanisms for long-term access to medication after large disasters
- Improve development and awareness of non-acute-care sites for post-disaster chronic disease care
- Improve criteria for placement of individuals in special medical needs shelters

We are a nation increasingly suffering from long-term health problems. If we do not give special consideration to the needs of this group, events will only grow to be more devastating to all of our families and communities, no matter the type of disaster or where it strikes next.

introduction

Sixty percent of Americans have at least one chronic condition, with more than 40% having multiple and spending for these conditions making up 86% of total healthcare spending in the United States.[4, 7] By contrast, those living under 200% of the Federal Poverty Line make up 30% of the U.S. population, children 24%, the elderly 15%, disabled individuals 13%, and those with limited English proficiency 8%.[8-12] Those receiving long-term care, including at adult day services centers, nursing homes, hospice, residential care communities, or via home health care agencies account for 2.7% of the population.[13]

Global recognition of the importance of this population in disasters is also evidenced in the United Nations' Sendai Framework for Disaster Risk Reduction 2015-2030 as well as in the minimum standards in health action put forward by the Sphere Project.[14, 15]

In addition to the need for access to medications immediately after an event, many continue to have poor access to care (e.g. routine appointments, diagnostic and treatment appointments) and suboptimal medical and psychiatric outcomes in the extended recovery period after disasters.[16-18] Many also require access to medical equipment or supplies that rely on power, multi-stakeholder supply chains, or other infrastructure during response and recovery, failures of which can have a number of negative health effects.[19] Meeting the needs of this population maintains their health and prevents exacerbations that can be time and resource-intensive to treat in the immediate and extended wake of a disaster.

Many have focused on highlighting the burden of different medical conditions after disasters and assessing levels of personal preparedness and, to a lesser extent, interventions to improve individual-level preparedness activities among those with chronic conditions.[20-24] The application and manifestation of general preparedness issues (e.g. monitoring and surveillance needs, evacuation policies, procedures, and outcomes, and medication demands) within the chronic disease population have also been described.[25-27]

Several authors have also proposed a more comprehensive set of actions to address the needs of this population, including the use of a public health infrastructure framework and a research model to ensure continuity of care.[6, 28]

Existing research on this population, however, has been inconsistently integrated into practice across the globe. In recent years, authors have called for more evidence-based guidelines to help chronically ill patients prepare for disasters in developed countries and the WHO has proposed, in their own words, a "minimally adequate response" to noncommunicable diseases in emergencies.[5, 29, 30]

Our aim is to highlight how agencies and other stakeholders can better address the unique needs of individuals with chronic diseases in disasters by providing a resource to aid in planning for this population. We do so primarily by analyzing the results of 15 interviews with public health, public policy, and emergency management officials - several of whom have served in a direct response capacity during their careers - as well as direct service providers.

cont'd

introduction

The goal of our interviews is to better understand the current and/or past employment of specific strategies to mitigate, plan for, and respond to the needs of individuals and groups with chronic diseases across the disaster life cycle and to translate the perceived challenges and solutions in serving this population into actionable suggestions for how both private and public stakeholders can improve their activities oriented towards those with chronic diseases.

In the first section, we detail our search for research addressing chronic disease burden, management, and broader solutions across the disaster life cycle. We organize our findings into focus areas to consider throughout the phases of natural disasters, including: personal and community preparedness, overall burden of chronic disease, primary health care systems, medications and other supplies, infrastructure hazards, surveillance and data gathering, displacement and evacuation, special populations, existing recommendations, and other issues. The detailed results of these findings are included in the appendix.

In the second section, we present and analyze the results of 15 interviews conducted with direct service providers, as well as public health and policy leaders working at the local, state, and federal level.

In the final sections, we present a model focused on the need to establish, as well as improve, specific capacities and capabilities across different stakeholders to ensure continuity of care, business, and infrastructure required to maintain health and prevent development, exacerbation, or deterioration of the chronic conditions impacting these individuals.

content review

To provide informed characterization of existing literature prior to our interviews and aid development of an interview guide, we performed a literature search using PubMed, a premier database of medical and public health literature.

a. Inclusion Criteria

Noncommunicable, also defined as chronic, diseases are now responsible for the more than half of the global burden of disease.[31, 32] With the high number of Americans suffering from not just one, but multiple, chronic illnesses, the importance of chronic disease management after natural disasters is clear.[4]

The definition of the term chronic disease varies across academic and practice literature. The term noncommunicable disease (NCD), defined as synonymous with chronic disease by the WHO, is defined by the same agency as primarily those with cardiovascular disease, respiratory disease, cancer, and diabetes.[31] In 2018, PubMed added noncommunicable disease as a sub-heading under the term chronic disease and identified non-infectious disease as its synonym. In recent literature, those with chronic renal disease, disability, and mental health issues have also been included in the noncommunicable disease group.[23] The shared essence of both terms, especially in disaster settings, has been to communicate those with non-transmissible illnesses of longer duration, with general agreement that this excludes infectious disease and injury.[23] Whether to include mental health issues, disability, and medical issues outside of the 4 key WHO designations is a much less clear area of consensus which authors have both discussed and differed on.[23, 24]

In discussing the burden of chronic diseases after natural disasters, we define them as including the 4 WHO noncommunicable diseases designations, as well as chronic renal disease and mental health issues. Although we recognize the importance of planning separately for those with disability and recognize that many of those within the latter group have chronic illnesses, we focus on the WHO NCD designations given their clarity, wide usage in research literature, and recent efforts to move towards a common language in describing this population. Although we recognize that there are other chronic medical conditions that may warrant acknowledgement, such as back pain, as well as risk factors associated with chronic diseases such as obesity and reduced physical activity, we believe that our findings will remain applicable to these populations and limit our definition for clarity.[33, 34]

Because those who live in nursing homes or receive some other form of long-term care (e.g. home healthcare) traditionally have one or more chronic diseases, we also included those terms in our search.

We focused on peer-reviewed research in our review, but highlight anecdotal research and practice-oriented reports where we found such contributions valuable. We sought to provide the most recent literature on the burden of chronic diseases after natural disasters, proposed solutions, and the impact of interventions that have been implemented. We focus primarily on literature published during or after 2000.

b. Exclusion Criteria

We focused on natural disasters given the likely impact of climate change on increasing the severity of natural disasters in the future and the well-established and significant impact on morbidity and mortality that has been documented in the case of many different types of natural disasters.[3, 24, 35-42] Further, the $306.2 billion cost of the events in 2017 is highest annual cost of of natural disasters on record in the United States,

providing a timely opportunity to perform research on these specific types of events.[2] While we do not include man-made disasters in this review, we recognize that it is crucial to consider chronic diseases in these settings as well. However, the political dynamics, nature of evacuation and displacement in complex humanitarian emergencies, and global aid mechanisms for these man-made disasters warrant a separate discussion from chronic disease management in natural disaster settings.[43, 44]

c. Methods

Our search was performed during January, 2018 and yielded 2,422 results. Title review using inclusion and exclusion criteria yielded 530 articles, and subsequent abstract review yielded 307 articles. An additional collection of articles not identified in this formal search was identified via a number of exploratory searches prior to the development of our final search term.

d. Content review results

We identified the emergence of the following focus areas within the research literature relevant to this population in disaster settings and detail our findings in the Appendix to this report:

- Personal and community preparedeness
- Burden of chronic diseases
- Primary care provision
- Medications and other supplies
- Infrastructure hazards
- Surveillance and data gathering
- Displacement and evacuation
- Special populations: children, drug users, and those in addiction recovery
- Existing recommendations, models, and resources

We utilized articles emblematic of the trends in research within each particular focus area. While every article we identified as relevant is not included our findings, we reiterate that the purpose of this content review is to provide a summary of the informed exploration of research involved in creating our interview guide. A systematic review of literature in this space would be a valuable contribution.

e. Existing models, recommendations and resources

The current landscape of proposed solutions is built on decades of growing interest in this field as preparedness as a discipline has evolved (Figure 1).[45] Initial interest was stimulated by research and editorial commentary, which reiterated the direction of focus among agencies and researchers, while providing limited detail in the form of specific actions that agencies can act on.[26-28, 46, 47] Following this initial interest, many articles have focused on assessing the precise burden of these diseases after natural disasters and have proposed broad often disease-specific or disease-oriented solutions (Appendix, Tables 1-3). However, they are often presented with limited practical connection to the activities of emergency management or chronic disease officials and are focused on describing the problem rather than proposing solutions. Literature reviews and assessments of interventions provide more applied recommendations that have led to the development of publicly available resources, many of which are presented centrally within the ASPR TRACIE database but which are not uniformly evidence-based, are of varying quality and practical usefulness, and have been inconsistently adopted. In recent years, these components have led to the development of models proposing a more unified approach to this issue, including one based on the well-researched notion of public health infrastructure and another proposed by the authors from the World Health Organization and Doctors

content review

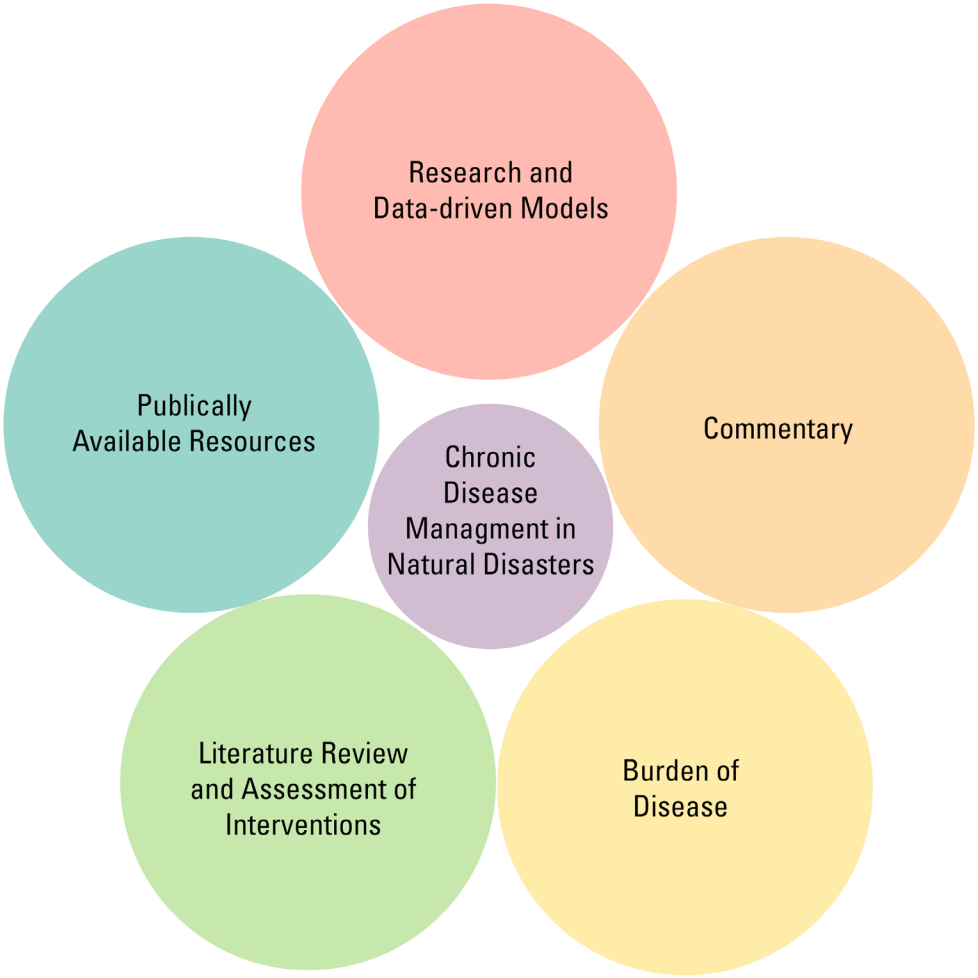
Without Borders.[5, 6, 48-50]

In addition to these models, many professional societies and public agencies have issued recommendations for patients, health care providers, and policy-makers on the needs of patients with chronic illness after disasters.[29] These recommendations were recently reviewed, with authors concluding that more recommendations needed to be evidence-based, consistency between recommendations should be improved, and recommendations must consider feasibility for patients, providers, and policymakers.[29] The number of interventions that are evaluated with scientific rigor has also increased, contributing to actionable steps that state and local agencies can take in addition to the adoption of general models for addressing this issue.

Following this review, we conducted 15 interviews. The methods, results, and integrated discussion of our literature review and interviews are detailed in the next sections.

Figure 1

Literature and resource landscape of chronic disease management in natural disasters



interviews

Following our content review, we developed an interview guide for use in semi-structured interviews with various providers and public health and policy officials. The interview guide allowed for development of broad questions and themes to be explored that were similar, but not identical to, the areas identified in our content review. However, the same questions were not asked to every participant and several of the questions and topics discussed arose from organic conversation. We conducted 15 interviews (denoted I1-I15).

a. Methods

Interviewees were a purposive sample of individuals working at the local, state, and federal levels, as well as several who had worked at one or more of these levels in the past but who are now primarily working in the nonprofit sector or for an academic institution. Including overlap with substantial previous work experiences, the distribution of interviews was the following: 6 federal, 4 state, 4 local, 4 academic, and 2 healthcare providers. Of note, both providers worked together closely and within the same institution on post-Hurricane Harvey response.

Interviews were semi-structured and recorded conversations varied in length from 22 to 105 minutes, with the average length being 47 minutes. Two interviews were unable to be recorded as a result of technical difficulties. Their contributions have been included based on notes taken by the interviewer during each conversation. The thirteen recorded interviews were conducted over the phone, then either transcribed manually or with the aid of a online automated transcription service. These required significant manual correction and were frequently re-transcribed manually. All interviews were conducted in accordance with an institutionally (Columbia University) approved IRB-protocol (AAAR6035).

Although we defined chronic disease to make the parameters of our content review more precise, we determined that for practitioners and agency officials, this definition was likely to be more fluid and adhere imperfectly to our own or the WHO's traditional definition. For this reason, we allowed interviewees to discuss and define chronic disease on their own, sharing the definition we used in our content review if asked for clarification but maintaining with interviewees that they were free to expand, contract, or alter in scope their discussion of this topic. Thus, our approach towards defining chronic disease was primarily inductive, as was our interpretation and discussion of the surrounding specific elements to support this population, but also consistent with grounded-theory approach adopted in previous literature on this same topic.[28] This distinction is notable because we identified only one published article which adopted a grounded-theory approach to chronic disease burden and management after disasters.[28] We believe that the outcome of this discussion will be particularly useful to a variety of stakeholders.

cont'd

interviews

b. Codebook development

To analyze our interviews, we developed a codebook using the United States Centers for Disease Control (CDC) Public Health Emergency Preparedness (PHEP) Capabilities as well as literature and reports detailing the European CDC's capacities and capabilities in response to emergencies.[51-54] Based on their definitions, several codes within each framework were collapsible. In these cases, concepts were included within one code derived from either framework that was most inclusive. To the extent possible, codes were defined using the same definitions of capabilities and capacities outlined within each model. Each of the U.S. CDC PHEP capabilities included several functions, which were not directly included within the definition of each capability but which were reviewed by the coding author and provided additional guidance in analysis and disucssion.

c. Conceptual framework

To analyze our results, we adopted a capacity, capability, and competency framework.

Efforts within public health preparedness and response have varied in their adoption and application of conceptual models used to describe the necessary actions in various areas. Adoption of the C-MIST (Communication, Maintaining Health, Independence, Support/Services/Self-determination, Transportation) methodology has guided the approach to interventions to support the functional and access needs, or whole community, approach.[55] Recent literature on crisis management in disasters has employed Dynes' typology as a framework for managing the emerging needs and functions that individuals and agencies should anticipate during and after disasters.[56] Novel approaches to preparedness and response issues continue to be developed from existing literature, including on risk communication and community resilience.[57, 58]

For our analysis, we chose to adopt a unified capacity, capability, and competency - or 3C - framework. Previous literature has identified the importance of each of these in developing and assessing effective individual, organizational, or agency-wide approaches to needed actions across the disaster cycle.[52, 53] We defined capacities as the baseline resources, relationships, policies, and procedures upon which capabilities can be exercised and defined the latter as "the ability to use [capacities] to effectively identify, characterize, and respond to emergencies".[53] We define dcompetency as "combinations of knowledge and skills that are required to perform a task effectively".[54]

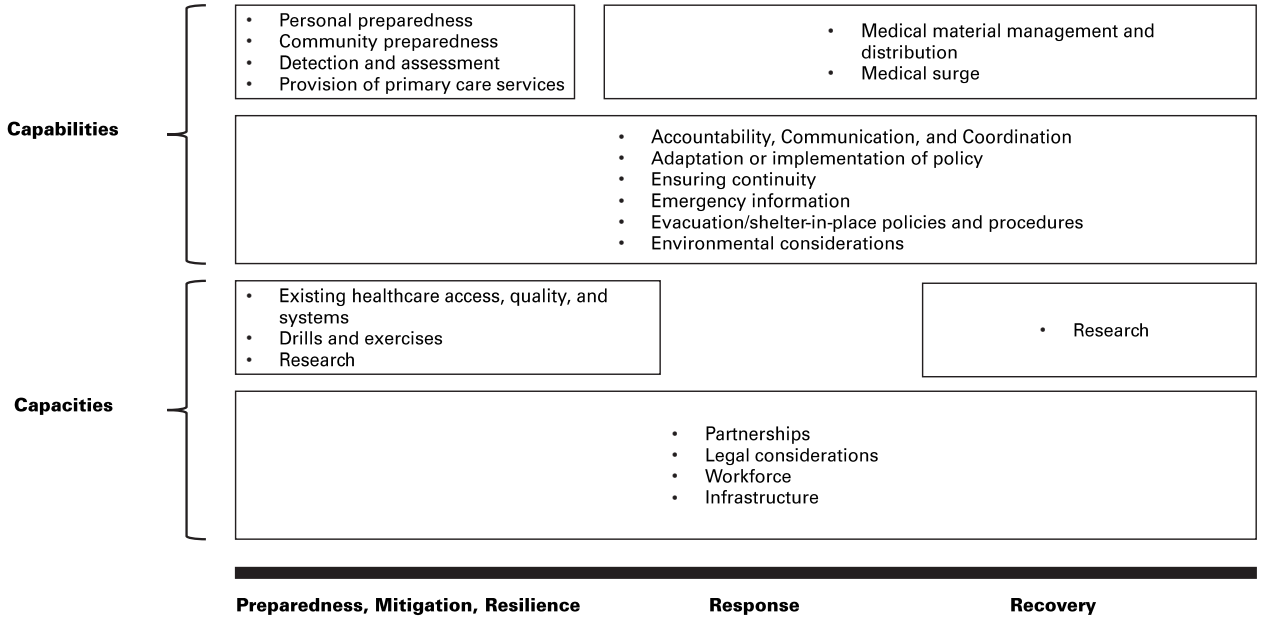
We arranged our codes and key underlying concepts to be explored in interviews into a visual representation of the capacities and capabilities underlying organizational and agency-wide support of those with chronic diseases across the disaster life cycle (Figure 2).

d. Interview Results

1. Challenges

Interviewees were not unified on how to define those with chronic disease, with few naming specific illnesses. The most commonly mentioned diseases were diabetes, hypertension, and chronic renal and pulmonary disease requiring dialysis or a ventilator, respectively. Mental health disorders, including addiction, were mentioned by several interviewees as well. Several interviewees also commented on the enumeration of the functional and access needs population, which is defined within the National Response Framework as "persons who may have additional needs before, during and after an incident in functional areas, including but not limited to: maintaining health, independence, communication, transportation, support, services, self-determination, and medical care. Individuals in need of additional response assistance may include those who have disabilities; live in institutionalized settings; are older adults; are children; are from diverse cultures;

Figure 2
Capacities and capabilities across the disaster life cycle



have limited English proficiency or are non-English speaking; or are transportation disadvantaged."[59] Several interviewees demonstrated the belief that this population was too inclusive to be useful while others more strongly communicated meaningful differences between functionally and diagnostically impaired groups and others.

There was acknowledgement that planning for sub-populations was important but that "overprescribing" our approach to planning for specific populations could lead to a "planning cycle that would never be completed, or started in most cases" (I7, I12). Still, when discussing the purpose of the study, all interviewees acknowledged the importance of addressing the needs of the population with most interviewees expressing appreciation and recognition of relevance for the aims of the project.

The needs of those with chronic diseases in the disaster recovery period were discussed frequently from the perspective that this populations' needs are most effectively met with preparation before disasters. Several interviewees acknowledged the need to improve resource planning and system-wide considerations for this population in the recovery period, particularly around medication availability.

2. Solutions

Dialysis centers and those engaged in kidney disease preparedness and response efforts were mentioned frequently as stakeholders who have successfully been involved and engaged because of the regimented schedule of dialysis, the need for critical infrastructure, clean water, patient education, availability of trained personnel and providers, and diverse partnerships required to provide emergency and post-disaster dialysis.

An additional solution that was widely suggested was theoretical adoption of a more inclusive community-based approach, and as one interviewee states, a

"concerted approach, and a focus, but I don't think we can routinize it beyond knowing that we need to work on it" (I6-I9, I13). Most interviewees identified with this sentiment, with two different interviewees stating that (1) "the whole-community, one approach, gets you 70% of the way there" and (2) "almost everything can fit very nicely under the physical accessibility/program accessibility/effective communication accessibility rubric" (I6, I12). No interviewees revealed an aspect of planning, response, or recovery that they were involved in or heard about that specifically considered the needs of this population.

3. Capacities

The capacities discussed in interviews are highlighted in Appendix Table 1, and here we identify the most common trends within interview statements surrounding each capacity.

Partnerships: There were several acknowledgements of the importance of healthcare coalitions. Several interviewees perceived that a number of partners essential to serving the needs of this population were not integrated well enough into existing planning for preparedness, response, and recovery efforts. Partners included references to entire sectors, such as infrastructure (in particular, electricity), agency or organization-wide departments such as operations, and others which were or had been engaged in concrete efforts by interviewees to help address the needs of those with chronic disease in disaster settings, such as radio stations, private insurance companies, and non-governmental search and rescue groups. Existing partnerships were identified as needing strengthening and clarification of their roles, including those (1) within local and state healthcare coalitions (2) between healthcare systems for surge planning in disaster events (3) between healthcare providers and those who expect or plan for them to communicate preparedness information to their patients, and (4) between facilities newly incorporated into the formal federal healthcare preparedness milieu via the Centers for Medicare and Medicaid Services (CMS) Emergency Preparedness Rule. No interviewee suggested that all the partnerships required to serve this population had been fully formed, developed, or optimized.

Existing healthcare access, quality, and systems: Interviewees widely agreed that an effective and improved pre-disaster healthcare system should be the foundation of preparedness and mitigation efforts for this population and that the same is critical to carrying through effective response and recovery. One interviewee stated that in the current system "whether or not I have health insurance is no longer a given. If I don't have health insurance, whether I show up someplace else or not, my ability to maintain my health is going to be [significantly] compromised" (I6). In addition to these broad prerequisites, interviewees acknowledged the need for health systems (entities under unified or coordinated leadership that include hospitals and other outpatient treatment and diagnostic facilities) to share information, for example, to manage expectations for surge care in the case of an event, even though "with the competition in healthcare we don't always think sharing information with each other is a good idea" (I13). Interviewees also suggested that existing programs, such as the Emergency Prescription Assistance Program, were not publicized enough or applicable to many of those with chronic disease who could benefit from such a program.

Research: Across interviewees, the need for more purposeful research aims and questions, as well as an increased focus on operations and solution-oriented research was conveyed. Three interviewees acknowledged the direct use of research in informing their planning or response activities, although they also acknowledged the need for more research in the previously mentioned areas (I1, I9, I11). Research needs were characterized with the following: "for chronic health, the questions that come to mind would be, 'Why or why not do people with chronic health issues engage in preparedness?' or describing in what ways they do and do not and what the barriers are and how

cont'd

interviews

to mitigate them" (I12); "the repeated problem that we see in disaster related research is...people rise up, write a few papers, don't get funding, do something else, and then when the next disaster occurs...the research was really quite derivative and not advancing the needs in the area" (I10); "...show me the quality indicator that we [use to] assess health care delivery from an outcome standpoint.." (I3); "one area that hasn't had a lot of research that could really help us is the effectiveness of community resilience and community preparedness" (I9). When asked which concrete resources would be most helpful, local and state partners acknowledged learning about concrete, evidence-based strategies for preparedness and response activities as a key area for improvement of existing research and its translation.

Legal considerations: Two interviewees acknowledged the usefulness of memoranda of understanding (MOUs) with another acknowledging that their community dialysis centers have MOUs with hospitals to avoid overburdening emergency departments in disaster settings (I5, I10, I14). Another interviewee believed that the new CMS rule is "not prescriptive enough... about MOUs and transfer agreements" (I10). Providers responding to Hurricane Harvey in a rural community in Texas discussed the impending challenge and uncertainty of asking for a continued waiver that allowed them to practice outside their scope and jurisdiction during the recovery period after Hurricane Harvey. A final consideration is the overall legal or operational definition of a region that is in the response or recovery phase. One interviewee asserted the importance of the formal designation that is given because it "becomes really hard to allow for partners to work together when some, because of budgetary constraints, or their role in response, are shifting in to a recovery when others are still working on response" (I7).

Workforce: Attention to the workforce was largely limited to healthcare providers. Interviewees demonstrated a variety of beliefs regarding the degree of responsibility and existing resources to support providers (including physicians, pharmacists, etc...) in communicating preparedness, response, and recovery information to their patients with chronic disease. The importance of remaining "realistic" in expectations of what the provider workforce is responsible for communicating to this population was stated multiple times, with no interviewees referencing the existence of, or need for, clear, evidence-based, and/or widely adopted guidelines for the workforce in this regard (I4). With regards to involvement of the provider workforce in the existing framework of disaster preparedness, one interviewee stated that "chronic disease people don't care about disasters" while another interviewee highlighted an event at which "patient advocacy groups, public health, and some specific parts of the health care supply chain on issues of preparedness and response that are specific to those particular groups" are brought together (I7, I10, I15). Another interviewee stated the need for "a broader focus for our clinicians as they are talking to their patients" (I9).

Infrastructure: The role of the infrastructure sector was noted by several interviewees, one of whom stated that "electricity is everything" (I12). The latter element was most often mentioned by interviewees, particularly in the context of keeping medications for chronic diseases, especially diabetes, refrigerated and ensuring continued operation of critical medical equipment, such as ventilators and dialysis machines. Others discussed elements of infrastructure included maintaining transportation and supply chain systems to allow for medication distribution as well as the framing of essential needs rooted in critical infrastructure systems (e.g. water, food) as part of Maslow's hierarchy without which higher forms of organizational support for those with chronic disease cannot be achieved (I3). Finally, multiple interviewees acknowledged the importance of using disaster recovery as an opportunity to rebuild infrastructure as more resilient with barriers including "the competitive dynamics of

healthcare [where] the pressure is just to get the facility back up and running and to just make it what it was as opposed to build it back better for what the communities needs are" (I13). Two interviewees acknowledged the need for these kinds of infrastructure partners to be "at the table" in emergency preparedness, response, and recovery conversations (I6, I10).

Drills and exercises: Drills and exercises were identified as valuable by interviewees, with some considering the direct involvement of patients with chronic disease, such as those who require dialysis, in drills. One interviewee currently working at the federal level noted that "...honestly, exercises in most cases are going to be the best things, more so than even your plan..." (I13). Interviewees working at the local level stated that "to train and really drill, again, is a drain on your resources" and "putting on a community-wide exercise is very, very time consuming. And it's also very expensive" (I5, I9). In addition to these broad considerations, several interviewees spoke about the exercise requirement mandated by the CMS Emergency Preparedness Rule, with one interviewee working at the local level stating that the "...community exercise requirement is the big concern, I think even for some of our existing coalition partners" (I9).

4. Capabilities

The capabilities discussed in interviews are highlighted in Table 1, and here we identify the most common trends within interviews surrounding each capability.

Accountability: Multiple interviewees acknowledged the importance of "buy-in" in addressing the needs of this population and often specified the importance of buy-in across the clinical (e.g. providers), executive (e.g. health system leadership and management), and operational (e.g. emergency management, infrastructure) levels (I1, I5, I9, I13). One interviewee stated "we've got to have the clinical and executive engagement in the coalition to really be able to do alot of the planning for the whole community, not just the emergency department. And that's where I think alot of [coalitions] still have a tremendous amount of work to do" (I13). Several interviewees acknowledged the importance of issue ownership within a disaster, and across interviews, no one named a specific office, personnel, task force, etc... who is responsible for specifically addressing the needs of this population.

Continuity: Interviewees acknowledged the need for continued medication and care after a disaster. Although providers in Texas actively responding to Hurricane Harvey specifically discussed the non-medication-related recovery needs of patients with chronic disease, such as routine primary care appointments. Several interviewees discussed the need to consider preparedness, response, and recovery issues "from a business perspective", emphasizing continuity of operations and making the following comments (I6): "the last pillar of your list should be economics" (I3); "Remember that [healthcare providers and organizations] are, in most cases, small businesses. Small businesses have a whole unique set of challenges after a disaster, and it's not necessarily just medical stuff" (I12); "You're gonna have to get back to business, you know the business of healthcare is 24/7..." (I4); "One project...is really around making sure...organizations have planned, have continuity of operations plans, and [are] making sure that they can stay open during emergencies because we know that [residents] are going to rely on them even if we open shelters" (I9).

Personal and community preparedness: There was wide variety in the perceived importance of personal preparedness, with multiple interviewees endorsing the notion of community preparedness as more important, or more useful, than an isolated approach to personal preparedness. There was concern that research and interventions on the traditional personal preparedness activities that this population can undertake have been largely ineffective: "Have a kit, be prepared is the 'just say no' of the disaster world" (I12).

cont'd

interviews

Other interviewees promoted the importance of maintaining a focus on more traditional patient education, for example, "...understanding how to do things like get medicines refilled if you don't have a new prescription, or who you should call if you've lost your insurance card, or if you are uninsured...how you navigate getting a new prescription...I just don't think we do a good enough job right now educating on that" (I7). For this population in particular, many interviewees acknowledged the lack of feasibility in suggesting that individuals stockpile several days or weeks worth of medication. Another interviewee noted the lack of individual-level awareness of the EPAP program: "After Hurricane Sandy, [EPAP] was activated and there was a study done that showed that one week after disaster, only 11% of those eligible had even heard of the program" (I2). Those who endorsed community preparedness acknowledged the importance of individual-level actions but believed that community-wide efforts to engage traditional and non-traditional preparedness partners could allow for a wider and more effective dissemination of information to this population and others. Reflecting on the role of community preparedness, one interviewee stated "It's not enough to know that my local pharmacy knows me. There has to be a community plan in place, because otherwise I'm going to end up real sick real fast in your ER and that was entirely preventable. I took all the right steps. Unfortunately, the disaster made my best planning fail" (I6). Examples of preparedness that involved community-driven efforts were shared, including one city agency's effort to dialogue with community centers and faith-based organizations to help disseminate preparedness information and another local hospital's effort to develop and host free community preparedness courses.

Detection and assessment: Interviewees provided numerous existing examples of how they collect data or leverage existing databases to plan for and respond to the needs of patients with chronic diseases. The CMS EMPOWER database was referenced multiple times, although one interviewee referred to their city's unsuccessful effort to extract data recently in the wake of a natural disaster: "[We] put in an application for their EMPOWER data during [the disaster] and it took them 24-48 hours before they could get the data. From the time they thought about doing it to the time they arrived. That is just not adequate. There's no reason I can think of why public health departments can't be pre-certified to have that data. And the data refresh pushed to them every 3, 4, 6 months, every month even" (I2). Other forms of data referenced for use in disaster settings included (1) partnerships between government agencies and private insurance companies in which the latter is able to share and promote preparedness activities and information in advance of an event using its register of patients, and even link individuals to resources and (2) existing maps of operational pharmacies that agencies and patients can use after an event. Several interviewees spoke about the knowledge that local EMS providers have and how that knowledge has either been, or could be, more actively leveraged. Although interviewees acknowledged specific examples of this kind of data, none of the interviewees spoke about the legal considerations of sharing EMS information with health departments. The only data collection methodology that led to discussion of legal issues included the formation of registries, which were also often viewed as too resource-intensive to develop and often ineffective. Immediately post-disaster, providers in Texas performed needs assessments to guide service provision and spoke about using their experiences to inform their work as the response phase transitioned to recovery. Few interviewees spoke about leveraging data to guide efforts in the recovery phase.

Adaptation or implementation of policy: EPAP and the CMS Emergency Preparedness Rule were the existing policies most frequently discussed. EPAP was referred to both as a generally successful concept and one with significant issues in terms of patient awareness of the program and serving a limited subset of those with chronic diseases.

cont'd

interviews

One interviewee stated "And it's only activated in what were considered the worst storm impacted counties. You have a bunch of problems there. If it's only in storm impacted counties - evacuees don't live in storm impacted counties - they move out so those outside of those counties did not have any access to that program" (I2). The CMS Emergency Preparedness Rule was discussed by a majority of respondents with the following themes arising: (1) Because it is unfunded, it is likely to draw criticism from non-hospital agencies treating individuals with chronic diseases expected to follow through with some of the more resource-intensive requirements, such as the drill/exercise requirement (2) There is no formal mechanism for enforcing adherence to the rules, although there was disagreement on the impact this would have, with one interviewee stating "I know that one facility in California was already audited and dinged, just in the past few days based on the rule" and another working at the federal level stating that the "relatively generic requirements can be easily skirted" (I7, I10). Although it is unfunded, agencies have varying perspectives on whether this should or will impact agencies' adoption of the requirements. A distinction also emerged in these perspectives between those with federal backgrounds ("they don't need any more money to do it, they just need to do things smarter and more efficiently" (I3); "the truth of the matter is that the amount of work that is necessary to accomplish those very loose requirements is minimal" (I10)) and those working at the state or local level ("it's just not feasible when we have funding cuts that are happening all the time, every year" (I9); "the biggest barrier that they will face is something that a lot of other facilities face as well is the availability of resources, be it monetary, personnel, buy-in from staff" (I5)). Finally, there was widely held uncertainty regarding the likely overall impact of the rule, with one stating "..you can make all the laws and rules in the world and people always find ways to make it pointless, meaningless, or ineffective, and just check that box. It's not going to hurt anything...I shouldn't say that. Maybe it will, maybe it's an untoward burden for some health care facilities..." (I12).

Provision of primary care services: In the context of those with chronic disease, provision of primary care services in disaster settings was most often interpreted as the communication of critical preparedness information from providers to patients. The ability of physicians to actively and confidently share information and craft plans with their patients was frequently addressed with interviewees stating that we must "make sure that the provider community has more information to share with patients before events" and that in meeting the needs of these patients in recovery, "I think that's a patient education piece...I think that's about having a plan in place with their provider, right?" (I7). Other interviewees acknowledged the complexity of realizing this capability, with one discussing provider difficulty addressing the existing, non-disaster needs of patients ("it's hard to imagine adding that to the list of work that providers have to do") and another stating that while a "physician should be prepared if [a patient comes] back at the next visit and says, 'Hey doc, along with my new antacid medication, you gave me this stuff on crisis. What does that mean?'", we should not place providers "in the middle of a battle of being a conduit for [emergency preparedness officials and agencies] to communicate" (I2, I4). As noted, interviewees did discuss the role of primary care provision in both the pre- and post-disaster period. A federal interviewee also discussed "the repositioning of the NDMS DMAT teams to be more focused on the provision of primary care" in the response phase of a disaster (I10).

Emergency information: The creation and disbursal of information to the public and within agencies in advance of, during, and after an event, were all discussed at some point by most interviewees. One local agency reported creating its own materials for the public after an event and using or adapting information provided

by the CDC, noting that many organizations or facilities they partner with routinely have their own information to provide to patients, such as dialysis clinics. Another interviewee described an active partnership with a radio station to disseminate preparedness information locally. In describing a similar philosophy of partnership with community organizations to disseminate relevant information, one interviewee working in a densely populated urban area stated that "...we know that our residents are going to rely on [community organizations] even if we open shelters. If we open all of these sort of government resources, that's not always trusted by our residents..." (I9). With regards to broader agency-level planning, few higher-level reports and planning resources were acknowledged as being used or helpful in operations or planning efforts. Few interviewees discussed the recent development of the ASPR TRACIE database or other reports released by the CDC, Department of Health and Human Services, or local and state organizations and agencies that have provided additional documents and toolkits to aid in the planning, response, and recovery phases either directly for patients with chronic diseases or for other populations which include significant numbers of individuals with chronic disease, including the elderly and those with disabilities.

Medical material management and distribution: The need for a mechanism to accumulate medications before an event and ensure appropriate distribution immediately after and in the longer period after an event was widely recognized. One provider and federal official referred to the problem as "an issue of logistics and not clinical care," while another provider and academician stated that in response and recovery "you can't get trucks in and people can't get out. Or, you can't communicate to let people know where to go to get their medicines. Or, the medicines are made available to a slight portion of the community" (I10, I2). Perceived barriers to individual stockpiling included the mismatch between patient expectations and the policies and procedures of insurance companies towards allowing stockpiling outside of allotted prescriptions. Some interviewees did not mention these barriers and suggested that patients should be responsible for stockpiling medication as part of a standard preparedness plan and either did not mention or were inconsistent with others about the quantity that needed to be stockpiled. One provider in Texas, however, described the provision of emergency 30-day supplies of medication after Hurricane Harvey by a private pharmacy for patients with insurance, even if they did not have an active prescription or were out of refills for an existing one (I11). One interviewee highlighted the importance of medication needs in the extended period of recovery, stating that "we need to think about...[not just the] three to five day window of meds that [patients] might need in order to survive an event, but [the] longer term...[when] things really just don't go right back to normal after an event" (I7). In addition to medications, the need for replacement and maintained access to durable medical equipment (DME) (e.g. ventilators, wheelchairs, dialysis machines, etc...) was referenced by multiple interviewees. Given the varied size, cost, and operational requirements of this type of equipment compared to medication, interviewees spoke generally about this need and referenced the ability of the EMPOWER database to guide efforts to sustain access, at least for those obtaining DME through Medicare.

Medical surge: The discussion of surge was focused on the diversion of chronic disease patients with manageable pathology away from high-resource settings such as the emergency department. Many interviewees espoused the belief that these patients frequently plan and migrate to emergency rooms, in particular during and after disasters to satisfy medication and equipments needs. Many asserted that they should be better educated on the appropriate circumstances under which to present at these facilities while acknowledging the competing reality that current systems

for medication disbursal, equipment replacement or maintenance, and other healthcare needs in disaster settings are not established well enough to assure patients that their needs will be met unless they go to an emergency department. One provider working at the federal level also noted the role of the current burden on healthcare systems on their ability to accomodate surge in disaster periods, stating the main hospital in San Juan "was at a 110% bed capacity the day [Hurricane Maria] hit" (I13). Finally, there was acknowledgement by several interviewees that pre-disaster communication and coordination across healthcare systems, as well as between facilities and organizations that may not be within the same system could facilitate a more effective response to an unavoidable surge of acute and chronic patients in a disaster.

Evacuation and shelter-in-place policies and procedure: For individuals with chronic disease, the most frequent point of discussion around evacuation was the role and effectiveness of different types of shelters versus sheltering in place. As one federal interviewee states, "How do you care for someone? This whole concept of where do you put people with chronic health care issues – do you put them in general shelters, do you put them in special needs shelters, do you evacuate them ahead of time? All of the above have been tried, and it doesn't seem like any particular solution has really identified itself as the way to go" (I12). Interviewees acknowledged the safety risks of evacuation, even for healthy individuals, as well as the illegal separation of individuals from their families that "sometimes has to happen, whether it's because of a lack of planning on the state and local level or because their needs are just that much more significant than what can be provided in a medical shelter or even a general shelter" (I13). The successful pre-event evacuation of the "sickest" patients in the community where interviewees responded to Hurricane Harvey and the efforts of a separate local health department to create a evacuation preparedness task force were descriptions of successful preparedness activities that involved planning specifically for those with chronic disease or the entire population (I1, I11). Beyond two interviewees' discussion of the need to widen awareness and eligibility of the EPAP program, no interviewees discussed post-disaster re-integration of chronic disease patients into a disrupted healthcare system.

Environmental considerations: One interviewee discussed unexpected, widespread water damage to homes after a hurricane (I11). Otherwise, no references to potential or previous exposure to toxic or unknown substances that might exacerbate or contribute to the development of chronic illnesses (e.g. cancer) during and after disasters were made.

5. Competencies

Multiple interviewees expressed concerns about competency with regards to the CMS Emergency Preparedness Rule, including one who stated that "CMS does not have the expertise to execute the rule" and another who acknowledged that their agency was receiving daily requests for coordination and guidance in order to meet CMS requirements in the weeks before and after the rule went into effect (I3, I9). Another interviewee discussed the impact of poorly directed research grants, stating that their impact was the development of researchers "who have no actual disaster experience and don't understand the bulk of the literature, and so we get the same thing over and over again" (I10). Several interviewees spoke about partnerships with facilities taking care of chronic disease patients, providers, and/or patient groups as critical because they have preexisting expertise and knowledge about their population and the services needed. This sentiment applied to one interviewee's characterization of their work supporting stakeholders who they describe as "the folks who already know [what to do]" (I7).

discussion

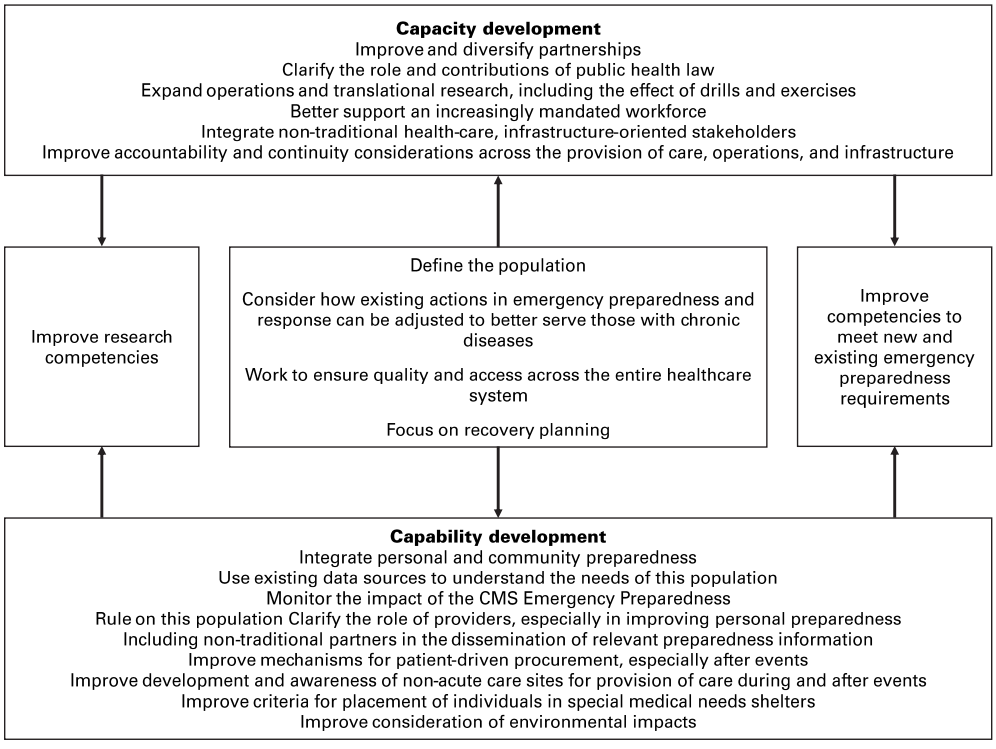
To our knowledge, this is the first effort to characterize the specific, system-wide needs of patients with chronic diseases before, during, and after natural disasters in the United States by considering the viewpoints of public health and policy agency senior staff, as well as providers of care in disaster settings.

Prior attempts in research literature to clarify and suggest actions to meet the needs of this population have included calls to action, suggestions for areas of focus guided primarily by the perspective of healthcare and social service providers, and the adoption of a public health infrastructure model to guide consideration of factors relevant to those with chronic disease which has allowed for the proposal of individual resilience and mitigation strategies across each dimension of public health infrastructure.[6, 28, 30] A recently created checklist for health sector resilence also presents a valuable contribution and acknowledges the importance of specific needs for those with chronic disease.[58] Our approach is intended to provide an additional layer to supplement models such as these and which local and state agencies can use to ensure they are meeting the needs of the chronic disease population. We believe that our focus on the 3C framework will allow for more realistic planning, integration of existing research, and rapid adoption of our recommendations into current agency planning for events.

The overall need for improved communication and coordination of activities is not a new theme within preparednes and thus is not given special attention here except to the extent that improvements in these areas are part of the tenets we discuss below.[60-63] Recommendations are summarized in Figure 3 below.

Figure 3

An approach to chronic disease management before, during, and after natural disasters



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discussion

1. Challenges

Defining the population: Chronic diseases have been variably defined across research and practice-oriented literature, necessitating a more unified and standardized definition. In the absence of prompting or leading the discussion, interviewees often perceived those with chronic diseases exclusively as those who need medication or durable medical equipment, whereas research has also highlighted the need for additional non-medication and non-equipment-related diagnostic and treatment considerations for this populations, such as ensuring continued routine or follow-up healthcare provider appointments (e.g. physician, occupational therapy, physical therapy, pain management), access to health insurance, and medical support services such as home health aids or visiting nurse services. A clearer definition would allow for more integrated planning to occur across various sub-populations which include considerable portions of those with chronic illness, including children, the disabled, and the elderly. We believe that the WHO definition of noncommunicable diseaeses is a useful starting point but that future research and resources for practitioners in this area should be more clear and inclusive.

Increased focus on the recovery period: There is not enough emphasis on the needs of those with chronic disease after events, especially given the nature of research that confirms poor outcomes for this population for months to years after the event. Although a focus on recovery has been emphasized in various forms within the field of disaster medicine and public health preparedness, more spending and attention should be allocated to serving the post-disaster needs of these patients by ensuring that the facilities and organizations supporting them receive aid and that the population is able to continue accessing healthcare. The latter may necessitate state or federal laws that extend the suspension of requirements to enrollment in Medicaid to allow those affected with chronic disease who require additional care or who have been displaced to receive the necessary services or allow for the extended period or expanded eligibility for programs like EPAP.

2. Solutions

The need for a unified approach: The need to consider planning for this population within an integrated approach that does not sacrifice the needs of one group for another took the form of several descriptors among interviewees, including planning for the whole-community or for those with access and functional needs. These are important principles that hold us accountable to foundational ethical and legal obligations in disaster preparedness, response, and recovery. As such, in our discussion we have attempted to describe actions that can be taken to support populations with chronic disease as a reorientation or re-framing in the scope of work already being done in preparedness. We describe the actions that follow as augmenting current principles in disaster preparedness to provide guidance on how to develop a more informed awareness of the particular needs of this population.

Consider the succes of dialysis centers: In considering the need for an integrated solution, interviewees and research have often discussed meeting the needs of dialysis patients as a successful model given the regimented schedule of dialysis, the need for critical infrastructure, clean water, patient education, availability of trained personnel and providers, and diverse partnerships required to provide emergency and post-disaster dialysis. Although much research has been performed and shared on how providers, facilities, third party organizations, and governments have come together to address these needs, less has been performed on translating how the planning, response, and recovery protocols for serving this population can be applied to other chronic diseases.

discussion

3. Capacities

We suggest the following improvements in existing capacities, or establishment of new ones, within public health, policy, and emergency management.

Partnerships: Non-traditional and local partners should be better integrated into traditional healthcare and emergency preparedness activities. The current establishment of healthcare coalitions in accordance with the CDC's Healthcare System Preparedness Capabilities and their likely expansion to aid in fulfillment of the CMS Preparedness Rule requirements has continued the movement towards improved partnerships in preparedness. For those with chronic disease, the existing trend will likely improve care across the disaster cycle. The inclusion of non-traditional and local partners, however, including local and state power providers, transportation agencies, and local organizations and businesses as conduits for dissemination of information to the public, as shelters, or in other capacities, can make these growing partnerships more responsive to the needs of those with chronic disease.

Existing healthcare access, quality, and systems: To ensure the optimal response and recovery, we must take better care of chronic disease patients before events so that they are better informed about their conditions, their needs in resource-limited settings, and so that their baseline health puts them at lower risk of exacerbations. The expansion of accountable care organizations and the medical home model, as well as recent passage of the CMS Emergency Preparedness Rule, continue to improve our nation's overall health infrastructure. Multiple interviewees acknowledged the importance of having a resilient overall healthcare system as a capacity to better respond and recover from events, and while it is out of the scope of this publication to explore the myriad of ways that overall health reform and systems strengthening improves disaster resilience, it is a priority that should not be forgotten as the healthcare debate resurfaces and opportunities to frame healthcare and preparedness reform as a matter of national security present themselves.

Research: Disaster scientists must be more purposeful in the questions they ask and the aims of their research - in particular, by increasing focus on operations and solutions-oriented research. This was a clear trend among interviewees, as was the request for evidence-based resources and strategies to aid in planning for the needs of this population. While few, if any, areas of disaster preparedness research have abundant research, the burden of various chronic diseases after natural disasters (and other types of disasters) has been increasingly well established in the peer-reviewed literature. There is, as demonstrated in our content review, less research in the area of interventions to better serve this population. However, numerous organizations and local, state, and federal agencies have created planning materials for strategies to better serve many sub-populations with considerable burdens of chronic disease, such as the elderly. The mismatch between available evidence on interventions and existing resources for planners and responders to serve this population specifically, although not a unique finding in the greater preparedness landscape, is important to consider and should help guide the research agenda. The continued proposal of frameworks and checklists will not suffice to protect this population from harm in natural disasters if we do not complement the creation of these resources with research on their effectiveness.

Legal considerations: Given the evident needs for acute care among those with chronic diseases in disaster settings, but also with the increasing recognition of their protracted needs, adjustments in disaster declarations, MOUs, and other intersecting areas of

discussion

law and public health need to be be better addressed. Disaster declarations allow for suspension of certain license requirements for providers, reciprocity, or expanded scope of practice. Their expansion and improved enumeration on the state level should be explored. Wider development and adoption of Memorandum of Understanding (MOU)s for partners involved in the care of chronic disease patients in disaster settings, as well as more clear guidelines for which providers can work outside of their formally approved jurisdiction, for how long, and the enumeration of the liability environment in these settings should also be considered.

Workforce: Agencies should be realistic about setting new expectations for planning, response, and recovery among workforce partners previously not engaged in preparedness activities, as well as provide adequate support for any new expectations that are imposed and involve the appropriate stakeholders in the development of additional requirements or expectations. For example, one interviewee stated that the CMS Emergency Preparedness Rule could have a negative impact by imposing an "undue burden" on the workforce who may not have the capacity to meet rule requirements (I12).

Infrastructure: Better integration of non-traditional healthcare infrastructure-oriented stakeholders, like electric companies and transportation agencies, into public health preparedness activities is necessary. The role of infrastructure, defined as the "physical and organizational structures and facilities (e.g. buildings, roads, power supplies) needed for the operation of a society or enterprise" as a precursor to any functional and/or longitudinal response was widely recognized.[64] Applications to the chronic disease community include the need for power to critical equipment such as dialysis machines and ventilators, as well as the integrity of roads and transportation systems to ensure that medication and other equipment necessary for the diagnosis and continued treatment of those with chronic diseases. In addition to reliable infrastructure to allow for adequate response, the rebuilding and remodeling of infrastructure in the recovery period should consider the needs of chronic disease patients, as well as the overall health profile of the community being considered so that these efforts are utilized as an opportunity to bolster resilience and mitigation of impacts for all populations, not just those with chronic diseases.

Drills and exercises: More research is required on the effectiveness of drills and exercises, and more consideration should be given to the resource investment required to run even a single drill by less well-resourced stakeholders. While some interviewees espoused the well-established value of drills and exercises, others were less certain and believed that having other capacities in place (e.g. well established partnerships, a resilient healthcare system) would better serve this population given the time and resources involved in running a drill for an organization with more limited capacity. While drills and exercises are likely to remain an established part of traditional emergency planning, we should consider how to tailor these drills to the needs of different patient populations, and as one interviewee suggested, potentially consider the direct involvement of chronic disease patients and those with other health issues to ensure that, in addition to having a plan, patients are able to carry through with the more detailed and critical aspects of it.

Accountability: There must be what many interviewees described as "buy-in," or accountability, across healthcare, business, and infrastructure. The accountability for healthcare facilities was increased with the CMS Emergency Preparedness Rule, although many interviewees expressed concern regarding whether consequences of failure to meet the rule will be enforced. Many interviewees also discussed the irregularity of investment in the preparedness process at the executive level of healthcare systems, which is likely to extend to non-healthcare related businesses. Although

codes for infrastrucutre often mandate some degree of preparedness, current funding for, enforcement of, and requirements for hazard-specific infrastructure development or rebuilding are inadequate. Accountability to carry through with a minimum level of healthcare system preparedness to serve not only this population, but the country, is essential. A strategy for improving accountability could include local or regional advocacy to establish minimum standards across these industries.

4. Capabilities

We suggest the following improvements in existing capabilities, or establishment of new ones, within public health, policy, and emergency management.

Personal and community preparedness: To better serve those with chronic disease, the integration of personal and community preparedness should continue. Our research confirms the movement towards community preparedness and resilience. This can take the form of local coalition development and subsequent planning meetings in advance of disasters community preparedness classes and other more effortful public education on available resources for personal preparedness activities, as well as community preparedness activities in the event of more serious events that require communication with or movement to local organizations. Especially for chronic disease patients, who have diverse needs and who will require help in understanding various contingency plans in disasters, personal preparedness should no longer be viewed as solely a personal responsibility which can be achieved without a broader effort by the health system and/or community.

Detection and assessment: Better leverage existing sources for pre- and post-event data collection and foster relationships can that allow for new avenues of data collection to occur. The request for better data to assess the pre-disaster burden of chronic disease populations was a common theme. Interviewees did, however, acknowledge numerous examples of well-established data sources, such as the Medicare EMPOWER database and obtaining information from EMS providers, as well as more innovative forms of leveraging data, such as the provision of insurance companies with preparedness information to push out to their clients with chronic conditions if local or state health departments could gain legal access to the information. The latter occurred in the setting of a healthcare coalition formed in response to guidance and receipt of funds from the Hospital Preparedness Program. Issues with existing data sources, such as the turnaround time for accessing EMPOWER data and the lack of acknowledgement regarding legal considerations permitting access to EMS data, suggest that these mechanisms can be improved and that stakeholders can better leverage existing sources of data and foster relationships through which data can be obtained.

Adaptation or implementation of policy: The CMS Emergency Preparedness Rule is an opportunity to begin building better planning and care for chronic disease patients into preparedness infrastructure. There were numerous concerns regarding the CMS Emergency Preparedness Rule, including its lack of attached funding, ability to hold facilities accountable, and whether it provided enough guidance and support to meet the requirements. Although a full discussion of the implications of the rule are out of our scope, it is worth mentioning that the establishment of the rule is an opportunity to, over time, begin building preparedness considerations into our healthcare systems. If agencies are not adequately supported and guided, most likely by involvement in coalitions and the development of effective partnerships, this will be a lost opportunity that may define how and whether these same facilities are willing to engage or abide by more advanced requirements that serve those with chronic disease more fully or specifically. EPAP is another

cont'd

discussion

existing policy that serves this population, the potential changes to which have been previously discussed.

Provision of primary care services: Across the healthcare spectrum (physicians, nurses, pharmacists, social workers, occupational therapists, physical therapists, etc…) clarification regarding the roles and responsibilities of direct service providers in the process of patient education and referral to existing resources is necessary. The importance of considering limitations on the capacity of the workforce has been discussed, and the capability that follows naturally is whether and how the provision of primary care services contributes to preparedness efforts. While there is consensus that the role of the provider is important, enumeration of the nature of their responsibility, perception of resources available to them, and formal recommendations to guide healthcare providers in the realm of public health preparedness are absent. While a number of resources for patient education are available, it is unclear whether patients or providers are utilizing them to aid patients with chronic diseases in planning for events. The establishment of recommendations by the United States Preventive Services Task Force to advise providers to have these discussions with patients is one suggested method by which primary care providers can be better guided in providing information to their patients.

Emergency Information: Traditional and non-traditional partners should be included in the dissemination of relevant preparedness information to the public, such as radio stations and faith-based organizations. For agencies and organizations, as well as individuals, there must be improved awareness of existing resources for planning, response, and recovery for individuals with chronic disease. Just as interviewees requested data to assess the burden of chronic disease before disasters, we must also request informed collection and dissemination of available resources for agencies, organizations, and individuals so that valuable resources are not expended re-creating resources that already exist. The recent establishment of the TRACIE database by the Department of Health and Human Services Office of the Assistant Secretary of Preparedness and Response is a valuable resource that has begun to achieve this goal and which was not discussed by interviewees. Efforts to publicize this resource and develop a version for consumers (e.g. the general public) may be helpful in achieving this goal.

Medical material management and distribution: We should re-evaluate encouragement of individual patient stockpiling of medications before a disaster unless there are known effective local and state mechanisms for ensuring the feasibility of such actions. In addition, existing resources which can aid systems attempting to manage and coordinate third party logistics information should be better publicized. The distribution of durable medical equipment has been significantly aided by the establishment of the EMPOWER database, and while these needs continue to be present, collecting data for non-Medicare patients with these needs through strategies to improve detection and assessment outlines above is a useful strategy.

Medical surge: There is a need to improve the development and awareness of non-acute-care sites for those with chronic disease to move to before, during, or after an event. During and after events, many individuals with chronic disease present to acute care facilities unnecessarily, although such a declaration may be inappropriate given that, for example, another way for them to get a medication refill is unavailable. As a result, the best way to improve surge capacity and management in events is to engage in pre-disaster education and awareness efforts of the resources and methods available to divert these patients from the emergency department.

discussion

Evacuation/shelter-in-place policies and procedures: Improved criteria for placement of individuals in special medical needs shelters and methods for re-connecting individuals into the healthcare system if evacuated are needed. Interviewees did report the successful evacuation of acutely sick patients in a community in rural Texas prior to Hurricane Harvey, although it has also been acknowledged that larger scale evacuations pose safety and logistical concerns. Efforts to plan and address the potential evacuation needs of those with chronic diseases depend largely on the ability of other well-developed disaster capabilities to support these patients in accessing the care so that evacuation is, in most cases, unnecessary.

Environmental considerations: The potential for exposure suggests that more awareness needs to be provided to this issue and environmental health professions should be a more integral part of the conversation in the planning, response, and recovery phases for patients with chronic diseases.

5. Competencies

Competencies were discussed less frequently and primarily in the context of new facilities meeting the CMS Emergency Preparedness Rule requirements. In addition, researchers must have the incentive, financial support, and understanding to perform operations and solution oriented-research that increasingly involves providers and organizations working at the more grassroots level (e.g. providers, patient interest groups, professional medication associations). Thus, competency surrounding the ability to achieve the overarching goals of the CMS Emergency Preparedness Rule and in cultivating responsiveness to the research agenda goals outlined here remain key focus areas for competency development to improve outcomes for those with chronic diseases after disasters.

limitations and conclusion

Limitations of this work include its primary applicability and reference to the United States healthcare system, although we believe that many concepts detailed here can be useful to other nations working towards the integration of whole community planning and the need to consider this particular subpopulation.

Indeed, our content review revealed that there are numerous similarities in the burden of chronic diseases after natural disasters in developed and developing countries as well as the solutions proposed by authors from both settings (Appendix, Tables 1-3). The cutoff date for our content review may have resulted in the exclusion of some relevant literature, although we believe that for the initially stated purpose of providing background to frame our research and inform our interviews, it remains a reasonable date allowing for the accurate summary of existing literature in this area.

We have highlighted research describing the burden of chronic diseases during and after natural disasters and demonstrated that more research is needed on the impact of operations, such as the distribution of medications and maintenance and establishment of better infrastructure to support chronic health needs, as well as successful interventions to better care for patients with chronic disease

Interviews with various stakeholders revealed that across four groups - federal agencies, state and local agencies, private healthcare entities, and private non-healthcare entities, a variety of actions can be taken to build on existing planning efforts in the United States to create a public health preparedness and response system that responds adequately to the needs of those with chronic diseases across the disaster lifecycle.

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useful resources & publications

Resources

TRACIE Topic Collections, Office of the Assistant Secretary of Preparedness and Response (ASPR): https://asprtracie.s3.amazonaws.com/documents/aspr-tracie-topic-collection.pdf

Natural Disaster Preparedness Webpage, ASPR: https://www.phe.gov/emergency/naturaldisasters/Pages/default.aspx

Emergency Prescription Assistance Program, ASPR: https://www.phe.gov/Preparedness/planning/epap/Pages/default.aspx

National Center for Disaster Medicine and Public Health Webinar Series, Building the Evidence Base for Disaster Risk Reduction for Health Systems in Response to Natural Disasters: https://www.usuhs.edu/ncdmph/research-education/webinars

Emergency Preparedness Rule, Centers for Medicare & Medicaid Services: https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertEmergPrep/Emergency-Prep-Rule.html

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APPENDIX

For full list of references or a specific reference, please contact ncdp@columbia.edu

TABLE 1. TRENDS IN DISEASE, PREPAREDNESS, AND INFRASTRUCTURE READINESS

Areas of focus	Findings
Burden of chronic disease	Sixty percent of Americans have at least 1 chronic illness, and 40% have multiple (Buttorff & Baumann 2017). After Hurricane Katrina, nearly a quarter of emergency room visits were related to chronic disease needs, and the burden among evacuees was reported to be as high as 56% (Sharma et al. 2008; Rodriguez et al. 2006). Across disasters in Indonesia, China, and El Salvador, the burden was as high as 79% (Guha-Sapir et al. 2007; Chan & Kim 2011; Woersching & Snyder 2003). One comprehensive recent review of chronic diseases after the Great East Japan Earthquake identified respiratory disease and mental health as the biggest issues, while another found that many chronic disease issues persisted more than 6 months after the disaster (Murakami et al. 2017; Suneja et al. 2018) *Cardiovascular disease*: For months, and even years, after disasters, cardiovascular risk factors like hypertension worsen in patients, as have the number of heart attacks when compared to pre-disaster levels, (Hayman et al. 2015; Kario et al. 2012; Hung et al. 2013; Tani et al. 2014; Swerdel et al. 2014; Peters et al. 2014; Gautam et al. 2009; Nakagawa et al. 2009)) . These trends have been demonstrated in literature examining disasters in the United States, China, and Japan. Exacerbations of chronic cardiovascular conditions like heart failure also occurred up to 3 years after the Great East Japan Earthquake (Yamauchi et al. 2013, Nakamura et al. 2016) *Diabetes*: The reasons for poor diabetes control after disasters include changes in the access to and dosing of medications, poor diet in food-constrained environments, and stress placed on the body as a result of the experience of the disaster and its outcomes, such as evacuation (Allweiss & Albright 2011; Nwakwuo 2016). Authors have found that this stress activates the body's "fight-or-flight" system for longer periods of time which can contribute to the development or worsening of diabetes (Tanaka et al 2015). After Hurricanes Katrina and Sandy, diabetic patients were more likely to visit emergency departments in the first week and to have poorer control of their diabetes in the long run over 16 months, respectively (Lee et al. 2016; Fonseca et al. 2009). It has been estimated that the cost of these complications, along with other chronic-disease related concerns after disasters costs over $500 million (Fonseca et al. 2009). *Respiratory disease*: One common respiratory disease is chronic obstructive pulmonary disease. After the Great East Japan earthquake, hospitalizations for this population increased, although authors have also found that these outcomes normalize over several weeks (Kobayashi et al. 2013). These patients also require oxygen as a critical piece of medical equipment, and authors did find that in a sample of patients in Japan, patients requiring oxygen were able to obtain it (Sato et al. 2013). In a systematic review of literatue related to the Great East Japan Earthquake, respiratory disease was one of the top two areas of research (Murakami et al. 2017). *Cancer*: We discovered little research addressing the impact that disaster can have on patients with cancer. However, after Hurricane Katrina those with head and neck cancer experienced decreased access to care (Loehn et al. 2011). Because cancer patients on treatment have compromised immune systems and a structured treatment regimen that often requires advanced medication and equipment, understanding how their care and outcomes are affected is important (Verna et al. 2017; Porzio et al. 2011; Imamura & Ueno 2011).

TABLE 1 (CONTD.). TRENDS IN DISEASE, PREPAREDNESS, AND INFRASTRUCTURE READINESS

	Chronic renal disease: Hospitalizations increased for those receiving dialysis after Hurricane Katrina (Howard et al. 2012). These patients, like those with cancer, often have complex medication, equipment, and dietary needs that need to be closely monitored because they can have an large impact on short and long-term health. The Kidney Community Emergency Response coalition and the Renal Disaster Relief Task Force are two agencies which are dedicated to addressing the needs of kidney damage in the immediate term after disasters. Because kidney disease is caused by both hypertension and diabetes, however, needs for these services may change and potentially increase in the more protracted period after disasters if hypertension and diabetes are poorly controlled (Kimmel 2007; Irvine et al. 2014; Deck 2010; Hamilton et al. 2009; McClellan 2001; Miller & Arquilla 2008; Lempert & Kopp 2013; Kleinpeter et al. 2006). Preparedness of this group of populations has also been studied, demonstrated than in one sample, less than 50% of dialysis patients knew of alternative sites to receive dialysis or had records to take with them if needed (Foster et al. 2011). *Mental health*: The burden of mental health issues after natural disasters has been increasingly discussed. Disaster in the United States, Nicaragua, Peru, Chile, China, Japan, the Netherlands, and Australia have documented negative impacts on mental health after natural disasters spanning from 2 weeks after the event up to 16 years afterwards (Benight & Harper 2002; Lopes et al. 2014; Cerda et al. 2013; Barreau et al. 2015; Cacchione et al. 2011; Jenkins et al. 2009; Laditka et al. 2008; Caldera et al. 2001; Jones et al. 2007; Milojevic et al. 2017; Inoue & Yamaoka 2017; Cao et al. 2014; Dorn et al. 2006; Flores et al. 2014; Chen et al. 2015; Thordardottir et al. 2016; Leiva-Bianchi et al. 2017; Brown et al. 2007; Hart et al. 2011; Powers et al. 2015; Reifels et al. 2015; Brown et al. 2010; Ren et al. 2017; Tang 2007; Wang et al. 2008). *Interventions to address chronic disease*: Research to address chronic disease needs in more restricted or altered care environments after disasters is limited. One systematic review of interventions to address chronic disease after humanitarian disaster in low and middle-income countries found only 8 studies out of nearly 5,000 articles that addressed the effectiveness of interventions (Ruby et al. 2015). Another review of recommendations for health providers, patients, and policy makers focusing on developed countries concluded that most recommendations were based on expert opinion or anecdote rather than evidence (Tomio & Sato 2014).
Summary: Overall, literature indicates a clear trend in the significant burden of chronic diseases in both the short and long term period after natural disasters. While implications and solutions depend on the type and severity of a specific disaster, disease profile of the affected community, and numerous other factors, more research should be done on interventions to address the burden of disease as opposed to characterizing the burden.	
Personal and community preparedness	Preparedness is generally measured by the ability of individuals or agencies to complete a set of concrete tasks that will mitigate the impact of disaster. *Individuals*: Recent studies of older adults in America found that up to 75% had no specific emergency plan and that up to 21% use devices requiring electricity (Al-Rousan et al. 2015; Bhall et al. 2015). Those with fair-to-poor health status, including non-elderly, also engage in preparedness activities less regularly compared to the healthier population (Bethel & Foreman 2011; Eisenman et al. 2009). Studies in South Korea and Japan have generally confirmed these results but also demonstrate that in some cases, older

TABLE 1 (CONTD.). TRENDS IN DISEASE, PREPAREDNESS, AND INFRASTRUCTURE READINESS

	patients may be more prepared when looking at metrics such as a 3-day supply of medication (Kang 2014; Tomio et al. 2012). The Federal Emergency Management Agency's 2014 Preparedness in America report revealed that individuals over the age of 75 were not prepared or confident that preparing for a disaster would help and were reliant on community organizations after disasters (Preparedness 2014). *Long-term care*: In 2012, the United States Department of Health and Human Services highlighted deficiencies in preparedness among nursing homes and made recommendations for remedying them (55). A group in California has suggested use of an "area coordinator system" for nursing home coordination during wildfires, although its effectiveness has not yet been studied (Blake et al. 2012)). In assessing how healthcare agencies improved their preparedness after Hurricane Katrina, authors found that organizations sustained efforts to improve patient preparedness, improved the provision of portable records for patients and rates of medication stockpiling, and expanded shelter options (Icenogle et al. 2016). They assert that preparedness must be incorporated "into the community fabric" for it to be effective (Icenogle et al. 2016). In recent years a "Hurricane Summit" was held for stakeholders across 5 states to discuss planning and response systems for long-term care facilities, later evolving into an initiative that produced a disaster management guide for use by long-term care facilities nationally (60,61). A non-profit has also developed a course-based intervention and demonstrated improvement in disaster planning, follow-through drills, and "linkages with local, state, and federal agencies" (O'Brien et al. 2009). *Home-based primary care*: The lack of preparedness among home-based primary care providers has been discussed in Georgia, California, and Louisiana (Daugherty et al. 2012; Kirkpatrick & Bryan 2007). In response to these needs, an assessment of a Veterans Health Administrated home-based primary care program was undertaken and found that practitioners received limited training in preparedness efforts and how to prepare patients for disaster (Claver et al. 2015; Wtyte-Lake et al. 2016). These authors later developed and reported on the effectiveness of a Home-Based Primary Care Preparedness Toolkit (Wtye-Lake et al. 2017). *Outpatient primary care sites*: The establishment of the Primary Care Emergency Preparedness Network in New York City was associated with improved completion of hazard vulnerability analyses, identification of services for continuity of operations, and other preparedness activities (Williams et al. 2017). In Iran, 9000 households exposed to a preparedness intervention implemented by the primary health care system showed improvements in all those who received it as well (Ardalan et al. 2013). The potential for primary care to be involved in preparedness efforts is significant and will be addressed in a later section.
Summary: While there are numerous, publicly available resources to help prepare patients with chronic disease, the state of personal preparedness for those suffering from chronic diseases or who are older suggests that there are unidentified barriers to the adoption of key preparedness activities. The importance of personal preparedness for this population cannot be overstated and as previous authors have stated, it may "reasonably be one of the most effective strategies to improve resilience during shelter-in-place or an evacuation event" (Risoe & Paturas 2013). Further, literature suggests that outside of personal preparedness, healthcare agencies can improve their ability to communicate with patients and engage in more community-based preparedness efforts.	

TABLE 1 (CONTD.). TRENDS IN DISEASE, PREPAREDNESS, AND INFRASTRUCTURE READINESS	
Infrastructure hazards	Difficulties accessing clean water, adequate sanitation and power, and managing new environmental exposures are concerns after a natural disaster (Du et al. 2010). *Electricity*: Up to 21% of older adults have a reported dependence on electrical devices, and many medications such as insulin require maintenance at a cooler temperature to remain usable (Bhalla et al. 2015). After the 2003 North American Blackout, many patients presented to the emergency room because of device failure and the need for planning to address these needs on a personal level was identified (Greenwald et al. 2004). In 2012 authors determined that dialysis centers were largely able to sustain operations in the wake of a large-scale power outage and based on their findings recommended the requirements for backup generators and more research on dialysis preparedness (Abir et al. 2013). After Hurricane Sandy, an assessment of 14 long-term care facilities found that most lost electricity for at least some period of time and slightly over half of facilities had backup generators, and another study of 40 healthcare sites showed similar results (Jiang et al. 2017; Sood et al. 2016). Finally, a systematic review of the health effects of power outages confirmed the wide array of health impacts that can occur for those with chronic diseases as a result, including loss of home oxygen supply, failed ventilators and dialysis machines, availability of certain drugs, and compromised transport and EMS systems (Klinger et al. 2014). *Food and water*: The need for other basic resources including food, water, shelter, and hygiene has been demonstrated (Daley et al. 2011; Kwanbunjan et al. 2006). The role of food and nutrition access in the face of climate change impacts on agricultural practices, and more generally on those with chronic disease who require specific diets for maintenance of health/prevention of exacerbations of cardiovascular disease, diabetes, and chronic kidney disease has been documented as well (Miller & Arquilla 2008; Blashki et al. 2007; Trento & Allen 2014; Yatabe et al. 2012). *Sanitation*: Poor sanitation for patients with cancer who have compromised immune systems can lead to deadly infections. Loss of these and other basic infrastructure components has been documented as the cause of evacuation for many hospitals after Hurricane Katrina (Gray & Hebert 2007). *Environmental exposures*: Mold growth as a result of water damage, or population-wide exposure to chemicals as a result of damage to industrial facilities has been documented as recently as with the events that transpired after Hurricane Harvey (Rath et al. 2011, Hamblin 2017, Friedrich 2017).
Summary: Infrastructure hazards have been increasingly identified as having significant negative effects on individuals with chronic disease who depend on electrical devices. In addition, basic needs such as food, water, and sanitation can suffer in the wake of a natural disaster but have not received extensive attention in the literature related to those with chronic diseases after disaster. The likelihood and impacts of environmental exposures likewise have not been widely discussed.	

TABLE 2. ASSESSING MEDICAL NEEDS AND PROVIDING CARE

Areas of Focus	Summary of Findings
Surveillance and data gathering	Understanding local and regional disease patterns allows agencies to better prepare for and respond to post-disaster needs. Across all disasters, the formal call has been made for these assessments to help guide response and recovery (Van den Berg et al. 2008). Authors have described the piloting of an internet-based form to monitor disease patterns after disasters, geographic information system mapping, predictive models to determine where reduction in access-to-care will be worst in disaster affected areas, and usage of existing data banks, such as the Behavioral Risk Factor Surveillance System, to inform efforts for response and recovery (Cookson et al. 2008; Sebek et al. 2014; Guclu et al. 2016; Ford et al. 2006; Holt et al. 2008). While population-level data collection is important, the need for portable and useful individual health information to aid caring for displaced patients has also been identified. Existing products like USB drives have also been examined for their potential to be included within the personal healthcare information discussion as user products that can convey important individual health information (Potini et al. 2011).
Summary: Surveillance and data gathering throughout the disaster life cycle require different methods including individual and population-based monitoring. While many methods have been discussed and some evaluated for effectiveness, there is no universal consensus or approach to addressing how these efforts do or should unfold for those with chronic diseases.	
Primary care provision	After disaster, many patients have needs for routine primary care initiation or follow-up. After Hurricane Katrina, access to primary care was reduced for residents of a FEMA trailer park for 2 years after the event (Shehab et al. 2008). In a separate population, 21% cut back on treatment in the 6 months after the hurricane and cited decreased access to physicians as the primary reason (Kessler 2007). After disasters in Pakistan, Thailand, and Japan, the disproportionate need for increased primary healthcare system service and resilience was also identified (Chan & Griffiths 2009; Schwartz et al. 2006; Ushizawa et al. 2013). The American Academy of Family Physicians has proposed a more organized role for primary care providers in the acute and chronic post-disaster care, however a review of the state of literature on primary care and disasters found minimal high quality literature on this intersection and called for increased quality and quality of research, as well as the development and validation of primary health care specific indicators related to disasters (Freedy & Simpson 2007; Redwood-Campbell & Abrahams 2011).
Summary: The role of primary care providers after disasters has not been widely detailed, Given that many needs after disasters are rooted in primary care, the role of these providers, understanding why access to them decreases after a disaster, and how the primary healthcare system overall can be made more resilient should be explored.	

TABLE 2 (CONTD.). ASSESSING MEDICAL NEEDS AND PROVIDING CARE	
Infrastructure hazards	Among others, they cited difficulty filing prescriptions and having their medications changed post-disaster as barriers (Krousel-Wood 2008). *Solutions*: The response to these concerns has involved the proposal to use pre-disaster data on the disbursal of medication to inform how resources are allocated during response and recovery, although this approach does not account for how prescription patterns will change after an event (Brown et al. 2008; Rottman 2008). The need for insurance companies and healthcare providers to arrange a formal legal system for allowing patients to stockpile medication or receive it without a prescription in a post-disaster setting has also been discussed (Carameli et al. 2013). Authors have identified that barriers to implementing such a system include patient resistance as a result of higher copays, physician resistance to the increased time required to help patients secure a disaster supply of medications, and general resistance among insurers to the concept (Carameli et al. 2013). Pharmacy preparedness is also a critical element of getting in front of the provision of medications in disaster settings, and it is notable that in 2013, in preparation for anticipated historic flooding, authors in Iowa were unable to find a disaster preparedness manual for community pharmacies and described the process by which they develop one (Noe & Smith 2003). Finally, the addition of medications tailored to primary care needs to the World Organization's Interagency Emergency Health Kit, which is intended to include enough supplies to address primary care concerns for 10,000 individuals for 3 months, has been debated (Aebischer Perone & Beran 2017; Tonelli et al. 2016).
Summary: Medications are a common concern in post-disaster periods for multiple reasons, including legal barriers to patients ability to stockpile, transportation preventing the normal supply chain activity of medications, and changes in health status after an event that necessitate new medication or treatment that is difficult to access after an event. Other supplies, although not discussed in detail here, include durable medical equipment.	

TABLE 3. SPECIAL ISSUES

Areas of Focus	Summary of Findings
Displacement and evacuation	A full discussion of field of displacement and evacuation of healthcare facilities is out of the scope of this review, although it is worth noting that literature on patient needs and outcomes, institutional or individual barriers, and solutions to mandatory and suboptimal evacuation, for hospitals, ICU units, nursing homes, and home healthcare facilities exists (Petinaux & Yadav 2013; Hicks & Glick 2015; Dosa et al. 2012; Dosa et al. 2007; Schultz et al. 2003; Christensen 2007; Laditka et al. 2009; Missildine et al. 2009; Schultz et al. 2005; Cocanour et al. 2002; King et al. 2016; Adalja et al. 2014; Downey et al. 2013; Dobalian et al. 2010). In the discussion of whether to evacuate, benefits must be weighed against negative impacts, especially in facilities with chronically ill elderly patients in nursing homes, who have been demonstrated in a systematic review to have increased mortality for up to 6 months after evacuation (Willoughby et al. 2017). Another review of best practices for evacuation versus sheltering-in-place for long-term care facilities found that sheltering-in-place is more favorable (Baxter 2017).
Vulnerable populations	*Children*: The special needs of children in disasters have been increasingly recognized, including (1) the 2017 Report on Children and Resilience (2) the 2010 Report to the President and Congress by the National Commission on Children and Disasters (3) the formation of the Children's HHS Interagency Leadership on Disasters (CHILD) working group in that same year and (4) the development of guidelines by the HHS Administration of Children and Families to help state and local partners establish a Children and Youth Task Force (Policy 2010; Kelly 2010; 2010 Report; 2014-2015 Report; Children 2013). In their 2014 report the CHILD working group calls out the need to address those with chronic disease, however in their 2015 statement on ensuring the health of children in disasters, the American Academy of Pediatrics does not mention diabetes or asthma – two common chronic diseases impacting children (2014-2015 Report; Ensuring 2015). Preparedness of caregivers has also been reported to be low in some cases. In one study less than 20% of caregivers to children with special medical needs had an emergency supply kit or family communication plan (Baker & Baker 2010). Results have been inconsistent, however, with 95% of parents of children with diabetes reporting that they were generally to moderately prepared before Hurricane Sandy (Heptulla et al. 2016). Regardless of preparation, access may also be reduced as, for example, those children affected by Hurricane Katrina were 20% less likely to have a health provider than those who were unaffected (Stehling-Ariza et al. 2012). Solutions that have improved care and done so at reasonable cost include the implementation of a Medicaid waiver for children with diabetes after Hurricane Katrina and a medical home care coordination model that improved care coordination at a cost of $36.88 per year per child with a special healthcare need (Berry et al. 2011). *Elderly*: The unique needs of elderly populations are clear. They suffer disproportionately from chronic diseases and have a unique set of vulnerabilities (Jenkins et al. 2014; Evans 2010). In one group of Medicare enrollees after Hurricane Katrina, there was a 12.6% increase in morbidity compared to 3.4% in the general population of Medicare enrollees (Burton et al. 2009). The 2009 National Council on Disability released a report investigating strategies to improve emergency management for disabled individuals and populations, and FEMA's Office of Disability and inclusion has continued to work in this area (National 2009). In 2012, the CDC released a report detailing that none of the legal mechanisms being utilized to plan for addressing the needs of vulnerable older adults were evidence-based and that there were key gaps in legal mandates to protect vulnerable adults (Prevention 2012).

TABLE 3 (CONTD.). SPECIAL ISSUES	
	Drug users and those in addiction recovery: Drug users are at risk of experiencing life-threatening withdrawal after disasters, and those in addiction recovery often have elements of their treatment that depend on regular contact with a provider who can prescribe medications. In two separate studies performed after Hurricane Sandy, patients using buprenorphine, which can be prescribed by a physician in an outpatient setting, experienced less barriers to continuing their care compared to those visiting methadone clinics (Tofighi et al. 2014; McClure et al. 2014). Both modalities of opioid maintenance presented barriers including communication between providers to refer patients to other locations if they were unable to accommodate them and regulatory barriers associated with patients moving to different sites (Tofighi et al. 2014; McClure et al. 2014).
Additional issues	*Legal issues*: Memoranda of understanding and legal tools for handing public health emergencies, such as emergency declarations and the resulting ability to deploy and distribute resources, can be expanded in the current handing of chronic diseases during and after natural disasters for both children and adults (Rutkow, Vernick, Wissow et al. 2013; Rutkow, Vernick, Spira et al. 2013; Prevention 2012; Brown et al. 2007; Lane & McGrady 2016; Hodge et al. 2011). *Other chronic diseases*: End-of-life care and pain management are dimensions of many chronic diseases that warrant separate discussion and have been previously explored (Missildine et al. 2009; Frahm et al. 2011; McGrady et al. 2014; Potash et al. 2009; Stys 2010). The unique needs of women, especially related to obstetrics and chronic gynecologic care, must also be considered (Arosemena et al. 2013; Sohrabizadeh et al. 2016; Bloem & Miller 2013). *Economic considerations*: Authors have also recently demonstrated the role that formal economic analysis can play in justifying and guiding preparedness policies (Stryckman et al. 2015). *Low and middle income countries*: This review has examined and demonstrated that the burden of chronic diseases presents many similar issues across different types of disasters, and even across different levels of economic and healthcare system development across countries. It is, however, important to note that in some settings, basic healthcare infrastructure considerations, such as the number of healthcare personnel, quality of training, availability of emergency care facilities, and the overall emergency preparedness infrastructure makes considerations for preparing for the needs of those with chronic disease extremely different (Fuady et al. 2011; Garfield & Hamid 2006; Martinez et al. 2015; Phalkey et al. 2012; Van Minh et al. 2014; Zhiheng et al. 2012; Brember 2003; Gaitonde & Gopichandran 2016; Olu 2017). *Awareness of existing resources and problems*: There are many resources available for state and local partners to utilize in planning for those with chronic diseases, or more commonly, for populations suffering from increased rates of chronic disease, such as the elderly. The Office of the Assistant Secretary highlights many of these resources within its recently created TRACIE database. Although these exist, we came across little reference to whether the models and methods proposed in these guidance documents have been either widely used or tested for their effectiveness. Further, there is significant redundant literature and a mixed set of perspectives on priorities for chronic disease patients, including one set of authors in Ecuador who recently stated that chronic disease medication adherence is an "infrequently reported public health problem" (Tamariz et al. 2017). While this may be true in the country-specific context, reporting it broadly as such is not accurate and suggests that more needs to be done to centralize available resources.