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## Chronic Illness and Disasters: Development of a Theoretical Framework

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## Chronic Illness and Disasters: Development of a Theoretical Framework

### Abstract

In a disaster, individuals with chronic illnesses risk poor outcomes. This grounded theory study sought to develop a framework that describes how these individuals manage health-related challenges during disasters. The five phases of disaster response (non-disaster, pre-disaster, impact, emergency, reconstruction) and the individual, local, state, and federal level model served as conceptual frameworks. Using purposive sampling, 30 individuals with chronic illnesses and 10 lay caregivers were recruited from Florida and New Orleans. Data sources included interviews and media data. Constant comparative analysis techniques were used to build the theoretical framework. Transcript analysis suggested that participants used four unique ways to shift priorities from illness to disaster-related challenges. Each way related to media impact, evacuation, preparation, attention, and recovery. If evacuated over a week, many could address some health-related concerns from afar. Those remaining home were more apt to ignore health-related concerns to deal with home and family issues.

### Keywords

Chronic Illness, Disaster, Evacuation, Grounded Theory, Theoretical Framework

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*In a disaster, individuals with chronic illnesses risk poor outcomes. This grounded theory study sought to develop a framework that describes how these individuals manage health-related challenges during disasters. The five phases of disaster response (non-disaster, pre-disaster, impact, emergency, reconstruction) and the individual, local, state, and federal level model served as conceptual frameworks. Using purposive sampling, 30 individuals with chronic illnesses and 10 lay caregivers were recruited from Florida and New Orleans. Data sources included interviews and media data. Constant comparative analysis techniques were used to build the theoretical framework. Transcript analysis suggested that participants used four unique ways to shift priorities from illness to disaster-related challenges. Each way related to media impact, evacuation, preparation, attention, and recovery. If evacuated over a week, many could address some health-related concerns from afar. Those remaining home were more apt to ignore health-related concerns to deal with home and family issues. Keywords: Chronic Illness, Disaster, Evacuation, Grounded Theory, Theoretical Framework*

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Incidence of both natural disasters and chronic illnesses has increased worldwide, and in the United States, over the past 10 to 20 years. (IEG World Bank, 2007; World Health Organization, 2009). Disasters have increasing numbers of victims, public health threats, and financial implications (Cherry & Trainer, 2008; Ginter et al., 2006). In 2005, 133 million Americans were diagnosed with at least one chronic illness (Centers for Disease Control and Prevention, 2012). During disasters, persons with chronic illnesses face risks above those of the general population including exposure to infectious disease, respiratory compromise, disrupted skin integrity (Cherry & Trainer, 2008), medication separation (Greenough et al., 2008; Howe, Victor, & Price, 2008), and loss of access to healthcare records (Pate, 2008; Smith & Macdonald, 2006).

A disaster is considered a sudden or serious event that disrupts humans and the environment to the extent that overwhelms both individual and local resources and requires extraordinary effort to recover (Noji, 2000). Disaster response typically comprises five phases: non-disaster, pre-disaster, impact, emergency, and reconstruction, which may occur at individual, local, regional, and federal levels (Veenema, 2007). Preparedness activities taken during early stages improve response to a disaster regardless of the scope or type of event (Arrieta, Foreman, Crook, & Icenogle, 2008; Chan & Sondorp, 2007).

Disaster preparedness is more complex for those with chronic illness, who may require specific planning to address unique needs (Jones, 2006a). A chronic disease (e.g., cardiovascular disease, renal failure, diabetes) persists at least three months or more and cannot be prevented by vaccines or cured with medication (U.S. National Center for Health Statistics, 2007).

Exploring the simultaneous burden of disaster response and chronic disease can help

responders better understand needs of specific populations and design collaborative efforts among responding agencies. The aim of this study was to describe how individuals with chronic illnesses who have experienced a disaster managed health-related challenges such as medication needs, food and water intake, and wound management during the disaster using disaster preparedness or response activities.

### **Review of Literature**

There is strong evidence that those who have chronic illness(es) are particularly vulnerable to negative outcomes during a disaster (Arrieta et al., 2008; Mokdad, Mensah, Posner, Reed, Simoes, & Engelgau, 2005; Saunders, 2007; Zoraster, Vanholder, & Sever, 2007). These outcomes may be a result of illness (e.g., increased susceptibility to injury and/or infection) and the disaster itself (e.g., separation from medication or treatment, inhaled toxins or crush/blast injuries, contamination of food and water; Miller & Arquilla, 2008).

Research studies have suggested that individuals with chronic illnesses will take actions to self-manage their disease (Gregg & Callaghan, 2007; Whittemore & Dixon, 2008). Preparedness activities (e.g., preparation for possible evacuation) taken during non- and pre-disaster stages improved response to a disaster regardless of the scope or type of event (Arrieta et al., 2008; Chan & Sondorp, 2007), suggesting the possibility that such activities by persons with chronic illness may well help them to manage their disease during the actual event. Response activities that include collaboration among resources and response at several or all levels, including needs-based assessments, and consensus-based protocols, was supported as the ideal structure for effective and timely disaster response in several articles (Chan & Sondorp, 2007; Howe et al., 2008; Jones, 2006b; Klein, Pepe, Burkle, Nagel, & Swienton, 2008; Kumagai, Edwards, & Carroll, 2006).

Critical factors such resource accessibility and distribution remains an area with differing expectations about response effort at various levels and timeframe (Kumagai et al., 2006). Medication separation is a serious concern (Jhung et al., 2007; Krousel-Wood et al., 2008; Miller & Aquilla, 2008; Zoraster et al., 2007), as well as access to health history via previous health records and use of technology to improve this process (Pate, 2008; Smith & Macdonald, 2006). Controversy continues as to the most effective method to assess risk, both in disaster preparedness and response and the challenge for health educators is to provide education for both (Whitty & Burnett, 2009).

More attention is needed toward advance planning to consider health needs in pre-disaster planning stages. Researchers who completed studies after Hurricane Katrina (Krol, Redlener, Shapiro, & Wajnberg, 2007; Rath et al., 2007) noted a high proportion of visits for chronic illness concerns, but these studies did not address degree of preparation or actions taken toward patient self-management. There is renewed interest in the concept of preparedness, including evacuation plans, for those with chronic illnesses (Eisenman, Zhou, Ong, Asch, Glik, & Long, 2009; Renukuntla, Hassan, Wheat, & Heptulla, 2009; Uscher-Pines, Hausman, Powell, DeMara, Heake, & Hagen, 2009). Recent studies (Horney, Macdonald, Van Willigen, Berke, & Kaufman, 2010; Smith & McCarty, 2009) suggested the benefit of evacuating, but there are still challenges related to public education about appropriate plans for individuals and communities.

While the literature supports the ideas that natural disasters and chronic illness are frequently occurring events and their concurrence carries inherent increased risk to health, little is known about how individuals diagnosed with chronic illnesses specifically manage those illnesses during disasters. The purpose of this study was to develop a theoretical framework that describes how individuals with chronic illnesses who have experienced a disaster managed their health-related challenges during the disaster event.

The first author has been a nurse since 1980. I first became interested in disaster response as the recipient of services from a responding organization after a fire in an apartment complex that involved many victims. My nursing career has included serving on a community emergency response team and working in a factory during a public health outbreak that involved a federal level response. I also spent time as a patient receiving treatment for a serious chronic illness. Each of these experiences contributed to my query to greater understand how individuals with chronic illnesses manage the illnesses during a disaster event and to my desire to improve what I feel is an area of disaster preparation and response that is often overlooked. It is my hope that the study findings, and any further work in this area, can help persons with chronic illnesses to mitigate their vulnerability during disaster events by offering evidence to support the value of targeted preparation and informed responses.

The second author has been a nurse for more than 40 years and has clinical experience as a psychiatric/mental health nurse in inpatient and outpatient settings at both the staff nurse and advance practice levels. My expertise for this study is in the use of grounded theory methods. I have conducted two large, federally-funded studies in which our research teams used this method. I have co-authored more than 20 articles in which we have presented findings from these studies. I do have personal experience with disasters and have been evacuated by the United States military in both Hurricane Agnes (Pennsylvania, 1972) and the Haiti Earthquake (Port-au-Prince, Haiti, 2010). Furthermore, I sheltered family members for four months after their evacuation from New Orleans in Hurricane Katrina (Louisiana, 2005).

## Methods

This study utilized a qualitative design from the grounded theory (Glaser & Strauss, 1967) tradition develop a theoretical framework to explain how individuals with chronic illnesses who have experienced disaster manage health-related challenges during the event. The underlying philosophy of the qualitative perspective of research, and thus methods derived from this stance, is the anti-realist view of truth as created in the mind as human beliefs/concepts (Polifroni, 1999; Polit & Beck, 2009). Qualitative inquiry is based on the naturalistic paradigm. This type of inquiry utilizes narratives, observations, and emergent design. The goal of the inquiry is illumination of patterns and rich descriptions of experiences and/or processes. Grounded theory approaches have evolved since the seminal work of Glaser and Strauss (1967) and include such differences as preconception of categories and use of inductive and deductive reasoning (Charmaz, 2006; Denzin & Lincoln, 2011; Strauss & Corbin, 1990). Researchers utilizing the grounded theory tradition begin with an assumption that their participants share one or more experiences (Schreiber & Stern, 2001). The grounded theory tradition also assumes that the researcher desires to describe the processes of shared social interactions, rather than describing a given phenomenon. Other assumptions include the idea that the theory or framework is generated from the data; that data collection and analysis are concurrent and each piece of data is compared with every other piece; and that the social process is best studied in its natural setting.

For this study, we assumed that individuals with chronic illnesses who have experienced a disaster would share the problem of having to manage their health concerns related to the chronic illness during a disaster event. We also assumed that the psychosocial process(es) used by these individuals would be similar. Classic “Glaserian” grounded theory tradition (Glaser & Strauss, 1967), which assumes strict inductive reasoning and the development of data driven categories and subsequent theory that emerges from that data, with no preconceived categories, was an appropriate methodology to support the development of a theoretical framework firmly grounded in the data obtained from

participant interviews and media data.

## **Sample**

Network and snowball sample techniques were used in two southeastern states in the United States that are susceptible to hurricanes (National Weather Service, 2008) to recruit participants who had chronic illnesses and had experienced a disaster. This type of sampling utilizes contacts appropriate to the study aims to help identify additional potential participants who may be able to provide the type of rich descriptions desired to address the research purpose and/or question(s) (Polit & Beck, 2009). The researchers used contacts with community leaders and placement of flyers to disseminate information about the study and provide a toll free number for information. In addition to having or caring for someone with at least one chronic illness and managing the illness during a disaster, participants were required to speak English and be medically healthy enough to participate in an interview. For the purpose of this study, the disaster had to disrupt normal services (e.g., communication, transportation, utilities) for longer than 48 hours. Participants received a stipend of \$35 for time and travel. The study was approved by the Institutional Review Board at the authors' university.

## **Data**

The first author conducted semi-structured interviews with individuals with chronic illnesses and/or caregivers who had experienced a disaster. Caregivers provided additional description about how some individuals managed chronic illness concerns during the disaster. Interviews were conducted in Louisiana and Florida. The interviewer kept process notes to briefly record descriptive information during interviews and concluding debriefing notes (e.g., key discussion points, possible subsequent questions; Polit & Beck, 2010).

The interviewer used a question guide to direct the interview process. We created three open ended questions appropriate to qualitative research. The intent of the questions was to elicit the richest description possible of how individuals managed chronic illnesses during disasters. To establish a baseline, the researcher posed the first question by which she encouraged participants to share information about how they managed their illness each day. The intent of the second question was to direct participants to tell a story about the disaster they experienced. The researcher posed the third question to invite participants to tell a story about how they managed their illness during the time of the disaster. We also developed more specific questions to use as needed to help participants tell their story in greater detail. Examples of these questions were, "Can you describe for me what type of disaster this was?", "Can you describe for me the steps you had to take to manage your illness?", and "Describe for me what types of activities were more difficult to manage during this time." We designed these questions to guide participants to describe the process and/or steps of managing their illness, as is appropriate to grounded theory inquiry (Glaser & Strauss, 1967). Database searches that included AccuNet/AP Multimedia Archive (Associated Press images), America's Newspapers, Newspaper Source, LexisNexis Academic, and WorldCat provided media reports of events that participants described to add contextual descriptions of disasters. Since we intended that the media data provide related information specific to the disasters described by participants, the search terms varied. Examples of search terms most frequently used were the name of the individual disaster(s) given by a participant, the word "hurricane," the state where the disaster occurred, and the year of the disaster. These terms were sufficient to easily access information about the disasters discussed. Inclusion criteria for media data were: (a) U.S. local or national lay publications, and (b) text in English.

## **Data Management and Analysis**

Data included verbatim transcripts of recorded interviews; process notes; and media reports. We used the constant comparative method developed by Glaser and Strauss (1967) and operationalized by Schreiber (2001) to analyze the data. In constant comparative analysis, each piece of data is compared with every other piece using first, second, and third level coding processes. Data collection and analysis are concurrent. In first level coding, researchers immerse themselves in data to identify keywords and phrases. The goal of second level coding is to study the words and phrases until patterns or themes emerge. In third level coding the theory emerges as researchers identify potential relationships related to these themes (Schreiber, 2001).

After interviews were transcribed, we checked each for accuracy and imported it into the NVivo8 qualitative software program (QSR, 2007) to manage the data. NVivo8 uses a tree-node system to designate categories or themes (nodes) and relationships (hierarchical parent-child nodes). The tree-node system organized the data and thus visually and conceptually aided in the development of the theoretical framework. Process notes kept by the researcher and media data were also imported into the NVivo8 software and linked with interview transcripts using the tree-node system described above.

The first level coding process in this study involved researcher immersion into the data by reading all transcripts and achieving consensus upon initial categories. These categories that emerged were created electronically in NVivo8 as nodes and then narrative data were coded by dividing them into text units (e.g., key words and phrases identified in interview transcripts). In second level coding, we studied the words and phrases for each category; expanding or collapsing some of these codes after discussion. In the third level of coding, we sought theoretical relationships related to the themes (Glaser & Strauss, 1967; Schreiber, 2001).

Theoretical sampling is a conscious effort by the researcher to concentrate and set the limits of data collection and to allow change to seek enough information (i.e., emergent design) to build the theory (Glaser, 1998). We utilized this technique to promote data saturation. We also used theoretical sampling in this study to obtain additional data in response to emerging concepts to build the theory. Specific examples of theoretical sampling in this study were querying the data for comparison data from caregivers or contrasting cases and aligning media data sources with appropriate theoretical model concepts.

## **Trustworthiness**

The study followed Guba's (1981) recommendations for trustworthiness related to credibility; dependability and confirmability; and transferability. Credibility is the plausibility of findings. Dependability reflects consistency of data, while confirmability supports objectivity. Transferability considers how one might determine if findings of a given study might apply in other contexts.

In this study, we addressed credibility by conducting interview summaries and data triangulation (i.e., participant interviews and media data). For example, near the conclusion of each interview, the interviewer asked participants if they wanted to add anything, briefly summarized responses, and concluded by asking participants to verify their summaries.

To assure dependability and confirmability, researcher process notes were compared with audiotaped transcripts, thus providing a consistency check of the data. A detailed record of data reduction and analysis process (audit trail) was maintained using NVivo8 software.

We attempted to confirm earlier findings in later interviews to help establish consensus and eventually data saturation (Guba, 1981; Polit & Hungler, 1999; QSR, 2007).

Regarding transferability of study findings, Guba (1981) asserted that some transferability between two contexts may occur because of similarity, or fittingness, between these contexts. In this light, Sim (1998) described two different types of generalizations, empirical generalization based on statistical representativeness of the sample population to the target population (the probabilistic quantitative approach) and theoretical generalization between two contexts by logical or conceptual comparability. Sim (1998) asserted that research using data obtained from qualitative research can benefit others when theoretical generalization is utilized. Thus in the analysis and discussion of the findings in this study, we considered the extent to which data from this specific context might be applicable in another context, seeking logical conceptual or theoretical parallels between individual cases studied (Guba, 1981; Sim, 1998).

## Results

Data for analysis included 40 transcribed interviews conducted with individuals who have experienced disaster (27 individuals with chronic illness; seven caregivers of individuals with chronic illnesses; and six caregivers also with their own chronic illness). The most frequent chronic illnesses cited by participants included anxiety, coronary artery disease, pulmonary disease, dementia, depression, diabetes, and hypertension. Less frequently cited were bipolar disease, irritable bowel syndrome, scleroderma, and schizophrenia. Over half (63%) managed more than one chronic illness.

Media reports (n = 24) of events that participants described were also analyzed. Participants described experiences with storms classified as New Millennium hurricanes (Barnes, 2007). These included Charley (August 13, 2004); Frances (September 5-6, 2004); Ivan (September 16, 2004); Jeanne (September 25-27, 2004); Katrina (August 25-29, 2005); and Wilma (October 24, 2005). Table 1 provides additional information about data and study participant demographics.

Individuals managed health-related challenges minimally, if at all, due to demands of evacuation or survival, and reconstruction activities. The resulting theoretical framework, named the Backburning Model, describes the processes people used to manage health-related challenges. Pseudonyms are used for all participants.

Table 1. Participant and Media Source Demographics (Source: Authors)

Participants		
Gender	Male    Female	n = 10 n = 30
Age Range	50 - 91	
Marital Status	Single	n = 23
	Married	n = 14
	Not given	n = 3
Race	African American	n = 4
	Caucasian	n = 34
	American Indian	n = 1
	>1 race	n = 1
Income in thousands	<10	n = 5
	10-14	n = 8
	15-19	n = 2
	20-29	n = 8
	30-39	n = 4
	40-49	n = 4
	50-59	n = 3



Participants	
60-69	n = 1
70-99	n = 1
100-199	n = 1
200+	n = 0
Not given	n = 2

**Louisiana.** Participants were from greater New Orleans and Slidell; all experienced Hurricane Katrina. Although the geographical area was more limited than in Florida, people from eight different zip codes were included, and no more than three individuals were from any single zip code. Participants from Louisiana indicated six different religious preferences.

**Florida.** Participants experienced a wider range of hurricanes; many endured four hurricanes (Charley, Frances, Ivan, and Jeanne) in approximately six weeks from mid-August to the end of September in 2004. The geographical range included cities on both the east and west coast of Florida. Participants represented 16 different zip codes, with no more than four from any given area. There were nine religious preferences noted by Florida participants.

Media Data
Source: News articles (n = 16) Books (n = 4) Television clips (n = 2) Description from a local radio program manager (n = 1)  Documentary film (n = 1)
Databases searched: AccuNet/AP Multimedia Archive (Associated Press images), America's Newspapers, Newspaper Source, LexisNexis Academic, and WorldCat Internet

## Theoretical Framework: The Backburning Model

Something on the back burner is defined as “not getting or needing immediate attention” (Heacock, 2003, p. 52). Conversely, an item on somebody's front burner gets attention. Backburning in the context of hurricanes occurs when individuals shift priority from health-related challenges to address other needs deemed of greater priority. Every participant described the process of backburning health-related challenges.

Cordelia, a middle-aged, African American woman who lost her job and health insurance during Katrina, stated explicitly, “I kind of let my health go for a little bit...I used to always go to the doctors and have everything checked. But because of insurance problems, I kind of put myself on the back burner....” Others implied the process by stating immediate, non-health-related priorities or redirecting conversation to other concerns despite repeated inquiries about health issues.

Each participant carried out the process backburning (see Figure 1) in one of four unique ways. Five factors determined the differences between the four ways of backburning:

- 1) media impact,
- 2) evacuation,
- 3) preparation,
- 4) focus of attention, and
- 5) recovery.

Figure 1. Backburnering Model (Source: Authors)

<b>BACKBURNERING MODEL</b>					
<b>The Core Category: How Participants Backburnered</b>					
<b>Four Ways Describe Backburnering</b>	<b>Factor 1. Media Impact</b>	<b>Factor 2. Evacuation</b>	<b>Factor 3. Preparation</b>	<b>Factor 4. Attention</b>	<b>Factor 5. Recovery</b>
<b>Way 1: Prudent Backburnering (n=15)</b>	Used media in all phases; impact phase focus was monitoring damage from afar	Pre-arranged evacuation	Individually prepared in advance to evacuate	Careful and/or planned non-attention to health-related concerns	Preparation a plus; frequently resumed health-related activities if sustained evacuation or returned to stable environment; returned to own home
<b>Way 2: Impromptu Backburnering (n=9)</b>	Used media mostly in impact/emergency phases; impact phase focus was evacuation travel	Last minute evacuation	Scrambled to prepare to evacuate	Spontaneous non-attention to health-related concerns	Lack of preparation required seeking providers to resume health-related activities; this happened if sustained evacuation; returned to seek new home; often rental
<b>Way 3: Deliberate Backburnering (n=8)</b>	Used media in all phases; impact phase focus was family and monitoring local conditions	Opted to not evacuate	Individually prepared to stay	Intentional non-attention to health-related concerns	Planned shelter-in-place until stability returned; ignored health related activities to concentrate on home damages and repairs
<b>Way 4: Unforeseen Backburnering (n=8)</b>	Used media in emergency, impact, and reconstruction phases; impact phase focus was support system to survive	Situational non-evacuation	Not prepared at all	Reactive non-attention to health related concerns	Unavoidable shelter-in-place until stability returned; ignored health-related activities to focus on continued survival; may have spent part of reconstruction time in alternative housing

Table 2 defines these factors.

Table 2. Backburnering Model Factor Definitions (Source: Authors)

Model Factor	Study Definition
<b>Media impact</b> was a factor because it influenced how participants learned what to prepare, decided when to leave and/or return, and accessed supplies.	Participants used some form of media-provided information (e.g., television, radio, print materials) during one or more disaster phases during the event they described.
<b>Evacuation</b> was a factor because it impacted whether or not participants could attend to health-related concerns.	Leaving one's primary residence, either by mandatory directive or by choice, during the pre-, impact, or emergency phase of the disaster. Participants who described ways 1 and 2 evacuated and those who did not evacuate described ways 3 and 4.
<b>Preparation</b> was a factor because there was evidence that whether or not participants prepared determined how they backburnered.	Participants were "not prepared" if they met at least one of the following criteria: <ul style="list-style-type: none"> <li>• new to the area or had never experienced a hurricane, and thus did not prepare</li> <li>• lived in an area with hurricane threats and directives in place but stated they didn't prepare</li> </ul> Participants were defined as "prepared" if they: <ul style="list-style-type: none"> <li>• had experienced at least one disaster and described personal preparation for the hurricane discussed in the interview</li> <li>• lived in an area with hurricane threats and directives in place which they acted upon</li> <li>• had never experienced a hurricane, but lived in an area with hurricane threats and described personal preparation activities even without knowledge of a community plan</li> </ul>
<b>Attention</b> was a factor because whether and how they attended to health-related concerns (e.g., mindfully or as a reaction to events) was often impacted by the other factors (e.g., evacuation status, level of preparation).	Actions taken or not taken related to participants' individual-level priorities (e.g., safety, health concerns) during the disaster.
<b>Recovery</b> , or resumption of some level of attention to health-related challenges, was impacted by the decision to evacuate, and/or the duration of evacuation.	Taking some action related to health-related concerns during the reconstruction phase.

## Four Ways of Backburnering: Core Process

### Way 1: *Prudent Backburnering*

Prudent is defined as "wise in handling practical matters, exercising good judgment or common sense; careful in regard to one's own interests" (American Heritage Dictionary, 2009c, para. 1). People in this group ( $n = 15$ ) showed prudence by evacuating using pre-disaster preparations that included some attention to health-related concerns.

#### Media

Participants who used prudent backburnering used media-provided communications in all phases of the disaster. They initially used media in the non-disaster phase to learn how to prepare. For example, Alma, 84, advised, "...you can get pamphlets to read about it all. Some people never pick one up, but they better." Once evacuated, these participants purposefully accessed media during the impact and/or emergency phases to keep track of reported damage and determine advisability of return. Many were homeowners eager to

gauge property damage. Janice, a 91 year old participant from Punta Gorda, Florida stated,

“We had the radio and we listened to that. That was our lifeline, was this radio because you didn’t know how bad it was. You knew that part of your world was gone...”

Many cited The Weather Channel<sup>®</sup> as an information source in all disaster phases.

### **Evacuation**

These participants prepared for evacuation before the hurricane by researching shelter availability, preparing items to take, and making a pre-determined decision about factors that would determine staying or leaving. Many had registered for access to special needs shelters for persons with chronic illness(es). The participants used the Saffir-Simpson Hurricane Wind Scale (National Weather Service, 2010) with five categories to gauge wind speed and severity to make informed decisions. Janice described, “...we decided that we would stay when it was a 1 and then we kind of grudgingly said, ‘well if it’s a 2 we’ll stay’ but when it came over the radio that it was a 4, I said, ‘I’m going,’ [to a protected shelter] and Buck was right behind me...” While no one was pleased about the prospect of evacuation, these participants realized the importance of doing so.

### **Preparation**

These participants prepared well in advance of any threat by gathering helpful documents; medications; animals, and food and water. Alma compiled household documents, “...you might not have a home to go back to and so you get all of those together in a folder like insurance papers, your birth certificate...” They had no difficulty with medication refills because they prepared in advance, using national chain pharmacies so regular prescriptions could be easily refilled. Marcy, 55, diagnosed with diabetes and hypertension, noted, “I took all of my insulin, my pills in the original prescription bottles so I could refill...at the Target pharmacy somewhere else.” Needs of animals were a priority. Some found shelters that accept small animals; others made arrangements with hotels or family.

### **Focus of Attention**

Worry about property damage was a common justification for prudent backburning of health-related activities. Participants described more pressing situations (e.g., frightening events during evacuation or watching from afar, managing the evacuation and return process, damage to house); a lack of necessities (e.g., a home, electricity); and managing dual households (i.e., living elsewhere but working on their homes). Cordelia lived in Georgia for 18 months and returned to New Orleans regularly to repair her home. She noted, “It was difficult because you weren’t in your house, you were not able to say I’m going to manage and buy this and this is what I’m going to eat in the morning and the evening. I went off track...” She described decisions about testing blood sugar, which she knowingly both checked and omitted, due to lack of health insurance, “I ended up going to urgent care to get test strips and medication because I ran out. I did get off the medicine for a while...It was frustrating. I kind of let my health go a little bit.”

### **Recovery**

Factors that influenced recovery, or return to some health-related activities, included

length of evacuation and stability of home environment (e.g., utilities, road access). If evacuation was less than one week (this describes most Florida participants), typically participants returned home to minimal or no damage, cleaned up debris, and returned to normal activities. If the evacuation extended beyond one week (Louisiana evacuees), participants had to determine when to return. Marcy, a diabetic, prudently delayed return until utilities were restored, “I did not come back to Slidell until I knew that we had electricity...it was the vials and syringes so I really needed to keep them cold.” If participants remained evacuated while their home area was unstable, they often initiated some recovery activities (e.g., seeking healthcare providers) from afar and continued after returning home. Extended reconstruction (e.g., Katrina) often delayed provider visits due to inability to find or get to one.

Once home, everyone concentrated on home and/or family concerns over health-related issues. Water damage and mold were frequent concerns. Chuck, 80, balanced his roles as caregiver and homeowner:

We had carpeting...it was completely shot [due to mold]...It was hard for me because I had to leave her [his 78 year old wife] to do it, leave her in the motel, you know. But, she did OK. And, I didn't have another choice.

## **Way 2: *Impromptu Backburnering***

Impromptu Backburnering illustrated the second way. Impromptu is defined as “prompted by the occasion rather than being planned in advance; done...with little or no preparation; extemporaneous” (American Heritage Dictionary, 2009b, para. 1). Evacuees who backburnered health concerns in an impromptu fashion ( $n = 9$ ) were not prepared. They often relied on confidence from past experiences with good outcomes. They evacuated in a hurried or unplanned fashion; but still often recovered earlier than those who stayed home.

## **Media**

Media communications helped participants primarily in the impact/emergency phases. They casually watched news reports but gave no evidence of doing this for advance preparation. Once the disaster arrived, media resources helped them focus on evacuation. Wanda, 50, recalled getting comfort from the still-working television as a positive sign during Katrina, “We can't get out. Don't worry, the people are goin' come and get us. The TV and stuff was still workin'.” Eva, 66, evacuated for five days during Fay in a two bedroom trailer with eight adults and five children. Eagerly awaiting their return home, she followed the storm, “Watching it, the TV, every day, the whole state of Florida is completely engulfed by the storm. It's not going anywhere; it's still sitting there, still spinning...will we ever go home?” Rose (2005/2007) noted one possible influence on the decision to delay evacuation, family members who would not leave, “We left my in-laws behind in Picayune. They wouldn't come with us. Self-sufficient country folk; sometimes you can't tell 'em nothing.” (p. 7).

## **Evacuation**

Participants in the impromptu backburnering group initially were casual about the disaster. Neighborhood gatherings and barbecues were common during the impending arrival of a hurricane. . When someone perceived danger, evacuation was considered. Bernadette, 55, explained:

...it was about at our knees, we were just playing in the water. The next thing we see a barbeque grill going down the road. I was like, “Y’all, now this is getting serious, for real...we need to think about doing something, we need to start some sandwiches and make sure we got toilet paper.” See, nobody was thinking about that. Everybody just wanted to drink beer and eat....

Media sources (Folkenflik, 2007; Frontline, 2005a) supported the impromptu nature of Katrina evacuations that increased challenges for those who chose not to evacuate early.

### **Preparation**

Impromptu evacuations required two actions: selecting items to take and finding somewhere to stay. During the scramble to assemble items, participants did not include any long term plans related to health challenges. Some included basic medications and supplies. Bernadette recalled items she took walking from New Orleans, “I took some green masking tape, tied my birth certificate, my medical records, I took a sandwich bag and put my little \$300 in it, I had my momma’s pictures...my grandmother’s rosary...”. Eva, who left Florida, noted, “We just packed up what we could and left...what medicine I had [2 days], a hair brush, toothbrush, toothpaste and that’s about it.” Finding some way out and somewhere to go prevailed. They stayed with anyone willing to take them.

### **Focus of Attention**

Pressing situations included very frightening events and/or rescues (e.g., wild animals, dead bodies, no shoes to protect feet, sun exposure). These events took priority over anything else during evacuation, including health-related challenges. Priorities during evacuation included immediate physical safety and emotional control.

### **Recovery**

Participants discussed managing chronic illness primarily during the reconstruction phase. Priorities were finding a provider and/or supplies wherever they were; getting home; addressing family concerns; and dealing with frustration and emotions. Most people who impromptu backburnered lived in rental properties, and were evacuated for longer than six months. They lived in different dwellings upon return and did not discuss homeowner-related concerns. Those evacuated beyond one week often sought health care providers in their new locations. Some of those evacuated less than one week had to address one or two health-related concerns.

Connie, evacuated six months while managing diabetes and heart disease, described trying to get supplies. Her first difficulty involved the mail, “...That was a mess because...we was in a motel, and it [diabetes supplies] was supposed to go to the motel, but we had already been moved...” Then she found a doctor, but he wanted new blood tests and she resisted:

...I’m not going through these tests when I know what’s wrong with me and as soon as I go back home, I’m going back to the doctor I’ve had for years. You’re not going to be my permanent doctor because I’m not staying here.

Those back early faced instability (e.g., debris) causing them to back burner even significant health challenges. They created a new normal, which often meant

dealing with frustration and many emotions.

### **Way 3: *Deliberate Backburnering***

As people elected and prepared to weather the storm at home (i.e., shelter-in-place), they had to deliberately ignore health-related concerns to survive. Definitions of deliberate include, “done with or marked by full consciousness of the nature and effects; intentional; arising from or marked by careful consideration;” (American Heritage Dictionary, 2009a, para 1). This group (n = 8) prepared at the individual level in the non- and pre-disaster phases. In the impact phase, they frequently used storm intensity categories to guide the decision to shelter-in-place.

#### **Media**

Similar to the prudent backburnering group, these participants used media-provided communications in all disaster phases. They initially used media to learn about how best to prepare. Deborah, 58, recalled:

Listening to newscasts and...what you need to do to prepare...realizing if I was at plan A, I needed to step it up to plan B in regards to what we needed to have in the house, my meds, my girlfriend's meds and all of that, early on.

Once the pre-disaster phase arrived, they used this information. Steve, 54, described how his family prepared, “...getting all the meds in line and all the typical things you hear on television and radio about water supply....” As the impact arrived, they continued to use media reports. Dan from Florida noted, “When they start, you follow the weather and you find out for sure if it's going to come...Charley was the real deal.”

During the impact/emergency phases, people used media to learn about local damage; survival tactics; and communication with family. Some felt more secure at home because they had purchased generators. Dave, 55, stated, “...because we had a generator we were able to run our TV. We kept informed by a TV station...”

Sharon, 57, used media to find supplies, “You would go and get in line in your car, wherever they were set up and I would listen to my battery radio every morning to find out where....” She noted the importance of advanced preparation on the ability to successfully stay at home, “If you couldn't communicate with your family and friends, then if you needed emergency care or something or needed medication, I mean no one to help you, it [staying home] really is about preparation.”

#### **Evacuation**

They did not evacuate because they:

- a) worried about homes;
- b) had cumulative burden of multiple evacuations (evacuation fatigue); and
- c) had insufficient time or means to leave.

Their priority was to prepare quickly to shelter-in-place. They still described a plan, such as using categories to determine actions. Charley turned unexpectedly and victims had to shelter-in-place. Others tried to evacuate, but found too many challenges to overcome, even with pre-arranged procedures. Steve, a Floridian who tried to evacuate, noted, “...the hardest

part was getting a household, four people and a big dog, all who were elderly, I'm in my 50s, into a minivan, bag and baggage, meds, water, cooler, stinky dog...we did have all the systems in place...." They turned back an hour later, unable to endure crowded highways.

### **Preparation**

Actions that helped this group prepare for a hurricane included prepurchasing supplies and preparing their homes. Some advanced preparation specifically related to health-challenges. Deborah described a classic example of taking individual responsibility for advanced preparation as it related to health:

I never experienced [hurricanes]...I know the hurricanes are here and it is just part of our being...If I've chosen to live here, then I have to make the necessary arrangements so that I make sure that my health is taken care of...particularly in my case, because I have diabetes, hypertension, polymyositis, dermatomyositis, osteo pain, yeah, osteoarthritis, osteo pain of the jaw...I was preparing for the things...around the house, make sure papers are in the right place but also that I had the proper medications, that I had enough....

Staying for previous storms and knowledge of storm categories increased confidence in ability to manage at home using pre-existing procedures. Sharon described, "...it was getting closer and instead of coming as a category 2 they said that it could ramp up to a 4." This family had used mattresses and specific locations (hallway) in the past for adequate protection during impact. It was clear they had some plan in place, "I had been telling my husband, we better take the mattress into the hallway...they said it was coming in as a 4, he said grab that mattress...."

### **Focus of Attention**

Although this group backburnered health concerns at the time of the storm, they prepared in advance as well as possible. As withstanding the impact moved to the forefront of their priorities, they then ignored health-related challenges. They described frightening events (e.g., rescues, looting) that preoccupied their thoughts. Gathering to grill food and dealing with interrupted utilities were common. Typically, they did not even discuss attending to health concerns.

Some intentional backburning in impact/emergency phases was obvious by delay of health-related activities (e.g., medications, eating healthy food) or disregard of restrictions. Dave noted he had other priorities that required attention:

I had had angioplasty in May and I was supposed to be taking it easy but, you know, during and after the hurricane I didn't have time to take it easy...but probably if my cardiologist knew what I was doing, my getting out day after day in the hot sun, cleaning up my back yard...

People managed creatively. Deborah, a Florida resident with insulin-dependent diabetes, backburnered during the impact by not eating appropriately and not taking insulin because, without power, she had no refrigeration. She resumed her activities after brainstorming with neighbors, "We got power back on a grid on one side of the street only...we strung electric cords across the street." This participant was prepared, able to refill



her insulin, keep the new medicine cold, and resume her regimen within a few days.

### **Recovery**

Overall, as they worked to recover from the storm's impact, they continued to deliberately ignore or minimally address health-related challenges. Again, delay in going to a provider was often inability to find or get to one. Dave described the challenges to find providers, post-Katrina, "At the community level there really was no healthcare...Not just getting the hospital doors open but getting the nurses, the aides, the physicians, the administrators...People had evacuated and they couldn't get back."

#### **Way 4: Unforeseen Backburning**

Unforeseen is "not felt or realized beforehand; unexpected" (American Heritage Dictionary, 2009d, para. 1). People in this group did not evacuate nor prepare, and had a delayed recovery. Priorities, health and otherwise, in this group were totally unforeseen and their goal was survival.

### **Media**

This group did not use media to assist with preparation in the non-disaster phase. Pre-disaster, they discussed the impending event with neighbors and friends, and sometimes listened to TV or radio to assess severity and decide about evacuation, but they did not leave. Some monitored conditions, but described reluctance to leave. Red, 71, noted, "...we're sitting there and we see on the news that it [Charley] was coming...many hurricanes have gone by and never hit here...maybe it wouldn't amount to much. So, we waited for a while and I watched to see what was happening."

Eventually realizing the magnitude of Charley, they could do nothing but shelter-in-place.

In the reconstruction phase, this group (many who experienced Charley) used media communication as a lifeline as they tried to recover from the storm. Nancy, 66, did not qualify for FEMA assistance for her older mobile home, but used the media successfully to get a blue tarp to cover her roof, "...I was able to call the radio station and I asked...if somebody having their roof repaired if I could have their tarp...."

### **Evacuation**

Reasons for non-evacuation were typically determined by the situation. They included lack of time and age and/or mobility issues. Nancy (a caregiver diagnosed with depression) described how quickly news of Charley came, "I heard as I was on my way over [to person she cared for] that it was turning and coming in our direction...It all happened so fast...There was no thought or time for evacuation..." Media sources (Barnes, 2007) confirmed descriptions of too little time to evacuate for Charley.

Age and mobility issues sometimes factored into inability to evacuate. One caregiver, away from her 90 year old father at the actual time of Charley, tried to help him manage from afar. Her dad had no time to evacuate, and she felt likely wouldn't have given his age.

### **Preparation**

These participants described scrambling to brace the house for impact as well as

possible (e.g., moving car, closing shutters). Nancy stated, "...We didn't have time to think if we had water...So, we ran in and tried to shut up everything the best we could."

### **Focus of Attention**

This group did not describe attention to managing health-related activities. They ignored health-related concerns and focused on unexpected, immediate priorities of the impact/emergency phases, such as frightening events or securing and/or repairing their home.

Earl (2009) provided a graphic description of backburning health-related concerns to focus on the priority of one's home:

I was up on the ladder, having a heart attack, but going on anyway [fixing damaged roof]. It was a do-or-die situation; Constant rain and yet another hurricane making up in the Atlantic, we weren't going to get dry weather soon. I could worry about chest and arm pain later...I was pounding in nails, gritting my teeth, fighting pain in my chest, and right arm, and jaw... (p. 483).

He explained how he managed his symptoms, "...I was moving heavy furniture...I was still having heart attack symptoms all along but when they'd happened I'd sit down and waited until it went away..."

### **Recovery**

Instability in the area after storms required people to backburner health concerns. A media clip from MSNBC (2004) reported people, "...skipping their prescription drugs and, with no air conditioning and with window screens blown away, exposing themselves to mosquitoes carrying diseases..." Barnes (2007) noted, "...additional fatalities were reported as the cleanup got underway... [people] killed in accidents or by heart attacks" (p. 332). This substantiates reports by participants who remained at home in unstable conditions (e.g., no water or utilities, home damage, no local travel) and ignored challenges of chronic illness to address other priorities.

People reacted to health challenges as needed, frequently disregarding symptoms. Nancy ignored her anxiety and kept herself busy, "I was fine as long as I could be of use or help somewhere..." Mona, a Floridian who did not evacuate, described ignoring back problems to repair her damaged home, "I was lifting things I wasn't supposed to...you forget that you're not supposed to...when it was happening we did what we had to do. Truthfully, I did not even think about my conditions..."

Visits to providers and purchase of prescription refills were delayed for urgent home-related concerns or occasionally inability to find or access one. This group did not address health-related concerns until the reconstruction phase and then only if absolutely necessary, even given emotional or physical pain.

In summary, managing chronic illness health-related challenges during disasters was described using the concept of backburning. Health concerns were backburned in four ways: prudent, impromptu, deliberate, or unforeseen. These four ways differed on use of media, evacuation, preparation, focus of attention, and recovery

### **Discussion**

Findings in this study were similar to previously reported findings related to general disaster considerations, impact of the disaster on health conditions (e.g., cardiovascular and

respiratory sequelae), and the advantages of evacuation from a health perspective.

### **General disaster considerations**

There is a wide variation in preparedness actions. Most citizens perform little to no preparedness activities (Ablah, Konda, & Kelley, 2009; Bolland, 2006; Eisenman et al., 2006; Gheyntanchi et al., 2007). Findings in this study supported that variation: only 43% of Louisiana participants prepared and 72% of Florida residents performed some preparedness activities. This suggests a more sophisticated local and regional level disaster preparedness and response plan in Florida. Residents readily described local and/or state policies regarding evacuation, special needs shelters, and immediate response efforts. Descriptions from participants from Louisiana differed greatly. They often voiced perceptions of mismanagement. Participants infrequently described any local or regional action plan, although media review did quote local and state officials describing these activities from their perspectives. It is important to note that about one third of the study participants were from Louisiana and two thirds were from Florida.

Almost everyone described the massive power outages common in literature reports. Many noted this as a barrier to access food, water, and/or healthcare. Elements related to the event (e.g., impassable roads, debris, injuries); preexisting qualities of the population (e.g., disabilities); and misperceptions related to cognitive factors (e.g., media exaggeration, assumptions about immediate government response) can delay individual access to resources (Kumagai et al., 2006). In this study, participants frequently described massive debris, blocked roads, and restricted local travel. Occasionally disabilities were a barrier. Statements that the government did not try to drop food or provide rescue addressed expectations of immediate response and may have contributed to a lack of motivation to prepare. Many people praised extraordinary efforts of newspapers and radio stations to provide information.

### **Impact on health conditions**

Gautam, Menachem, Srivastav, Delafontaine, and Irimpen (2009) reported a three-fold increase in myocardial infarction two years post Katrina, possibly due to stressors of long term reconstruction (e.g., rebuilding, seeking employment). Howe et al. (2008) reported cardiovascular and endocrine as the most requested classes of medication post Katrina. In this sample of 40 participants, two participants explicitly described ignoring cardiac symptoms and/or restrictions to attend to their homes.

Bloom, Grimsley, Pehrson, Lewis, and Larsson (2009) studied mold and mildew and documented related health threats. Many participants in this study described difficulties from mold and mildew, ranging from a cleaning nuisance to pulmonary-related health threats.

### **Evacuation**

Evacuation is typically beneficial (Anderson, Cohen, Kutner, Kopp, Kimmel, & Muntner, 2009; Horney et al., 2010; Smith & McCarty, 2009). Findings from this study supported this assertion; evacuation strongly impacted the ability of the study participants to address at least some health-related concerns. In general, individual preparedness to evacuate and attention to special needs varies widely (Eisenman et al., 2009; Renukuntla et al., 2009; Uscher-Pines et al., 2009). Several Florida residents in this study were very knowledgeable about and/or had used special needs shelters. Although several participants from New Orleans who had mental health issues were able to connect with providers once they settled wherever they had evacuated, in similar fashion to reports in the literature, they did not have any

evacuation plan in place and fell into the category of impromptu backburners.

A significant difference from previous literature findings concerned medication separation. Studies have noted that disaster victims are often separated from medication needed to manage chronic illnesses (Greenough et al., 2008; Howe et al., 2008; Jhung et al., 2007; Krousel-Wood et al., 2008; Miller & Aquilla, 2008). Very few of these participants struggled to obtain prescription refills, especially if they evacuated. Many used national chain pharmacies to assure ability to refill medications while evacuated. Non-evacuees had trouble because local retailers were not open, further substantiating the finding that evacuation contributed to more positive health behaviors. Denial of insurance coverage contributed to the inability to stockpile an emergency supply of medication (Howe et al., 2008); several participants confirmed this difficulty.

Researchers (Arrieta et al., 2008; Mokdad et al., 2005; Saunders, 2007) have noted that, during Katrina, those with chronic illnesses were less likely to evacuate; had fewer monetary resources; and frequently depended on local institutions, with few resources left to offer, for care. In this study, a difference noted was that most participants who experienced Katrina did evacuate, however, they typically fell into the impromptu backburning category, scrambling to leave with little to no preparation. They did describe financial concerns and dependence on local responders and/or organizations to leave the area and settle elsewhere.

This study had limitations. Findings reflected self-reported viewpoints of those individuals with chronic illnesses and/or caregivers who experienced a hurricane. While these findings may hold similarities to other disasters, especially those with advanced notice (e.g., blizzard), there are likely some differences in the event of instantaneous disaster events for which evacuation is not possible (e.g., tornadoes). Thus responses were unique to this type of disaster.

A methodological limitation is the retrospective study design. However, most participants easily recalled specific details and provided rich narratives of the disaster experience, some making statements such as “I’ll never forget....”

## **Implications**

The study suggests several implications related to disaster preparedness. Study participant descriptions clearly supported the effectiveness of preparedness actions on health outcomes. It is important to educate providers and persons with chronic illnesses regarding the importance of preparedness actions. It would be beneficial to teach illness-specific preparedness actions, such as how to prioritize the most and least important actions for a given condition in a disaster scenario. Given the strong support for the benefit of evacuation in both the literature and this study, it is important to provide education about benefits and risks of health outcomes suggested by the decision whether or not to evacuate.

Healthcare providers should encourage and help patients and/or caregivers to create an evacuation plan to assist with decision-making, including registration for special needs shelters, if appropriate. Many study participants who followed the prudent backburning way described preparing copies of important records and discussed the helpfulness of these items. Providers can offer copies of important medical information and encourage patients to create medical records to provide information in such an event or to use electronic health records if possible. Finally, explore and discuss options for medication refills that will allow current prescription records to be accessed via a national database (e.g., chain pharmacy) in the event of evacuation.

## Future Research

Given the single context of disasters represented by this study, further study of how individuals with chronic illness(es) and/or their caretakers managed health-related concerns in the context of other disasters, especially those without advanced warning, would be beneficial. The concept of evacuation remains an important area of potential study. Despite known advantages to both preparedness actions and evacuation, the complexities associated with this process are many (e.g., animal care; traffic; job-related concerns; expenses; family and homeowner responsibilities). Study of the psychosocial process to determine whether and to what degree people will prepare and/or evacuate would be helpful to continue to learn how to best educate, encourage, and assist people with chronic illness to plan for and undertake this often difficult process.

## Conclusion

Every participant described the process of backburnering; managing these types of concerns was not their first priority. Participant descriptions suggest considerations related to evacuation and use of media. First, evacuation is a clear advantage to managing health-related concerns and the study related this action directly to positive health outcomes for those with chronic illness and suggested a tangible timeframe of benefit. Participants were often able to address at least some health-related concerns from afar. This was especially so if the disaster involved lengthy emergency and reconstruction phases and victims were evacuated for longer than a week, allowing them to contact temporary providers and/or resume health-related activities. If they did not evacuate, or returned while their home area was still unstable, they either ignored health-related concerns, or described a backward slide from any success they achieved while away. Second, local media efforts to relay information are clearly used and appreciated by victims. These efforts help people access resources; make disaster-related decisions and manage health-related concerns; and provide reassurance and emotional comfort. Findings from this study can guide efforts to inform providers, policy-makers, and persons with chronic illnesses about effective ways to manage health-related concerns, especially by the use of preparedness activities and evacuation whenever feasible.

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