HOW INDIVIDUALS WITH CHRONIC ILLNESSES MANAGE HEALTH-RELATED
CONCERNS DURING DISASTERS:
DEVELOPMENT OF A THEORETICAL FRAMEWORK

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fulfillment of the requirements for the degree of Doctor of Philosophy

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NURSING

HOW INDIVIDUALS WITH CHRONIC ILLNESSES MANAGE HEALTH-RELATED CONCERNS DURING DISASTERS: DEVELOPMENT OF A THEORETICAL FRAMEWORK

Director of Dissertation: Donna S. Martsof

Disaster preparedness frequently does not address populations less able to prepare for disaster such as those with chronic illness. Individuals with chronic illnesses are at particular risk of poor outcomes, including death. The purpose of the study was to develop a theoretical framework that describes how individuals with chronic illnesses who have experienced a disaster managed health-related challenges during the disaster. Theory about the five phases of disaster response (non-disaster, pre-disaster, impact, emergency, and reconstruction) and the individual, local, state, and federal level model served as conceptual frameworks.

Purposive sampling was used to recruit the sample. Thirty individuals with chronic illnesses who have experienced disaster and 10 lay caregivers were recruited from Florida and New Orleans. This study used grounded theory methods from the qualitative tradition. Three data sources were used: interviews with individuals with chronic illnesses and caregivers who have experienced disasters, and media data. Combined interviews from the perspectives of those who have experienced disaster (individuals with chronic illness and caregivers) with media reports added contextual description of circumstances surrounding the disaster. Constant comparative analysis techniques were used to build the theoretical framework. Trustworthiness was addressed by member checks, audit trail, and data triangulation.

Analysis of the transcripts suggested that participants shifted the priorities of their illness to deal with the challenges of the disaster. There were four ways in which participants used the process of backburning their chronic illness, which we named prudent, impromptu, deliberate, and unforeseen. Each way of backburning related to five factors: media impact, evacuation, preparation, attention, and recovery. If participants were evacuated for longer than one week or returned to no or minimal damage to their home, many recovered from the disaster events enough to address at least some health-related concerns from afar. Those remaining home were more apt to ignore health-related concerns longer to deal with home and family issues. The study provided in-depth insight into how a vulnerable population manages health-related concerns specifically in the context of disaster response which can be used to guide future research and interventions.

CHAPTER I

BACKGROUND AND SIGNIFICANCE OF THE PROBLEM

Overview of the Problem

The incidence of disasters is rising and the importance of the resulting public health threats and the financial implications of adequate preparation are receiving increased attention (Arnold, 2002; Cherry & Trainer, 2008; Ginter et al., 2006; Noji, 2003). A disaster has been defined as, "...a vast ecological breakdown in the relation between humans and their environment, a serious or sudden event on such a scale that the stricken community needs extraordinary efforts to cope with it, often with outside help or international aid" (Noji, 2000, p. 147). According to the IEG World Bank (2007) the number of reported natural disasters worldwide has rapidly increased; fewer than 100 were reported in 1975 and greater than 400 in 2005. Natural disasters on the rise in North America are tropical storms and wildfires. In addition, the number of victims of natural disasters has increased considerably on an annual basis, nearly quadrupling from 1975–84 to 1996–2005 due to increasing population and urbanization (IEG World Bank, 2007).

The vast ecological breakdown during disasters demands a response on several levels (e.g., individual, regional, and possibly federal) in order for a community to cope and recover. The Federal Emergency Management Agency (FEMA) (2007a) defines disaster response as, "Activities to address the immediate and short-term effects of an

emergency or disaster. Response includes immediate actions to save lives, protect property, and meet basic human needs” (para. 20). Disaster response is typically divided into five phases: non-disaster, pre-disaster, impact, emergency, and reconstruction. These five phases typically occur at several different levels: individual, local, regional, and federal (Langan & James, 2005; Veenema, 2007).

Preparedness activities taken during the non-disaster and pre-disaster stages, sometimes called disaster mitigation, can help persons better manage their response to a disaster regardless of the scope or type of event. The Federal Emergency Management Agency, (FEMA, 2007b) defines preparedness or mitigation as, “any sustained action taken to reduce or eliminate long-term risk to life and property from a hazard event” (para. 1). This process involves the following steps: organizing resources; assessing risks; developing a mitigation plan; and implementing the plan and monitoring progress (FEMA, 2007b). However, disaster preparedness frequently does not address populations who may have special needs (Disastersrus, n.d.; Jones, 2006a).

Some individuals are less able to prepare for disaster, or may need additional preparation due to special needs that increase their vulnerability and thus may make them more likely to be particularly affected by a disaster (Jones, 2006a; 2006b; National Organization on Disability, 2006). Examples of groups frequently noted as vulnerable populations in the disaster literature include the elderly; children; those medically fragile and/or disabled; pregnant women and fetuses; prisoners; victims who speak limited/no native language; single working parents; people without vehicles; people with learning disabilities; and healthcare providers (Bond & Beaton, 2005; Brodie, Weltzein, Altman, Blendon, & Benson, 2006; Chou et al., 2004; Deeny & McFetridge, 2005; FEMA, 2004;

Hohenhaus, 2005). These groups are disadvantaged in a disaster situation relative to factors of resource availability, comparative risk, physiological or psychological stress, and marginalization. The presence of one or more of the above factors then results in adverse health outcomes (e.g., exacerbation of illness, death) or health disparities (Bay, Kruehn, Shavers, & Currier, 2006; Hooper, 2005). Development of effective health messages that persuade those with increased vulnerability to engage in preparedness activities in the non- and pre-disaster stages may be one way to increase availability of resources, minimize stress, and decrease risk of a poor outcome by improving ability to cope with disaster situations. This may be especially important for individuals with chronic illness (Fawcett & Russell, 2001; Jones, 2006b; Langan & James, 2005; Noji, 2003).

A chronic disease persists over time, at least three months or more, and usually cannot be prevented by vaccines or cured by medication (U.S. National Center for Health Statistics, 2007). Chronic diseases (e.g., cardiovascular disease, some cancers, renal failure, diabetes) are now among the most prevalent, costly, and preventable of all health problems. Seven of every 10 annual deaths (or >1.7 million persons) in the United States (U.S.) each year are the result of a chronic disease (Centers for Disease Prevention and Control [CDC], 2008b). Chronic diseases affect quality of life of 90 million U.S. residents. Cost of medical care for persons with these diseases accounts for 70% of total medical care expenditures (Indicators, 2004).

Persons with chronic illnesses constitute a population at particular risk of poor outcomes during a disaster due to the critical nature of their medication support. Specifically, the events of a disaster may include a separation from medication (e.g.,

insulin, oral antihyperglycemic agents). This interrupted access to medication can lead to chemical imbalances and/or acute life-threatening events (e.g., diabetic ketoacidosis [DKA]). Persons with chronic illness are often more susceptible to other illnesses. In addition, once these illnesses are acquired, they are more likely to die. This is significant in the context of disasters due to such risks as infectious disease associated with contaminated water and/or food supply; respiratory compromise resulting from inhaled toxins; and disrupted skin integrity due to wounds. Persons with a chronic illness need to know how to protect their health and/or respond to disaster conditions (Cole, 2003; Conway-Welch, 2002; Patel, Arocha, & Kushniruk, 2002).

Nurses have always played essential roles in preparation for and response to disaster and/or mass casualty incidents (Jones, 2006b). The recent heightened focus on the possibility of future incidents presents many opportunities for nursing research (Cole, 2003; Conway-Welch, 2002). Research in the area of disaster response could help nurses understand more about how patients with chronic illness manage during a disaster. A rich and complex description of how persons with chronic illness manage their illness(es) in a disaster could assist nurses to improve nursing care related to disaster preparedness and response to a disaster event for any patient coping with a chronic disease, especially those with medication separation concerns.

Proposed Qualitative Study

Research Purpose

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.

Research Aims

Specific aims of this study were to:

1. 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.
2. Describe how individuals with chronic illnesses who have experienced a disaster interacted with healthcare workers during the impact and emergency phases of the disaster.
3. Describe how individuals with chronic illnesses who have experienced a disaster perceived the impact of regional and federal level disaster response activities on their efforts to manage their chronic illness at any or all phases during the disaster.

A long-term goal related to this research was to use the theoretical framework as a basis to develop a disease-specific guide for healthcare providers and patients with chronic illnesses to use to prepare for disaster response.

CHAPTER II

REVIEW OF THE LITERATURE

This review of literature focuses on the topic areas of disasters, disaster response, and chronic illness. Gaps in knowledge are noted and a proposed qualitative study to address these gaps is then suggested.

This review concentrates on disasters and chronic illness in the context of developed countries due to the significant difference in available resources (e.g., funds, responders, supplies) for response between developed and developing countries (Johnson, 2007) and the nature of the proposed study. Worldwide concerns are included in the discussion when appropriate (e.g., prevalence and incidence); however, the review of research findings was limited to developed areas such as the United States, Canada, and various European countries.

Disasters

The first section provides definitions of disaster, including natural and manmade disasters (sometimes called unintentional and intentional). Prevalence and incidence of disasters, with a focus on those occurring in the United States, is discussed.

Definitions of Disaster

The definition of disaster has several requirements: a disruption between humans and the environment; an event of a sudden and/or serious nature that overwhelms

individual and usual local resources; and the need for extraordinary and/or external efforts to respond and recover (Noji, 2000). A natural disaster is caused by forces in nature; a manmade disaster is either an intentional human act intended to cause destruction or an accidental occurrence (Jones, 2006b).

Prevalence

In the context of disaster, prevalence can consider: a) the number and types of disasters or, more frequently, b) the number of people potentially or actually affected by the event. Research related to the prevalence of disasters is thus often descriptive in nature with a goal of exploring how often and where disasters occur; and what and how large are the populations that were most affected. Each of these types of prevalence is discussed below.

Number and types of disasters. The assertion that disasters are on the rise, both in the United States and globally, is a theme frequently noted in the literature (IEG World Bank, 2007). Research attempts to quantify how many disasters occur over time (i.e., is the number increasing or decreasing) and in which areas what types of disasters are most prevalent. According to Briere and Elliott (2000), in the United States the most prevalent natural disaster has been an earthquake and the least prevalent a hurricane. However, recent tracking of Disaster Medical Assistance Teams (DMATs) indicated that of late, the response to hurricanes is rising (FEMA, 2003; Mace, Jones, & Bern, 2007). While there is no U.S. region considered disaster-free, the South and the West reported the most events.

Ginter et al. (2006) noted that greater than ninety percent of worldwide natural disasters, and those in the US reported in the past 100 years, have occurred in the last half

century. However, the ability to report and track disasters has also improved considerably in this time period. Even so, the number of disasters has demonstrated a rise in recent years when reporting methods have remained relatively similar; both intentional (e.g., acts of terrorism) and non-intentional (e.g., chemical spills, explosions, fires) have increased at an even higher rate since the 1970s (Arnold, 2002; Braine, 2006; Ginter et al.; Mace et al., 2007; Noji, 2003).

Number of people potentially affected. Earthquakes and hurricanes, as well as other frequently noted natural disasters, such as floods, wildfires, blizzards, and tornadoes, can affect a very large number of people and lead to significant health-related sequelae and financial burden (Arnold, 2002; FEMA, 2003; Noji, 2003).

Dominici, Levy, & Louis (2005) noted both the importance and the challenges of accurate estimation of prevalence. Given the uncertain nature of most disasters, there are few systems in place to accurately track exposures and/or health outcomes of affected populations. Even with prior notice, it can be difficult to accurately estimate the extent of people affected as onset of identifiable signs and symptoms may be significantly delayed by weeks or even months. Indeed, Dominici et al. asserted that “identifying the at-risk population is one of the biggest [methodological] challenges faced by researchers” (2005, p. 10) thus leading to biased estimates of prevalence. For example, selection bias can lead to an overestimate of the prevalence of a disaster-related syndrome (Dominici et al., 2005). Other factors that can affect the accuracy of determining populations affected and/or at risk include media impact; types and duration of disaster-related exposures; and the tendency to place blame (Dominici et al., 2005; Kumagai, Edwards, & Carroll, 2006).

Another theme related to prevalence of disasters is population density. A societal shift to urban dwelling has impacted the number of people at risk; the ability to accurately estimate prevalence; and the burden of the response effort (Dominici et al., 2005; Mitchell, 1999). According to Greenough et al. (2008), the very large population displaced to shelters during Hurricane Katrina had, "...a significant burden of disease, socioeconomic vulnerability, and marginalized health care access" (p. 426) to the extent that accurate estimation of these burdens was critical to the response effort.

Related to population density is the prevalence of specific community needs in a given disaster situation (Morbidity and Mortality Weekly Report [MMWR], 2004). For example, a frequently occurring challenge is electric power outages. Urban areas suffering a power outage affect proportionately more people given the population density. In turn, power outage affects access to food, water, and healthcare (Bayleyegn et al., 2006; MMWR, 2004). The concepts of access to healthcare, disease burden, and vulnerability will be discussed in greater detail below.

Incidence

The concept of incidence can also be considered from a dual perspective, i.e., the number of disasters that occur on an annual basis and the number of people affected in a given year. Each of these is considered in the following section.

Number of disasters per year. Tracking of the number of reported natural disasters worldwide is done by IEG World Bank. Research by this organization reported a notable increase, with the number of disasters per year nearly quadrupling in the annual reporting periods between 1975 and 2005 (IEG World Bank, 2007).

In the United States, the annual number of reported disasters between the years 1991 and 2000 ranged from approximately 80 in 1994 to 195 in the year 2000. Each year from 1994 to 2000 noted an annual increase (Emerging trends, n.d.). Natural disasters on the rise specifically in North America are tropical storms and wildfires, which have demonstrated annual increases of late.

Number of people affected per year. The number of victims of natural disasters has increased on an annual basis due to increasing population and urbanization (IEG World Bank). The United Nations (2003) reported the following worldwide annual statistics for the years 1986 to 2002: 46,000 deaths due to natural disasters and 600 million people left injured and/or homeless. The next section considers research related to disaster response.

Disaster Response

Overview of Disaster Response Research

Research related to disaster response is largely outside the discipline of nursing. In addition, the overall contribution to the state of the science thus far is on the lower end of the hierarchy of evidence (Norris, 2006; Polit & Beck, 2009; Uscher-Pines, 2009; Uscher-Pines et al., 2009). According to Norris, cross-sectional, after-only designs using convenience sampling methods are the most common methodology noted in her review of 225 disaster studies. Small sample sizes were also common to these studies. Desirable characteristics, such as longitudinal and experimental designs and probability sampling, are less frequent. Many studies are retrospective, post incident case reviews. While this is appropriate to the topic area; retrospective, descriptive and case studies are

limited in the contribution that can be made toward generation of knowledge. Specific gaps noted from review of these studies are discussed in more detail below.

Similar variables considered in disaster response research included skills, such as preparedness; communication; and response proficiency and/or competency; and consumables, such as adequacy of supplies. A key difference noted was the context of evaluation. Some studies looked at these variables in one setting, such as a specific institution and others from the perspective of multiple levels. Others measured the variables by ethnic subculture or preparedness for/response to a certain type of disaster (e.g., hurricane).

Strengths noted in disaster response research included an increasing focus on specific populations (e.g., pediatric, dialysis) and a considerable body of work related to post disaster mental health sequelae. Fewer studies were noted that address the needs of the elderly population; many studies in disaster research that focused on the elderly were in the context of an infectious pandemic rather than a natural or manmade physical disaster. Another gap noted was research that focused on what individuals actually do in response to the disaster event; far greater was the focus on the individual health-related physical and/or emotional responses.

The following section provides definitions related to disaster response, including the most common five phases (Langan & James, 2005; Veenema, 2007). It is followed by a basic introduction to the individual, local, state, and federal level structure typically used in disaster response with additional explanation about how these phases and levels are combined in this review of literature.

Definitions of Disaster Response

Definitions of disaster response typically include activities intended to address the short and long term effects of the event (FEMA, 2007a). However, many definitions structure activities into phases that also include pre-disaster activities to mitigate risk. For example, health literature that defines disaster response uses a model that most frequently divides the response actions into five phases: non-disaster, pre-disaster, impact, emergency, and reconstruction (Langan & James, 2005; Veenema, 2007). Sometimes the pre-disaster stage does not occur; some sources divide these stages into pre-impact (non-disaster and pre-disaster); impact; and post-impact (emergency and reconstruction; Veenema). Langan and James define the five phases as follows:

1. Non-disaster stage is the time before a threat of a disaster is present,
2. Pre-disaster stage is when the disaster has been identified but has not yet occurred,
3. Impact stage starts when the disaster occurs and lasts until the threat of further destruction has passed,
4. Emergency stage starts when the impact phase ends and continues until the threat of injury has passed, and
5. Reconstruction stage begins sometime during the emergency phase and continues until the community is functioning in an orderly and stable fashion.

Due to the overlapping nature of many actions in these phases, they are sometimes combined (e.g., non- and pre-disaster combined for a four phase model or a two phase model including mitigation/preparation and response/recovery; Barnes et al., 2008). All literature reviewed essentially incorporated one or more of these five phases.

Levels of Disaster Response

Collaboration among resources and response at the individual, local, state, and federal level is the ideal structure for effective and timely disaster response (Berg, 2004; Bostick et al., 2008; Braun et al., 2006; Dainiak, Berger, & Albanese, 2007; Johnson, 2007; Jones, 2006b; Kumagai et al., 2006; Mattox, 2006; Parvis, 2002). A common perception, sometimes enhanced by media coverage, is that the federal response to a major disaster will, or should, cover all needs of the population affected (Barnes et al., 2008; Stratton & Tyler, 2006). However, individual and local response is first to occur. Several experts recommend that individuals and local disaster relief agencies should be prepared to meet community needs for 24 to 96 hours (Boland, 2006; Booker, 2000; Resnick, Zablotzky, Nachman, & Burke, 2008; Shover, 2007; Stratton & Tyler; Teeter, 1996; Watson-Alvan & Alves-Dunkerson, 2007; Yurt et al., 2008). Malilay (2000) conducted a review of eight CDC rapid assessments and concluded that while each of these needs assessments conducted by the federal agency was conducted within one week after the disaster, most of them were performed in the third to tenth day range, thus substantiating the above recommendation.

This section reviews literature related to disaster response efforts for each of these levels (individual, local, state, and federal) using the five phase model noted above. Given the challenges of conducting research in disaster response noted above, studies frequently take into account more than one of these phases. Also, very little, if any, research considers disaster response at a single level, but rather inquires as to how preparedness or response actions at one or more of these levels (e.g., individual

preparedness or federal response) might have positively or negatively impacted the response effort.

This review of literature combines the non- and pre-disaster phases as those that involve preparatory actions (labeled *Preparedness Actions*) and impact, emergency, and reconstruction as those that involve direct response to an event that has occurred (labeled *Response Actions*). Since collaboration among response levels is a strong theme noted in the literature, the review will synthesize what is known at the individual, local, state, and federal level about both preparedness and response actions by further categorizing them to reflect individual (including family); regional (local and state governments or institutions); and federal efforts. Due to the multiple areas of study in disaster response (e.g., geographic instability, likelihood of terrorism, impacts on humans and animals), this review will be limited to those studies that, in the opinion of the author, had direct impact on health-related concerns to humans (e.g., injuries and illnesses; availability of shelter, food, water, and medicines; mental health sequelae).

Preparedness Actions

Individual level preparedness. Very few studies have considered the level of individual preparedness for disaster events. Those that do report a wide variation in preparedness actions, with the majority of citizens performing little to no preparedness activities (e.g., purchasing emergency supplies, developing a family plan; Ablah, Konda, & Kelley, 2009; Boland, 2006; Eisenman et al., 2006; Gheyntanchi et al., 2007; Stallwood, 2006; Weir, 2005). Study findings were inconsistent related to preparedness actions for African Americans and Latinos. Earlier studies listed these two groups among the least prepared (Faupel, Kelley, & Petee, 1992; Turner, Nigg, Paz, & Young, 1980). However,

recent studies (Eisenman et al., 2006; Torabi & Seo, 2004) reported these groups had the highest rate of individual preparedness, especially if they were also able to afford medical care on a pre-disaster basis (Ablah et al., 2009). Individual preparedness was also positively associated with educational level (Eisenman et al., 2006; Torabi & Seo, 2004) and age (30 to 64 years) and exposure to other lifetime traumas (Boscarino, Adams, Figley, Galea, & Foa, 2006). Other characteristics associated with an increase in preparedness behaviors were living with dependents or having a disability (Ablah et al., 2009). In the Eisenman et al. (2006) study, single persons and Asian and Pacific Islanders were least likely to report individual preparation.

Regional level preparedness. A study of 1750 U.S. hospitals conducted by Braun et al. (2006) found that most hospitals participated in at least some collaborative (i.e., with local, state, and federal agencies) drills and analyses. While there was room for improvement in these collaborative relationships, performance in preparatory activities was higher among urban facilities that had more resources (e.g., mobile medical units) and/or perceived a greater threat (Braun et al., 2006; Krol, Redlener, Shapiro, & Wajnberg, 2007; Lurie, Wasserman, & Nelson, 2006; Savoia, Rodday, & Stoto, 2009; Yurt et al, 2008). Rural areas still noted significant differences among various geographic regions, especially related to confidence in preparedness competencies and need for response training (Ghosh, Patnaik, & Vogt, 2007; Hsu et al., 2006; Watson-Alvan & Alves-Dunkerson, 2007; Williams, 2008). Inadequate preparation and/or lack of resources to enact surge capacity (i.e., the maximum patient load that responding agencies can accommodate) when needed and contradictory information (such as protocols at different levels based upon varying sources of exposure limits) among levels

were also concerns (Barbisch & Koenig, 2006; Berg, 2004; Carmona, 2006; Jederberg, 2005; Langan & James, 2005).

One lesson learned from study of Hurricane Katrina was the high level of preparedness still needed for the long-term care (LTC) system (Cherry & Trainer, 2008; Gheyntanchi et al., 2007; Hyer, Brown, Berman, & Polivka-West, 2006; Resnick et al., 2008; Rhoads & Clayman, 2008; Ziskin & Harris, 2007). Use of preparedness modeling has emerged to enhance planning efforts at the local and state levels (Rosenfeld et al., 2009; Tran, Weireter, Sokolowski, Lawsure, & Sokolowski, 2009). For example, Florida has a model of Medicaid nursing home reimbursement that has demonstrated usefulness for hurricane-related costs and care and contributed to the state's preparedness efforts in long term care (Thomas, Hyer, Brown, Polivka-West, & Branch, 2010). Areas identified for improvement included: coordination of emergency management with LTC facilities; development of guidelines and tracking systems for evacuation; education of staff and residents; and improved communication infrastructure (Hyer et al., 2006). Initiatives by such groups as The Joint Commission and the U.S. Department of Health and Human Services to address these issues have begun to improve disaster preparedness efforts at the regional level (Sauer, McCarthy, Knebel, & Brewster, 2009).

Federal level preparedness. Very little research is published regarding the specific topic of federal level preparedness activities (as opposed to federal level response activities, which have been researched and are discussed below). Only two studies (Brody, Zahran, Highfield, Bernhardt, & Vedlitz, 2009; Resnick et al., 2008) specifically considered preparedness activities in the context of evaluation of measures to create infrastructure sufficient to support environmental public health. The Resnick et al.

(2008) study was not exclusively federal as it used a regional setting (24 local environmental public health agencies in Maryland). However, this multistep case study review did include preparedness guidelines from the CDC, a federal agency, as a framework for evaluation, and also included in the data collection support measures in place from the CDC related to building surge capacity. Brody et al. (2009) examined the change in Florida preparedness policies related to flooding by analyzing FEMA's Community Rating System (CRS); this longitudinal study demonstrated that local areas do adjust mitigation activities in response to historical data.

Other non-research articles (e.g., clinical and trade publication articles) in scholarly literature call for sustained and/or increased federal fund allocation toward disaster preparedness activities (Berg, 2004; Cherry & Trainer, 2008; Lubell, 2008; Remick, Crapo, & Woodruff, 2005; Watson-Alvan & Alves-Dunkerson, 2007). Increased federal funding for preparedness efforts has been recently available given the catalyst event of September 11. However, historically it has been a challenge to secure consistent funds for preparatory actions at any level as the focus is usually on reallocation of funds from elsewhere to initiate or sustain a response effort (Arnold, 2002; Cherry & Trainer; Ginter et al., 2006; Noji, 2003). Another concern noted was that formulas used to allocate funds do not take into consideration such factors as geographic variations in availability or cost of services (Buehler & Holtgrave, 2007). Funding impacts not only federal response, but many state and local efforts as well (Berg, 2004; Ziskin & Harris, 2007).

Multilevel preparedness efforts. Research supported collaboration among levels in the areas of disaster response education and preparedness activities, such as

preparation for possible evacuation (Arrieta, Foreman, Crook, & Icenogle, 2008; Chan & Sondorp, 2007). Specific improvements in preparedness noted in recent years at multiple levels included formation of new partnerships among responding agencies; development of new technologies; increased focus on the pediatric and dialysis populations as a model for customized preparedness plans; and formal organizational structures to define the roles of each level (Booker, 2000; Fendya, 2006; Ginter et al., 2006; Kizer, Cushing, & Nishimi, 2000; Kleinpeter, 2007, 2009; Kopp et al., 2007; Lengua, Long, & Meltzoff, 2006; Lurie et al., 2006; Martin, Bush, & Lynch, 2008; Parvis, 2002; Pina et al., 2008). These improvements in preparedness actions have cost implications as well. One cost-benefit model predicted that improving the bioterrorism surveillance capability to the goal of treatment in 48 hours or less (in the impact and emergency phases) can yield economic savings in billions of dollars (the exact amount dependent on the nature of the release of the agent; Schneider, 2005).

Response Actions

Individual level response. Research related to the individual response to a disaster event focuses on three main areas most likely to occur in the impact and/or emergency phases: a) the most common health-related sequelae (as opposed to what individuals might actually physically do in response to the disaster), b) whether or not and how they chose to access available resources, and c) medication separation. This section first discusses commonly studied individual responses to a disaster event (e.g., post traumatic stress disorder (PTSD) and other mental health disorders, use of mental health services, and risk to responders); factors identified by research related to access to resources; concerns about medication separation, and finally, evacuation status.

A strength noted in disaster research is study of mental health disorders that may follow a disaster event. A review of 52 studies by Rubonis and Bickman in 1991 established a consistent relationship between large scale disasters and psychopathologies (e.g., depression, anxiety, stress, phobias, substance abuse). Many individual studies since 1991 continue to examine, and often support, the elevated risk of psychopathology in both the short and long term range (Abramson, Stehling-Ariza, Garfield, & Redlener, 2008; Ahern & Galea, 2006; Briere & Elliott, 2000; Ford, Adams, & Dailey, 2006; Galea et al., 2007; Kessler et al., 2008; Marshall, Schell, Elliott, Rayburn, & Jaycox, 2007; Mezuk et al., 2009; van den Berg, Grievink, Stellato, Yzermans, & Lebrecht, 2005; Yzermans et al., 2005).

Other factors found to be possible contributors to PTSD specifically and mental health disorders in general were female gender; genetic structure, financial loss; post disaster stressors and traumatic events; low social support (Abramson et al., 2008; Ahern & Galea, 2006; Amstadter et al., 2010; Boscarino & Adams, 2009; Ford, Adams, & Dailey, 2007; Ford, Mokdad, et al., 2006; Galea, Tracy, Norris, & Coffey, 2008; Mills, Edmondson, & Park, 2007; Osofsky, Osofsky, Kronenberg, Brennan, & Hansel, 2009; Person, Tracy, & Galea, 2006; Zimering, Gulliver, Knight, Munroe, & Keane, 2006; Weems et al., 2010); households with greater numbers of children; fatalistic outlook; poor self-efficacy (Abramson et al.; Benight & Harper, 2002; Callaghan, 2005); media exposure (Ford et al., 2007); and positive psychiatric history (Ford et al., 2007; Mills et al.).

Variables that have been correlated with increased use of mental health services (i.e., seeking use of services in response to the disaster) included a younger age,

immigrant status, use of public assistance prior to the disaster, relocation and/or physical injuries, and chronic diseases (den Ouden et al., 2007). Forced relocation contributed to a higher level of mental distress and use of services, but not relocating did not prevent it (Yzermans et al., 2005). Conversely, possessing qualities of resilience; being married; and age greater than 65 were found to protect victims from severe mental distress and symptoms of PTSD (Bonanno, Galea, Bucciarelli, & Vlahov, 2006, 2007; Ford et al., 2007).

Responders (both healthcare providers and volunteers) were found to be at risk for symptoms of PTSD, but this risk decreased with prior training or experience (Jones, 2006b; Perrin et al., 2007; Witteveen et al., 2007). This population was somewhat more likely to seek mental health services. A four year longitudinal study of over 3000 rescue workers noted that commonly reported outcomes by responders were increased use of sick leave; musculoskeletal, psychological, and respiratory complaints; and general malaise (Morren, Dirkzwager, Kessels, & Yzermans, 2007).

A second area of research on the individual level response was how persons sought access to available resources. For example, studies considered how quickly individuals could access appropriate resources available to them after a disaster through local, regional, or federal efforts and/or the reason(s) for a delay in such access (Malilay, 2000; Stratton & Tyler, 2006). Malilay found that most needs assessments performed within three to 10 days of the event focused on demographics, health status, food and water, and restoring utilities. When the needs assessments were performed in that time period, adjustments were typically made to enhance the ability of affected individuals to access resources. Stratton and Tyler (2006) concluded that individual response to access

resources was essentially limited to efforts at the personal or at best, community, level for a minimum of 24 hours; access to higher level resources provided by state and federal agencies typically required 24 to 96 hours. Kumagai et al. (2006) presented a conceptual framework suggesting that delayed access to resources that are of impact at the individual response level were elements related to the event itself (e.g., blocked roads, physical challenges of the site, physical injuries); preexisting qualities of the population (e.g., disabilities); and misperceptions related to cognitive factors (e.g., media exaggeration or lack of media access for information; assumptions that government agencies will provide immediate response effort).

Another challenge that occurred at the individual level included medication separation, which may be critical to an individual with a chronic illness. Studies noted that victims are often separated from medication needed to manage chronic illnesses (Greenough et al., 2008; Howe, Victor, & Price, 2008; Jhung et al., 2007; Krousel-Wood et al.; 2008; Miller & Aquilla, 2008). Krousel-Wood et al. (2008) noted that some patients did not bring their medications when evacuating during Hurricane Katrina. However, Miller and Aquilla (2008) noted that during the Katrina relocations, some evacuees came prepared with several days of prepackaged medication only to have it confiscated.

Studies are beginning to emerge that address evacuation. These studies examined evacuation behaviors related to perceived risk (Boscarino et al., 2006; Horney, Mac Donald, Van Willigen, Berke, & Kaufman, 2010; Smith & McCarty, 2009) and health outcomes related to evacuation status (Anderson et al., 2009). All of these early studies supported the benefit of evacuation when possible.

Concerns such as medication protocol and perceived risk are not just at the individual level, but related to ineffectiveness of or confusion in regional response protocol. The next section discusses regional level responses.

Regional level response. Regional level responses include both state and local efforts. Response efforts at this level can continue for years after the disaster, and thus encompass the impact, emergency, and reconstruction phases previously mentioned. This section reviews research that considered several areas of concern at the regional level. First, research that studied types and effectiveness of needs assessment and planning is discussed. This is followed by discussion of research to identify barriers to meeting needs at the regional level, and then effectiveness of efforts to overcome post-disaster challenges (e.g., preventing crime, maintaining food and water supply, providing critical incident stress debriefing [CISD]).

Priorities noted related to planning for disaster response at the regional level were communication, volunteer training and coordination, and donation management (Arrieta et al., 2008; Blanchard & Dosa, 2009; Eisenman, Cordasco, Asch, Golden, & Glik, 2007; Elledge, Boatright, Woodson, Clinkenbeard, & Brand, 2007; Gheyntanchi et al., 2007; Mattox, 2006; Shover, 2007). At this level, risk-based assessments are done as one method of planning to identify and quantify risks to a particular geographical area and/or population. Need-based assessments are appropriate to the post-disaster stages of impact, emergency, and reconstruction and help the regional responders to assess and plan what is needed to best respond. A consensus-based triage protocol considers response agencies at all levels to reach mutual agreement about the needs, priorities, and responsibilities of each agency as it relates to the triage process in the impact and

emergency stages. Study of the response effort to Hurricane Katrina provided both support for the effectiveness of need-based assessments (versus risk-based assessments more appropriate to preparedness actions taken in the non- or pre-disaster stages) and consensus-based triage protocols utilized and call for continued development of these types of plans (Chan & Sondorp, 2007; Ghosh et al., 2007; Howe, Victor, & Price, 2008; Klein, Pepe, Burkle, Nagel, & Swienton, 2008).

Barriers noted at the regional level included a lack of evidence-based protocols to support patient care (Barbisch & Koenig, 2006; Howe et al., 2008). Another current topic in disaster research is management of health records. The lack of access to these records at the regional level, where healthcare is usually managed, can be a significant barrier. Technology is under development to assist in tracking outcomes, making rapid diagnoses, and providing access to past medical history for displaced victims (Pate, 2008; Smith & Macdonald, 2006). Research in the area of health records built on previous conclusions that use of standardized data collection forms enhances access to care by improving organization and efficiency of the response effort (Fisher, 1977; Leonard, Stringer, & Alson, 1995). Another study (Kleinpeter, 2009) indicated that collaboration with dialysis providers that evacuees used during Hurricane Katrina allowed use of these same providers in subsequent evacuations, enhancing health outcomes and minimizing disruption of treatment during the evacuation period.

Regional efforts continue months, and even years, beyond the event itself, thus some research considered the effectiveness of regional efforts to help individual victims and communities to overcome challenges in the post-disaster phases (e.g., physical and mental health concerns). Research noted that long term priorities at this level to improve

and sustain the efforts during the reconstruction phase are crime prevention, sustaining food supply, and access to mental health services (Gheyntanchi et al., 2007; Kim, Plumb, Gredig, Rankin, & Taylor, 2008).

Mitchell, Sakraida, and Kameg (2003) reviewed multiple meta-analyses offering mixed results on the effectiveness of CISD; often performed at the regional level and thought to decrease occurrence or severity of PTSD. They noted that this intervention has solid research support and perceived clinical effectiveness, but needs further study related to the implementation process, which can be quite delayed. For example, Calderon-Abbo (2008) reported that the first acute, inpatient, adult psychiatric unit in New Orleans did not open until 12 months after Hurricane Katrina. Many of these regional level responses are dependent upon, or potentially enhanced by, the federal level response, which is discussed next.

Federal level response. In response to September 11, a number of new federal programs have been enhanced or created. These include such resources as federal departments related to radiological monitoring; Environmental Protection Agency (EPA) monitoring during both the emergency and recovery phases; newly structured triage teams; and civilian support teams (Remick et al., 2005). However, as noted above, the challenge of sustained funding to support federal programs remains (Conklin & Liotta, 2005; Remick et al.).

The challenge of mass evacuations for large scale disasters (e.g., hurricanes) applies to both the regional and federal levels. These efforts typically begin at the regional level, but management of emergency shelters is the responsibility of FEMA. Post-Katrina studies (Eisenman et al., 2007; Jacob, Mawson, Payton, & Guignard, 2008;

Pina et al., 2008) of mandatory mass evacuation suggested that a very high priority should be to keep families together during the evacuation and in these shelters in any way possible, to minimize deleterious effects on both physical and mental health, and to provide extrafamilial support for children to minimize PTSD. Studies related to the federal response activities post-Katrina identified the chaotic nature of the mass evacuation as an area for improvement, as well as other repeating themes in the literature, such as inefficient communication; confusion related to the chain of command; large variations in the level of disaster preparedness; and insufficient mental health resources (Gheytanchi et al., 2007; Shover, 2007). Also, one study specific to the National Guard response (Bochicchio, 2010) indicated that the role, mission, and capabilities of this organization in the context of disaster response are poorly understood by individuals and communities.

Mattox (2006) suggested that, to minimize confusion and inefficiency, even federal resources are best managed at the local level using a pre-developed plan. For example, while a federal agency such as the Federal Emergency Management Agency (FEMA, 2008) may orchestrate the response effort based on the framework of the national response plan, local agencies would be responsible for prioritizing scarce resources, such as provision of critical care (Devereaux et al., 2008).

Multilevel response efforts. Mobile medical vans have historically provided a way to reach disaster victims. These vans represent a successful collaborative response effort among local, county, state, and federal agencies, and have been determined an efficient method to provide medical care to populations who could not access existing facilities (Fisher, 1977; Taylor et al., 2007).

Summary of Disaster Response Literature

Research related to disaster response demonstrated collaborative and innovative efforts to increase access to care by improving estimation of prevalence (Dominici et al., 2005; Mitchell, 1999; MMWR, 2004) and efficiency related to health records and response. Conclusions from the studies reviewed strongly support the importance of disaster preparedness activities at all levels and the role that collaboration and communication plays during every phase of disaster response activities (Berg, 2004; Bostick et al., 2008; Braun et al., 2006; Dainiak et al., 2007; Johnson, 2007; Jones, 2006b; Kumagai et al., 2006; Mattox, 2006; Parvis, 2002). The next section considers the area of chronic illness.

Chronic Illness

Research related to chronic illnesses is plentiful and supports incorporating self-management behaviors in patients diagnosed with chronic illnesses. Research has typically focused on a single disease entity for study; often that research considers diabetes and patient self-management. There is less research addressing multiple chronic illnesses in the same study. This section defines chronic illness and reviews research related to the prevalence and incidence of chronic illness, cost burden, and self-management behaviors (Noji, 2003).

Studies related to chronic illness considered such similar variables as self-care strategies and barriers; community and practice level outcomes; and social support. A key difference noted overall was the context of evaluation, specifically the setting. Settings varied by population (rural versus urban) and healthcare delivery (practice-level versus community level). Again, some measured the variables by ethnic subculture (e.g.,

Latinos) or response of those with chronic illnesses in a certain type of disaster (e.g., earthquake). The main strength of the studies reviewed was sample size.

This section provides a definition of chronic illness and discusses the prevalence and incidence in the United States. In addition, the section reviews research related to negative outcomes, costs, and self-management of chronic illnesses.

Definition of Chronic Illness

According to the U.S. National Center for Health Statistics (2007), a chronic disease persists at least three months or more and typically includes such illnesses as cardiovascular disease, some cancers, renal failure, and diabetes. While these types of illnesses are often preventable or mitigated by healthy lifestyle choices, they cannot be prevented by vaccines or cured by medication(s).

Prevalence of Chronic Illness

It is known that chronic illnesses are quite prevalent. The U.S. CDC (2004) estimated that heart disease, cancer, stroke, COPD, and diabetes resulted in greater than two-thirds of deaths from chronic conditions.

According to Druss et al. (2001), about 25% of Americans are affected by just five chronic illnesses: diabetes, asthma, heart disease, hypertension, and mood disorders. Researchers from the Robert Wood Johnson Foundation (2002) estimated prevalence of several chronic conditions in adults over age 65 as follows: arthritis, 57%; hypertension, 55%; pulmonary disease, 38%; diabetes, 17%; cancer, 17%; and osteoporosis, 15%.

A systematic review (Vogeli et al., 2007) of 123 articles summarized the state of our understanding of the prevalence of chronic illness in the United States. First, the prevalence of chronic illnesses has continued to rise and include those of a younger age

(i.e. middle aged and near elderly). Vogeli et al.'s (2007) review added to what is known about the occurrence of chronic illnesses by including the prevalence of comorbidities, estimating that 21% of Americans have been diagnosed with two or more chronic conditions.

Incidence of Chronic Illnesses

Incidence statistics report how many new cases of chronic illnesses are diagnosed in a year. To estimate the incidence of chronic illness in the United States, the Centers for Disease Control and Prevention, in collaboration with the National Institutes of Health (NIH), conduct the National Health and Nutrition Examination Survey (NHANES) to track health indicators. Examples of other tracking that contribute to incidence statistics in the United States include cancer registries, the Behavioral Risk Factor Surveillance System (BRFSS), hospital discharge and death certificate data (Baptiste et al., 2004; CDC, 2005; Holt et al., 2008).

Due to the large number of chronic illnesses and frequent occurrence of comorbid conditions, estimating the overall incidence of chronic illness in the United States as a single entity is a very complex challenge. Therefore, most available data, whether at the federal, state, or regional level, indicate the incidence of a specific chronic illness (e.g., cardiovascular disease or cancer). One statistic reported by the CDC (2008b) that takes into account all chronic illnesses, and thus suggests the high incidence of chronic illnesses as a single variable, is that seven of 10 United States (U.S.) residents who die each year, die of a chronic illness.

Negative Outcomes of Chronic Illnesses

The prevalence of chronic illnesses affects health-related quality of life (HRQOL) of 90 million U.S. residents (CDC, 2008b). Chronic illnesses may contribute to and/or result from poor lifestyle choices (e.g., smoking, obesity, physical inactivity, substance abuse) that further complicate successful management of the disease process or increase the occurrence of comorbidities (Strine, Chapman, Balluz, Moriarty, & Mokdad, 2008; Weiner, Helfrich, Savitz, & Swiger, 2008; Whittemore & Dixon, 2008). Quality of life in persons with chronic illness may also be impacted by fatigue, pain, depression, and stress (Sullivan, Weinert, & Cudney, 2003).

Vogeli et al. (2007) concluded that the high prevalence of multiple chronic illnesses presents several health challenges: a) certain (but not all) clusters of chronic illnesses were associated with higher levels of disability than each disease in isolation; b) those with multiple chronic conditions use a variety of health services and thus coordination of care is often difficult; however, some clusters (e.g., diabetes and heart failure) actually received better quality care; and c) multiple chronic conditions are more difficult for patients to self-manage their conditions. As might be expected, costs were also increased in the context of treating comorbidities and, given the challenges mentioned previously, this increase in cost did not always translate into better care, disease management, and/or outcomes (Druss et al., 2001; Joyce, Keeler, Shang, & Goldman, 2005; Steiner et al., 2008; Vogeli et al.; Weiner et al., 2007). For example, although a great deal of research focuses on diabetes, a chronic illness often associated with one or more comorbidities, Nobel (2006) noted that just a fraction over one third of diabetics typically achieve adequate glycemic control.

Costs Associated with Chronic Illnesses

It is well known that chronic illnesses can be very costly to both individual patients and families, and society as a whole (CDC, 2008a; 2008b). CDC (2008a) annual cost estimates for specific chronic illnesses listed the cost of diabetes at \$174 billion, obesity at almost \$117 billion, cancer at \$89 billion, and arthritis at \$81 billion. In sum, annual cost of medical care for persons with chronic illnesses accounts for greater than 75% of the United States' two trillion dollars in health-related expenditures (Baptiste et al., 2004; Indicators, 2004).

Although some studies suggested that self-management behaviors (discussed below) can reduce costs, more research in this area is needed (Graves et al., 2006; Groessl & Cronan, 2000; McGillon et al., 2008; Whittemore & Dixon, 2008; Vogeli et al., 2007). A gap noted in the literature was the need to incorporate formal cost-benefit analysis models into research that studies the cost effectiveness of self-management of chronic illnesses (Graves et al., 2006; Groessl & Cronan, 2000).

Self-Management of Chronic Illness

Many complex factors interact to influence health outcomes in patients with chronic illness(es) (Bayliss et al., 2007; Newbould, Taylor, & Bury, 2006; Whittemore & Dixon, 2008). Factors common to self-management include recognition of symptoms; appropriate follow up activities; implementation of complex self-management regimens (including medications); embracing lifestyle changes; and development of strategies to enhance psychological adjustment to the illness (Giarelli, Bernhardt, Mack, & Pyeritz, 2008; Wagner, Austin, et al., 2001; Whittemore & Dixon, 2008). This section reviews major aspects of research related to benefits of, barriers to, and factors that may support

self-management behaviors; and also possibly useful models to develop interventions to encourage these behaviors.

Benefits. Disease management programs that lead to improved self-management have demonstrated reduced costs. Several studies have supported improved perception of quality of life (QOL) and decreased utilization of healthcare services (Afifi, Morisky, Kominski, & Kotlerman, 2007; Lorig et al., 1999; Osborne, Wilson, Lorig, & McColl, 2007; Rossiter et al., 2000; Wheller, 2003).

Barriers. Low health literacy can be a barrier to successful management of chronic illness (Villaire & Mayer, 2007). The additional complexity required to manage some chronic diseases (e.g., diabetes) can be a barrier to positive outcomes, but is not insurmountable (Bayliss et al., 2007; Ockleford, Shaw, Willars, & Dixon-Woods, 2008; Redman, 2007; Renders et al., 2001; Weiner et al., 2007). Another factor that can be a barrier includes limited access to healthcare and support groups often inherent with rural residence; social context (e.g., gender specific support groups) can be important to self-management (Kokanovic & Manderson, 2006; Nobel, 2006; Sullivan et al., 2003). In general, healthcare disparities in vulnerable populations in both rural and urban settings can limit effective self-management of chronic disease (Nobel, 2006).

Factors that support self-management behaviors. According to Whittemore and Dixon (2008), self-management requires both new behaviors and ongoing adjustment to changing life circumstances. Some factors were demonstrated to support patient self-management behaviors. Studies advocated formal training and interventions such as health coaching, structured group teaching, and role modeling (Crespo & Shrewsbury, 2007; Huffman, 2007; Jerant, Kravitz, Moore-Hill, & Franks, 2008; Ockleford et al.,

2008; Redman, 2007). Individuals in greater need (e.g., those with more severe and/or frequent depressive symptoms) actually demonstrated more gain in self-efficacy and thus increased self-management behaviors (Jerant et al., 2008). Social support was also a significant factor (Bayliss et al., 2007; Kokanovic & Manderson, 2006; Shaw, Gallant, Riley-Jacome, & Spokane 2006; Zhang, Norris, Gregg, & Beckles, 2007). Higher levels of social support were associated with less risk of death (Zhang et al., 2007).

A review of the evidence by Newbould et al. (2006) concluded that self-management by persons with chronic illnesses fared better with patient input, less rigidity, and focus on short term benefits. Another critical element is inclusion of tailored, patient-centered goals, often with the inclusions of negotiation (Bayliss et al., 2007; Leventhal, Riegel, Carlson, & DeGeest, 2005). Other supporting factors were a formal system to enhance patient self-management behaviors (Crespo & Shrewsbury, 2007) and multiple approaches to enhance self-management (Ockleford et al., 2008).

Useful models. Several models demonstrated usefulness as a framework with which to study chronic illnesses and/or develop interventions to encourage self-management behaviors. Quantitative studies, many considering a population of diabetic patients, used Wagner's Chronic Care Model (CCM) (Wagner, Austin et al., 2001; Wagner, Glasgow, 2001) as a theoretical framework (Gregg & Callaghan, 2007; Hibbard, Mahoney, Stock, & Tusler, 2007; Liebman, Heffernan, & Sarvela, 2007; Nutting et al., 2007; Piatt et al., 2006) to consider such variables as self-management behaviors; income; ethnicity; and relationship among clinical practice style, outcomes, and quality of care. Other commonly utilized conceptual frameworks included qualities of resiliency

(Bradshaw et al., 2007), the Health Belief Model (Powell, Hill, & Clancy, 2007), and Orem's Self Care Deficit Theory of Nursing (El-Mallakh, 2006).

Summary of Chronic Illness Literature

Research reviewed suggested that patients desire, and are willing, to take action to manage chronic illnesses (Powell et al., 2007; Whittemore & Dixon, 2008). Evidence supported the use of model-based interventions (e.g., the CCM) to improve self-management behaviors and patient outcomes (Gregg & Callaghan, 2007; Hibbard et al., 2007; Liebman et al., 2007; Nutting et al., 2007; Piatt et al., 2006). Many barriers to self-management were noted (Bayliss et al., 2007; Gee et al., 2007; Haas & Polonsky, 2007; Kokanovic & Manderson, 2006; Nagelkerk, Reick, & Meengs, 2006; Nobel, 2006; Ockleford et al., 2008; Redman, 2007; Renders et al., 2001; Shaw et al., 2006; Sullivan et al., 2003; Weiner et al., 2007; Zhang et al., 2007); those particularly germane to disaster preparedness and response are: helplessness and frustration; limited resources; medication concerns; sources of support, and physical limitations. Also pertinent to the topic of disaster response, study findings indicated that individuals from urban areas (as noted above, considered more vulnerable in a disaster situation due to increased population) had more support to manage chronic conditions, and that support from neighbors, family, and friends was important (Shaw et al., 2006).

Finally, the recent active hurricane seasons in the United States have been a factor in a research trend that increasingly considers chronic illnesses in the context of disasters. The next section considers research related to both disaster response and chronic illness.

Disaster Response and Chronic Illness

According to Miller and Arquilla (2008), the state of Florida was affected by five hurricanes in just under a two month period. In 2005, Hurricanes Katrina and Rita affected Louisiana, Alabama, Texas, and Florida (National Weather Service, 2008). Since the recent major hurricanes (e.g., Charley, Jeanne, Katrina, Rita) affecting the southeastern United States, researchers have begun to focus specifically on the dual variables of disaster and chronic illness.

Many of these studies were descriptive in nature and attempted to retrospectively quantify the burden of the disaster on those seeking services and the concerns related to overlooking needs related to chronic illness(es) (Ford, Mokdad, et al., 2006; Miller & Arquilla, 2008; Vest & Valadez, 2006). This section reviews research that considered disaster preparedness and response actions in the context of chronic illness.

Vulnerable Populations in the Context of Disasters

Some populations present unique challenges related to access of resources in a disaster response. Demographic characteristics often associated with vulnerability in a disaster context included female gender; marital status of single, widowed, or divorced; work status of under or unemployed; immigrant status, dependence on public assistance; lack of homeownership and/or health insurance; and those with one or more chronic illnesses (Greenough et al., 2008; Leung, Ho, Kiss, Gundlapalli, & Hwang, 2008; van den Berg et al., 2009; Zoraster, 2010).

Increased vulnerability of persons with chronic illnesses during a disaster event is a strong theme throughout the literature (Aldrich & Benson, 2008; Arrieta et al., 2008; Baggett, 2006; Clinton, Hagebak, Sirmons, & Brennan, 1995; Fonseca et al., 2009; Kessler, 2007; Mokdad et al., 2005; Saunders, 2007; Sharma et al 2008; Stallwood, 2006;

Weir, 2005; Zoraster, Vanholder, & Sever, 2007). Sharma et al. (2008) reviewed surveillance data specific to chronic illness care during Hurricane Katrina; their study supported the increased vulnerability of this population (e.g., those with diabetes, COPD, and cardiovascular disease) during a disaster event by noting the increase in visits to emergency treatment facilities for these conditions. This phenomenon is not exclusive to Hurricane Katrina; during Hurricane Rita, almost 60% of the shelter population was persons with chronic conditions (Patton-Levine, Vest, & Valadez, 2007). Several studies (Arrieta et al., 2008; Mokdad et al., 2005; Saunders, 2007) noted that, during Hurricane Katrina, those with chronic illnesses were less likely to evacuate, had less monetary resources, and frequently depended on local institutions for their care, institutions often with few resources left to offer. Another emerging area of disaster research and chronic illness is the impact of mold and mildew, frequently seen after disasters that include water damage, on health conditions (Bloom, Grimsley, Pehrson, Lewis, & Larsson, 2009).

Elderly persons with chronic illnesses (approximately 80% of the elderly population) had increased visits for care (Aldrich & Benson; 2008; Baggett, 2006; Jones, 2006a, 2006b; Lamb, O'Brien, & Fenza, 2008). One study (Sharma et al., 2008) demonstrated that the rate of subsequent hospitalization was more than twice that for persons without chronic illnesses and seven times of that for those with post disaster acute injuries. Other studies confirmed that the most common health problems treated were related to chronic illnesses (Jhung et al., 2007; Kessler; Millin, Jenkins, & Kirsch, 2006; MMWR, 2006).

Morbidity and Mortality Weekly Report (2006) reported that in the first three weeks after Hurricane Katrina, various chronic illnesses were the most commonly reported category among those seeking assistance in evaluation shelters, accounting for about one third of total visits. This was second only to hurricane-related injuries. Other estimates assert that between one quarter to almost one half of the total population living in areas affected by Hurricanes Katrina and Rita were persons with one or more chronic illnesses (Miller & Arquilla, 2008). A study also recently documented a 3-fold increase in acute myocardial infarction in the first two years post Katrina (Gautam, Menachem, Srivastav, Delafontaine, & Irimpen, 2009).

Preparedness Actions Specific to Persons with Chronic Illness

Very few studies exist that examine individual level preparedness actions for persons with chronic illnesses. Three that do demonstrated conflicting results. Uscher-Pines et al. (2009) reported that households with a special needs member were more likely to arrange a place to meet for evacuation, locate a shelter, and/or pack a bag of supplies. However, this same group was not more likely to engage in extensive advanced planning (e.g., learning an evacuation route, pre-purchasing a large quantity of supplies, or creating an emergency plan to guide evacuation decisions). In a survey randomly distributed to the general populace in the Los Angeles area, Eisenman et al. (2009) found that about half of persons who rated their health as excellent had disaster supplies prepared as opposed to only slightly greater than one third of those rating their health as fair or poor. Similar results were obtained related to whether or not they had an emergency plan in place. Not unexpectedly, those with mental health issues had the most challenges and were least likely to have taken any preparedness actions (Eisenman et al.,

2009). Finally, Renukuntla, Hassan, Wheat, and Heptulla (2009) found that the families of children with diabetes were better prepared for a disaster (i.e., had adequate supplies for three days), especially if they were in moderate or high income strata; previous experience, age, gender, and ethnicity did not correlate to preparedness actions.

Patton-Levine et al. (2007) and Baggett (2006) concluded that local shelters need to prepare for a large population of patients with chronic illness and also assume that accompanying caregivers will have separate needs and may not be able to perform caregiver functions. Preparation to provide mass transportation, a longer period of post disaster help to those with chronic illnesses, and face-to-face liaisons were also suggested (Baggett, 2006; Clinton et al., 1995; Hatanaka et al., 2009).

Response Actions Specific to Persons with Chronic Illness

Miller & Arquilla (2008) noted that poorly controlled chronic diseases presented a particular threat during the emergency response phase of a disaster, creating a significant disease burden. Some retrospective studies have attempted to accurately determine the extent of medication separation and demand for various classes of drugs used to treat chronic illnesses (Jhung et al., 2007; Zoraster et al., 2007). A retrospective review post-Katrina considered specific patient complaints and diagnoses and concluded that the most requested classes of medication for chronic illnesses were cardiovascular and endocrine (Howe, Victor, & Price, 2008). Denial of insurance coverage for emergency supplies of medications for chronic illnesses also contributed to medication separation during the response effort as some individuals were unable to stockpile an emergency supply of medication to serve as a backup.

Chan & Sondorp (2007) noted that the need for chronic care is often missed or underestimated due to the use of risk-based assessments more appropriate to the non- and pre-disaster stages and a focus on even minor acute injuries during the impact and emergency phases, even though the injury rate may be far below the rate of exacerbation of chronic illnesses during these phases. Other disaster response concerns of vulnerable populations often overlooked included effects of relocation; unique regional and cultural needs (e.g., increased symptoms of altitude sickness in populations with chronic illness when evacuated to higher elevations such as Denver, Colorado); lack of baseline information; and the complex nature of chronic illnesses (Chan & Sondorp, 2007; Ghosh et al., 2007; Hsu et al., 2006; Uscher-Pines, 2009).

Summary of Disaster Response and Chronic Illness Literature

The increased vulnerability of persons with chronic illnesses in a disaster event and the need for specific planning to address their unique needs are well supported. The necessity to acquire baseline information is noted and various methods to use the accuracy and efficiency of technology to this end have been suggested. There remains a need for research studies to describe how and if individuals with chronic illness(es) prepare for and respond to disaster events; how to best implement the technology in the context of the collaborative structure identified as the best practice in disaster response literature; and whether or not technology has positively impacted the process and/or cost of meeting the needs of this population in a disaster event.

The final section of the literature review summarizes existing knowledge about the topic areas of disasters, chronic illness, and disaster response. Gaps in existing

knowledge are then discussed and summarized and the contribution of the proposed qualitative study is suggested.

Summary of Literature Review

Existing Knowledge

Disasters. The number of people in the United States affected by disasters, both intentional and non-intentional, has demonstrated a rise, whether due to an actual increase in disasters, or improved methods of reporting. Disasters affect individuals in all areas of the United States (Arnold, 2002; Braine, 2006; Ginter et al., 2006; IEG World Bank, 2007; Mace et al., 2007; Noji, 2003). Negative effects of disasters on humans include public health threats such as mass casualties due to injuries, infections and lack of adequate basic resources (e.g., water, shelter, food; Arnold, 2002; Bloom et al., 2009; Cherry & Trainer, 2008; Ginter et al., 2006; IEG World Bank, 2007; Noji, 2003).

Chronic illness. The impact of chronic illnesses on United States residents is well documented. Approximately one quarter of Americans are affected by diabetes, asthma, heart disease, hypertension, and/or mood disorders (Druss et al., 2001). The prevalence of chronic illnesses in the United States has continued to increase and now includes middle aged and near elderly individuals aged 40 to 65 (Vogeli et al., 2007).

Chronic illnesses have negative effects on both the individuals who have them and on society. These negative effects may include death and/or decreased quality of life and financial implications. In addition to chronic illness as the cause of seven of 10 U.S. deaths each year, chronic diseases affect the quality of life of 90 million U.S. residents and account for over 70% of total medical care expenditures (Indicators, 2004).

There is strong evidence that those who have chronic illness(es) are particularly vulnerable to negative outcomes during a disaster (Aldrich & Benson, 2008; Arrieta et al., 2008; Baggett, 2006; Clinton, Hagebak, Sirmons, & Brennan, 1995; Kessler, 2007; Mokdad et al., 2005; Saunders, 2007; Sharma et al., 2008; Stallwood, 2006; Weir, 2005; Zoraster et al., 2007). These outcomes may be a result of both their illness (e.g., increased susceptibility to injury and/or infection, complications or exacerbations of an illness) 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). For example, some individuals are less able to prepare for disaster, or may need additional preparation (Jones, 2006a; 2006b; National Organization on Disability, 2006). Research after Hurricane Katrina noted those with chronic illnesses had more concerns than those without related to evacuation and finances, and frequently depended on local shelters for care (Arrieta et al. 2008; Mokdad et al., 2005; Patton-Levine et al., 2007; Saunders, 2007). Disaster preparedness has often failed to address populations who may have special needs (Disastersrus, n.d.; Jones, 2006a). However, research studies that utilized the Chronic Care Model and the Health Belief Model as a theoretical framework have suggested that individuals with chronic illnesses will take actions toward self-management of their disease (Gregg & Callaghan, 2007; Hibbard et al., 2007; Liebman et al., 2007; Nutting et al., 2007; Piatt et al., 2006; Powell et al., 2007; Wagner, Austin et al., 2001; Wagner, Glasgow et al., 2001; Whittemore & Dixon, 2008). This may serve as a foundation for assisting individuals with chronic illnesses to self-manage their chronic illness(es) during a disaster.

Disaster response. Methods exist in public health to mitigate the negative outcomes discussed above through disaster preparedness and response activities. 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). Response activities that include the use of needs-based assessments and consensus-based protocols to structure triage activities were supported by several studies (Chan & Sondorp, 2007; Ghosh et al., 2007; Howe et al., 2008; Klein et al., 2008).

These activities were most effective when conducted at the individual, regional, and federal levels. Collaboration among resources and response at several or all levels was supported as the ideal structure for effective and timely disaster response (Berg, 2004; Bostick et al., 2008; Braun et al., 2006; Dainiak et al., 2007; Johnson, 2007; Jones, 2006b; Kumagai et al., 2006; Mattox, 2006; Parvis, 2002) and has demonstrated positive financial implications as well (Arnold, 2002; Cherry & Trainer, 2008; Ginter et al., 2006; IEG World Bank, 2007; Noji, 2003).

Discussion of Gaps in Existing Knowledge

As mentioned previously in chapter I, the process of disaster preparedness involves several steps: organizing resources; assessing risks; developing a mitigation plan; and implementing the plan and monitoring progress (FEMA, 2007b). Research reviewed addresses each of these steps to some extent, but gaps are also evident. Nursing leaders in disaster response (Bakken, 2002; Gebbie & Qureshi, 2002; Heitkamper & Bond, 2003; Langan & James, 2005; Mondy, Cardenas, & Avila, 2003; Veenema, 2007) also offer for consideration gaps that suggest areas for nursing research.

Organizing resources. While studies have begun to address critical factors such as when resources are accessible and what resources are available to whom, this is an area that has great potential for development of new knowledge. Mixed expectations about response effort at various levels and timeframe were noted in some research (Kumagai et al., 2006); inquiry about how to efficiently organize the response effort and accurately disseminate information to individuals regarding resource needs and availability will continue to improve this area of disaster response. Medication separation remains 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). This is an area that benefits from collaboration and would be appropriate for interdisciplinary research.

Assessing risks. Controversy remains as to the most effective method to assess risk, both in disaster preparedness and response. One challenge for health educators is to provide education for both (Perez, Pinzon-Perez, & Sowby, 2002; Whitty & Burnett, 2009). Increasing the knowledge base of laypersons and healthcare providers can encourage accurate self-assessment of potential risk and appropriate actions at both the individual and regional levels. Research needed in this area must incorporate pre-disaster needs and subsequent dissemination of knowledge, but also must be used to quickly identify needs in the event of a mass casualty incident. This is especially so in the case of victims who may be separated from medications critical to their survival, which surely includes those with chronic illnesses.

Developing a mitigation plan. Kaselman, Slaughter, & Patel (2005) noted that specific inquiry about comprehension of disaster-related health messages at the individual level and disaster-related stress is largely unexplored (this is in the context of the impact of these two specific variables on a plan to mitigate negative outcomes; exploration of disaster-related stress in other contexts, such as factors that might be associated with PTSD, is actually a strength of this body of research). As noted above, many studies considered health needs (including separation from medication) of individuals with chronic illness(es), but these were retrospective in nature. More attention is needed toward developing a plan in advance (i.e., preparedness as opposed to response) to determine how these health needs can be considered in the pre-disaster planning stages. For example, studies completed after Hurricane Katrina (Krol et al., 2007; Rath et al., 2007) noted that a high proportion of visits were for chronic medical problems, but these studies did not address degree of preparation or actions taken toward patient self-management.

Since Hurricane Katrina, there is renewed interest in the concept of preparedness, including evacuation plans, for those with chronic illnesses (Eisenman et al., 2009; Renukuntla et al., 2009; Uscher-Pines et al., 2009). Recent studies (Horney et al., 2010; Smith & McCarty, 2009) suggested the benefit of evacuating, but there are still challenges related to educating the public and having an appropriate plan in place at the individual and community level.

Implementing and monitoring the progress. Although FEMA (2007b) lists this as a single step, this could be considered two separate areas for potential research. Since these steps build on the above disaster preparedness actions (organizing resources,

assessing risks, and developing a mitigation plan) research in the above areas needs developed to a point whereby specific resource models, risk profiles, and mitigation plans are identified. This area would then benefit from research to determine evidence-based best practices for disaster planning related to each of these respective preparedness actions.

Suggestions for nursing research. Specific calls for nursing research noted in the nursing literature include examination of healthcare delivery systems involved in community response, especially as related to communication; the role of advanced practice nurses; methods to incorporate nursing informatics into surveillance and case-finding; and methods to identify and teach core competencies for nurses (Bakken, 2002; Gebbie & Qureshi, 2002; Langan & James, 2005; Mondy et al., 2003; Veenema, 2007). Also important to consider are the potential physical and psychological impact on the general citizenry and vulnerable populations (Heitkamper & Bond, 2003), such as those with chronic illness(es). There is a need for research to explore how society might balance the consumer voice and policy decisions made to ensure public health during these events and also how vulnerable populations might be included as participants in specific planning related to their needs during disaster preparedness and response.

Summary of Gaps

It is clear that both chronic illnesses and disasters are on the rise; further studies at each of the disaster response levels that explore the simultaneous burden of disaster response and chronic disease can build on what is already known about such areas as needs of specific populations, increased risk, medication separation concerns, factors that

may improve surveillance, and collaborative efforts among responding agencies to meet the needs of affected citizens.

Multiple areas related to disaster response and vulnerable populations such as individuals with chronic illnesses lend themselves to study in both the quantitative and qualitative arenas. However, federal, state, and even some local agencies have in place at least basic retrospective review to assess the response effort. Additional research related to disaster response at the individual level, the least researched perspective noted in this review, would be very beneficial. For example, it is not known how individuals with chronic illnesses manage these illnesses in the context of a disaster. Unexplored areas include how, or if, they take preparedness actions in the non- and pre-disaster phases; how they manage during the various post-disaster phases (impact, emergency, and reconstruction); and how, or if, their efforts to manage their chronic illness(es) are impacted by activities of regional and federal agencies.

Implications for research related to the area of disaster response nursing might include the study of disaster preparedness and response self-management behaviors (or behavioral intentions) of those individuals with chronic illnesses who have experienced a disaster. The next section discusses the contribution of the proposed nursing research study purported to address this gap in knowledge.

Contribution of Proposed Nursing Research Study

Given the above gaps noted in existing knowledge about chronic illnesses in the context of disasters, the qualitative study proposed below will add to nursing knowledge in at least two ways: (a) the development of a theoretical framework to support future research and interventions in this area, and (b) an in-depth insight into how a vulnerable

population, individuals with chronic illness, manages health-related concerns specifically in the context of disaster response. This will contribute to the body of nursing knowledge related to individual level response. Shover (2007) noted the synergistic and cumulative nature of disaster preparedness and response, “Each disaster response begins with the individual’s preparedness at the local level and all disaster preparedness must incorporate training of health professionals, citizens, and families in local disaster drills...Every disaster begins on a local level and may, depending on size, evolve to a state or federal disaster response” (p. 4). The additional insight at the individual level from this proposed study will hopefully inform specific planning at higher levels related to their needs during disaster preparedness and response, and also encourage their participation in such efforts.

CHAPTER III

OVERVIEW OF METHODS/DESIGN

Philosophical Underpinnings of Qualitative Research Methods

This study utilized a qualitative design from the grounded theory tradition to build a theoretical framework. The underlying philosophy of the qualitative perspective of research, and thus methods derived from this stance, is the antirealist view of truth. The antirealist, or idealist perspective views truth as created in the mind as human beliefs/concepts. Antirealists believe that the universe is an embodiment of the mind. Truth is not an absolute, but becomes “known” from a human consciousness perspective (Polifrani, 1999; Polit & Beck, 2009).

Qualitative inquiry stems from the naturalistic paradigm, which espouses the postmodernist viewpoint. Naturalistic inquiry maintains the pre-existence of phenomena in the world and in the consciousness of the researcher and subjects. Methods emanating from this paradigm incorporate ongoing, unavoidable, and desirable interaction between the researcher, the topic, and the subjects; absolute objectivity is considered unattainable from this philosophical perspective. The phenomenon is viewed, as much as possible, from the holistic viewpoint. This type of inquiry features narratives, observations, and emergent design, as opposed to the elements of control emphasized in the scientific method. The goal is not generalizability, but rather illumination of patterns and rich

descriptions of experiences and/or processes (Polit & Beck, 2009; Polit & Hungler, 1999).

Nurse researchers who use qualitative methods feel that nursing science must extend beyond causality. Nurses deal with unique human beings, and thus nursing science should aim to understand and interpret the human experience as related to health and illness. Advantages of naturalistic inquiry methods noted by Leonard (1999) include applicability to the study of the phenomena of health and illness, and especially using a holistic approach to study a phenomenon; and the ability to overcome the extremes of objectification (reduction to objects of study) and subjectivism (studying a single, idiosyncratic situation). Phenomenological inquiry is subject to evaluation of rigor using criteria established for trustworthiness.

Epistemological and Ontological Perspectives

Nursing science following the naturalistic paradigm considers how we know what we know, or the epistemological perspective, as “knowing” through the interaction of the researcher with the participants and/or phenomenon(a). The ontological assumption is that the nature of reality is multiple and subjective (Polit & Beck, 2009).

Schreiber and Stern (2001) stated that grounded theorists, “begin with an assumption that participants share a problematic situation...” (p. 62). It is assumed that individuals with chronic illnesses who have experienced a disaster share the problem of having to manage health-related concerns related to their chronic illness(es) during a disaster event. Schreiber and Stern further indicated grounded theory is useful for research in areas where a new perspective is desired.

Symbolic interactionism, first attributed to George Herbert Mead in the 1930s, describes the process of human socialization to achieve rational thought and a sense of self. From the perspective of grounded theory methodology, symbolic interactionism is the focus on the social process, human behavior and interaction, and meaning of events to people in their natural setting(s).

Major assumptions of grounded theory as noted by Stern (1980) include: a) the framework is generated from the data; b) the researcher is concerned with describing the processes in the social interactions, rather than the describing a phenomenon itself; c) each piece of data is compared with every other piece (constant comparative analysis), thus data collection and analysis are concurrent; d) the social process is best studied in its natural setting; e) data collection may be modified as the theory emerges.

Constant comparative analysis is essential to the grounded theory tradition. As the theory emerges from the data, questions and/or topics are eliminated if they do not support the ongoing analysis. Likewise, questions may be modified to seek deeper, richer data as necessary. Conceptualization, categorization, and coding of data are used simultaneously to reduce data, suggest relationships, and formulate hypotheses (Stern, 1980).

The assumptions that supported the choice of grounded theory methodology to seek answers to the research aims of this study are twofold. First, it was assumed that individuals with chronic illnesses who have experienced a disaster may have shared similar psychosocial problems while managing their health-related challenges during the disaster. Second, it is assumed then that the psychosocial process(es) used by these individuals to manage these problem are similar. A deeper understanding of these

similarities may assist providers to help individuals with chronic illnesses to better prepare for and respond to a disaster.

As noted in chapter one, the specific aims of this study were to:

1. 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.
2. Describe how individuals with chronic illnesses who have experienced a disaster interacted with healthcare workers during the impact and emergency phases of the disaster.
3. Describe how individuals with chronic illnesses who have experienced a disaster perceived the impact of regional and federal level disaster response activities on their efforts to manage their chronic illness at any or all phases during the disaster.

Study Methods

This section describes the methods that were used in the study. Procedures for sampling and data collection are discussed first, followed by methods for data analysis and establishing trustworthiness.

Sampling Plan for Interviews

Three data sources were used to generate data to answer the research questions. The first two were interviews with individuals with chronic illnesses who have experienced a disaster and their caregivers and the third was media data.

Inclusion and exclusion criteria. Participants for this study were recruited from patients with chronic illnesses and their caregivers who were over the age of 18 and living in coastal areas in the southeastern United States susceptible to frequent hurricanes (National Weather Service, 2008). Co-morbid conditions, such as more than one chronic illness, were acceptable as long as the participant was managing health-related challenges either alone or with assistance of caregivers. Caregivers of the individuals with chronic illnesses were invited to participate to provide additional information about how the individual managed his/her health concerns during the disaster.

The deciding factor in selection of appropriate participants was not the type or severity of disaster (e.g., in a hurricane event, the actual disaster can be flooding or tornados) but rather the disruption of access to community resources for at least 12 hours. Given the chemical imbalances and acute life-threatening events that can occur rapidly in individuals with chronic illnesses, it was assumed that any interruption of resources for this period of time (or longer) required him/her to manage health challenges related to this disruption.

Inclusion criteria for individuals with chronic illnesses:

1. The ability to understand and speak English.
2. A medical diagnosis of a chronic illness during the time of the disaster.
3. Chronic illness controlled with one or more prescription medication(s).
4. An experience as a victim of a disaster with interruption of access to community resources such as communication or supplies or mandated evacuation.

Exclusion criterion for individuals with chronic illnesses:

1. An experience with disaster on a personal (non-community) level only, such as house fire or house flood.

Inclusion criteria for caregivers:

1. The ability to understand and speak English.
2. To be a lay caregiver (e.g., family or significant other) of a patient with a medical diagnosis of one or more chronic illnesses during the time of the disaster, controlled with one or more prescription medication(s);
3. Provided some level of care at the time of the disaster (e.g., present during the disaster or assisted the individual via phone).

Sample size. Purposive sampling involves seeking the most appropriate examples in the setting that is most likely to provide rich data. The selection of a qualitative perspective as a basis from which to explore this research question discourages calculation of an exact sample size *a priori*. A published estimate of approximate sample sizes for different qualitative methods (Morse, 1994) suggests 30 to 50 interviews or observations for a grounded theory study. For this study, 30 individuals with chronic illness(es) and 10 caregivers were sought.

Strategies to gain entrée. The contacts described above were sought from individuals living in coastal areas in the southern United States. Contacts used were community leaders, such as pastors and parish nurses, who are often in a position to assist in disaster preparedness and response. Several strategies recommended in the literature were used to facilitate entrée into sites where individuals with chronic illness who have experienced a disaster might be recruited. These included learning about and accessing the proper chain of command, careful attention to note logistical details, (i.e., the need for

pre-approval, schedules), demonstration of an attitude of flexibility and accommodation to the work day or participant's schedule, and presentation of a clearly stated plan (Lamb, Puskar, & Tusaie-Mumford, 2001).

Participant Recruitment

Network and snowball sampling techniques were utilized to identify appropriate potential informants. Specific techniques that were used included: a) explaining the study to gatekeepers (community leaders) who agreed to provide a flyer and one page description of the study to individuals with chronic illness (inquiring whether they have experienced a disaster and are interested in more information); b) posting flyers in the facilities of these gatekeepers and in other community facilities; and c) travel to southern United States to meet with gatekeepers and recruit potential informants. Each of these strategies is discussed below.

Gatekeepers. A script was used for initial contacts with gatekeepers (Appendix A). The researcher initially contacted approximately 20 to 30 community agencies (e.g., community government leaders, community centers, and churches) in Florida and Louisiana, and several in Ohio with contacts in Louisiana.

An initial researcher contact was made to these community agencies to explain the purpose of the study, establish familiarity, and generate interest in the study. The researcher requested that facility leaders share information about the study with community members and their friends/family. They provided a flyer (Appendix B) and one page description of the study (Appendix C) to potential participants.

Flyers. The sampling plan included posting of flyers (Appendix B) in community facilities to promote the study. These were placed with permission by the contacts listed above.

Travel. The primary investigator scheduled extended travel times from March 2009 through May 2009 for data collection. Housing and transportation were available to her during this time. The possibility of further trips for additional data collection in summer of 2009 was also an option, but ultimately was not necessary.

Coordination of out-of-state recruitment activities. The following chart (Figure 1) provides specific details related to key contacts, travel dates, and activities for out-of-state data collection. Also included in narrative form is the general plan used for coordination of recruitment that addressed several possible decisions that occurred during the data collection period.

Figure 1. Coordination of Travel Activities

Travel dates	Target communities	Researcher activities
March 8 – 15, 2009	<ol style="list-style-type: none"> 1. Daytona Beach, FL 2. Cocoa Beach, FL 3. New Smyrna Beach, FL 4. Venice, FL 5. Largo, FL <p>NOTE: Daytona Beach, Cocoa Beach, and New Smyrna Beach are communities on the east coast of Florida; Venice and</p>	<ol style="list-style-type: none"> 1. Met with key contacts at east and west coast Florida locations 2. Visited other potential contacts as listed above to explain study and request additional support <p>NOTE: This was prior to Institutional Review Board (IRB) approval; no recruiting or data collection was done at this time.</p>

	Largo are communities on the west coast.	
June 1 – 7, 2009	1. Greater New Orleans	Participant Interviews
June 15 – 25, 2009	1. Daytona Beach, FL 2. Cocoa Beach, FL 3. New Smyrna Beach, FL 4. Venice, FL 5. Largo, FL	Participant Interviews

Recruitment and data collection began in Ohio as soon as IRB approval was finalized. It was not feasible to include participants from every possible disaster by geographical frequency in United States (e.g., west coast wildfires and/or earthquakes). However, the researcher had access to and support in the areas above and the intention of this travel was to seek the most appropriate examples in a setting likely to provide rich data, as per the tenets of purposive sampling in the qualitative tradition (Polit & Hungler, 1999).

Several guidelines were used to determine the extent of data collection in these out-of-state regions, as follows:

- A concerted attempt was made to maintain ongoing communication with key contacts (especially in areas that could not be visited in advance of data collection) and to provide a consistent and streamlined process to

publicize the study and set up interview space with those who agreed to donate this space.

- The intent was to collect data as able during the travel times listed above. Contacts were made by phone with reminders by phone and/or mail prior to the scheduled visits.
- The following alternative plan was used, with the approval of the researcher's advisor, for out-of-state individuals who met eligibility criteria and were unavailable to meet during the above travel dates or contacted the researcher after she had returned to Ohio:
 - The researcher asked the participant if he/she was willing to complete a phone interview at a mutually convenient time. If so, consent information was postal mailed to the individual. Upon receipt of signed consent by the researcher, the participant was contacted and a time was agreed upon. The researcher called the participants to avoid any phone expense on their part.
 - Phone interviews always served as a back up to initial data collection efforts; phone interviews were also be taped and the participants received the same compensation and considerations as face-to-face participants.

Contact information. A toll free phone line was dedicated to the study for participants to call to leave contact information. The researcher was the only person to contact, screen, and schedule potential participants. Scripts were used for the toll free phone line answering machine (Appendix D) and the screening contacts (Appendices E

and F). A time and place mutually acceptable to both parties was identified. If plans were finalized greater than seven days in advance of the interview, a reminder call was placed to reconfirm the details.

Human Subjects Protection

Permission to conduct this study was requested from several sources. First, a summary of the research proposal was presented for review to the appropriate contacts (e.g., community leaders as described above). Upon receiving permission to conduct the research in cooperation with these contacts, an application for approval to use human research participants was submitted to the Kent State University Institutional Review Board and approved (IRB Protocol # 09-166) on April 15, 2009. Follow up contact was made with the contacts to communicate approval by the university IRB.

Participants received a one page written explanation of the study purpose and procedures (Appendix C). Contact names and phone numbers were provided in the consent form (Appendix G) for use at any time throughout the study. Participants also signed an audiotape consent form (Appendix H). All documents were typed on Kent State University letterhead. Informed consent was obtained for all participants prior to study participation. The researcher's advisor retained the signed consent forms in a locked file in her university office and a copy of the form was provided to the participants.

Anticipated risks that participants might have incurred during this study were minimal given the retrospective nature of the questions. To maintain confidentiality, the researcher used only first names of participants during the taped interview and then assigned an identifying number for the purpose of transcription. Audio tapes containing

first names of participants were destroyed upon completion of the study after accurate transcription was verified. All transcripts were identified by number only and kept in a locked cabinet in the researcher's home office. To minimize risk of anxiety, subjects were not pressured into participating in any aspect of the study. They were informed that participation was totally voluntary and could be terminated at any point. The researcher is an advanced practice nurse with familiarity in emergency response and stress reaction in the event a participant experienced distress during the interview process. In the unlikely event that the interview revealed that the participant required psychological, social, or healthcare resources, a list of local community services was prepared and ready to be provided. This need did not arise.

Data Collection Procedure for Interviews

This study used interviews as the data collection method to gain insight into how individuals with chronic illness who have experienced a disaster managed their health-related challenges during the disaster. A data collection method using oral communication, such as interviews, is suitable for adults of varying literacy skills and thus appropriate for this study. Principles for interviewing that were incorporated into the planning and implementation of the data collection included: a) do not take for granted that participants know what the interviewer wants to know, take time to clarify the purpose of the interview, b) avoid display of surprise or shock, c) reassure participants that their answers will not be shared with other people, d) begin with an open-ended question that encourages free recall to elicit the participant's perspective (Docherty & Sandelowski, 1999). An outline of the proposed interview sequence can be found in Appendix I.

Specific sites for interviewing were identified and approved in advance. The safety of the participants and the researcher were considered in the selection of all sites and the timing of the interviews. Examples of safety considerations included: 1) locations easily accessible via public transportation, 2) provision of adequate lighting, 3) private space suitable for interviews, but not isolated, and 4) scheduling of interviews during normal day or evening business hours.

Participants were informed that interviews were expected to last approximately 30 to 60 minutes. Each participant received \$35.00 at the completion of the interview. An opening interview script and proposed interview questions to generate discussion were prepared in advance. These questions progressed from general to specific (Appendix J). Effort was made to engage each participant in the interview process and establish a respectful atmosphere to promote comfort in responding to questions. Demographic information was collected at the end of the interview (Appendix K).

All interviews were openly audiotaped for transcription and analysis. The researcher took minimal notes, such as listing key words to summarize major points and aid in redirection or expansion of question topics.

At several points during the data collection process, the researcher conducted a literature search to locate available media reports of the specific disaster described by the interviewee. Media reports were reviewed for general information about the disaster such as number of people affected, extent of disruption of resources, and response at local, state, and/or federal level. This information was obtained via internet and/or library search.

Media Data

The third data source was lay media reports about the specific disaster described by participants. Media reports of the specific disaster described by the participant were gathered to add a contextual description of the circumstances surrounding the disaster beyond what an individual victim would be capable of sharing. Theoretical sampling was used to seek additional data in response to emerging concepts to further guide the researcher's theorizing as the study progressed. This section describes the sampling and data collection plans used for media data.

Sampling Plan for Media Data

Media data were obtained through library access and internet searches to obtain lay newspaper reports, books, and clips. Whether or not to include a media source, and how many media sources to include, was determined using the pre-established inclusion/exclusion criteria for media data detailed below. Media data were reviewed by the researcher and her dissertation chair, with a conscious effort to evaluate whether or not a media source added to the context as intended (i.e., to further support or refute the emerging theory).

Inclusion and Exclusion criteria. Inclusion criteria for media data included:

1. Data from local or national sources in the United States.
2. Text in English.
3. Media sources were lay (i.e., non-scholarly, non-peer-reviewed) publications or productions, such as newspaper or magazine articles; images; and/or media clips.

4. Subject of media source was related to a single disaster discussed by one or more of the study participants.

Exclusion criteria were as follows:

1. Since the purpose of the media review was to add context related to a specific disaster event, media selected could describe any non-disaster planning activities of a general nature suitable for any disaster; i.e., media had to clearly relate to at least one phase of the pre-disaster (e.g., evacuation plans specific to one event) and/or post-disaster (impact, emergency, and/or reconstruction activities) time period.
2. Media sources that discuss more than one disaster or post-disaster response activities from a general, non-specific perspective were excluded.
3. Media sources discussing aspects of the disaster that clearly extended beyond the concerns of the participant(s) and his/her description of managing health-related challenges during the disaster (e.g., long-term reconstruction is continuing, but the participant's life has stabilized) were excluded.

Sample size. Purposive sampling was again used to seek the most appropriate examples to provide rich descriptive data. Disaster response efforts in the reconstruction phase can persist for many years (Gheytanchi et al., 2007; Kim et al., 2008; Langan & James, 2005; Veenema, 2007) without a clearly defined endpoint and media accounts are numerous, thus the determination of whether or not to include a media source, and how many media sources to include, proceeded using the following guidelines: a) apply the

inclusion/exclusion criteria noted above; b) confer with advisor regarding any discrepancies or concerns; c) make a conscious effort to evaluate whether or not a media source adds to the context as intended (also discussed in section on theoretical sampling below). An initial estimate of sample size was five media samples per disaster event. This included the assumption that more than one participant would discuss a given event.

Data Collection Procedures for Media Data

Media data were obtained through library access and internet searches to obtain lay published accounts (e.g., newspaper and magazine reports) of the disasters described by the persons interviewed. Databases searched included: AccuNet/AP Multimedia Archive (Associated Press images), America's Newspapers, Newspaper Source, LexisNexis Academic, and WorldCat.

Data Management and Analysis

Data for this study included transcripts of tape recorded interviews with individuals with chronic illnesses who managed health-related concerns during a disaster and/or caregivers; process notes taken during and after the interview sessions; and media reports of disasters. The study used the constant comparative method developed by Glaser and Strauss (1967) and operationalized by Schreiber (2001) to analyze the data. Data management used the computer program NVivo8, the most recent version of the NUD*IST software for qualitative analysis (QSR, 2007). This section discusses the analysis process for each form of data collected.

Transcripts. Transcript analysis considered full, unabridged verbatim transcripts of each interview session. In step one (First Level Coding) of this analysis, the researcher read all transcripts several times and in step two (Second Level Coding),

words and phrases were studied with intentional reflection until themes emerged (e.g., any words and phrases that were repeated).

Data were managed using the qualitative analysis computer program NVivo8 (QSR, 2007). Interviews were transcribed, checked for accuracy by the researcher, and imported into the NVivo program. NVivo8 uses a tree-node system to designate categories or themes (nodes) and relationships (hierarchical parent-child nodes). The tree-node system served to organize the data and aided in the development of the theoretical framework. Process notes and media reports (see below) were also imported into the NVivo8 software and linked with interview transcripts using the tree-node system described above.

The researcher and her dissertation chair immersed themselves into the data by reading all transcripts and agreeing upon initial categories (First Level Coding). These categories that emerged were created electronically in NVivo8 as nodes and narrative data were coded by dividing it into text units (e.g., key words and phrases identified in the interview transcripts).

In Second Level Coding, words and phrases in each category were studied with intention. Some codes were expanded or collapsed after discussion. In step three (Third Level Coding), we sought theoretical relationships related to the themes. Theoretical sampling was conducted by querying the data and also by aligning media data sources with appropriate theoretical model concepts.

Process notes. Researcher process notes included descriptive information collected openly during the interview session by the researcher and debriefing notes jotted down at the conclusion of the interview. Examples of this descriptive information

were key discussion points and sequence to indicate priorities, and notes related to possible subsequent questions for clarification or expansion of a topic (Polit & Hungler, 1999; Sim, 1998). These additional data were used during analysis for clarification as necessary.

The researcher and her advisor conferred after the initial interview and then every three to six interviews to review the data and share observations, thoughts, and concerns. Interview data were hand delivered to the transcriber and the researcher's advisor. Suggestions based on these conferences were used to guide subsequent interviews. The suggestions and discussions were recorded in writing and served as additional process notes.

Media reports. As noted above, the researcher conducted a literature search to locate available media reports of the specific disaster described by the participant. It was anticipated these additional data would add context to the description of the circumstances surrounding the disaster beyond what an individual victim would be capable of sharing. These reports were linked with the appropriate interview transcript(s) and constituted a portion of the coding process described above.

Theoretical sampling. A conscious effort to concentrate and set the limits of data collection, or theoretical sampling, was utilized to promote saturation where appropriate and allow change to seek enough information (i.e., emergent design) to build the theory (Glaser, 1998). Theoretical sampling involves seeking additional data in response to emerging concepts to further guide the researcher's theorizing as the study progresses. Examples of this strategy include seeking comparison (e.g., caregivers) or

contrasting cases and review of news and media reports of disasters that informants describe to provide additional contextual data.

Trustworthiness of Data

This study followed Guba's (1981) recommendations for establishing trustworthiness in qualitative studies. These recommendations address credibility; dependability and confirmability; and transferability. Credibility is the plausibility (truth value) of the findings. Dependability reflects reliability (consistency), while confirmability supports objectivity. Both dependability and confirmability utilize an audit trail to determine consistency and objectivity/plausibility. Transferability asks how one might determine if findings of a given study might apply in other contexts. In addressing transferability, the qualitative researcher attempts to understand the degree of fit between similar contexts. This section will outline how these aspects of trustworthiness were addressed in this study.

Credibility. Credibility was evidenced by interview summaries and data triangulation. At the end of each interview, the researcher asked the participant if he/she wanted to add anything and then briefly summarized the responses and asked the participant to verify her summary. Data triangulation was achieved by considering both oral interview (from individuals with chronic illness and lay caregivers) and print media reports.

Dependability and confirmability. Raw data included transcripts, and process notes from member checks. 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 (Guba, 1981; Polit

& Hungler, 1999; QSR, 2007). Two doctorally-prepared qualitative researchers reviewed the coding process and analytical decisions with the researcher. The researcher attempted to confirm earlier findings in later interviews to help establish consensus and eventually data saturation (Sim, 1998.).

Transferability. Qualitative researchers are often cautioned not to generalize from their findings. Yet Guba (1981) and Sim (1998) both assert that some transferability between two contexts may occur because of similarity, or fittingness, between the contexts. Sim (1998) purports that disallowing any possibility of generalizing qualitative data is to err by denying that members of homogenous groups share commonalities that may transfer to other settings with similarities in context. In this light, Sim (1998) differentiates two types of generalizations: a) empirical generalization, i.e., generalization based on statistical representativeness of the sample population sharing attributes with the target population, thus reflecting the probabilistic quantitative approach; and b) theoretical generalization, i.e., generalization between two contexts by logical or conceptual comparability. Sim (1998) asserts research using data obtained from qualitative research can benefit others when theoretical generalization is utilized. The analysis and discussion in this study 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).

CHAPTER IV

DATA ANALYSIS AND FINDINGS

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. This study used the constant comparative method developed by Glaser and Strauss (1967) and operationalized by Schreiber (2001) to analyze the data. Data analysis, initiated in the planning stage, was ongoing throughout actual data collection during the interviews and media review. Specific aims of this study were to:

1. 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.
2. Describe how individuals with chronic illnesses who have experienced a disaster interacted with healthcare workers during the impact and emergency phases of the disaster.
3. Describe how individuals with chronic illnesses who have experienced a disaster perceived the impact of regional and federal level disaster response

activities on their efforts to manage their chronic illness at any or all phases during the disaster.

The first section of this chapter describes the study sample, including the participants interviewed and the media data reviewed. Following this description is an explanation of the constant comparative (Schreiber, 2001) and textual (Charmaz, 2006) data analysis that illustrates how the core process that we labeled backburnering emerged. Pseudonyms appropriate to age and race are used for all participant quotes. The chapter ends with a description of how the findings address each of the study research aims.

Study Sample

Participants

The first two data sources were 40 interviews with individuals with chronic illnesses who have experienced a disaster ($n = 27$); their caregivers ($n = 7$); and several who had both, i.e. were caregivers for an individual with a chronic illness and also had a chronic illness of their own to manage ($n = 6$). Examples of the chronic illnesses frequently cited included allergies, anxiety, coronary artery disease, chronic obstructive pulmonary disease, dementia, depression, diabetes, hypertension, and osteoarthritis. Also included were several participants dealing with less frequently cited diseases such as bipolar disease, chronic pain, gastroesophageal reflux disorder, irritable bowel syndrome, panic disorder, scleroderma, schizophrenia, and stage 4 cancer. Over half of the participants (63%) were managing more than one chronic illness at the time of the disaster.

All interviews were completed in Louisiana and Florida in June and July of 2009. The Table illustrates the study participant demographics.

Louisiana. Participants in Louisiana (n = 14) were from greater New Orleans and Slidell; all experienced Hurricane Katrina, and some Hurricanes Rita and Wilma. 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. Florida participants (n = 26) experienced a wider range of hurricanes; many experiencing 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.

Table. Participant Demographics

		All	Louisiana	Florida
		Participants	Participants	Participants
Gender	Male	n = 10	n = 3	n = 7
	Female	n = 30	n = 11	n = 19
Age Range		50 - 91	50 - 78	54 - 91
Marital Status	Single	n = 23	n = 8	n = 15
	Married	n = 14	n = 4	n = 10
	Not given	n = 3	n = 2	n = 1
Race	African	n = 4	n = 3	n = 1
	American			
	Caucasian	n = 34	n = 10	n = 24

		All	Louisiana	Florida
		Participants	Participants	Participants
	American	n = 1	n = 1	n = 0
	Indian			
	>1 race	n = 1	n = 1	n = 0
Income	<10	n = 5	n = 3	n = 2
in thousands	10-14	n = 8	n = 2	n = 6
	15-19	n = 2	n = 1	n = 1
	20-29	n = 8	n = 1	n = 7
	30-39	n = 4	n = 1	n = 3
	40-49	n = 4	n = 2	n = 2
	50-59	n = 3	n = 1	n = 2
	60-69	n = 1	n = 0	n = 1
	70-99	n = 1	n = 1	n = 0
	100-199	n = 1	n = 1	n = 0
	200+	n = 0	n = 0	n = 0
	Not given	n = 2	n = 1	n = 1
Employment	Full time	n = 6	n = 5	n = 1
	Part time	n = 5	n = 0	n = 5
	Disabled	n = 2	n = 1	n = 1
	Unemployed	n = 4	n = 1	n = 3
	Retired	n = 21	n = 6	n = 15
	Not given	n = 2	n = 1	n = 1

Media Data

All participants in this study described their experiences with hurricanes classified by Barnes (2007) as the New Millennium hurricanes. These storms were 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). All selected media data related to one or more of these storms and included news articles (n = 16), books (n = 4), television clips (n = 2), a description from a local radio disc jockey and program manager, and a documentary film. See Appendix L for a complete list of those included in the study sample.

Searches of databases (e.g., AccuNet/AP Multimedia Archive, America's Newspapers, Newspaper Source) were conducted using search terms such as the names of the relevant hurricanes combined with health-related terms (e.g., chronic illness); terms related to the geographical response model (e.g., individual, local, state, and federal) used as a guiding conceptual framework for the study; and local newspapers published in cities affected by the hurricanes (e.g., *The Times-Picayune* for Louisiana and the *Charlotte Herald Sun* and *Orlando Sentinel* for Florida). The description from the local radio program manager was arranged with the assistance of one of the Florida participants after it was noted that many of the participants in the Charlotte/Punta Gorda area who experienced Hurricane Charley cited the heroic efforts of this radio station during the immediate aftermath of the hurricane as a major influence on how they were able to manage. The documentary *Greetings from FEMA City* (Griffiths, 2007) was recommended by a curator during a visit to the Punta Gorda Historical Society during the data collection process.

Research Aims: Answers Emerging from Study Data

Research Aim 1: Managing Health-Related Challenges

The first research aim was: 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. Analysis of the data strongly suggested that individuals with chronic illnesses who have experienced a disaster managed their health-related challenges minimally, if at all, due to the pressing demands of dealing with evacuation and/or survival, and reconstruction activities. This research aim was answered in detail by the description of the backburnering process described below.

Theoretical Framework: The Backburnering Model

As we considered data that described how individuals with chronic illnesses who have experienced a disaster managed health-related challenges during the disaster, a core process emerged that we named “backburnering.” The definition of backburnering in the context of hurricanes is when individuals shift the priority of health-related challenges to address other needs that they deem a greater priority. The theoretical framework described in the next section, the Backburnering Model, contains five factors: media impact, evacuation, preparation, attention, and recovery. The core process of backburnering illustrates four ways that describe how participants backburnered.

Brief Description

Something put on the back burner is defined as “not getting or needing immediate attention” (Heacock, 2003, p.52) and conversely, an item on somebody’s front burner is getting or needing that attention. These idioms originate from the process of cooking on old-fashioned wood stoves. The wood burned in the center of the stove and thus the stovetop temperature varied from front to back; cooks shifted pots around to the

appropriate spot based on their decision that the food either needed immediate attention, or could simmer on the back burner (Heacock, 2003).

Every participant, at some point, described the process of backburning health-related challenges, demonstrating that managing these types of concerns was not their highest priority. Some participants described this very explicitly. In fact, Cordelia, a 55-year-old African American woman who lost her job and health insurance, and evacuated to Georgia during Hurricane Katrina, stated this in so many words:

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 the insurance problems, I kind of left myself, put myself on the back burner, you know.

Others implied the process either by stating their immediate priorities (which were not health-related in nature) or returning the conversation back to other concerns even when prompted several times with specific inquiry about their chronic health problems.

The data suggested four different ways to describe the backburning process. Each of these four ways had five defining factors: media impact, evacuation, preparation, attention to health challenges, and recovery. Almost every participant described the impact of the media at one or more points in the process. Regarding evacuation, the four ways were divided into two main categories: those who evacuated (ways 1 and 2) and those who did not evacuate (ways 3 and 4). Both participants who evacuated and those who did not described backburning health-related concerns. Thus one factor that strongly determined the way that they backburned was whether or not they evacuated. When participants backburned, their level of preparation was another factor that determined how they moved through the process. A fourth factor that affected the

process was the attention (or lack thereof) to health-related challenges when a disaster came. The fifth factor that impacted the ways the participants backburnered was recovery time. Some participants demonstrated earlier activities related to recovery from the disaster and health management, especially those who evacuated and stayed in the place of evacuation for longer than one week. The factors are depicted in Figure 2.

Figure 2. Backburnering Model

BACKBURNERING MODEL					
The Core Category: How Participants Backburnered					
Four Ways Describe Backburnering	Factor 1. Media Impact	Factor 2. Evacuation	Factor 3. Preparation	Factor 4. Attention	Factor 5. Recovery
Way 1: Prudent Backburnering (n = 15)	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
Way 2: Impromptu Backburnering (n = 9)	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

Four Ways Describe Backburnering	Factor 1. Media Impact	Factor 2. Evacuation	Factor 3. Preparation	Factor 4. Attention	Factor 5. Recovery
Way 3: Deliberate Backburnering (n = 8)	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
Way 4: Unforeseen Backburnering (n = 8)	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

The Backburnering Model: Detailed Description of Process

Ways of Backburnering

Four ways describe how participants backburnered. There were five defining factors noted in all four of the ways that described how participants backburnered: media impact, evacuation, preparation, attention, and recovery. Media impact was a factor because it influenced how participants learned what to prepare, decided when to leave and/or return, and accessed supplies. The four ways were divided into two main categories related to evacuation status: participants who described ways 1 and 2 evacuated and those who did not evacuate described ways 3 and 4. Preparation was a factor because there was evidence that whether or not participants prepared determined how they backburnered. Attention 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). Finally, resumption of some level of attention to health-related challenges, or recovery, was obviously impacted by the decision to evacuate, and/or the duration of evacuation.

Definitions of Media Impact, Evacuation, Preparation, Attention, and Recovery

Media impact was defined as participants using some form of media-provided information (e.g., television, radio, print materials) during one or more disaster phases (e.g., non-, pre-, emergency, impact, reconstruction) during the disaster they described. Evacuation was defined as leaving one's primary residence, either by mandatory directive or by choice, during the pre-, impact, or emergency phase of the disaster. We defined participants as "not prepared" if they met at least one of the following criteria: they were new to the area or had never experienced a hurricane, and thus did not prepare; they lived

in an area with hurricane threats and directives in place but didn't prepare for such reasons as the area had never really experienced a hurricane, they had no time, or they were not able; and/or they lived in an area with hurricane threats but had no knowledge of a community plan for preparedness. Participants were defined as "prepared" if they had experienced at least one disaster and described personal preparation for the hurricane discussed in the interview; they lived in an area with hurricane threats and directives in place which they acted upon; and/or they 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. Attention was defined as actions taken or not taken related to the participants' individual-level priorities (e.g., safety, health concerns) during the disaster. Recovery was defined for the purpose of this analysis as taking some action related to health-related concerns during the reconstruction phase.

Core Process of the Backburnering Model Ways

Each of the four ways described by participants provided insight into the factors in the backburnering process. The four ways illustrated by the backburnering model are described and illustrated below with both participant quotes and supporting media data.

Descriptions of Evacuees: Ways 1 and 2

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; provident" (The American Heritage Dictionary, 2009c, para 1). The name *Prudent Backburnering* was selected to describe the first way that participants backburnered. People in this group (n = 15) were prudent because they evacuated using pre-established procedures that often included some attention to health-related needs and

thus described minimal need to backburner; they prepared in advance, including attention to evacuation needs; and had an earlier recovery.

Media Impact. Participants who described prudent backburning used media-provided communications in all phases of the disaster. They initially used these resources in the non-disaster phase to learn about how best to prepare. For example, Alma, an 84-year-old widow advised, “There are places in town where you can get pamphlets to read about it all [what to take with you]. Some people never pick one up, but they better. That’s my advice.” Many cited The Weather Channel® as a source of information, even in the non- and very early pre-disaster phases, such as Dorothy and Mary, two seniors who each described their family’s vigilance, “Well, first of all we watch the TV a lot, you know, the weather channel and the local channels to see what’s brewing out there in the Caribbean, Africa and places like that” and “...we watch the news every single night...I knew about it [recent flood] about two weeks before....he [newscaster] said, ‘This is a rain maker and it’s coming and it will be here next Tuesday.’”

In the pre-disaster phase, participants in this group often listened to media reports to watch for clues and assess severity, and secured their houses prior to leaving. Alma explained, “The main thing for people to do is to keep that TV on as long as they can. They give out good information, what’s happening and how bad it is and where it’s going to hit next...have little battery radios because that is what you really, really need, information.”

As the pre-disaster phase continued and impact approached, participants continued to use media as a resource to assist in as evacuation decisions. Marcy, a 55-

year-old Caucasian noted, “We were listening to The Weather Channel prior to the storm and realized it was not something we wanted to stay here for.” Once evacuated, most of these participants described purposeful access to media during the impact and/or emergency phases, primarily to keep track of the damage to the area reported by media and to determine when it was safe to return. Many were homeowners and they wanted to gauge possible damage to their property. Cordelia, watching from Georgia, stated:

We tuned into CNN [Cable News Network] and tried to see what was going on in New Orleans...we found out that the levies broke...and we saw aerial views on the computer about the water in our areas where we live. So, we knew that our areas got water.

Local media who were able to broadcast played a big part in helping many study participants. Those in way 1 who could receive a radio signal from the point of evacuation described this link to their hometown and their appreciation for the effort of the media personnel and non-evacuees who worked to maintain this connection. For example, 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...” and “...half of the building was gone that they were broadcasting from. People would bring gasoline and stuff into them so they could run their generators and run their stuff so they could get this word out on the radio.”

Several participants noted how hard it was to not watch from afar. Seniors Julia and Dorothy noted, “...we all watched The Weather Channel incessantly, all too

incessantly” and “...we stayed with them [family] for a week and we were sitting there watching the weather reports, of all things.”

This access also demonstrated the emotional impact on evacuees watching helplessly from afar. Betty Aasgaard-DeSchinckel (*The Times-Picayune* Katrina, 2006), who evacuated from New Orleans to Las Vegas, watched and worried. Aasgaard-DeSchinckel described her emotions watching from the point of evacuation after Katrina, “We are numb. We are dismayed. We are locked onto every national television station, remotes in hand, as we feel the nausea that overcomes us. We are homeless.” (2006, p. 84).

Finally, upon return, these participants used the media much like others in the reconstruction phase, to access supplies. Mary, who was pleased with the state response after a season with multiple hurricane threats in close proximity (i.e., 2004) noted, “...the government, the State of Florida and Jeb Bush were absolutely fantastic with their information, with their help...The TV was on most of the time giving us the news as to where it [food, ice] was.”

Evacuation. Participants in this group took several steps related to evacuation: 1) they researched options of places to go, 2) they prepared items to take, and 3) they determined in advance how a decision would be made as to whether or not they would leave. Typically, many participants in this group sought and registered for access to special needs shelters established to take persons with chronic illness(es). For example, Alma, an elderly woman with heart disease, reserved a spot in advance, noting that she had to “...call Volusia County Health Department with special needs.”

Once they knew to where they would evacuate, people in this group took actions to learn in advance what items were required and/or suggested, such as Janice who noted, “They asked you to take your food and take water, you know, bottles of water with you. If you wanted books to read or whatever. A little radio... We had all of that stuff jammed into a shopping bag and we took that with these two rolled up mats [for sleeping].” Media reports also confirmed the general preparedness of most Florida residents:

When news reports of Jeanne’s approach first hit the airwaves, millions of Florida residents took a deep breath and began to make plans. Many were already familiar with the evacuation drill, having just come home... Many did not even have to pack – their most valuable possessions were still stuffed into boxes or wrapped in plastic bags. (Barnes, 2007, p. 338).

Sometimes there was a mandatory evacuation order and some Florida residents left whenever such an order was given. More frequently, though, they used the Saffir-Simpson Hurricane Wind Scale (National Weather Service, 2010) with five categories to gauge wind speed and severity (categories 1, least winds, through 5, highest winds). Janice described using this system to decide whether or not to evacuate, “So, 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 or the TV that it was a 4, I said, ‘I’m going,’ and Doc was right behind me... [to a protected shelter in Punta Gorda - even though they did not have much time].

As the disaster approached, the process of evacuating moved to the forefront of participants’ thoughts and actions. After deciding if, when, and how to evacuate, they

initiated travel to the evacuation site. They stayed at a variety of protected sites, often a designated local shelter or hotel, or with friends, and/or family out of the city.

While no one was pleased at the prospect of evacuation, these participants realized the importance of doing it. This was true of both Florida and Louisiana participants. A quote in *The Times-Picayune Katrina* (2006) from Chuck Wallace, who evacuated from New Orleans to North Carolina, reflects the foresight of those who were able evacuate the city, “Most of us didn’t endure the despair of the Convention Center. We left the city before it became Hell on Earth...(p. 85).

Preparation. These participants prepared at the individual level in advance of the disaster in the non- and pre-disaster phases. As they described their preparatory actions, several common themes were noted: 1) helpful documents, 2) medications required, 3) animal needs, and 4) food and water.

People in this group noted the benefit of preparing documents in advance (e.g., medical records). Alma prepared by compiling general household documents, “I started first by getting out the important 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 certificates, your marriage license, fire insurance, household, everything...” Tina, a 61-year-old Caucasian woman from Slidell, Louisiana described the benefit of taking detailed medical records:

... if you’ve had to evacuate it’s an unbelievably traumatic experience being healthy and so being sick you don’t know where you are going to go for treatment or if you are going to be able to refill your medicines...I had copies of a lot of my

medical records...I keep a day planner and I write every single appointment and the results, every test and the results. And that proved to be a life saver...

These participants did not describe difficulty with medication refills, primarily because they had prepared in advance for this as well. Marcy, a 55-year-old diagnosed with diabetes and hypertension, noted, "I took all of my insulin, all of my pills with me, my pills in the original prescription bottles so I could refill them if I needed to at the Target pharmacy somewhere else." Participants often described using national chain pharmacies so that regular prescriptions could be easily refilled from afar using the chain's database.

Many participants noted the needs of their animals as a priority during the disaster, however, those who followed way 1 took steps in advance to prepare for these needs. For example, some were able to find a shelter that would accept small animals; others made arrangements to stay in a hotel or with family because animals could not accompany them to a shelter. Alma noted, "You have an animal, you have to prepare for that, too, because you have to take them with you. So, I got my dog's little collar with his name on and telephone number...papers that everything was up to date on his shots and his vaccines..."

These participants assembled supplies well in advance of a disaster event, especially food and water, as explained again by Alma, "I always started the first of June [start of hurricane season]. I had a grocery cart...full by the 2nd week of June...I really made myself a list so that I knew that I was getting everything that I needed."

The media also reiterated the need to prepare at the individual level. The following quote essentially sums up what people in the prudent backburnering group did,

prepare at the individual level and actively listen to communications from local, state, or federal government officials regarding the risk(s): “....The point is that the response has to come from the individual and the family. Government can do just so much, and the government’s major responsibility, at least as we see it in this situation, is to communicate the risk...” (Frontline, 2005a, para 2).

Attention. There was some intentional backburning in impact/emergency phases, as evidenced by delay of health-related activities (e.g., medications, eating healthy food, exercise). Participants had to intentionally backburner these activities most often due to: 1) more pressing situations (e.g., frightening events during evacuation or watching from afar, managing the evacuation and return process, damage to house), 2) lack of necessities (e.g., a home, electricity), and 3) managing dual households while evacuated or upon return (i.e., they could not live in their homes). These challenges caused participants’ attention to focus on the priorities of the moment and to ignore some health-related concerns.

One frequently noted reason for backburning health concerns was worry over damage to property. Mary noted both the concern over this damage, and the emotional impact of it, “...you want to look at the damage and you want to look at what’s going on, the place is a disaster, it is a war zone, it just is. Your mind can’t believe what you are seeing.”

Some who experienced Katrina lived in two places for awhile, working or trying to get resettled in New Orleans, but sleeping in another city. Cordelia lived in Georgia for approximately 18 months and returned throughout that time to New Orleans to work on 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 just kind of went off track..." This participant, a diabetic, had to make decisions about testing her blood sugar, which she knowingly both addressed, and then let go, due to lack of health insurance during the time of evacuation [she lost her job due to Katrina], as evidenced by the following quote, "I ended up going to Urgent Care Center to get my test strips and my medication because I ran out. I did get off the medicine for a while...It was kind of frustrating. I kind of let my health go for a little bit." National Public Radio (NPR, 2005) confirmed this challenge of 'dual homes,' noting that "People are going back to their workplaces even if they don't have housing yet in the city" (para. 8).

Recovery. Factors that influenced recovery, or return to some health-related activities, included length of evacuation and stability of home environment (e.g. utilities restored, ability to travel locally). If evacuation was less than one week (for this study, this describes most Florida participants), typically participants returned home to minimal or no damage, cleaned up debris, and returned to their normal activities. If the evacuation was extended longer than one week (Louisiana evacuees), participants had to determine when to come home.

Persons whose experiences were described by way 1, prudent backburning, noted some of the factors contributing to the decision to return home. For example, Marcy, a diabetic, prudently delayed return until utilities were restored, "I did not come back to Slidell until I knew that we had electricity because at that time...it was the vials and syringes so I really needed to keep them cold." However, even with this pre-

determined criterion, she went on to describe how she struggled to manage her diabetes given the emotional stress and limited food options upon her return:

...MREs were just high in carbohydrates. But I ate it anyway and it's like I wasn't worried about it because I was so stressed out just because I hate evacuations...when we came back we pretty much ate whatever we could find. Sometimes I probably wasn't even doing my blood sugars. Which I know is not good,...I was just happy that my home survived Katrina for the most part and my dogs...

These participants, if they remained evacuated while their home area was not stable, often initiated some recovery activities from the point of evacuation and continued them after returning home. Thus they had to seek providers while still evacuated and described addressing at least some health-related concerns even with the difficulty of sometimes living between two places well into the reconstruction phase. Cordelia noted, "...I decided to get up and call, look through the phone book when I was [evacuated] in Georgia and to find a doctor." Home for good approximately 18 months post-Katrina, she described her next health-related priority, managing her weight:

I have put some more weight back on but it didn't reach the weight that I had before when I was in Georgia. I was watching myself. I said, "OK, I have to make a decision sometime later to try to get on some type of routine." So, when I got back in my house, I said, "OK, I am going to start back over and I'm going to eat right." I started getting back to my walking...Still have about 10 or 15 more pounds to drop off that I'm working on....

Once home, everyone concentrated on significant home and/or family concerns (e.g., mold, whereabouts of family and friends, getting supplies) over health-related issues. Julia, a caregiver for her husband Ed, described the stress of finances and property damage, "...we were too worried about all of the stuff we were having to deal with [after return home]. I think both of us worried about that. The pressure at that time of monetary issues, that was a big deal."

Water damage and subsequent mold were very frequently noted by participants and in the media as a concern related to safe housing. Chuck, an 80-year-old caregiver for his 78-year-old wife, described role strain as he had to balance his roles as caregiver and homeowner:

We had carpeting on the porch...it was completely shot [due to mold]...and ripping it all up was nasty...It was hard for me because I had to leave her to do it, leave her in the motel, you know. But, she did OK. And, I didn't have another choice.

The Times-Picayune Katrina (2006) described the pervasiveness of this typical consequence of flooding, "As floodwaters receded, mold bloomed on rotting walls and ceilings, cabinets, furniture, beds, and carpets. It came in a variety of colors and patterns, creating a weird, post-Katrina wallpaper that could almost have been called pretty, if it weren't so destructive" (p. 179).

For those hurricanes with an extended reconstruction phase (e.g., Charley, Katrina) supplies were often difficult to come by and entailed waiting in long lines. The participants in this group did describe waiting in lines to get supplies such as food and water. Of concern from a health perspective is one media report (Barnes, 2007) that

noted, “Some residents gave up rather than wait in the miles-long line of cars that formed on U.S. 90 for FEMA’s distribution of ice and water” (p. 333).

Utilities, too, were often a factor. While Mary was able to manage her diet, she had to temporarily forgo exercise given the heat and no electricity. She noted, “I was able to stay on my diet; my exercising kind of went out the window until the A/C came back on.”

In an extended reconstruction phase, the delay in going to a provider was often due to inability to find or get to one. This was especially true after Hurricane Katrina. Cordelia, who traveled back and forth between Georgia and New Orleans, noted the frustration of trying to see a provider in New Orleans (she ultimately contacted a new provider in Georgia)

...when I tried to call doctors to set up an appointment, he was backed up and couldn’t see me for about 6 months from the time that I came back, I really wasn’t under a doctor’s care. I was really frustrated...because there wasn’t anyone I could see and they kept putting me off...Because of the health situation here in New Orleans after Katrina. We didn’t have many doctors here, very limited hospitals...

June, a 68-year-old retiree, also described her difficulties related to reconnecting with providers after Katrina, “...I lost my doctor, no one came back, he never returned, his home flooded, his office flooded...I lost my cardiologist, my primary doctor, and my neurologist...when I tried to locate my doctors, I couldn’t....”

Synopsis: Way 1 and Health-Related Challenges. In general, the participants in way 1 faced some challenges common to other study participants regarding resumption

of health-related activities: property concerns, accessing supplies, and lack of utilities. However, these participants were able to resume some health-related activities, if they remained evacuated and delayed return until their home area showed evidence of some stability, such as restored utilities and effective distribution of supplies. Frequently this entailed an evacuation period of at least two weeks.

In this study, persons from Florida who were examples of way 1 were evacuated one or two nights. Most were able to resume health-related activities fairly soon as, even if they had property damage, the local area was not unstable for a long period. Persons from Louisiana were evacuated from 2 weeks to 18 months; each of these participants was able to resume some health-related activities. This may be due to the evacuation itself that allowed resumption of activities from afar, and also due to preparatory activities taken by these individuals, such as assuring appropriate medical records and pharmacy access. Individuals who returned while the home environment remained unstable still voiced frustration in dealing with health-related challenges even with evacuation and individual preparation (e.g., having to eat MREs, having to leave wife in hotel to care for home, not able to find provider). However, they were at least able to acknowledge these challenges, even if they described varying levels of success in addressing them.

Way 2: Impromptu Backburnering. Impromptu is defined as “prompted by the occasion rather than being planned in advance; done...with little or no preparation; extemporaneous” (The American Heritage Dictionary, 2009b, para 1). We chose the name *Impromptu Backburnering* to illustrate the second way that participants backburnered. Evacuees who backburnered health concerns in an impromptu fashion (n

= 9) were not prepared, they often relied on confidence from past experiences where the outcome was good. They evacuated in a hurried or unplanned fashion; but still often had an earlier recovery, or return to some health-related concerns than those who did not evacuate.

Media Impact. Participants who described impromptu backburnering used media-provided communications primarily in the impact/emergency phases of the disaster. Congruent with their lack of preparation in other areas, these participants did not describe using the media in the non- or pre-disaster phases at all. Although they may have casually watched news reports on television (e.g., about the coming of Hurricane Katrina), unlike the prudent backburnering group, they gave no descriptions of doing such activities well in advance with the intent of preparation and decision-making support. They began to use the media resources once the disaster had arrived.

Several examples demonstrate how these participants used media resources during the impact phase. The focus of their discussion was on the actual evacuation, either going, staying away, or coming back. Wanda, a 50-year-old African American participant, recalled being comforted by the still-working television set as a sign that help was on its way 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’.” They also watched news from afar to see evidence of damage in their area and evaluate the possibility of returning home. Connie, a Caucasian senior from New Orleans noted, “Then we saw the house on the news...you could see where the paint had spilled [previously] on the back of the house. So, that’s why we knew it was their [her daughter’s] house.” Eva, age 66, was evacuated for five days during Hurricane Fay in a two bedroom trailer with eight adults and five

children. Eagerly awaiting their return home, she described how they followed the storm on television:

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. I'd put cartoons on...and a half of an hour later, turn it back and the storm was still sitting there. Will we ever go home, will we ever go home?

Evacuation. In the pre-disaster phase, the impromptu backburnering group described several steps. First, they typically discussed the impending event with family, neighbors, and friends, and sometimes listened to TV or radio to assess current severity and decide whether or not they would try to evacuate. They did not plan to evacuate, but did so on the spur of the moment. Thus the next step was to grab some items and leave for anywhere, often after the storm had arrived. As a result, they ended up wherever they could be housed and the final step related to evacuation was trying to make the best of it.

All but two of the study participants from New Orleans evacuated, and of those who did, over half (58%) met the criteria for the impromptu backburnering group. Rose (2005/2007) noted one dilemma of evacuation that may have influenced the decision to wait until the last minute, those whose family members would not come along, and also affirmed the reluctance to evacuate evident in this group:

I got out. I'm mystified by the notion that so many people didn't even try... 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. We don't know what happened to them. My wife's dad and her brother and their families: No word. Only hope (p. 7).

Many participants in this group described an initial laissez-faire attitude about the storm that was often displayed in the form of neighborhood gatherings and barbeques. At some point, one or more of them suddenly realized the severity of the danger and they would consider evacuating, as illustrated by Bernadette, a 55-year-old African American participant from New Orleans:

Like we were out playing in the water at first because it was about at our knees you know, 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.” I said, “Come on now, 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....

Others left at the last moment due to a mandatory evacuation, and were still unprepared, sometimes due to lack of experience. For example, Eva, who lives in Florida in an area with frequent evacuations, but infrequent actual hits, described her thoughts as the mandate was issued, “It’s a mandatory evacuation if you are not going to leave, let us notify the next of kin. That really scared me; I’d never been in...a storm where you have to leave....” and “...there wasn’t enough warning that it was that bad that we were going to have to get out....” Finally, these participants described calling family members to discuss evacuation. Connie noted, “So, I called my daughter...She says, Momma, we are packing.”

Because none of these evacuations was pre-planned, participants scrambled to get ready to leave. Connie described the impromptu, unplanned exit from New Orleans as she responded to her daughter’s urging to get ready to leave, “I said, “What do I have to

pack?” She said, “Mom, throw what papers that you think you need in a bag, take clothes for maybe three days at the most and call it a day...It [evacuation] was six months.”

Those who waited until the last minute to evacuate Katrina found the leaving a difficult experience, and this was strongly supported by media reports. A timeline (Hurricane Katrina Archive, n.d.) foreshadowing events leading up to Katrina from as far back as 1998 noted that the metropolitan area was “unable to evacuate without huge traffic jams and delays.” As a result, Louisiana developed a “contraflow” plan to reverse traffic patterns on interstates. The timeline listed other important chronological events that contributed to the delay in evacuation for Katrina, such as on Friday, August 26, 2005, most residents work a full day and decide to wait and see; on Saturday, “evacuations begin en masse and clogging all outbound arteries of the city for 48 hours” and several parishes (Orleans and Jefferson) announce voluntary evacuations; Sunday, August 28, 2005 brings the “first-ever mandatory evacuation” for Orleans Parish” and the contraflow plan is begun. (Hurricane Katrina Archive, n.d.).

Several other media sources support the last minute individual and regional impromptu nature of the Katrina evacuations that amounted to challenges for those who waited. NPR (Folkenflik, 2007) reported that some did not leave because they did not initially perceive the danger, “The storm hit Monday, and people initially thought New Orleans had ducked the big one [and did not evacuate].” (para. 8). PBS described the traffic, “...we had contraflow in place, but contraflow for a relatively short distance...And people were screaming bloody murder because it was taking 10, 12 hours to make a trip that usually takes an hour and a half to two” (Frontline, 2005a, para. 8).

Those participants who did evacuate, even at the last minute, tried to make the best of it. *The Times-Picayune Katrina* (2006) noted how relocated New Orleans residents created a new home while evacuated, even if temporary:

“Sociologists in search of a comparable dislocations cast back to the great mid-century migration north from the Mississippi delta in seeking to understand the cultural impact of the diaspora triggered by Katrina...Partly as an antidote to their isolation, partly because New Orleanians wouldn’t have it any other way, local menus and music halls began to feel the presence of the newcomers...Mardi Gras mask makers turned up in Virginia. Etoufee became a popular feature among the offerings at an Omaha pizza parlor...One hundred years from now, someone will ask, ‘How is it that Mardi Gras masks come from Norfolk?’” (pp. 83, 85).

Preparation. These participants did not prepare in advance to evacuate. Since the process of evacuating was initiated at the last minute, they essentially had two priorities: 1) selecting items to take (if there was even time) and 2) trying to get a place to stay.

While describing the last minute scramble to assemble items, participants did not include any long term plans related to health challenges. However, several participants did make an effort to include some medications and supplies related to managing illness. For example, Bernadette recalled what items she took with her when she traveled on foot in a last minute attempt to leave 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...I had the cross of my grandmother’s rosary...” Eva, who left Florida, noted:

We just packed up what we could and left. Mainly, well, we took the two animals, we took 4 or 5 days change of clothes, and what medicine that I had [enough for 2 days]. Like a hair brush, toothbrush, toothpaste and that's about it. She [daughter] said, "Come on let's go, we've got to go." And off we went.

Finding some way out and somewhere to go moved to the forefront of these participants' thoughts and actions. The participants in this study typically stayed with any friends or family willing or able to take them. Bernadette and Eva again illustrate the uncertainty of an impromptu evacuation with total lack of advanced preparation, "I mean it's a mess...chaos, torture, trauma, fear of not knowing...you're just going somewhere, but you don't know what's goin' to happen to you or where you're goin'. But ya just surviving, trying to survive, you're just goin' somewhere" and "We were supposed to go to Arkansas...Instead, we wound up in Tennessee..."

Attention. Both study participants and media sources sometimes described pressing situations that included very frightening events and/or rescue. The descriptions provided graphic illustrations of the frightening events that took priority over anything else in their lives as they evacuated, and also that these post-haste evacuations included health-related challenges (e.g., wild animals, dead bodies, no shoes to protect feet, sun exposure). Ignoring health-related needs, or impromptu backburning, in this group was evident in that they did not describe attention to health-related challenges at all during discussion about the impact/emergency phases of the disaster, even with prompting.

Examples of priorities during evacuation included immediate physical safety and emotional control. PBS (2005) reported about Katrina rescue efforts that:

...more and more people were being evacuated from their rooftops after being in the sun for long periods, or overnight, and being put on highways and levees and high ground, wherever folks in the boats and the helicopters could find high ground (para. 23).

Bernadette, who left New Orleans on foot with a friend when the water started to rise near her rented duplex house, recalled, "...we see the alligators...but they aren't bothering nobody because they're trying to get back to the Mississippi...we see this dead body. Sonny happened to pick it up and it's this guy we know, Charles..." and as they continued:

...for some reason God picked a way, I never knew that I could do what I did. Because I don't know how to swim...The water is up over my breasts. I'm tip toeing now and I have no more shoes because the water was so heavy and moving so much.

Recovery. These participants did discuss managing health conditions during the reconstruction phase. Those evacuated beyond one week often noted seeking a provider, and frequently initiated some reconstruction activities from the point of evacuation. Even some of those evacuated less than one week had to address at one or two health-related concerns. These participants eventually sought providers while still evacuated for concerns such as cholecystitis, chronic pain, and medication refills. This was noted along with, but even more frequently than, participants in way 1 (those who prepared and evacuated). In the reconstruction phase, the delay in going to a provider was often due to inability to find or get to one.

Most of the participants in this study who followed way 2 lived in rental properties, and were evacuated for longer than six months; thus they reestablished themselves in different dwellings upon return and did not discuss homeowner-related concerns. However, review of media reports suggest that once home, most owners concentrated on home (e.g. debris) and/or family concerns before health-related issues (e.g., *Times-Picayune* quote below re: Albert McKeen). They also noted the frustration of waiting. There was evidence of emotional struggle (e.g., loneliness, anxiety). In sum, during the reconstruction phase, participants in way 2 described several priorities: 1) finding a provider and/or supplies, either at the point of evacuation or while back at home, 2) getting home, 3) addressing home and family concerns, and 4) dealing with frustration and emotions.

Several participants described their efforts to address health-related needs (i.e., getting supplies and/or finding a provider) while evacuated for an extended period. Connie, who had to manage diabetes and heart disease while evacuated for six months, recalled several challenges. Her first difficulty involved mail-order supplies for diabetes, “...That [checking blood sugar] was mess because...we was in a motel, and it [package of supplies for diabetes from a mail-order company] was supposed to go to the motel, but we had already been moved from the motel to the other place.” Then she found a doctor while evacuated, but he wanted all new blood tests, and she resisted:

...I’m not going through all of 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.

Eva, who evacuated for five days, realized she needed to address at least one health need that could not wait for her return home,

... we had another argument and I said to her that I had to have my medicine [while evacuated], you know that when I'm depressed and I have anxiety and everything escalates...I knew when I snapped at the boys...I said, 'You've got to stop in town so that I can get my medicine. This isn't me to snap at these little boys.' It wasn't me.

Another priority at this point in the reconstruction phase was getting back home. This was both a physical need, due to the at least perceived imposition on others during evacuation, and an emotional one, as noted by *Times-Picayune* columnist Chris Rose, to Ken Picard (2008):

...the only thing worse than being in New Orleans – when you really have a stake in all this – is *not* being here. My most troubled and tormented friends and associates are those who were forced to move away and can't get back. At least the rest of us here have people around who understand (para. 17).

Many of those arriving back at home had to address home and family concerns before most other needs, and one of those concerns was the sheer amount of debris, as noted by Rose (2005/2007), “[in New Orleans] there are, about every hundred paces, like a dump – carpet, plaster, furniture, and televisions, lots of televisions” (p. 177). Similar to participants in way 1, those who came back early faced significant instability in the area that caused them to back burner even significant health challenges. *The Times-Picayune Katrina* (2006) reported:

It was the Big Easy, but for those bold enough to return early from evacuation, the living was anything but...Before Katrina bore down on Louisiana, Albert McKeen had been bracing for the onset of a different ordeal: chemotherapy. In late September, he survey[ed] the ruins of his home of Lakeview Drive (p. 127, 151).

In addition to the demands of the return home described above, participants had to work at recreating a new normal, which often meant dealing with frustration (e.g., waiting) and many different emotions. *The Times-Picayune* columnist Rose (2005/2007) reflected on these emotions in several pieces, “More than anything, the emptiness of it all is what stirs the soul. That’s what tells this story. Eight months later, the question still hammers home: Where the hell is everybody?” (p. 289) and:

Waiting for three cycles of lights to change on Causeway. Waiting three hours to get a new driver’s license. Waiting to see who comes back and who moves away. Waiting to hear what our mayor will say next. Waiting to feel better. Waiting to get worse. Waiting for a Better Break or Another Chance. Does that day ever come? Yeah, you’re right. And waiting for the next hurricane. Therein lies the rub. Even more than the suffering from anniversary anxiety – the cauldron of agony and memory that we are boiling in – it seems as though much of our communal psyche is caught up in the strange and fruitless wait for the next big storm to come our way to see how we handle it – physically, civically, and emotionally...Let’s pick up the pieces still. Put it back together more. Let life ramble on in the new New Orleans, where everything is different and everything is upside down in The Waiting Place. (pp. 320-321; 322).

While the study participants in the impromptu backburnering group did not have to face homeownership concerns like those reported in the media, they did face the frustration and emotional challenges inherent with their return touched on by columnist Rose above. Bernadette, hearing heavy thunder almost four years after Katrina and for the first time since her return, noted, “It’s hard. But, I’m back. I’m here an doin’ what I gotta do to make it. But it really hit me hard...today with that thunder and all. I just wasn’t expectin’ it to all get to me like that.”

At least one person in this group, composed primarily of New Orleans residents, also faced the dilemma of lack of available providers, which led to backburnering of health concerns. Doug, a 57-year-old Caucasian noted, “...actually I let them [medications] run out...about a year later I went back to the VA because it just reopened a little office in the VA Hospital and they kind of helped me along, too...the VA shut down for awhile.”

Synopsis: Way 2 and Health-Related Challenges. Participants in way 2 were able to resume some health-related activities from the point of evacuation. Again, an extended evacuation often provided stability to allow for contact with providers and resumption of health-related activities, even if on a temporary basis. This was evident even more frequently than participants in way 1 who prepared for evacuation. Possibly the lack of preparation and hurried evacuation for way 2 participants necessitated these actions for the impromptu backburnering group, while the prudent backburnering group had prepared supplies (medications) and or processes (e.g., using national pharmacy database) in place to deal with health concerns.

In this study, persons described by impromptu backburnering were predominately from the New Orleans area (7 of 9, or 77%). Only two people from Florida backburnered in this fashion. The New Orleans participants were evacuated from two weeks to three years; the Florida residents were evacuated for three and five days, respectively. These data supported the assertion that longer evacuation can be an advantage to managing health-related concerns. All of the New Orleans residents who were examples of way 2 discussed resuming health behaviors while evacuated, typically finding providers to treat their condition and/or provide a prescription to get medications for which they had none. One of the Florida residents did go so far as to get a refill of her current medications (having left with only two days' supply), but only after what she felt were significant symptoms and it became a point of contention between her and family.

All of these individuals returned after the home environment became fairly stable related to food, water, supplies, and utilities, and did not have home ownership concerns. However, those from New Orleans remain challenged by a lack of available providers in the area (a condition improving, but still evident in 2009, four years after Katrina).

Descriptions of Non-Evacuees: Ways 3 and 4

Way 3: Deliberate Backburnering. Definitions of deliberate include, “done with or marked by full consciousness of the nature and effects; intentional; arising from or marked by careful consideration; to think carefully...as about a choice to be made” (The American Heritage Dictionary, 2009a, para 1). The name *Deliberate Backburnering* was selected to describe the third way that participants backburnered because as they elected and prepared to weather the storm in place (often referred to as shelter-in-place), they had to deliberately ignore health-related concerns to concentrate on

priorities such as home protection and survival. Those in this group ($n = 8$) prepared at the individual level in the non- and pre-disaster phases. In the impact phase, they frequently used the category of the storm intensity to guide their decision to shelter-in-place.

Media Impact. Similar to participants in the prudent backburnering group, the participants who described deliberate backburnering used media-provided communications in all phases of the disaster. They, too, initially used these resources in the non-disaster phase to learn about how best to prepare. For example, Deborah, a 58-year-old African American participant, recalled how she used media to prepare in the early part of hurricane season:

Listening to the newscasts and I am on Florida Care and they sent out as soon as the season started...what you need to do to prepare, these are the kind of things you need to do and of that sort. So, that was all very helpful and just really listening to the news and trying to keep track of what was happening and realizing that 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, so, early on, early on.

Once the pre-disaster phase arrived, it was evident that these participants used the information they had sought in the non-disaster phase. Steve, age 54, described how his elderly father started to prepare for the upcoming storm, "...he's getting all of the meds in line and all of the typical things that you hear on television and radio and the media about water supply and all of that stuff." As the impact phase arrived, these participants continued to use media reports, as Dan from Daytona Beach, 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." Some of these participants felt more secure in their decision to remain at home, or shelter-in-place, because they had purchased generators in preparation for a storm. Dave, a 55-year-old professor from Slidell, Louisiana (just north of New Orleans), stated, "Fortunately, because we had a generator we were able to run our TV [throughout Katrina]. We kept informed by a TV station, it's a New Orleans TV station to the west of us in Slidell and to the east we were able to tune into the Biloxi, Mississippi TV station."

The focus of media usage for the deliberate backburnering group during the impact/emergency phases was to learn about local overall damage, survival, and communication with family. Some were so confined to their homes in the early days after Katrina (with varying degrees of utilities) that they could not conceptualize the extent of the storm and its damage until the media could report it. Dave talked about his interest in the storm's impact on the area, "Little by little, as the news media was able to get out and start taking photographs or videos of the destruction, we began to appreciate the magnitude of that event."

Sharon, age 57, talked about using the media to find supplies and survive the emergency phase, "You would just 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 those places were" and "It was just an interesting time; it was just foraging for what you could get to survive for a while. Ice and water being the critical thing, you know. I just basically drove around [after listening to the radio]...and filled coolers...."

Deborah described a concern of many, not being able to contact family, and how both parties depended on media coverage, "...letting people know that...this is what the situation is because our family and friends were concerned because they could not get in touch with us, they really couldn't...they heard what they could over the air..." She also noted the importance of advanced preparation on the ability successfully to weather the storm 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, so, it [being able to stay home] really is about preparation."

There was less discussion by this group related to media use during the reconstruction phase, possibly because they put a great deal of their time and effort into repairing their homes. However, some participants in the deliberate backburnering group still listened to media communications and reflected on the whole of the experience, such as Sharon, who stated, "It was an odd time, just an odd time. I think it brought a lot of people together in the community. I heard that, too. They were talking about that on the radio."

Evacuation. This group did not evacuate. Reasons they did not evacuate included: 1) they worried about their homes and/or they had evacuation fatigue (i.e., less willingness to evacuate for subsequent storms due to the cumulative burden of evacuations), and 2) they did not have the time to leave and/or tried and could not. Their priority was to prepare quickly to shelter-in-place. Even choosing not to evacuate, this group still described a plan, such as using categories to determine actions.

As evacuations mounted in a brief time period of six weeks for those in Florida in the year 2004, according to media reports, many who had evacuated earlier (for

Hurricanes Charley and Frances) elected to prepare to stay home for the later event (Hurricanes Ivan and Jeanne). Barnes (2007) noted:

...evacuations for the storm [Jeanne, after Charley and Frances] were far less complete than those for Frances...Many felt they needed to stay to protect their already damaged roofs from further wind and rain. Others were apparently disgusted with the evacuations and emotionally drained; they were tired of moving in and out of their homes (p. 338).

National Aeronautics and Space Administration (NASA) Earth Observatory (Binette, 2005) reported:

After the state [Florida] had been battered by three hurricanes...many residents ignored the threat and refused to leave...While the earlier storms helped to make residents more aware of the potential dangers from hurricanes, emergency managers also reported noticing more complacency as some residents grew weary of repeated hits (paras 1 and 2).

Many of these participants had stayed for previous storms and had confidence in their ability to manage at home using pre-existing procedures. They often described using the Saffir-Simpson Hurricane Wind Scale (National Weather Service, 2010) , as illustrated by Sharon's description, "...it was getting closer and instead of coming by us as a category 2 they said that it could ramp up to a 4." This family had used mattresses and specific house locations (hallway) in the past for adequate protection during the impact, and although they differed over the exact time to initiate their plan, it is clear they had a plan in place, "I had been telling my husband, we better take the mattress into the

hallway. He kept saying, “No, I don’t think so.” By the time they said it was coming in as a 4, he said just grab that mattress....”

In the case of Hurricane Charley, the storm turned unexpectedly and there was no time to evacuate; participants had to shelter-in-place. Other participants in way 3 tried to evacuate at least some of the time, but there were too many challenges to overcome, even with pre-arranged procedures. Steve, a Floridian who tried to evacuate with his elderly parents and grandmother, plus a big dog, noted that it was just too difficult for his group:

That was the hardest part was getting a household, four people and a big dog, all who were elderly, well I’m in my 50s, into a minivan, bag and baggage, meds, water bottles, cooler, stinky dog that was the toughest...we did have all of the systems in place so that when we made the decision to get up and go, we just went systematically, you know.

They made the decision to turn back an hour later, ultimately not evacuating the storm.

As the disaster approached, the group 3 participants assessed the situation and elected to not evacuate for various reasons (e.g., no time, thought house safe, previous bad experience with evacuation, and demands of evacuating many people in household).

Preparation. This group was prepared. They described several actions to prepare for a hurricane, including: 1) prepurchasing supplies, and 2) preparing their homes.

Participants in this group prepared well in advance of the hurricane, as illustrated by this description from Dave:

She [his wife, now deceased] was the kind of person who liked to just prepare for anything...she was the ultimate preparer...She always kept a hurricane survival kit...a plastic container that originally had dog food in it. It was around 2 to 2 ½

feet high and she had it stacked with all of these survival things that we might need and indeed, we needed them.

Media reports confirmed the preparedness of Florida residents. Postal (2004) reported, “Karen Davis...purchased several large coolers. Then she picked up ice, water, and cold drinks. ‘I got ...necessities for a hurricane, water and cold drinks.’” (paras. 16 & 17)

Some of this advanced preparation was specifically related to health-challenges. Pam, a 67-year-old FEMA employee, explained, “One of the things that I had done was to change all of my medications to a CVS drugstore, so that...I can always get my drugs. They can call and they will get them for me.” Deborah’s description is a classic example of taking individual responsibility to prepare. In the following two quotes she describes that responsibility for advanced preparation as it related to her health:

I never experienced [hurricanes]...I love Florida and I know the hurricanes are here and it is just part of our being. So, it’s just a fact of life. 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 and doing all of the proper things...I just try to keep prepared...I just try to be diligent about my health and being proactive, so that I don’t have to be reactive.

Well, I did all of the things that they told us to do just to prepare for hurricanes period...particularly in my case, because I have diabetes, hypertension, polymyositis, dermatomyositis, osteo pain, yeah, osteoarthritis, osteo pain of the jaw...not only was I preparing for the things that needed to be prepared around the house, make sure papers are in the right place but also that I had the proper medications, that I had enough....

Although this group backburned health concerns at the time of the storm (i.e., the impact/emergency phases), they did not backburner these concerns in advance, they prepared as well as they could.

Finally, this group worked to prepare their homes, assuring that storm shutters were in place and outside furniture and cars secured. FEMA (n.d.) noted the importance of storm shutters in Florida, “When installed, storm shutters maintain building integrity by protecting windows from direct wind pressure and windborne debris” (para. 3).

Attention. As withstanding the impact moved to the forefront of participants’ thoughts and actions and they ignored their health-related challenges. They described pressing situations, such as frightening events (e.g., rescues, looting) that preoccupied their thoughts during the impact phase. They told of activities such as gathering to grill food and dealing with interrupted utilities in the emergency phase. For the most part, they did not even discuss attending to health concerns.

The *Hurricane Katrina Archive* (n.d.) described some of the frightening events that those who stayed in New Orleans had to face. It is not unreasonable to surmise that surviving in a violent society with looting and martial law might take precedence over health-related concerns, even if one has prepared. The article also provided some insight into the amount of people in one area during Katrina with health-related issues:

By Monday, August 29, 2005, 317, 000 New Orleans houses have no power. On Tuesday, August 30, ‘...local media reports that martial law is declared in Orleans, Jefferson, and Plaquemines Parish...looting reports go national presenting New Orleans as a lawless and violent haven for those still trapped in the city’ and by Sunday, September 4, 2005, an ‘estimated 2, 000 people, many of

them with serious medical problems, [were] still housed inside Louis Armstrong International Airport' (*Hurricane Katrina Archive*, n.d., Table, Katrina Day By Day).

Thus there was some intentional backburning in impact and emergency phases, as evidenced by delay of health-related activities (e.g., medications, eating healthy food). Dave gave an example of deliberate backburning. He noted that he was supposed to be taking it easy but had other priorities that required his attention:

I had had angioplasty in May and I guess 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...

Sometimes participants thought of creative ways to manage while sheltering-in-place. Deborah, a Florida resident who has insulin-dependent diabetes, backburned initially during the impact phase by not following her diet and briefly did not take insulin because she had no way to keep it cold without power and was afraid to use it, first using it intermittently and then not at all. She ultimately had no power for 10 days, but was able to resume her activities after brainstorming with neighbors who got power after about six days, "We got power back on a grid that is on one side of the street only...So, we strung electric cords across the street." This participant was very prepared and was able to refill her insulin, keep the new medicine cold, and resume her regimen within a few days.

Occasionally a few participants did at least use preestablished procedures, such as Dan, who noted, "As far as my health, I just kept taking my medicine. And I check my

blood sugar; I check it a few times every day. When you are used to them [hurricanes], you don't panic..."

Recovery. These participants also described using preestablished supplies or procedures to manage health-related concerns in both the impact/emergency phases and sometimes in the reconstruction phase, so they were able to think about health-related challenges to some extent. In general, though, these participants heavily concentrated on home and/or family concerns over health-related issues. This group often described a delayed recovery related to health concerns. Health-related challenges continued to be deliberately minimally addressed or ignored as they worked to recover from the impact of the storm. In the reconstruction phase, the delay in going to a provider was often due to inability to find or get to one.

Dave described the challenges in finding a provider, post-Katrina:

At the community level there really was no healthcare. Gradually as some of the larger churches got re-established, they were offering some limited service. The hospitals as quickly as they could get their personnel back were re-opening and operating but that was a major, major problem. Not just getting the hospital doors open but getting the nurses, the aides, the physicians, the administrators back...They were just gone...People had evacuated and they couldn't get back.

Synopsis: Way 3 and Health-Related Challenges. Most of the participants from this group were from Florida (7 of 8, or 88%). Many were homeowners and/or owned rental properties. Participants in way 3 placed their home concerns before their health. These participants discussed health-related concerns when asked specifically, but returned to discussion of their home priorities during the storm. They talked about

making a deliberate decision to remain at home, and also deliberate decisions to at least temporarily back burner health concerns (e.g., cardiac conditions, diabetes management).

Since the participants in this group did prepare, they occasionally were able to address some health challenges by using pre-established procedures and/or creative solutions. Sometimes these participants backburnered health-related concerns because they could not locate, or travel to, a provider.

Way 4: Unforeseen Backburnering. The definition of unforeseen is “not felt or realized beforehand; unexpected” (The American Heritage Dictionary, 2009d, para 1). The name *Unforeseen Backburnering* described the fourth way that participants backburnered. People in this group did not evacuate, were not prepared, and had a delayed recovery; priorities, health and otherwise, in this group were totally unforeseen and their goal was survival.

Media Impact. Participants in the unforeseen backburnering group did not prepare in advance, and thus did not describe using the media to assist with advance preparation in the non-disaster phase. They used the media in the very late pre-disaster phase, when it was often too late to evacuate. Chadwick (2005) noted that in New Orleans, “The people most affected were people who perhaps aren’t as plugged into the media and don’t have means to evacuate” (para. 15) (in this study, most of those from New Orleans did evacuate, however many did so after conditions deteriorated significantly and they scrambled to leave; they might just as easily have met the criteria for the way 4 group had they been unsuccessful in their attempts to leave).

Some used the media to monitor the conditions, but described reluctance to leave since a hurricane had never directly hit the area. Red, a 71-year-old Caucasian male from

Punta Gorda, Florida noted, "...we're sitting there and we see on the news that it 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." By the time they realized the magnitude of the storm [Charley, a storm which changed direction quickly], "...there was a big squall line with some tornadoes headed in our general direction", it was too late to do anything except shelter-in-place.

Nancy, a 66-year-old caregiver who also deals with depression, also experienced Charley. She was on her way to an older friend's house to help care for her when the storm turned, "...I heard as I was on my way over to her house on the radio that it was turning and that it was coming in our direction." She quickly battened down the hatches at her friend's house as best she could, and described listening to a radio to keep abreast of the storm, "...we went through all of that and just kind of tried to remain calm and tried to be aware of what was going on, trying to listen, mostly had a little radio communication because I had the transistor." A conversation with the program manager/disc jockey at the radio station in Florida mentioned by several participants who experienced Hurricane Charley confirmed the heroic efforts of the station employees to remain on the air to provide information and reassurance to those riding out the storm, even with their own lives in danger. He noted:

...we were doing, what they call cybercasting...live on all 5 of our stations to let everyone know what was happening minute by minute...we are here to keep the people informed and hopefully help to make them safe, and that's what we are going to do no matter what...we didn't give it a second thought...Basically what we did was spend the night talking to people and talking to the audience who

were listening: ‘Don’t try to venture out. Stay where you are. Stay in your neighborhoods. We got to get through the night. Help is massing. We know it’s on the way. Now is just a matter of trying to keep your head.’ (personal communication, June 28, 2009, station disc jockey)

In the reconstruction phase, this group, many of whom lived in Florida and experienced Hurricane Charley, used media communication as a lifeline as they tried to recover from the storm. Nancy, frustrated because she did not qualify for FEMA assistance for her old mobile home, used the media successfully to get a blue tarp to cover her roof:

So, we had a radio station that had been able to stay on the air...I was able to call the radio station and I asked if anyone could help me, if somebody having their roof repaired if I could have their tarp...

Evacuation. In the pre-disaster phase, participants in this group described discussing the impending event with neighbors and friends, and sometimes listening to TV or radio as the impending storm approached to assess severity and decide whether or not they would evacuate. They did not evacuate. Reasons for non evacuation in way 4 were typically determined by the situation and included: 1) lack of time to do so (frequently cited by this group), 2) age and/or mobility issues, and 3) belief that the hurricane would not hit their exact area.

Nancy described how quickly the news of Charley came:

Within about 20 minutes I heard as I was on my way over to her house [person she cared for] on the radio that it was turning and that it was coming in our direction...by the time I got to the bridge they wouldn’t let us across the bridge.

They had already closed it. It all happened so fast...There was no thought or time of evacuation and there was only one road anyway. Where are you going to go?...

Multiple media sources confirmed Florida participants' descriptions noting that there was too little time to evacuate for Hurricane Charley. CBS News (Shetty, 2004) announced that "...the storm surprised Florida authorities by veering to the right at the last moment...." (para. 6). Barnes (2007) reported:

[Charley] appeared to track toward Tampa. Sometime just after noon, a slight increase in southwesterly winds in the upper atmosphere nudged Charley to the right, sending it on a new course that would take it into Charlotte County...Thousands rode it out crammed in darkened closets, bathtubs, and hallways while ear-popping winds shrieked overhead. (p. 308).

Other media sources noted the mismanagement (especially regarding communication) and subsequent frustration in New Orleans that hampered evacuation efforts during Hurricane Katrina. NASA Earth Observatory (Binette, 2005) reported, "During hurricanes, we often see a lack of information, rumors, and misinformation...Katrina. Residents were apparently confused, agitated and resistant to an orderly rescue effort" (para. 8).

Age and mobility issues were sometimes a factor in the ability to evacuate. One caregiver, who was away from her 90-year-old father at the actual time of Hurricane Charley and was trying to help him manage from afar, noted that her dad couldn't (due to lack of time), and likely wouldn't (due to his age), have evacuated. But, he did not want her to know the extent of the poor conditions, "Dad kind of lied about the damage to the

house. We were surprised when we got there because it was worse than what he had let us know....”

Finally, some residents just didn’t think it would actually hit their area. Earl (2009) wrote, “...Charlie [sic], which was supposed to go right up the Gulf, missing us, was making an unexpected right turn...our new home its very target...that’s just what it did. We hadn’t worried...Hurricanes had churned up the Gulf, none had hit here” (p. 480).

Preparation. Participants who followed way 4 did not describe any non-disaster phase preparation. Their pre-disaster preparation was minimal or non-existent, sometimes due to the nature of the disaster (e.g., Charley turning at last minute). Since the decision to not evacuate was sometimes last minute, these participants sometimes described reacting to the event by scrambling to prepare the house for impact as well as possible (e.g., moving car, closing shutters). For example, Nancy stated, “...We didn’t have time to think if we had water, we didn’t have time to think about the toilet...So, we ran in and tried to shut up everything the best we could.

Attention. Given the unforeseen nature of the event for this group, they often did not describe attention to managing health-related activities. They ignored health-related concerns by putting them on the back burner to focus on unexpected pressing situations, or the more immediate priorities of the impact and emergency phases, such as frightening events or securing and/or repairing their home.

Mona, a 56-year-old multi-racial participant from Florida described the dilemma of leaving one’s home to possible looters, which she and her husband did not expect “...the insurance company sends their extractor for the water. He said, “You can’t stay

[due to mold].” It was my husband who was staying because there were looters around...if you leave your house unattended...they don’t care. So, my husband was staying at nights there.” Her husband had to backburner his health by living in the moldy house rather than leave it to looters, even after the insurance company threatened to notify police to force him to leave.

People riding out Katrina also described frightening conditions, “I never thought I’d make it. Oh, God, I thought I’d die in there [Superdome]. I’ve never been through anything this awful” (MSNBC, 2005). Reporter Leslie Williams described the scary conditions as the storm impact phase hit, “Pine trees bow to the ferocious winds until the trees snap like twigs....One breaks...then another, then dozens, like popcorn beginning to pop on a kitchen stove...we wait for the tree that will smash the house, and us.” (*The Times-Picayune Katrina*, 2006, p. 27).

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 before next hurricane on its way]. 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...My heart passes stress tests fine now [after stents] but I was having a heart attack then. I was pounding in nails, gritting my teeth, fighting pain in my chest, and right arm, and jaw... (p. 483).

He continued on, explaining how he ultimately managed his symptoms:

...I was moving heavy furniture and getting by with it for quite a little bit. The problem eased actually for a while.... So, it got easier...I was still having heart attack symptoms all along but when they'd happened I'd sit down and waited until it went away...The kind of thing where your arm starts hurting, your chest hurts and your jaw hurts and stuff like that. With me it was the left side that would go bad. The typical symptoms. If I sit down and relaxed it would go away.

Lack of stability in the area after Charley and Katrina caused people to backburner their health, even in the face of health threats. MSNBC (2004) reported, “[People] are skipping their prescription drugs and, with no air conditioning and with window screens blown away, exposing themselves to mosquitoes carrying diseases such as West Nile virus.” Barnes (2007) noted, “As is quite common in the days following major hurricanes, additional fatalities were reported as the cleanup got underway...[people] were killed in accidents or by heart attacks” (p. 332). This is not difficult to imagine given the reports of participants in this group who remained at home in very unstable conditions (e.g., no water or utilities, significant home damages, inability to travel locally) and backburnered health challenges to address other priorities. New Orleans residents faced health threats simply due to the crowded and unsanitary conditions as they sheltered-in-place in the Superdome. MSNBC (2005) reported, “Inside and outside the Superdome – including the concourse around it and a 50 yard bridge that connects it to a shopping center – was a sea of trash up to 5 feet deep.”

Recovery. When these participants did discuss health-related activities, they discussed reacting to health challenges as they arose (e.g., managing depression/anxiety

by staying busy) or, very frequently, just ignoring signs and symptoms. In essence, they addressed health-related concerns only if absolutely necessary well into the reconstruction phase, even given emotional pain and anxiety. In this phase, the delay in going to a provider was often due to pressing needs to manage home-related concerns, but occasionally noted was inability to find or get to one.

Nancy described the change from the stresses of the impact and emergency phases, "...I can only go from second to second, I can't think in terms of a minute, I can't think in terms of today. I can't do that, I have to get through this second to survive..." to the challenges of the reconstruction phase, "...I still had an animal to take care of, you know. I had to have a place to be, so it's just like my nerves were shot to hell." She ignored her symptoms of anxiety and instead kept herself busy, "I was fine as long as I could be of use or help somewhere I was fine. It was just being by myself and having to think..."

Other people just did not even have time to think about health-related concerns, even during the reconstruction phase. Mona, a Floridian who did not evacuate, but did relocate temporarily in the city after the hurricane due to damages in her home, described ignoring her back problem to work on her home:

Apart from my back problems, I was lifting things that I wasn't supposed to lift but, you know, at that time I think you forget that you're not supposed to do this...when it was happening we did what we had to do. Truthfully, I did not even think about my conditions, other than I knew the mold was not good for us and we had to stay out of the house.

Sometimes just the thought of health concerns during the reconstruction phase was overwhelming. *Times-Picayune* feature writer Renee Peck (Folkenflik, 2007) was assigned to write a column, This MOLD House, which helped people address health concerns such as, “What do you do when you’re coming back after the flood? Do you need tetanus shots? Do you need hepatitis [shots]? What do you do if there are snakes in the water?”

This group also experienced delays in contacting providers due to damage to facilities. Barnes, (2007), reported, “All three hospitals in the county suffered damages, including Charlotte Regional Medical Center, where over 200 ambulances had to be called in to transfer the entire patient population to other locations” (p. 311).

Synopsis: Way 4 and Health-Related Challenges. Seven of the 8 participants (88%) who were in the unforeseen backburning group were from Florida, and most of those experienced Hurricane Charley. Participants in way 4 faced challenges related to survival. Since they could or did not evacuate, and lack of preparation was a significant factor, they were very delayed in resumption of health-related activities. They ignored health challenges during the impact/emergency phases just to survive what was, for this study’s participants, a fast, unforeseen change in conditions. The rapidity of the disaster event limited their ability to foresee health-related problems that might occur and necessitated that they backburner almost everything to address survival first. Backburning of health-related concerns often continued into the reconstruction phase.

Conclusion: Core Process of the Backburning Model Ways

In conclusion, study participants described backburning in a way that was prudent, impromptu, deliberate, or unforeseen. Five factors described the ways that

participants backburnered health concerns during a disaster. Factor one involved the impact of the media, and often occurred in many stages throughout the process of the disaster experience. Factor two involved evacuation status. This factor occurred during the pre and/or impact stages of the disaster. The third factor, preparation, described individual level preparatory actions in the wait for a hurricane. This factor occurred in the non- and pre-disaster phases. Factor four involved paying attention to the most important concerns, or actions that participants took related to prioritizing and delaying health-related needs because of imminent decisions placed before them by the arrival of the hurricane, such as whether or not to evacuate. Chronologically, this factor included the impact and emergency phases. The fifth factor, recovery, occurred in the reconstruction phase and was distinguished by actions that participants took related to seeking a return to normal health-related behaviors or establishing the new normal after the hurricane. The complexity and/or immediacy of each these factors contributed to the way that the participants backburnered health-related concerns, either intentionally or subconsciously.

Research Aim 2: Interaction with Healthcare Workers

The second research aim was: describe how individuals with chronic illnesses who have experienced a disaster interacted with healthcare workers during the impact and emergency phases of the disaster. Two themes that emerged related to interactions with providers were: 1) the helpfulness of providers, and 2) inaccessibility to previous providers and/or facilities. Each of these themes is discussed below.

Theme 1: Helpfulness of Providers. When participants discussed interaction with healthcare workers, it was most often in a very positive manner. They also found healthcare providers to be helpful at various phases of the disaster event.

Non-disaster phase. In the non-disaster phase, it was sometimes healthcare providers who helped people access information about special needs shelters. Amy, a 76-year-old retiree from Venice, Florida, recalled, “I’m pretty sure it was through my doctor is how I found out” [about how to register for special needs shelter]. She also explained how he tried to give her samples to help her stockpile medications in advance during hurricane season, “...sometimes he has samples for half a month. They have 30 puffs on them instead of 60.”

Emergency/Impact phases. As previously noted, many evacuees were able to make contact with providers from afar. Tina was undergoing chemotherapy for stage 4 cancer prior to Katrina and explained that she was very anxious about the prospect of missing treatment. However, upon her arrival in Texas, she found the providers very efficient and helpful:

So, when we got there I ended up calling the University of Texas Cancer Research Center. They were fabulous. Absolutely wonderful. They would continue treatment because they could call M.D. Anderson and get some of their records and some of the tests that I had. That helped...I went there and I was able to start treatment that day. These people were so efficient and so nice.

Another elderly participant who evacuated Katrina to Alabama, Leona, suffered with chronic pain and ran out of her medication. She noted, “...we found a doctor in Fairhope. This doctor in Fairhope was so accommodating...he just gave me whatever I

needed until I could get in touch with my doctor... It was just a very smooth transition as far as doctors.” June, who was evacuated from New Orleans for 4 months, was also able to access a provider from afar, “I had gone to the Red Cross in Georgia...and I did get a prescription through [a doctor there] because I really would have been up the creek. I will never let that happen again.”

Theme 2: Inaccessibility to Previous Providers/Facilities. The greatest challenge to participants was getting to a provider, or finding a new one if their previous one had evacuated and not returned. This was a concern for non-evacuees, or early returners who tried to travel to a provider. The problem of inaccessibility extended to the reconstruction phase if there was extensive damage, such as with Hurricanes Katrina and Charley. Typically, participants described that they became frustrated with the slow return of healthcare services and providers during the reconstruction phase, but noted positive interactions and outcomes from those providers they did access.

Extensive analysis related to accessibility of providers (or lack thereof) by specific geographic location is beyond the scope of this study, however, participants from Louisiana did describe differences in their experiences. For example, Patsy, age 57, who was evacuated from Katrina for two weeks, noted that while she could not see her own physician, she was able to access a provider:

After we came back home a lot of doctors weren't back in town yet. But I remember...I went to a different place on their campus to see a doctor and I didn't know the doctor that I saw but he was able to write any prescriptions that I might need renewed. So, I did have access that way to a doctor just not my own doctor because I didn't know where my own doctor was.

Other participants had opposite experiences. Cordelia, a diabetic, returned to New Orleans after approximately 18 months and still struggled with access to a provider. She noted:

...when I tried to call doctors to set up an appointment, he was backed up and couldn't see me for about 6 months from the time that I came back. I really wasn't under a doctor's care. I was really frustrated, you know about that because there wasn't anyone I could see and they kept putting me off...Because of the health situation here in New Orleans after Katrina. We didn't have many doctors here, very limited hospitals.

Dave described healthcare in the greater New Orleans community as follows, "At the community level there really was no healthcare. Gradually as some of the larger churches got re-established, they were offering some limited service." June, who accessed a Red Cross physician in Georgia for immediate needs, could not locate her providers upon return to New Orleans:

I lost my doctor, no one came back, he never returned, his home flooded, his office flooded and he didn't come back. I lost my cardiologist, my primary doctor, and my neurologist, I'd been going to that neurologist for about 18 years. That was really a problem coming back.

While most participants from Florida were evacuated only a short time, the exception was those who experienced Hurricane Charley. Descriptions below from Red and Janice, respectively, discuss issues related to provider and health record inaccessibility during the emergency and reconstruction phases after Hurricane Charley: "...it was a real problem with it because the hospitals were closed. They were shut down.

They had some kind of an aid center under a tent...” and “There were several doctors that lost their offices. People’s records were all over Charlotte County and never recovered.”

Conclusion. For the participants in this study, interaction with healthcare providers was described as a positive, helpful experience. Review of the data pertinent to this research aim further supported the previous assertion that those who evacuated long enough to gain some stability did contact providers to manage health-related concerns from afar.

The greatest challenge related to healthcare providers was inaccessibility, sometimes prolonged, following the most devastating of the hurricanes they experienced. Review of media data supported the experiences described by participants in this study. *The New York Times* (Eaton, 2007) noted:

Only one of the city’s seven general hospitals is operating at its pre-hurricane level; two more are partially open, and four remain closed. The number of hospital beds in New Orleans has dropped by two-thirds...Studies suggest that hundreds of doctors never returned (paras, 7, 9)

When the researcher collected data in Louisiana in the summer of 2009, almost four years after Katrina, there were still major hospital systems not yet functioning. Perhaps more importantly, many satellite locations supported by healthcare institutions and small buildings housing physicians’ groups were lost in the hurricane and had not been replaced, leaving residents still challenged to access providers.

Research Aim 3: Response Activities and Chronic Illness

The third research aim was: describe how individuals with chronic illnesses who have experienced a disaster perceived the impact of regional and federal level disaster

response activities on their efforts to manage their chronic illness at any or all phases during the disaster. One theme that emerged from the data in relation to this aim was the difference in perspectives from a geographic standpoint (i.e., Florida participants versus Louisiana participants). A second theme noted was the impact of the response efforts specific to short term needs that may affect health (e.g., access to food and water), versus long term threats to health (e.g., mold and mildew concerns). This section discusses each of these two themes related to the impact of regional and federal level disaster response activities on efforts to manage chronic illness.

Theme 1: Geographical Perspectives Related to Response Activities and Health. Most, but not all, participants from Florida felt that the local, state, and federal level responses were helpful and well-orchestrated. Participants from New Orleans who experienced Katrina held very different opinions. Specific discussion related to the response from participants from both areas described access to food, water, and supplies; communication; and unsafe conditions.

Florida. Participants who experienced Hurricane Charley provided the most insight into response efforts in the state of Florida. In general, they were able to access food and water. Access to supplies (e.g., tarps, generators, fans) was not impossible, but more difficult. Red, Nancy, and Mary described what many participants noted, “Food was not a problem because everyone was giving it away. The local Moose...was taking donations of anything and cooking it up. You could always go there and get a meal. No telling what it would be...”; “...twice a day had some kind of hot meal for us. I guess it was Red Cross...People would come by like with ice on trucks and call out, ‘Does anybody need water, does anybody need ice and things?’”; and “...the Salvation Army or

the American Red Cross came through with meals for about three days. Just how many people are in the house and what do you need...” Participants found out where to obtain food and water by radio, or TV once power was restored. Mary was very pleased with the local level communication, “It was just fantastic the information that was on there. The TV was on most of the time giving us the news as to where it [food, water] was.”

In addition to places and/or agencies that distributed food and water, local groups, often churches, set up stations, as described by Nancy, “...there’s a little church and even though they had a lot of damage they were able to...set it up...a little survival center.” Not only did this local effort provide food and water for this participant and the person with dementia for whom she gave care, but over the course of the extended emergency and reconstruction phases after Hurricane Charley, it provided caregiver support:

We would go every morning, at 7:30 they would open and we would go because I had to do something with her, I had to keep her occupied...I would make the coffee and she would set up all of the supplies that the people could come and get like crackers, bread or whatever that they were able to get into us.

Many participants in this study who experienced Charley repeatedly touted the efforts of locally-based media to communicate information about the recovery effort. This information was so vital that people brought gasoline whenever they could to support the efforts of one heroic local radio station to remain on the air, as described by Janice, “...half of the building was gone that they were broadcasting from. People would bring gasoline and stuff into them so they could run their generators and run their stuff so they could get this word out on the radio.” This same radio station also provided a forum

to help residents get much-needed supplies; Nancy described her efforts to get a blue tarp for her roof:

So, I was able to call the radio station and I asked if anyone could help me, if somebody having their roof repaired if I could have their tarp because you know, Jeanne and Francis coming through [after Charley]...somebody over in Punta Gorda Isles called me and said I could have their tarp and I went over and got it...

Several Florida participants spoke very positively about the higher levels of response from the state and federal governments. For example, Mary noted, "...the government, the State of Florida and Jeb Bush were absolutely fantastic with their information, with their help" and "It is just a reassurance to see the Governor...on television and you saw him doing it in Spanish and...in sign language, you saw him right there out with it. That really made a difference." Barnes (2007) also noted how the various government agencies collaborated in the response effort:

While Frances was still churning across the Gulf, Florida governor Jeb Bush and an entourage of twenty state and federal officials began their tour of the damaged areas [from Charley]. They flew into West Palm Beach...met with local officials, and urged residents not to venture out into the streets...Bush assured local officials that even though many state and federal resources had been devoted to Charley, there were more than enough in reserve to send to the area. The governor told the *South Florida Sun-Sentinel*: 'We have the resources. We have a great partner in FEMA.' (p. 323)

Unsafe conditions described after Charley were primarily due to debris (described by many participants) and lack of utilities. An MSNBC media clip (2004) noted that,

“Roads [after Charley] had been cleared of storm debris but there was no power or drinkable water...” However, even with the general perception that the government response was helpful, there was still a generally held opinion of unsafe conditions in the tent city set up by FEMA. Nancy vividly described this perception:

...Do not go to FEMA village. You don't want to be there...[some] people had no choice and had to be out there... You talk about having life that was really bad. No way to live. Thank God it was there, better than nothing but you know after ah, everything, after a while, it just got worse and worse.

Louisiana. New Orleans residents described similar topics related to the response effort but voiced a different overall perspective. Not everyone had ready access to food and water, and some people held the perception that this was because of a mismanaged response by multiple levels of government. Wanda, who mentioned local, state, and federal officials involved in the response, made this perception very clear in her description:

The policemen and National Guard weren't doin nothin. Old people were just sitting there dying one by one, they just have them in a wheel chair and they'd throw a blanket over their heads. People was hungry, they [the government] didn't try to drop them water or nothing. All because of Bush put a hold and told Blanco what to do while Nagin, everybody already knew that, stood outside the Governor's office telling all three to get the boot.

This opinion was not exclusive to the study participants. In an NPR broadcast, Chadwick (2006) stated:

Certainly state and local officials are not blameless in this. There was always the possibility and it was discussed that the city could perhaps muster an armada of school buses...to take people out in advance of the storm coming. Perhaps they like everyone else was waiting for the calvary (sic), which is to say the federal government, to come in and do just that.

There was an atmosphere of confusion and rumor suggested among both media sources and study participants. However, media data demonstrated that, in New Orleans, some regional level responders felt they were responding appropriately. For example, in a PBS (Frontline, 2005b) interview the governor of Louisiana described her instructions to citizens regarding preparation to leave, many of which went unheeded, and her contact with other government officials:

I [Governor Kathleen Blanco] went into New Orleans right after the press conference with [Jefferson Parish President] Aaron Broussard and stood behind Mayor Nagin and emphasized the need to leave. I gave people clues on how to pack....And we referred them to the maps [and said] ‘Plan your route carefully. Pack carefully. Pack as though you’re going on a camping trip. Bring enough to sustain yourself, your family, your children...(Frontline, 2005b)

In the end, several study participants felt that the most assistance came from volunteers and not government agencies on any level. Tina, from Slidell, noted:

...actually the civilians, the volunteers did much more and are still doing more for this area than the government ever did. As far as that goes, volunteers a Mormon church group from Tennessee came in and they cleared our trees that came down. They really worked hard.

Many participants also touted the work of volunteers and the helpfulness of faith-based efforts, such as Dave who stated, “By Friday...volunteers were starting to show up from all over the place....churches were doing all of the reaching out, initially. There’s nobody else here to do that except churches and these were church people from all over the country.” In direct contrast to the comments above from Floridians who perceived the government response as generally well done, participants from New Orleans either did not discuss the government level response(s) or perceived it as unorganized, unhelpful, or non-existent.

Those who experienced Katrina also noted the unsafe conditions, and much more so than the Florida residents who experienced Charley. June, who originally tried to ride out Katrina in the city, decided to evacuate when conditions deteriorated in her neighborhood (the Garden District) without response from safety forces:

Then the violence started [day 3]. Every commercial building in this area was broken into....Someone had stolen a fork lift and rammed it into Rite Aid...they were not stealing food and water...They were stealing drugs, alcohol, cigarettes, anything else...I saw people attack each other, pull out guns...we left because it got violent and it was time to go.

Reporter Gordon Russell, quoted in *The Times-Picayune* Katrina (2006), affirmed the lack of response and escalating violence described by participants in this study:

While much of the first week after Katrina was infused with a sense of danger; Thursday, for me was the day that felt like it was all over for New Orleans. The promised troops and buses had failed to materialize. The stores had been looted,

and flood victims still trapped in the city were getting very jumpy. So were the cops. (p. 72)

Comments from study participants and review of media data both supported the overall poor perception of the local, state, and federal level responses to Hurricane Katrina.

Theme 2: Response to Short Term versus Long Term Health Threats. A

second theme noted was the impact of the response related to short term versus long term threats to health. Local and regional response efforts from faith-based and community level groups and response from the National Guard were often noted as very helpful in meeting short terms needs. Federal level response from FEMA was frequently problematic in the perceptions of participants.

Short term health threats. A large number of participants noted the helpfulness of faith-based groups in all phases of the response effort. For those experiencing Katrina, there are still recovery efforts sponsored by both local and visiting churches. However, these efforts were noted as particularly helpful in regard to health threats in the short term (i.e., the impact/emergency phases) such as meeting the need for food, water, ice, and power.

Many participants recalled that food, water, and even ice were fairly easy to obtain in the early days due to the efforts of local churches and regional and/or state level agencies that arrived to help. Marcy, from Slidell, and Dan, from Daytona Beach, noted the helpfulness of the local community response, "...a lot of the faith based groups were here and that would give you hot meals, too. So, we did fine as far as food goes...we were well fed" and "The community really rallies around...they put together a kiosk with water, to help people that need these things...."

Some of these response efforts specifically targeted the needs of people with challenges. Pam described such an early response effort by relief agencies at the state/regional level, “[for] handicap people, Salvation Army and Red Cross were right there on the spot to try and help everybody. They are a big help...they are the first responders.” Sharon was dealing with her own chronic illness (irritable bowel syndrome) and was also concerned for her husband, a veteran with severe PTSD symptoms. She recalled that they were very relieved by the following response effort that allowed him to get medication, “...I heard on the radio that veterans here that needed medicine, they set up a place down on 41 and should come down there if they needed meds.”

Pam was a temporary relief worker for FEMA who was assigned to emergency phase relief efforts in both Florida in 2004 and New Orleans in 2005. During this time period, she was temporarily living in the areas of devastation while simultaneously managing her own chronic illness, osteoarthritis with decreased mobility. She provided a detailed description of a typical FEMA early response effort as it related to helping people with illnesses:

They [FEMA] bring in make shift hospitals...portable hospitals. They usually work with the existing hospital from whatever condition it is in. Sometimes it's not in good condition but they work together...anybody with health problems or disabilities or handicapped, they are pretty well taken care of. They are the priority....

...we purchased big water troughs and then we filled them up with ice...we would put water in there or anything else that needed to be cool. A lot of times, medications went in there because a lot of us that were out there had medications

that had to be refrigerated and then we had to keep them on ice. FEMA usually has in their warehouses, small refrigerator or even full size ones for medical help or for a nurse on site...for shots or for allergies, for diabetes or a number of things and that has to be iced...those are the types of things we would take care of early on.

Another early response that was described as very helpful both for general needs and for health-related challenges in the short term was anything that provided financial assistance. Participants credited churches, the Red Cross, and local retailers with providing financial assistance. For example, Tina, who was evacuated for approximately one month after Katrina, described a church relief effort with food and money after she returned and was continuing chemotherapy, "...a friend of mine took me to another church where they were giving out food and they were also giving out a \$100 gift card." Doug concurred, noting, "People were coming to New Orleans to help, to supply food, water, dollars, medical attention...."

Francine, age 61, one of the few in this study from New Orleans who did not evacuate, was especially pleased when a retailer was willing to waive a co-pay so she could refill a prescription for her husband who had COPD. She stated, "...waiving that co-pay was one of the biggest helps that everybody had because you didn't have a lot of money to do anything with." However, although many noted that money helped, even having money did not mean supplies could be had. Patsy, who lived in Slidell, Louisiana, recalled a time approximately 4 to 6 weeks after Katrina, "...when we started getting mail though it was interesting...I had friends in Tennessee that sent me money but yet there weren't really any places to spend it."

Long term health threats. To manage long term health threats, i.e., those in the emergency and reconstruction phases, participants typically needed help either: 1) to make their own home livable, or 2) to find a way to return to the city. This frequently involved finding new housing, sometimes to live in while repairing their home (e.g., FEMA trailers) and other times because they left a rental that was no longer an option.

Many participants spoke about the challenges of getting and living in FEMA trailers. Tina described her ambivalence: first the difficulty in getting a trailer, “And we waited for the FEMA trailer. That was my job to get that FEMA trailer. That was very frustrating” and then, after trying to live in the trailer, stated even more frustration, “...we went in the FEMA trailer and we were there 4 months. And finally I told the guys doing my house that it was as finished as I wanted it.” Several others referred to the fumes in FEMA trailers that caused problems for inhabitants, such as Connie, who described what occurred in her daughter’s family, “The formaldehyde in the trailer. My grandchildren got sick, she [her daughter] got sick. The mold and the formaldehyde. She was so sick I thought I was going to lose her.” Connie, like several others in the study, was attending to her own health needs (diabetes, heart disease) and simultaneously caring for her daughter and grandchildren at several points in the aftermath of Katrina. In general, most people described the FEMA trailers as helpful and a short term necessity, but they worried over possible long term health effects, a valid concern in their perception since people lived in these trailers for extended periods. Some people still live in them, as noted by the researcher during her visit to collect data in 2009. The trailers are habitable, but small, analogous to a family camping out for several years.

Mold and/or mildew were long term health threats that presented problems for many of the study participants. These were long term health threats that did not seem to be easily solved by any response effort; the victims were essentially left to deal with it the best that they could. Mold was especially problematic for those who had breathing difficulties due to COPD or allergies. Dorothy, age 78, who has scleroderma and COPD, described how this was both a health-related and financial challenge for her family, “The mildew was terrible and my doctor said, ‘You can’t stay there with that mildew.’...I stayed at the motel for 12 days. Of course, FEMA didn’t give us anything for that. We had to pay for it.” Chuck, a caregiver for Dorothy, also struggled with removing the threat of mold and having to leave his wife in a hotel while he worked on the house to make it livable. He noted, “Breathing was her biggest problem...[Scleroderma] takes the elasticity out of the lungs and they stiffen up and anytime you have a problem with breathing it compounds the whole thing, you know...the mold that is the worst thing in the world....” Mona agreed, stating, “I heard about mold but you never know what mold is until you have to live through it.”

Review of media data also confirmed mold as a topic of great interest and concern to all. Earl (2009) noted the response from FEMA after Charley, “After days of standing in lines, the most FEMA could do was give us shovels, brooms, mops, and cleaning supplies, and bleach for fighting mold, with a few hundred dollars for immediate necessities” (p. 484). In New Orleans, Renee Peck, feature writer for *The Times-Picayune* authored a column called ‘This MOLD house.’ (Folkenflik, 2007)

During the latter part of the emergency phase and extending into the reconstruction phase, those participants not working to make their homes livable were

typically trying to return to the city and make a new home. Faith-based organizations were (and still are, in the case of Hurricane Katrina) often a critical asset to the success of this effort, and thus were a positive contribution to the health of those in need by providing physical, emotional, and financial support. Ava, a 67-year-old Caucasian participant, returned to New Orleans about four months after Katrina. She maintained contact with her church leaders and described how they assisted in her relocation, “I kept track with the archdiocese when exactly to move in and I told my priest...He helped me to move in, December 5th...When I did, they had a little party for us...” Bernadette, who was evacuated for four years after Katrina, has a history of substance abuse and suffers from depression. With the help of a church relocation effort, she was able to return to New Orleans in 2009. She described the joy of returning and the assistance she received, “...it’s amazing to me, it [the apartment] had everything in there that I needed and I didn’t purchase not one item...the only personal things that I purchased was my sheets, my towels, my dishes, and my glasses.” Wanda, who has multiple chronic illnesses (schizophrenia, depression, bipolar disorder, hypertension, and diabetes), was able find relocation help from an agency to return to New Orleans in 2008. She stated, “Found Volunteers of America, been dealing with them for years, they found me the first house which was just across the river on Whitney.”

For those who remain in FEMA trailers who have not yet been able to return to their homes, the efforts continue. Dave confirmed the observation of the researcher that families are still in these trailers, and noted:

Of course, that is still going on here in the metropolitan New Orleans area. The church that I belong to in Slidell is posting a program this summer for visitors

who are here to help, not so much with debris cleanup anymore but with rebuilding. They are going out and working with groups like Habitat [for Humanity[®]] on rebuilding homes and in some cases, still gutting homes.

Conclusion. Individuals with chronic illnesses who have experienced a disaster perceived the impact of regional level disaster response activities on their efforts to manage their chronic illness as helpful in general. They had the most positive comments about the efforts of faith-based groups and local and/or regional level agency responses (e.g., Red Cross). Florida participants voiced much more satisfaction with state and federal level response efforts than did the participants from Louisiana. Each of the post disaster phases held health-related challenges and as might be expected, there were differing needs noted in the short term versus the long term response efforts. Challenges of the short term, such as food and water, were well-managed, even in New Orleans. Financial assistance during this timeframe was especially appreciated. Long term challenges, such as clean up, mold and mildew, and relocation, were more complex. Managing these possible threats to health often involved waiting for response from federal level agencies (e.g., FEMA). Resolution of these concerns could extend for years after the disaster occurred.

Summary

Analysis of data obtained from 40 interviews and review of media data suggested that participants backburnered, or disregarded, health-related concerns to address more immediate priorities during the disaster. The data suggested four different ways to describe the backburnering process: prudent backburnering, impromptu backburnering, deliberate backburnering, and unforeseen backburnering. Each of these

four ways had five defining factors: media impact, evacuation, preparation, attention to health challenges, and recovery. One factor that strongly determined the way that they backburnered was whether or not they evacuated. Other themes that emerged related to the study research aims included helpfulness of providers; inaccessibility to previous providers and/or facilities; geographical difference in perspectives related to response efforts; and impact of the response efforts specific to short term and long term threats to health.

CHAPTER V

DISCUSSION

This research study sought to develop a theoretical framework to describe how individuals with chronic illnesses who have experienced a disaster managed their health-related challenges during the disaster event. This chapter discusses the findings of this study as they relate to the literature addressing chronic illness and disasters. In addition, limitations of the study, along with implications for research and practice are discussed.

The three specific aims of this study were to:

1. 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.
2. Describe how individuals with chronic illnesses who have experienced a disaster interacted with healthcare workers during the impact and emergency phases of the disaster.
3. Describe how individuals with chronic illnesses who have experienced a disaster perceived the impact of regional and federal level disaster response activities on their efforts to manage their chronic illness at any or all phases during the disaster.

Brief Review of Study Findings

Analysis of the transcripts suggested four ways in which participants used the process of backburning their chronic illness which we named prudent, impromptu, deliberate, and unforeseen. Each of these ways related to five factors: media impact (factor 1), evacuation (factor 2), preparation (factor 3), attention (factor 4), and recovery (factor 5). Most importantly, review of the data suggested that if participants were evacuated for longer than one week (and thus had opportunity to settle in somewhere away from the hurricane), or returned to no or minimal damage to their home, many recovered from the disaster events enough to address at least some health-related concerns from afar. Those remaining home were more apt to ignore health-related concerns longer to deal with home and family issues.

Discussion of Study Findings

Research Aim 1: Managing Health-Related Challenges

Findings in this study that held similarity to previous findings in the literature related to disaster conditions, impact of the disaster on specific health conditions (e.g., cardiovascular and respiratory sequelae), and the advantages of evacuation from a health perspective. For example, almost all of the participants described the massive power outages discussed in the literature (Bayleyegn, 2006; MMWR, 2004) and many noted this as a significant barrier to access food, water, and/or healthcare.

Gautam et al. (2009) recently reported that there was a 3-fold increase in acute myocardial infarction in the first two years post Katrina, possibly due to the stressors of the long term reconstruction period (e.g., rebuilding house, looking for employment). Also, Howe et al. (2008) reported that the most requested classes of medication post

Katrina were cardiovascular and endocrine. Interestingly, even in this sample of 40 participants, two participants explicitly described ignoring cardiac symptoms and/or restrictions to attend to damages at their homes. Bloom et al. (2009) studied mold and mildew and documented the presence of several health threats related to this common occurrence. Many participants in this study described difficulties that dealt with mold and mildew, ranging from the nuisance of clean up to the health threat of breathing difficulties.

Recent studies (Anderson et al., 2009; Horney et al., 2010; Smith & McCarty, 2009) supported the benefit of evacuation when possible. Findings from this study supported this assertion and strongly impacted the ability of the current study participants to address at least some health-related concerns.

A significant difference from previous literature findings concerned medication separation. Many studies in the literature noted that victims in a disaster event 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). However, in this study, very few participants had difficulty obtaining prescription refills, especially if they evacuated. Many used national chain pharmacies to assure that current information would be available for them to refill prescriptions while evacuated. Those who did not evacuate often had trouble because local retailers were not open for business, further substantiating the finding that evacuation contributed to more positive health behaviors. Denial of insurance coverage was a contributor to the inability to stockpile an emergency supply of medication (Howe et al., 2008); several participants confirmed that this was an issue for them.

Findings from this study related to two areas of concern to health outcomes, preparedness actions and decision to evacuate. These findings held both similarities and differences to current literature reports. Many studies (Ablah et al., 2009; Boland, 2006; Eisenman et al., 2006; Gheyntchi et al., 2007; Stallwood, 2006; Weir, 2005) reported a wide variation in preparedness actions, with the majority of citizens performing little to no preparedness activities (e.g., purchasing emergency supplies, developing a family plan). In this study, that wide variation was supported: less than half of the participants from New Orleans (43%) prepared, however, 72% of the Florida residents performed at least some type of preparedness activities. While the wide variation was a similarity, it is clear that the vast majority of Florida residents in this study did perform preparedness activities, a difference from reports in the literature from at least one (Florida) of the two geographical perspectives presented herein.

Kumagai et al. (2006) suggested that delayed access to resources of significance at the individual response level were elements related to the event itself (e.g., blocked roads, physical challenges of the site, physical injuries); preexisting qualities of the population (e.g., disabilities); and misperceptions related to cognitive factors (e.g., media exaggeration or lack of media access for information; assumptions that government agencies will provide immediate response effort). Similarly, in this study, participants frequently described the massive amounts of debris, blocked roads, and inability to travel locally. Occasionally disabilities were mentioned as a barrier, and the expectation that the government would provide an immediate response was addressed with statements that the government did not try to drop food or provide rescue. However, a significant difference from Kumagai et al.'s (2006) findings was that almost all of the many

participants who discussed this topic (media impact) praised the effectiveness of the media and the extraordinary efforts of newspapers and radio stations to provide information in the face of great challenges.

Eisenman et al. (2009), Uscher-Pines et al. (2009), and Renukuntla (2009) reported mixed findings related to individual preparedness and special needs. Several Florida residents in this study were very knowledgeable about special needs shelters. Although several participants from New Orleans who had mental health issues were able to connect with providers once they settled in to wherever they evacuated, in similar fashion to reports in the literature, they did not have any type of evacuation plan in place and fell into the category of impromptu backburners.

Several studies (Arrieta et al., 2008; Mokdad et al., 2005; Saunders, 2007) noted that, during Hurricane Katrina, those with chronic illnesses were less likely to evacuate, had less monetary resources, and frequently depended on local institutions for their care, institutions often with few resources left to offer. In this study, a difference noted was that most of the 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 get settled elsewhere.

Findings from the current study extend what is known about the advantages of evacuation by relating this action directly to positive health outcomes for those with chronic illness and suggesting a tangible timeframe of benefit. As noted above, multiple studies (Anderson et al., 2009; Horney et al., 2010; Smith & McCarty, 2009) supported the benefits of evacuation. Findings from this study suggested that study participants

were able to address at least some health-related concerns from afar if they were evacuated longer than one week. Conversely, if they did not evacuate, or returned while their home area was still unstable (i.e., no water or other utilities), they either ignored health-related concerns, or described a backward slide from the success they achieved when they were away.

This study's findings add to what is known by providing detailed description of the media effort and its positive impact on helping participants in all stages of disaster. Participants clearly utilized media information in one or more of the disaster stages, and described in detail the ways that this information helped them to manage health-related concerns.

Research Aim 2: Interaction with Healthcare Workers

Findings from this study compared to those from previous literature related to research aim 2 were mixed. While participants overwhelmingly described positive interactions with providers, the participant descriptions did not clearly support or challenge current literature reports related to interacting with healthcare providers. Lack of access to health records, whether because of evacuation or lost records from damaged facilities was a barrier noted in the literature (Pate, 2008; Smith & Macdonald, 2006). Some participants in this study differed from this report, describing better than expected access to their records from afar and a fairly smooth transition to new permanent or temporary providers; others supported this concern and described lost records that were a problem.

Research Aim 3: Response Activities and Chronic Illness

Similarities to literature reports were noted in the study findings in the area of response activities at all levels. Stratton and Tyler (2006) concluded that individual response to access resources was essentially limited to efforts at the personal or at best, community, level for a minimum of 24 hours; access to higher level resources provided by state and federal agencies typically required 24 to 96 hours. Participants in this study who did not evacuate (40% of the study sample) confirmed that approximate timeline with descriptions of the local, regional, and federal assistance efforts.

Review of literature (Berg, 2004; Bostick et al., 2008; Braun et al., 2006; Dainiak et al., 2007; Johnson, 2007; Jones, 2006b; Kumagai et al., 2006; Mattox, 2006; Parvis, 2002) has also strongly supported the idea that collaboration among resources and response at the individual, local, state, and federal level is essential to positive outcomes after disaster events. Participant descriptions in this study supported the effectiveness of successful collaboration. They definitely noted, and clearly described, when the system worked well, and likewise when it did not, i.e., they felt that there was miscommunication, rumors, and inadequate collaboration to provide an effective response.

There was mixed support for previous findings in the literature in the present study findings for the idea of preparedness activities designed to support an effective response from upper level responders (i.e., those above the individual level). For example, preparedness modeling is currently used to enhance planning efforts at the local and state levels (Rosenfeld et al., 2009; Tran et al., 2009). Thomas et al. (2010) studied a Florida-based model of Medicaid nursing home reimbursement that has demonstrated

usefulness for hurricane-related costs and care and contributed to the state's preparedness efforts in long term care. In this study there was a great amount of difference in the descriptions of preparedness activities and local resources between participants from Florida and those from Louisiana, suggesting a much more sophisticated local and regional level disaster preparedness and response plan at these levels. Residents of Florida readily described local and/or state policy in place regarding evacuation, shelters for people with special needs, and immediate response efforts. Conversely, descriptions from participants from Louisiana differed greatly. They often described their perceptions of mismanagement and participants infrequently described any type of local or regional plan of action, although lay media review did have quotes from local and state officials describing these types of activities from their perspectives. It is important to keep in mind though that, in this study, about one third of the participants were from Louisiana and two thirds were from Florida.

Findings from this study add to the literature a rich description that affirms the perceived importance and effectiveness of the local lay response. Many participants from both areas touted the efforts of volunteers, most frequently faith-based groups, as very helpful to them in managing health-related concerns. Examples of the positive outcomes they described ranged from acquisition of food and water, emotional support, physical assistance to remove debris and provide safe living conditions, referral to providers, and financial assistance. This assistance was from local churches and also itinerant laborers who volunteered on a temporary basis as able. It continues to this day in some areas of New Orleans.

Study Limitations

The qualitative tradition expects that the researcher earnestly attempts to identify preconceived beliefs or opinions with potential to impact the process of data collection and analysis, a process known as bracketing (Polit & Beck, 2009). Potential biases of the researcher included: personal perceptions of chronic illness management behaviors, disaster preparedness and response activities in general, and for hurricanes. These perceptions may have been influenced by her education as a nurse and as a member of her community emergency response team. Use of an interview guide was a step taken to keep the interview on topic and prevent these biases from consideration in descriptions and answers given by participants; however, it is possible that some of these biases may have influenced responses.

The findings of this study reflected the homogeneity of the disaster event as all participants in this study discussed their experiences in a hurricane. Therefore the findings reflected only the 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 in which there is advanced notice of the disaster event (e.g., mudslide, blizzard), there are likely some differences in the event of instantaneous disaster events for which evacuation is not even possible, such as tornadoes and earthquakes. Thus responses given in this study were unique to this type of disaster. These same questions about managing chronic illness(es) during disaster events may have received very different responses while considering another type of disaster event.

Use of a self report method, interviews, to gather data has limitations inherent to this form of data collection. Potential limitations of this study included the possibility of

participants providing socially desirable responses (e.g., overstating disaster preparation or illness management) rather than responses that reflected their real actions. The presence of the interviewer and the tape recorder may affect both what participants say and how they say it. However, reviews of the transcripts clearly indicated that all participants described some form of backburning their illness management (thus its selection as the core category); those who did not engage in preparation said as much, and those who did were frequently able to relate the specifics of their preparedness actions to positive outcomes during the disaster event.

Another methodological limitation is the retrospective design of the study. Disaster-related priorities that participants described as hindrances to managing illness-related concerns present similar challenges to conducting research while the disaster is fresh, especially in the emergency and impact phases. Interviews conducted several years after the fact miss those who may have left the area of impact and are also affected by ability for accurate recall. Although some participants also referred to long ago hurricanes of their childhood that occurred in the 1960s, all of the discussion about managing chronic illness(es) described hurricane events that occurred in the years 2004 and 2005. Most participants easily recalled specific details and provided rich narratives of the disaster experience, some making statements such as “I’ll never forget....”

Transferability

Research using data obtained from qualitative research can benefit others when theoretical generalization is utilized (Sim, 1998). Some transferability between the findings about how individuals with chronic illnesses who have experienced hurricanes managed their illness(es) during the disaster, or the backburning model, may occur

because of similarity, or fittingness, between the context of a hurricane and other disasters with conceptually similar chronological or physical features. For example, from a theoretical perspective, the four ways in which the participants in this study backburnered, and the five factors that describe those ways, could be very similar in other types of disasters which feature some advance warning (allowing ability to prepare in the non- and/or pre-disaster phases) and similar outcomes of water damage (e.g., mold, mildew) and/or dealing with heat.

Study Implications

The study suggests several implications related to nursing practice. There are also implications for healthcare policy.

Practice Implications

Study participant descriptions clearly supported the effectiveness of preparedness actions on health outcomes. It is important for nurses to educate providers and patients regarding the importance of preparedness actions. Whenever possible, nurses should 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 very important to educate patients regarding the benefits and risks of health outcomes suggested by their decision whether or not to evacuate.

Nurses can 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 following the prudent backburnering way described preparing copies of important records and discussed the helpfulness of having

these items. Nurses can provide 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, in addition to creating copies of appropriate records, explore options for medication refills with patients that will allow current prescription records to be accessed via a national database (e.g., use of a national chain pharmacy) in the event of evacuation.

Policy Implications

In addition to educating patients about the health advantages of evacuation in a disaster event, it is also critical to inform policy-makers about research supporting the positive outcomes of evacuation and help decision-makers at all government levels to understand how and why well-developed evacuation plans likely support better management of health concerns. Other policy implications suggested by the findings of this study include advocating for delayed or waived co-pays for medication refills during times of disaster and advocating for continued development and use of electronic health records to provide easier access during temporary relocations or when usual facilities are not available. Since faith-based groups were noted by study participants to be a very important source of assistance and collaboration among responders, it may be of benefit to educate local and regional disaster planners as to these findings and further encourage partnerships that sustain and further situate these groups as a mainstay in local disaster response plans.

Future Research

Given the single context of disasters represented by this study, further study of how individuals with chronic illness(es) and/or their caregivers managed health-related

concerns in the context of other disasters would be beneficial. It would be especially useful to study these research aims in the context of disasters without advance warning where any preparedness actions would have to be completed in the non-disaster phase.

The concept of evacuation remains an important area of potential study, likely heightened by the events of the very active 2004 hurricane season described by many of these participants and huge evacuation challenges associated with Hurricane Katrina in 2005. As noted above, recent studies have reported the benefit of evacuation, and a body of literature clearly supporting this action is developing. But, despite the known advantages to both preparedness actions and evacuation, the complexities associated with this process are many (animal care, traffic, job-related concerns, expenses, family and homeowner responsibilities, to name just a few). 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(es) to plan for and undertake this often difficult process.

Conclusion

Every participant described the process of backburning; managing these types of concerns was not their first priority. Continued research in the area of disaster response helps nurses and other providers understand more about how patients with chronic illness can, or fail to, manage their health-related challenges during a disaster such as a hurricane. The rich descriptions provided by the participants in this study helped the researcher to meet the purpose of the study, to develop a theoretical framework that describes how these individuals with chronic illnesses who have experienced a disaster managed during the disaster.

Twenty seven individuals with chronic illnesses who experienced a disaster, seven caregivers, and six individuals who met both criteria participated in interviews to provide insight about how they managed health-related concerns during hurricanes. Analysis using the constant comparative method identified four ways that individuals backburnered health concerns as they dealt with pressing situations posed by the disaster event. These four ways, prudent, impromptu, deliberate, and unforeseen backburnering, were unique and complex. The ways featured five common factors: media impact, evacuation, preparation, attention, and recovery. Additional findings supported the helpfulness of providers, the dilemma of inaccessibility to previous providers and/or facilities, a strong geographical difference in perspectives related to response efforts, and impact of response efforts specific to short term and long term threats to health.

Findings from these participant descriptions added to or extended nursing knowledge about disasters and managing chronic illness in several ways. First, evacuation is a clear advantage to manage health-related concerns, especially so if the disaster involves lengthy emergency and reconstruction phases and victims are evacuated for longer than a week (allowing them to contact providers and/or resume health-related activities from afar). Second, local media efforts to relay information are appreciated and help victims access resources, make disaster-related decisions, and provide reassurance and emotional comfort. Third, faith-based and other local level efforts are perceived as a significant source of assistance to manage health-related concerns. Findings from this study can guide efforts to inform providers, policy-makers, and persons with chronic illnesses as to effective ways to manage health-related concerns, especially by the use of preparedness activities and evacuation whenever feasible.

Appendix A

Script for Initial Contact with Gatekeepers

I am a nurse and a student at Kent State University. I am studying disaster response and am trying to learn more about how individuals with chronic illness who have experienced a disaster managed their health-related challenges during the disaster. I would like to interview individuals who had a medical diagnosis of one or more chronic illnesses controlled with prescription medications, such as diabetes or heart disease, during the time of a disaster. To meet study goals, the disaster must have involved interruption of access to community resources, such as communication or supplies (e.g., community flood, tornado, or hurricane).

I would like to describe how individuals with chronic illness who have experienced a disaster managed health-related challenges such as medication needs, food and water intake, and wound management during the disaster. I believe that detailed description of the process of managing these challenges will help healthcare providers to work with individuals with chronic illnesses to better prepare to manage their health during a disaster.

I hope to talk with at least 30 individuals or their caregivers who could share these types of experiences. Would you be willing to help me in the following ways?

(Example using church leaders)

1. Allow me to post flyers about the study in your church from May 2009 to approximately September 2009?
2. Provide an information sheet about the study to your church members during that time period.
3. Allow me to visit XYZ church when I am in the area to explain the study briefly and recruit possible participants.

Appendix B

Recruitment Flyer

Chronic Illness and Disaster Preparedness Study Kent State University College of Nursing

- **DO YOU HAVE A CHRONIC ILLNESS?**
(such as diabetes, asthma, high blood pressure, bipolar disorder, depression)
- **HAVE YOU EXPERIENCED A DISASTER THAT INTERRUPTED SERVICES SUCH AS:**
 - **COMMUNICATION**
 - no telephone service or computer access
 - **TRANSPORTATION**
 - you getting out or others getting to you
 - **UTILITIES**
 - gas or electric disconnected for an extended period
 - **GETTING SUPPLIES**
 - food, water, or your medication
- **HAVE YOU BEEN TOLD TO EVACUATE YOUR HOME?**

I am a registered nurse and a student at the KSU College of Nursing. I want to learn more about how individuals with chronic illness managed health-related challenges during a disaster.

In this study:

- Participate in a 30-60 minute interview.
- Interviews scheduled at convenient time and safe location.
- Receive \$35 for participation.

Interested? Call 1-800-555-9999 (toll free) and leave your name, telephone number, or other way I might reach you. I will return your call as soon as possible to give you more information.

Thank you for considering this project!

Jackie Owens, MSN, RN, CNS, COHN-S
Graduate Student
Kent State University
College of Nursing

Appendix C

One Page Description of Study for Potential Participants

KSU Letterhead

Chronic Illness and Disaster Preparedness Study

I am a nurse and a student at Kent State University. I am studying disaster reponse and am trying to learn more about how individuals with chronic illness who have experienced a disaster managed during the disaster.

I would like to interview individuals who had a medical diagnosis of one or more chronic illnesses during the time of a disaster. The disaster must have involved interruption of access to community resources, such as communication or supplies. I am also interested in talking to caregivers who may have helped individuals with chronic illnesses to manage during a disaster.

I would like to describe how individuals with chronic illness who have experienced a disaster managed health-related challenges such as medication needs, food and water intake, and wound management during the disaster. I believe that a detailed description of the process of managing these challenges will help healthcare providers to work with individuals with chronic illness to better prepare to manage their health during a disaster.

This study will involve an interview that will last approximately 30-60 minutes. You will receive \$35 for your time and transportation expenses.

If you are interested in further information about the study , the first step is to call the study toll-free number, 1-800-555-9999 to leave your name, telephone number, or other way I might reach you. Please indicate if I may leave a message on your voice mail or answering machine. I will return your call as soon as possible.

Thank you for considering this project!

Jackie Owens, MSN, RN, CNS, COHN-S
Graduate Student
Kent State University
College of Nursing

Appendix D

Telephone Script

Telephone script for toll free line:

Thank you for calling the Chronic Illness and Disaster Preparedness Study phone line! My name is Jackie Owens and I am a registered nurse. I am a graduate student in the Kent State University College of Nursing conducting a research project for my doctoral degree in nursing.

This study will help me to learn more about how individuals with chronic illness who have experienced a disaster managed their health-related challenges during the disaster. If you have a medical diagnosis of one or more chronic illnesses, such as diabetes, heart disease, or renal failure, and have had to manage your illness during a disaster, I would like to talk to you to see if you qualify to participate in the study.

Please leave your first and last name, telephone number, and a brief message telling me the best time to contact you after the tone. Tell me if I can leave a message on your voice mail or answering machine. Please speak slowly and clearly. Thanks again for your interest in this study!

Appendix E

Screening Script: Individual with Chronic Illness

Screening/scheduling script for follow up calls to individuals with chronic illness:

May I speak with XXXX? Thanks for calling the Chronic Illness and Disaster Preparedness Study phone line! I am Jackie Owens. Are you still interested in learning more about the Chronic Illness and Disaster Preparedness Study? Y N

If YES, continue as follows:

As I said in the message I am a registered nurse and a graduate student in the Kent State University College of Nursing. I am conducting this study to learn more about how individuals with chronic illness who have experienced a disaster managed their health-related challenges during the disaster.

To ensure that you are eligible for the study and that participation would be in your best interest, I need to ask several questions. May I proceed with these questions? Y N

If YES, ask the following questions:

5. Have you been a victim of a disaster? Y N
6. Did the disaster interrupt your ability to use community resources such as communication or supplies? Y N
7. What type of disaster did you experience? _____
8. When did you experience this disaster? _____
9. How long were you without your usual community resources?

10. Did you have a medical diagnosis of one or more chronic illnesses during the time of the disaster? Y N
 - a. How did you control your illness(es) at that time?

11. Do you feel you have any illness that would prevent you from active participation in our interview? Y N
12. Do you feel you have any illness that would prevent you from accurately recalling the events of the disaster? Y N

If answers fit inclusion criteria, individuals will be informed that they meet the study criteria, informed as to what is expected of them, and scheduled as follows:	If individual does not meet the inclusion criteria (i.e., answers NO to one or more of the above the
---	--

		questions):
<p>1 You meet the criteria to be a part of this study. Let me tell you about the study. You will be asked to participate in an interview. It will last about 30-60 minutes. I will tape the interview to help me recall what we talk about.</p> <p>2 You will receive \$35 for your time and transportation expenses.</p> <p>3 Are you still interested in participating in this study? Y N</p>		<p>1 I'm sorry, you don't meet the criteria to be a part of this study. Thank you for your interest in the study! Would you like me to send you information about preparing to manage chronic illnesses in a disaster situation?</p>
<p>YES:</p> <p>I have set up several places to hold interviews. They are</p> <p>1. Which of these places would be the best location for you? _____</p> <p>2. What day(s) of the week do you prefer? _____</p> <p>3. I would like to complete interviews during normal business hours to ensure your safety. Is there a time between 9am and 6pm that you would be available on (day/date)? _____</p> <p>After interview is scheduled:</p> <p>Thanks for agreeing to be part of the study! I have you scheduled for an interview with me on Friday, May 30 at 1pm. We will meet at the XXXs building on XYZ Road in XXX, FL. Do you need directions? Y N</p> <p>Please report to room XXX on the second floor. There is an information desk in the main lobby if you need directions to the interview room. When you arrive I will answer any further questions you have and provide the consents that need to be signed before we begin. You will receive \$35 for your participation in this study.</p> <p>Do you have any questions? Y N</p> <p>If NO:</p> <p>Thanks for your time. I'm looking forward to talking with you on May 30th at XXXX.</p>	<p>NO:</p> <p>Thank you for your interest in the study! Would you like me to send you information about preparing to manage chronic illnesses in a disaster situation?</p>	

Appendix F

Screening Script: Caregiver

Screening/scheduling script for follow up calls to caregivers of individuals with chronic illness:

May I speak with XXXX? I am Jackie Owens. I am a registered nurse and a graduate student in the Kent State University College of Nursing. I am conducting a study to learn more about how individuals with chronic illness who have experienced a disaster managed their health-related challenges during the disaster.

I understand you are a caregiver for XXXXX who had to manage his/her (fill in type of illness) during a (fill in type of disaster). He/she indicated that I might call you to see if you would be interested in participating in the study to provide additional information about how XXXXXX managed during the (fill in type of disaster).

In order to ensure that you are eligible for the study and that participation would be in your best interest, I need to ask several questions. May I proceed with these questions? Y
N

If YES, ask the following questions:

1. Did you provide some level of care at the time of the disaster? Y N
2. How were you available to XXXX at the time of the disaster? (e.g., present during the disaster or assisted by phone).

If answers fit inclusion criteria, individuals will be informed that they meet the study criteria, informed as to what is expected of them, and scheduled as follows:		If individual does not meet the inclusion criteria (i.e., answers NO to one or more of the above the questions):
4 You meet the criteria to be a part of this study. Let me tell you about the study. You will be asked to participate in an interview. It will last about 30-60 minutes. I will tape the interview to help me recall what we talk about. 5 You will receive \$35 for your time and transportation expenses. 6 Are you still interested in participating in this study? Y N		2 I'm sorry, you don't meet the criteria to be a part of this study. Thank you for your interest in the study! Would you like me to send you
YES:	NO:	

<p>I have set up several places to hold interviews. They are</p> <p>4. Which of these places would be the best location for you? _____</p> <p>5. What day(s) of the week do you prefer? _____</p> <p>6. I would like to complete interviews during normal business hours to ensure your safety. Is there a time between 9am and 6pm that you would be available on (day/date)?_____</p> <p>After interview is scheduled:</p> <p>Thanks for agreeing to be part of the study! I have you scheduled for an interview with me on Friday, May 30 at 1pm. We will meet at the XXXs building on XYZ Road in XXX, FL. Do you need directions? Y N</p> <p>Please report to room XXX on the second floor. There is an information desk in the main lobby if you need directions to the interview room. When you arrive I will answer any further questions you have and provide the consents that need to be signed before we begin. You will receive \$35 for your participation in this study.</p> <p>Do you have any questions? Y N</p> <p>If NO:</p> <p>Thanks for your time. I'm looking forward to talking with you on May 30th at XXXX.</p>	<p>Thank you for your interest in the study! Would you like me to send you information about preparing to manage chronic illnesses in a disaster situation?</p>	<p>information about preparing to manage chronic illnesses in a disaster situation?</p>
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Appendix G

Consent Forms: Individual with Chronic Illness and Caregivers

1 Consent Form: Individual with Chronic Illness

Consent Form: Chronic Illness and Disaster Preparedness Study

Consent form on KSU departmental letterhead

I want to do research on Chronic Illness and Disaster Preparedness. I want to do this because I would like to be able to describe how individuals with chronic illness who have experienced a disaster managed health-related challenges such as medication needs, food and water intake, and wound management during the disaster. I believe that detailed description of the process of managing these challenges will help healthcare providers to work with individuals with chronic illnesses to better prepare to manage their health during a disaster.

I would like you to take part in this project. If you decide to do this, you will be asked to discuss your experiences related to managing your health-related challenges during a disaster in an interview. The interview will last approximately 30-60 minutes and you will receive \$35 for your participation.

The interview will be audiotaped to help me remember what we talk about. We will use your first name only and your identity will be kept strictly confidential. There are minimal foreseeable risks since participation is completely voluntary and you may change your decision to participate at any time without any penalty. However, should you experience emotional distress while recalling the events of the disaster; we can stop the interview at any point and I will provide a list of local community services or refer you to emergency services via the 911 emergency response system.

If you take part in this project you may help healthcare providers to better understand how to help individuals with chronic illness learn to manage their health-related needs during a disaster. Taking part in this project is entirely up to you, and no one will hold it against you if you decide not to do it. As noted above, if you do take part, you may stop at any time.

If you want to know more about this research project, please call me at [phone #; include adviser's name and phone number, if appropriate]. The project has been approved by Kent State University. If you have questions about Kent State University's rules for research, please call Dr. John West, Vice President of Research, Division of Research and Graduate Studies (Tel. 330.672.2704).

You will get a copy of this consent form.

Sincerely,
Jackie Owens, MSN, RN, CNS, COHN-S
Graduate Student
Kent State University
College of Nursing

B. CONSENT STATEMENT(S)

1. **I agree to take part in this project. I know what I will have to do and that I can stop at any time.**

Signature

Date

RESEARCHER COPY

Consent Form: Chronic Illness and Disaster Preparedness Study

Consent form on KSU departmental letterhead

I want to do research on Chronic Illness and Disaster Preparedness. I want to do this because I would like to be able to describe how individuals with chronic illness who have experienced a disaster managed health-related challenges such as medication needs, food and water intake, and wound management during the disaster. I believe that detailed description of the process of managing these challenges will help healthcare providers to work with individuals with chronic illnesses to better prepare to manage their health during a disaster.

I would like you to take part in this project. If you decide to do this, you will be asked to discuss your experiences related to managing your health-related challenges during a disaster in an interview. The interview will last approximately 30-60 minutes and you will receive \$35 for your participation.

The interview will be audiotaped to help me remember what we talk about. We will use your first name only and your identity will be kept strictly confidential. There are minimal foreseeable risks since participation is completely voluntary and you may change your decision to participate at any time without any penalty. However, should you experience emotional distress while recalling the events of the disaster; we can stop the interview at any point and I will provide a list of local community services or refer you to emergency services via the 911 emergency response system.

If you take part in this project you may help healthcare providers to better understand how to help individuals with chronic illness learn to manage their health-related needs during a disaster. Taking part in this project is entirely up to you, and no one will hold it against you if you decide not to do it. As noted above, if you do take part, you may stop at any time.

If you want to know more about this research project, please call me at [phone #; include adviser's name and phone number, if appropriate]. The project has been approved by Kent State University. If you have questions about Kent State University's rules for research, please call Dr. John West, Vice President of Research, Division of Research and Graduate Studies (Tel. 330.672.2704).

You will get a copy of this consent form.

Sincerely,
Jackie Owens, MSN, RN, CNS, COHN-S
Graduate Student
Kent State University
College of Nursing

B. CONSENT STATEMENT(S)

1. **I agree to take part in this project. I know what I will have to do and that I can stop at any time.**

Signature

Date

PARTICIPANT COPY

2 Consent Form: Caregiver

Consent Form: Chronic Illness and Disaster Preparedness Study

Consent form on KSU departmental letterhead

I want to do research on Chronic Illness and Disaster Preparedness. I want to do this because I would like to be able to describe how individuals with chronic illness who have experienced a disaster managed health-related challenges such as medication needs, food and water intake, and wound management during the disaster. I believe that detailed description of the process of managing these challenges will help healthcare providers to work with individuals with chronic illnesses to better prepare to manage their health during a disaster.

I would like you to take part in this project. If you decide to do this, you will be asked to discuss your experiences related to helping your patient manage health-related challenges during a disaster in an interview. The interview will last approximately 30-60 minutes and you will receive \$35 for your participation.

The interview will be audiotaped to help me remember what we talk about. We will use your first name only and your identity will be kept strictly confidential. There are minimal foreseeable risks since participation is completely voluntary and you may change your decision to participate at any time without any penalty. However, should you experience emotional distress while recalling the events of the disaster; we can stop the interview at any point and I will provide a list of local community services or refer you to emergency services via the 911 emergency response system.

If you take part in this project you may help healthcare providers to better understand how to help individuals with chronic illness learn to manage their health-related needs during a disaster. Taking part in this project is entirely up to you, and no one will hold it against you if you decide not to do it. As noted above, if you do take part, you may stop at any time.

If you want to know more about this research project, please call me at [phone #; include adviser's name and phone number, if appropriate]. The project has been approved by Kent State University. If you have questions about Kent State University's rules for research, please call Dr. John West, Vice President of Research, Division of Research and Graduate Studies (Tel. 330.672.2704).

You will get a copy of this consent form.

Sincerely,
Jackie Owens, MSN, RN, CNS, COHN-S
Graduate Student
Kent State University
College of Nursing

B. CONSENT STATEMENT(S)

1. **I agree to take part in this project. I know what I will have to do and that I can stop at any time.**

Signature

Date

RESEARCHER COPY

Consent Form: Chronic Illness and Disaster Preparedness Study

Consent form on KSU departmental letterhead

I want to do research on Chronic Illness and Disaster Preparedness. I want to do this because I would like to be able to describe how individuals with chronic illness who have experienced a disaster managed health-related challenges such as medication needs, food and water intake, and wound management during the disaster. I believe that detailed description of the process of managing these challenges will help healthcare providers to work with individuals with chronic illnesses to better prepare to manage their health during a disaster.

I would like you to take part in this project. If you decide to do this, you will be asked to discuss your experiences related to helping your patient manage health-related challenges during a disaster in an interview. The interview will last approximately 30-60 minutes and you will receive \$35 for your participation.

The interview will be audiotaped to help me remember what we talk about. We will use your first name only and your identity will be kept strictly confidential. There are minimal foreseeable risks since participation is completely voluntary and you may change your decision to participate at any time without any penalty. However, should you experience emotional distress while recalling the events of the disaster; we can stop the interview at any point and I will provide a list of local community services or refer you to emergency services via the 911 emergency response system.

If you take part in this project you may help healthcare providers to better understand how to help individuals with chronic illness learn to manage their health-related needs during a disaster. Taking part in this project is entirely up to you, and no one will hold it against you if you decide not to do it. As noted above, if you do take part, you may stop at any time.

If you want to know more about this research project, please call me at [phone #; include adviser's name and phone number, if appropriate]. The project has been approved by Kent State University. If you have questions about Kent State University's rules for research, please call Dr. John West, Vice President of Research, Division of Research and Graduate Studies (Tel. 330.672.2704).

You will get a copy of this consent form.

Sincerely,

Jackie Owens, MSN, RN, CNS, COHN-S
Graduate Student
Kent State University
College of Nursing

B. CONSENT STATEMENT(S)

1. **I agree to take part in this project. I know what I will have to do and that I can stop at any time.**

Signature

Date

PARTICIPANT COPY

3 Consent Form to Recontact Participants

Consent form on KSU departmental letterhead

Participant # _____

CONTACT FORM

Study: Chronic Illness and Disaster Preparedness Study

- Are you interested in receiving a copy of the research findings from this project?
_____ Yes _____ No
- Are you interested in receiving correspondence regarding the project?
_____ Yes _____ No

If Yes to either question, how/where should I send this information to:

Name/Initials

(How should I address the envelope): _____

Street/Box #: _____

City: _____ State: _____ Zip Code: _____

- It may be useful for me to ask for brief clarification about something we talked about in the interview, or some additional information about a topic. This would take no longer than 15 minutes. There is no compensation for this part of the study, but I would appreciate the opportunity to recontact you in the event that this would help me understand your health-related challenges as best as I can. Would you be willing to be contacted by phone, if necessary?

_____ Yes _____ No

If yes, please provide a telephone number where I can reach you

_____.

May I leave a message? _____ Yes _____ No

Appendix H
Audiotape Consent Forms

KSU Letterhead

AUDIO/VIDEOTAPE/PHOTOGRAPH CONSENT FORM

I agree to audiotaping at _____
on _____.

I understand that tapes will be erased upon completion of the study.

Signature

Date

RESEARCHER COPY

KSU Letterhead

AUDIO/VIDEOTAPE/PHOTOGRAPH CONSENT FORM

I agree to audiotaping at _____
on _____.

I understand that tapes will be erased upon completion of the study.

Signature

Date

PARTICIPANT COPY

Appendix I

Proposed Interview Sequence of Activities

Discussion Outline

1. Entry (Jackie Owens - Researcher)
 - a. Welcome and introduction (ice-breaking)
 - b. Reaffirm purpose of study
 - c. Verbal assent and signing of written consent
2. Tape recorder in use
 - a. Start/stop audio by Jackie
3. Sharing (Jackie & participant)
 - a. Researcher-led interview (30-60 minutes)
 - i. Assure comfort of surroundings
 - ii. Begin questioning using interview guide
 - iii. Process notes
 1. Key discussion points and sequence
 2. Obvious body language
 3. Indications of mood
 4. Striking themes
 - iv. Brief summary of responses for member check
 - v. Completion of demographic information sheet
4. Post-interview Dialogue (Jackie and advisor)
 - a. Observations
 - b. Potential changes/improvements
5. Logistics
 - a. Jackie – researcher
 - i. Assures assent/consent
 - ii. Communication with interview site personnel as needed
 - iii. Secures location; set-up/clean up
 - iv. Brings/operates equipment
 - v. Takes process notes
 - vi. Participates in wrap up summary and post interview reflection

Appendix J

Interview Opening and Question Guide

Opening Script:

The researcher will use this script at the start of interviews to obtain assent and consent from the participants:

"Hi, I'm Jackie Owens. Are you Matilda? And you're here to participate in the Chronic Illness and Disaster Preparedness Study? We'll spend about 30 to 60 minutes talking about your experiences in the disaster you told me about briefly on the phone. We can stop this interview at any time – just let me know if you change your mind. I will be audiotaping our interview to help me recall what you tell me. I may also be writing some things down to help me remember what you say so I will get it right. Also, we will just call each other by first name.

Are you still willing to be interviewed today? Y N

I have the consent forms we talked about on the phone here for you to sign. Please take as long as you need to read them over. Feel free to ask me any questions or share any concerns you have before we start.

Interview Question Guide: Individual With Chronic Illness

You indicated that you have a chronic illness and have had to manage health-related concerns during the time of a disaster. I am interested in learning more about how you managed your illness during this time.

1. First I'd like you to share with me some information about how you manage your illness each day.
2. Now, tell me the story about the disaster you experienced. Start when you first were aware that it might be coming.
 - a. Can you describe for me what type of disaster this was?
 - b. Can you describe for me what types of services or resources you usually have that you didn't have at the time of this disaster?
 - c. How long did interruption of services last?
3. Tell me a story about how you went about managing your illness during the time of this disaster.
 - a. Can you describe for me the steps you had to take to manage XXX?
 - b. Can you tell me about what you felt went well in managing XXXX?
 - c. Describe for me what types of activities were more difficult to manage during this time.
 - d. Can you think about anything that might have made it easier to manage your health concerns during this time?
 - e. Tell me about anything you might do differently since you had this experience.

- f. Think once more about what you told me went well and what was difficult for you in managing your illness during the disaster. Can you share with me any steps that you feel might have made the difference between them?
- g. What type of contact did you have with a nurse or doctor during this time?
- h. Tell me about any help you received from local, state, or federal government responders?

Interview Question Guide: Caregiver

You indicated that you care for a person with a chronic illness who had to manage health-related concerns during a disaster. I am interested in learning more about how that person managed his/her chronic illness during this time.

1. First I'd like you to share with me some information about how Ethel manages her illness each day.
 - a. Tell me about what type of assistance you give her to manage this illness.
2. Now, tell me the story about the disaster that the two of you experienced.
 - a. Can you describe for me what type of disaster this was?
 - b. Can you describe for me what types of services or resources you usually have that you didn't have at the time of this disaster?
 - c. How long did interruption of services last?
3. Share with me a story about how Ethel went about managing her illness during the time of this disaster.
 - a. Can you describe for me the steps she or you had to take to manage XXX?
 - b. Can you tell me about what you felt went well in managing Ethel's XXXX?
 - c. Describe for me what types of activities were more difficult to manage during this time.

- d. Can you think about anything that might have made it easier to manage Ethel's health concerns during this time?
- e. Tell me about anything you might do differently since you had this experience.
- f. Think once more about what you told me went well and what was difficult related to managing Ethel's illness during the disaster. Can you share with me any steps that you feel might have made the difference between them?
- g. What type of contact did you have with Ethel during this time? What type of contact did you have with other providers or government responding agencies during this time?

Appendix K

Demographic Data Sheet Chronic Illness and Disaster Preparedness Study

Participant # _____

Please fill out the following information to help me have an overall idea of what types of people participated in this study. **All information is optional.** If you need help to fill this out, I am glad to help you.

Age: _____

Gender: MALE / FEMALE (Circle)

Which ONE of the following BEST describes how you see yourself?

- ____ American Indian or Alaska Native
- ____ Asian
- ____ Native Hawaiian or Other Pacific Islander
- ____ Black or African American
- ____ Hispanic or Latino
- ____ White or Caucasian
- ____ More than one race
- ____ Other

Circle the work status you feel BEST describes you:

Work Status: Employed FULL TIME Employed PART TIME RETIRED
UNEMPLOYED

Marital status: MARRIED SINGLE (Circle)

Number in household: _____

Number of Children: _____

Zip code: _____

Religious affiliation: _____

Current annual income: ENTER LETTER _____

- A. less than \$10, 000/year
- B. \$10, 000 - \$14, 999/year
- C. \$15, 000 - \$19, 999/year
- D. \$20, 000 - \$29, 999/year
- E. \$30, 000 - \$39, 999/year
- F. \$40, 000 - \$49, 999/year
- G. \$50, 000 - \$59, 999/year
- H. \$60, 000 - \$69, 999/year
- I. \$70, 000 - \$99, 999/year
- J. \$100, 000 - \$199, 999/year
- K. \$200, 000 or more/year

Appendix L

Bibliography of Media Data Included in Study Sample

I. Articles (n = 16)

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