

2019

## Improving Disaster Preparedness and Planning for Chronic Disease Populations

Gladys N. Gichomo  
*Walden University*

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# Walden University

College of Health Sciences

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Gladys Gichomo

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2019

Abstract

Improving Disaster Preparedness and Planning for Chronic Disease Populations

by

Gladys Gichomo

MBA, University of Baltimore, 2005

MSN, University of Maryland, 2003

BSN, Towson University, Baltimore, 2001

Proposal Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health

Walden University

November 2019

## Abstract

The significant rise of both chronic diseases and disasters in the last 20 years and the healthcare outcomes of individuals with chronic diseases during and in the aftermath of disasters have raised concerns among public health practitioners, healthcare providers, the U.S government, and the general public. Researchers have indicated that during disasters, the health outcomes of individuals with chronic diseases are significantly unfavorable compared to the general public. However, there is inadequate information on the management of chronic diseases, quality of care, and resource identification and allocation by disaster responders. This qualitative, grounded theory study, explored how the study participants addressed chronic disease needs during and after disasters. A total of 15 adult disaster relief responders who had been involved in disaster planning, response, or care management of individuals with chronic diseases, were recruited through snowballing, public/bulleting postings, and social media. Using the ecological model of disaster management allowed the identification of individual and societal influences that hinder disaster preparedness and chronic disease management. Data collection consisted of semistructured in-depth open-ended interview questions, allowing participants to share their lived experiences. Data were analyzed through open, axial, and selective coding and managed using the Atlas ti8 software. The findings supported the ecological model of disaster management and strategies such as the use of special needs shelters during impending disasters. Such strategies could enhance disaster preparedness and planning efforts and potentially improve health outcomes during and after disasters.

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## Dedication

With a lot of love and gratitude, I dedicate this dissertation to my family: my kind and loving husband Ken, whose unwavering support was beyond measure. To my wonderful children: Patience, Troy, Trisha, and Trey, whose understanding and prayers kept me going. I pray that this will be an inspiration for them to be lifelong learners, and for all of us to always work hard and be determined so as to accomplish the goals we set forth.

I also dedicate this study to my parents, Gilbert and Rose Gichomo, who have been there since day one, cheering and excited when I was accepted to the PhD program, being there to make sure the journey was bearable, praying for me and encouraging me to aim for the sky, believing in me even when I faltered, giving me tough love to make me stronger, and being by my side as I journeyed towards my goals; to my sister Susan, for her encouragement and her definition of a PhD which still tickles me; to my cousins, Monicah and Charles (Ubiro) for their support with the children; to my grandmother (Wachabi) who despite been from a different era, appreciates the quest and value of education and always encourages and prays for me each time we talked on the phone or in person; and to my nieces and nephews who think a PhD is foreign and out of reach.

I pray that this success and accomplishment is a reminder to all of us that time is of great value, procrastination is expensive, and there is need to set goals and keep them aligned. But most of all, trusting and believing in God in all we do is the key to any success, and God's timing is always the right timing. Stay blessed!

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## Chapter 1: Introduction to the Study

### **Introduction**

The healthcare outcomes of people with chronic diseases during and in the aftermath of a disaster, and increased incidents of natural disasters have raised concerns among public health practitioners, healthcare providers, the government, disaster responders, and the general public. The United States and the rest of the world have experienced an increase in catastrophic disasters in the last 20 years. Disaster planning strategies for before, during, and after disasters are constantly evolving to allow for better management and coordinated efforts (Centers for Disease Control and Prevention [CDC] 2016a; Ko, Strine, & Allweiss, 2014; Ward, Schiller, & Goodman, 2014). Public health practitioners are involved and concerned with the increasing trend of disasters and chronic diseases and therefore are dedicated to improving disaster preparedness and responses for individuals with chronic diseases. To meet the health needs of populations during and in the aftermath of a disaster, the public health sector is accountable for employing coordinated emergency response efforts that allow collaboration in terms of disaster planning, response, and recovery across the health care system and other emergency response sectors (Shoaf, 2014).

With this study, I sought to develop new strategies and enhance existing strategies for disaster preparedness, planning, and management of chronic diseases during disasters. By carrying out this grounded theory study and focusing on disaster planners and relief responders who had planned for or managed the care of individuals with chronic diseases,

I was able to accomplish the aim of the study. Exploring the experiences of these individuals enabled the review of strategies that were successful in their efforts for disaster response and management of chronic diseases. It also allowed the development of other strategies that can be used for managing chronic diseases during disasters and potentially improves healthcare outcomes of individuals with chronic diseases.

This study will influence and encourage public health practitioners, regulatory agencies, relief workers, first responders, nonprofit organizations, and communities to take active roles in preparedness planning for disaster response and recovery efforts for individuals with chronic diseases. These strategies also empower individuals with chronic diseases to better prepare for disasters given their vulnerabilities. Anticipating community needs for those with chronic diseases and identifying strategies for disaster response and management allows for adequate allocation of resources and care provision for those in need. Further implications for social change include the alleviation of suffering, prevention of further injuries, sickness, morbidity, lost productivity, death, and ensuring maintenance of quality life through disaster preparedness and planning for individuals with chronic diseases.

This chapter provides the foundation of the research study and starts by providing an introduction of the research problem and its significance. Next, I provide major background literature highlights regarding the research problem, and then discuss the problem statement, purpose of the study, research questions, and conceptual framework. Following that is a discussion regarding the type of study, in this case the qualitative



grounded theory methodology. I then discuss the nature of the study, define key concepts, and discuss assumptions and the scope of the study. Lastly, I elaborate on the study's contribution to society and literature.

### **Background**

The prevalence of chronic diseases and rise in natural disasters is a public health issue given the effects of both. A growing concern is the incidence and prevalence of chronic diseases for all ages, but especially the older adult population, and the rising trend in natural disasters across the United States (Arrieta, Foreman, Crook, & Icenogle, 2009; CDC, 2009; CDC, 2013; Demaio et al., 2013; Owens & Martsolf, 2014; Raghupathi, & Raghupathi, 2018). During disasters, individuals with chronic diseases experience increased devastation, vulnerability, reduced quality of life, and death more than the rest of individuals not compromised by chronic diseases (Demaio et al., 2013; Ryan et al., 2015). After major disasters, there are reports of increase in mental health consequences, impaired social functioning of adults and children, disease exacerbations and delay of care, and loss of healthcare infrastructure and inaccessibility of medical records as well as medical personnel (Chinen, 2017; Paterson, Wright, & Harris, 2018).

The two major disaster categories are natural disasters that occur as acts of God (tornados, earthquakes, storms, hurricanes, and floods) and manmade disasters that are acts of man due to negligence or inappropriate acts such as terrorism, fires, and war (Cannon, 1994). This study focused on natural disasters given their frequency and adverse effects on vulnerable communities. According to Guha-Sapir, Vos, Below, &

Ponserre (2011), natural disasters are further classified as geophysical (earthquakes and volcanoes), meteorological (storms, hurricanes, and tornadoes), climatological (droughts and wildfires), and hydrological (floods). When such disaster events occur, they affect the economic, social, health, and infrastructure of communities (Khan, Schwartz, & Johnson, 2014; Knap & Rusyn, 2016).

Chronic diseases among all age groups, but especially among older populations are the leading causes of poor health, disability, healthcare expenditure, and death in the United States, as well as the cause of close to two-thirds of death globally (Bauer, Briss, Goodman, & Bowman, 2014; CDC, 2016a; Raghupathi & Raghupathi, 2018).

Approximately 45% of all adults (133 million) have had at least one or more chronic diseases (CDC, 2016a; Ward et al., 2014). Every year, chronic diseases such as stroke, hypertension, respiratory infections, cancer, and diabetes account for 70% of all deaths in the United States, while over 25 million people with chronic diseases have some form of disability (CDC, 2016a). Additionally, treatment of individuals with chronic diseases accounts for 86% of healthcare costs in the United States (CDC, 2014; Gerteis et al., 2014).

Individuals with chronic diseases are adversely affected by disasters more than the general population (Bethel, Foreman, & Burke, 2011; Icenogle, Eastburn, & Arrieta, 2016). Issues noted for those with chronic diseases include medication interruption, lack of medical equipment, disruption of care, exacerbation of symptoms, increased stress, increased risk of morbidity, and mortality (Bethel et al., 2011; Davis, Wilson, Brock-

Martin, Glover, & Svendsen, 2010). Furthermore, the destruction of infrastructure, loss of life, displacement of communities, injuries, and spread of infectious diseases further compromise an already vulnerable population (Ford et al., 2006; Paterson et al., 2018). According to Bagget (2006), in the aftermath of a disaster, those with chronic diseases are at increased risks of symptom exacerbation and threat to life when medical facilities are destroyed, medical resources are inaccessible, and treatment options for chronic conditions are inadequate and limited.

The impact of disasters on chronic diseases became more evident in the Katrina disaster of 2005 where the greatest post disaster need was treatment of individuals with chronic diseases such as diabetes, heart disease, hypertension, asthma, and kidney diseases (Bagget, 2006; Owens & Martsolf, 2014; Sharma et al., 2008). As disasters have increased and the prevalence of chronic diseases continued to rise, individuals with chronic diseases and communities are still faced with challenges involving inadequate chronic disease management and poor health outcomes (Knap & Rusyn, 2016; Paterson et al., 2018; Raghupathi & Raghupathi, 2018). In addition, the destruction of infrastructure and displacement of communities after a disaster threatens the lives and wellbeing of individuals with chronic diseases (Chinen 2017; Ford et al., 2006; Paterson et al., 2018; Owens & Martsolf, 2014). After disasters, inadequate care, resources, and lack of continuity of care for chronic diseases such as cardiovascular diseases, asthma, diabetes, renal diseases, and HIV/AIDS led to increased symptom exacerbation that

resulted in increased morbidity and mortality among these populations (Chan & Kim, 2011; DeMaio et al., 2013; Robinson, Werdell, & Gruber, 2011).

The lack of individual and system-wide disaster preparedness is one of the factors that lead to unfavorable outcomes for individuals with chronic diseases when disasters strike (Arrieta et al., 2009; Banks, 2013). During disasters, individuals with chronic diseases were identified as not having disaster preparedness plans and being less likely to have them compared to the general population. In addition, disaster responders were not well equipped to manage the care of individuals with chronic diseases (Arrieta et al., 2009; Banks, 2013; Bethel et al., 2011). Challenges persist in terms of addressing chronic health needs and ensuring continuity of care for individuals with chronic diseases despite efforts to implement changes after Katrina (Horn & Kirsh, 2018; Icenogle et al., 2016).

### **Problem Statement**

The significant rise in both chronic diseases and disasters in the last two decades and healthcare outcomes of individuals with chronic diseases during and in the aftermath of disasters continues to raise concerns among public health practitioners, healthcare providers, the government, and the general public globally (CDC, 2009; CDC, 2016a; World Health Organization [WHO], 2016). Although chronic diseases are common among older adults, they affect people of all ages, are the leading causes of disability and death, hinder economic development, and are a growing global health concern (CDC, 2009; Ward et al., 2014; WHO, 2016). According to the CDC (2016a) and Ward et al. (2014), of the 117 million Americans with at least one chronic disease, 51.3% (60

million) have an additional two or more chronic diseases contributing to significant limitations, disabilities, and vulnerabilities to disasters. The number of individuals with chronic diseases is expected to rise to 157 million by the year 2020 while the number of those with more than one chronic disease is expected to rise from 63 million in 2005 to 81 million in 2020 (Bodenheimer, Chen, & Bennett, 2009).

Disaster events contribute to risk factors for chronic disease exacerbation through infrastructural damage, human and financial loss, strain on emergency and local health care response, and effects on health and the environment (CDC, 2016b). Evidence of the impact of disasters on chronic diseases was highlighted during Hurricane Katrina disaster in 2005, Hurricane Sandy of 2012, and Hurricanes Harvey and Irma of 2017. The greatest post disaster need identified after those disasters was treatment of individuals with chronic diseases such as diabetes, heart disease, hypertension, and kidney diseases (Bagget, 2006; Chinen, 2017; Murakami et al., 2015; Paterson et al., 2018; WHO, 2013). Emergencies lead to acute exacerbation or life-threatening deterioration of health for people with chronic diseases as a result of forced displacement, physical injuries, interruption of care, and degradation of living conditions (WHO, 2013).

The existence of chronic diseases is complicated by major disaster events that are in themselves stressful and destabilizing to individuals and communities, especially in the wake of inadequate disaster preparedness (Horn & Kirsh, 2018; Owens & Martsolf, 2014). There is, however, inadequate data regarding how disaster relief workers and health practitioners address needs of those with chronic diseases during and after

disasters (Demaio et al., 2013). There is a need for chronic disease management, quality care, and resource identification during and after disasters. To address this gap, conducting this study provides a platform for readers to have an in-depth understanding of the lived experiences of disaster planners and disaster relief responders in terms of chronic disease management, care, and resource identification during and in the aftermath of disasters.

### **Purpose of the Study**

The purpose of this qualitative grounded research study was to explore how disaster planners and relief responders address the needs of individuals with chronic diseases during and after disasters. This exploration enabled the development of disaster preparedness and management strategies for all stakeholders (individuals, public health practitioners, healthcare providers, disaster responders, all levels of government, and the local communities) to ensure appropriate and adequate disaster response measures are in place and applicable for these vulnerable communities. Having policies and strategies for chronic disease management during disasters that are derived from the experiences of relief workers and disaster planners allows for appropriate interventions that could help reduce the incidence of acute chronic illnesses, disease burden, and mortality rates. The study is an effort to improve disaster preparedness and chronic disease management for individuals before, during, and in the aftermath of disasters.

### **Research Questions**

The primary research question for this study is:

*RQ*: How do disaster relief planners and relief responders address the needs of individuals with chronic diseases during and in the aftermath of a disaster?

From the primary question, the following sub questions were derived:

*SQ1*: How do disaster planners and relief responders manage chronic disease exacerbations?

*SQ2*: In what ways are individuals with chronic diseases prepared during a disaster as reported by disaster relief responders and planners?

*SQ3*: In what ways were the disaster communities prepared for the response and management of individuals with chronic diseases as reported by disaster relief responders and planners?

*SQ4*: What strategies for chronic disease preparedness work following disasters as reported by disaster relief responders and planners?

*SQ5*: What strategies for chronic disease preparedness do not work following disasters as reported by disaster relief responders and planners?

### **Theoretical Framework**

This study used as a guide the ecological model of disaster management. This model was developed as a guiding framework for occupational health nurses in developing disaster management programs (Beaton et al., 2008). It was designed to guide occupational health nurses with systematic and strategic reasoning in the roles of disaster planners and collaborators. The model is broad in scope as it incorporates processes and structures of disaster planning, preparedness, response, and recovery (Beaton et al.,

2008). The model has been used in different communities by several researchers (Johnson, 2011; Phillip, Ring, & Hackett, 2011; Radhakrishman & Jacelon, 2009) with the aims of getting a better description and understanding of complex human behaviors in relation to disaster management.

In the ecological model of disaster management, Beaton (2008) proposes that effective disaster management, planning, preparedness, and response occurs at the individual/family level as well as community, state, federal, and global levels. When there is integration and interaction among these levels, there is enhanced disaster preparedness and management for both individuals and organizations (Beaton et al., 2008). Therefore, using this model for disaster preparedness among individuals with chronic diseases allowed the exploration of individual and societal influences that may hinder disease management and disaster preparedness. In addition, it enabled the search for experiences of disaster planners and disaster relief workers as they planned and managed the care of individuals with chronic diseases during disasters. In Chapter 2, I provide a detailed discussion of the ecological model of disaster management.

### **Nature of the Study**

The study is a qualitative research design using the grounded theory approach. The qualitative design was chosen given its inductive, flexible, and naturalistic outlook and holistic approach that puts emphasis on validity as explained by Creswell, 2003 and Taylor, Bogdan, & DeVault, 2015). Although there are four main qualitative approaches, I chose to use the grounded theory approach to allow for the exploration and deeper



understanding of how disaster planners and disaster relief workers plan and manage chronic diseases during and in the aftermath of disasters. In using in-depth interviewing, I was able to obtain firsthand insights and experiences involving how relief workers and responders manage chronic diseases and preparedness strategies that work as well as those that do not work during and after disasters.

The three concepts explored in this study were the effects of disasters on individuals with chronic diseases, disaster relief workers' and planners' approaches to chronic diseases during disasters and in the aftermath of disasters, and strategies for chronic disease management during and after disasters. The after effects of disasters continue to be of concern especially for those with chronic diseases. Information on the direct and indirect effects of disasters may enable responders and practitioners to better prepare for disasters. Direct effects include morbidity, mortality, structural and nonstructural damage to healthcare facilities, service delivery interruption, and stress while indirect effects include delayed access to care and population displacement (Ciottone et al., 2016; Koenig & Schultz, 2016).

Approaches to chronic diseases during disasters used by relief workers were another concept explored in this study. Investigating practices that disaster relief workers and planners have used to manage chronic diseases during disasters allows these individuals to provide their firsthand experiences in caring for those with chronic diseases. This exploration allows the researcher to gather information on the approach methods used by disaster responders, their challenges, as well as their successes. The last

concept explored was the strategies for disease management during and after disasters. Exploring these strategies may allow for determining areas of chronic disease management that require improvement and a platform for developing new strategies for disease management and maintenance during disasters.

The study participants were adult disaster relief responders and workers and planners who have planned, responded, or been involved in disaster response or the management of those with chronic diseases during and after disasters. These selection criteria allowed participants to share firsthand their experiences in planning or managing the care of those with chronic diseases. Data collection for the study was through an in-depth open-ended semi structured questionnaire administered over the phone and face to face. The use of in-depth questioning was important in exploring the participants' processes for managing chronic diseases during and in the aftermath of disasters. I carried out data analysis by use of the three coding stages for grounded theory (open, axial, and selective coding) and Atlas ti8 software for data management and organization.

### **Definition of Terms**

*Chronic diseases:* Health conditions not cured after 3 months once acquired or lasting up to a year or more. It has a slow progression and long duration, may or may not limit activities of daily living, and may or may not require ongoing medical care. Examples include hypertension, diabetes, asthma, arthritis, and diabetes (Benjamin, 2010; WHO, 2015).

*Disasters:* Sudden calamitous events that may potentially disrupt the functioning of a community or society and cause human, material, economic, and environmental loss exceeding the community or society's ability to cope using its own resources (International Federation of Red Cross and Red Crescent Societies [IFRC], 2015).

*Disaster Management:* The organization, responsibility, and resource management of all humanitarian aspects of emergencies to reduce disasters and improve response and recovery measures as well as policies, decisions, and operational activities for all types of disasters (Blanchard, 2008).

*Disaster Preparedness:* Planning, organizing, training, coordinating, and evaluating activities to prepare for and minimize the effects of disasters as well as reduce duplication of efforts (IFRC, 2015).

*Disaster relief workers:* Volunteers or agency employees who respond to disasters and provide humanitarian aid to people and their communities with an aim of getting their lives back to normal after disaster events (New World Encyclopedia, 2015).

*Healthcare practitioners:* Individuals trained and licensed to provide preventive, curative, and promotional healthcare to individuals and communities with the goal of meeting their health needs and improving population health outcomes (WHO, 2013b).

*Natural disasters:* A naturally occurring physical phenomena of rapid or slow onset classified as geophysical, climatological, hydrological, or meteorological (Guha-Sapir et al., 2011).

### **Assumptions**

There were several assumptions that drove my study. The first one was that the study participants would answer questions truthfully and honestly based on their experiences with no manipulation to reflect their perceptions. Another assumption was that those interviewed would not apply any bias in their responses but would be objective and sincere to allow objectivity when coding and analyzing the interviews. My other assumption was that the data collected would allow me to develop strategies for improving disaster response and management for individuals with chronic diseases. With the passage of time, memory fades and this led to another assumption involving the possibility of recall decay among participants.

### **Scope and Delimitations**

This study focused on the experiences of disaster relief workers and planners who have planned for or managed the care of individuals with chronic diseases during and after disasters. Inadequate individual and system wide disaster preparedness (Arrieta et al. (2009) and lack of chronic disease management during and after disasters (Banks (2013), are some of the factors that lead to unfavorable outcomes for these populations. The aim of the study was to understand firsthand the challenges, strategies, and successes of chronic disease management for participants. Understanding their experiences in terms of caring for these individuals allowed the development of strategies that could improve disaster preparedness and chronic disease management during and after disasters.

Disaster responders who responded to disasters but have not managed the care of individuals with chronic diseases were not included in the study as they lack firsthand experience involving caring for these individuals. This exclusion was determined through prescreened responses during the selection process. This study did not focus on individuals with chronic diseases who were involved in disasters as their perspective is not what the study sought. To ensure potential transferability of study results, I ensured that I provided an in-depth description of the study's aims, lived experiences of participants, and assumptions that drove the study.

### **Limitations**

A limitation of this study was the use of interviews as the source of data collection. Glasser (1992) recommended using both interviews and observations for grounded theory research to ensure a better understanding of both lived experiences and improve validity of the study. Having a small sample size in qualitative research is another limitation. Polit and Beck (2010) said that a small sample size hinders the transferability and generalization of study results because small sample sizes may not be representative of a larger population. Another potential limitation is that the participant's experiences may not easily be generalized to the general public because they responded to disasters in different locations and at different times and this presents different challenges, resources, and strategies. One bias that potentially influenced the study outcome was past researcher bias. However, I eliminated this by using the clarifying

researcher bias, a method that involves a self-reflection process that creates openness and honesty on how my background and beliefs may shape interpretation of findings.

### **Significance**

My study focused on the management of chronic diseases during and after disasters by exploring the experiences of disaster planners and relief workers during the planning and care management of individuals with chronic diseases. The findings contributed knowledge to public health practitioners, planners, responders, policymakers, and the general public regarding individual and organizational preparedness, management of chronic diseases, strategies that work do not work, and strategies that require improvement. In addition, findings allow the identification of strategies that could be developed to improve disaster preparedness and management for those with chronic diseases during and after disasters. This new knowledge will potentially advance practice in the areas of disaster preparedness, response, and disease management for those populations with chronic diseases. It will also enhance integration and collaborative efforts between governments, private community-based organizations, relief workers, and health practitioners in terms of enhancing disaster response and management for those with chronic diseases.

The study's implication for social change involves positive health outcomes for populations with chronic diseases after disasters. Potentially, the study will influence social change through developing strategies that encourage public health practitioners, regulatory agencies, nonprofit organizations, communities, and individuals to take active

roles in disaster planning and preparedness, recovery efforts, and chronic disease management. The results may also empower individuals to take charge of their health and wellbeing as well as personal preparedness plans and steps to improve or maintain their health status. Another potential implication for social change is to influence health practitioners, relief workers, community organizations, and the general public in engaging and mobilizing efforts to minimize impact of disasters on symptom exacerbation, morbidity, and mortality.

### **Summary**

In this chapter, I provided a description of the study topic and an explanation of why the study is needed and potential implications for public health. This study's aim was to develop strategies that would improve disaster preparedness, response, and management for individuals with chronic diseases during and after disasters. Exploring firsthand the experiences of disaster planners and relief workers in the planning, response, and management of chronic diseases during and after disasters allowed for the development of strategies that could improve disaster response and management for individuals with chronic diseases. After introducing the study, I provided some background information on related literature and the gap in literature, explained the problem statement as well as the main purpose of the study and its significance, and addressed the research questions. In Chapter 2, I will provide a detailed literature overview of disasters and chronic diseases pertinent to the study.

## Chapter 2: Literature Review

### **Introduction**

After a catastrophic event such as a disaster, communities and nations experience unexplainable devastation, anxiety, and disorientation due to injuries, death, and structural damage that they witness. Unexpected catastrophic events destabilize the normal routines of communities, rendering them helpless and vulnerable and impacting them in the short and long term after disasters (Nomura et al., 2016). Destabilizing disaster repercussions include overcrowding, substandard sheltering, poor sanitation, disease outbreak, inadequate food supply, disability, and death (Demaio et al., 2013; Nomura et al., 2016). Health and public practitioners continually strive to respond to such repercussions and minimize damage the best they can. Of great importance is the increased devastation, vulnerability, and reduced quality of life experienced by individuals with chronic diseases during and after disasters, and the lack of disaster preparedness and management for these populations (Demaio et al., 2013).

This study involved the development of strategies that could improve disaster preparedness and management for individuals with chronic diseases. The study specifically used the ecological model of disaster preparedness to explain how disaster relief workers managed the needs of those with chronic diseases during and in the aftermath of disasters. Using the model enabled the generation and development of chronic disease disaster preparedness and management strategies for both citizens and disaster responders. Having such strategies that focus on individuals with chronic



diseases during disasters will ensure that appropriate and adequate disaster response measures are in place. The goal is to improve disaster response and management of individuals with chronic diseases, which ultimately improves their quality of life and wellbeing.

There has been an increase in natural disasters in the last two decades as well as an increase in the prevalence of chronic diseases, and a projected increase to 157 million by the year 2020 (Bodenheimer et al., 2009). Disasters often leave behind infrastructural damage, community displacements, injuries, communicable diseases, loss of life, and devastation among affected communities (Ford et al., 2006). Of concern to the health practitioners and other stakeholders is the increased risk of adverse health outcomes for individuals with chronic diseases after disasters. In addition to the adverse health outcomes after disasters, there is inadequate disaster preparedness and care management for chronic disease individuals (Arrieta et al., 2009; Davis et al., 2010; Horn & Kirsh, 2018; Holt et al., 2008). It is therefore important to improve health outcomes of individuals with chronic diseases after disasters through better disaster preparedness, planning, and management strategies that target these vulnerable populations.

In this chapter, I describe through the literature review the health and life impact on individuals with chronic diseases during disasters and the research gap regarding preparedness and management of chronic diseases during disasters. I start with the search strategy that I used to obtain relevant literature for review, followed by an extensive discussion of the theoretical framework used for the study. I then follow with a

discussion of the literature related to key variables and concepts of the study and my approach to the identified problems. Lastly, I will discuss the research gap and provide a summary of the themes that emerged from the review of the literature.

### **Literature Search Strategy**

My search for studies about chronic diseases and disaster preparedness planning and management involved several electronic databases: CINAHL, MEDLINE, PubMed, Science Direct, Thoreau, Nursing and Allied Health Source, Public License of Science (PLOS), BioMed Central, Elsevier, Wiley Online Library, Oxford Journals, Research Gate, Library of Congress, JSTOR, and Google Scholar. In addition to these databases, I used websites of organizations such as: CDC, WHO, World Bank, Department of Homeland Security, and Federal Emergency Management (FEMA). I also used disaster and chronic disease related published books. The key words used in the search strategy were *prevalence of chronic diseases, types of disasters, frequency of disasters, impact of disasters, management of chronic diseases in disasters, disaster preparedness for individuals with chronic diseases, first responders and disaster preparedness, first responders and chronic diseases, health practitioners and chronic diseases in a disaster, disasters and chronic diseases, health outcomes for chronic disease individuals after a disaster, and management of chronic diseases in a disaster.*

### **Theoretical Framework**

The key concepts explored in this study were effects of disasters on chronic diseases, disaster relief responders and workers' approaches to chronic diseases during

and in the aftermath of disasters, and strategies for chronic disease management during and after disasters. This study used the ecological model of disaster management. This model was developed as a guiding framework for occupational health nurses in developing disaster management programs. The model has been used by other researchers to understand complex human behavior (Beaton et al., 2008). The model was designed to guide occupational health nurses in terms of systematic and strategic reasoning in the roles of disaster planners and collaborators. It is, however, a model that is broader in scope and incorporates processes and structures of disaster planning, preparedness, response and recovery.

This disaster management model is a framework whose premise indicates that systems are dynamic where everything is interconnected (Beaton et al., 2008). The model has puts emphasis on the interdependence of the various levels of disaster management (Microcosm (individual and family), organizational level (workplace, schools), community level, state level, federal level, and the macrocosm (global) level), during the whole disaster cycle. For this model to be effective, disaster management must occur with mutual interdependence at all the levels, from the disaster planning stages to the recovery phase (Beaton et al., 2008). According to Radhakrishnan and Jacelon (2009), the assumptions of the ecological model of disaster management are that: planning, preparedness, response, and recovery of disasters occur at various levels of organizations (Microcosm, organizational, community, state, federal, and macrocosm). Each level of the

model, is embedded within a more complex level and planning efforts at each level should be coordinated with the other levels in the disaster model.

### **Levels of the Ecological Model**

The model has six levels that are mutually interdependent and interact to influence the whole disaster management process and outcomes. The interactions are supposedly stronger between levels that are embedded closely together (Beaton et al., 2008). The six levels are microcosm (individual and family), organizational level (workplace, schools), community level, state level, federal level, and the macrocosm (global) level (Beaton et al., 2008). For this model to be effective, disaster-planning strategies at both state and federal levels need to incorporate the other levels. This works to influence the overall disaster process by addressing public health concerns regarding disaster preparedness and management.

### **Individual and Family Level System**

A recommendation for individuals and families is to develop a disaster plan and compile resources to last 3 to 7 days in the event a disaster occurs, which also includes an escape and evacuation plan (Der-Martirosian et al., 2014; Owens & Martsolf, 2014; Thomas, 2018). Developing such a disaster plan is basic; however, it has a positive effect on disaster response at both the organizational and community levels. The model encourages individual and family preparedness so that healthcare providers and other responders may respond to disasters knowing that their families' disaster related risks are minimized due to their preparedness (Beaton et al., 2008). Literature on disaster response

indicates that first responders often are disaster survivors and those trained in first aid and other medical skills may provide aid and assistance to their own family members (Beaton et al., 2008; Ripley, 2008). The ecological model therefore emphasizes how disaster-prepared individuals and families enhance the workplace and community levels of disaster response (Beaton et al., 2008).

### **Organizational Level**

This level refers to the workplace, schools, hospitals and such establishments. Focus is on the employees, workplace, and facilities and the need for disaster plans, evacuation routes, and disaster supplies. The need for disaster training at the workplace enhances the employee's skills in administering first aid, advice, and direction to their families, co-workers, and other disaster victims in the communities (Maiden, Paul, & Thompson, 2008). There is need also for organizations to have disaster business continuity and recovery plans for economic, legal, and ethical reasons (FEMA, 2014). In the aftermath of a disaster, communities and regions greatly depend on major employer's economic resilience. Ensuring minimal job losses after disasters minimizes the effects and recovery of that community (FEMA, 2014). According to the model, institutions such as the hospitals are vital for the recovery of disaster victims and may reduce the adverse effects on the health and the recovery of the entire community (Beaton et al., 2008).

### **Community Level**

Disaster preparedness measures at this level aim at the community at large. When disasters occur in an area, the responsibility falls on the local cities, municipalities, and counties. However, the ecological theory posits that the individual, family, and work place levels are interconnected and make the community layer. Despite managing some disaster management aspects at the community level, this theory encourages preparation and partnerships with individuals, families, local businesses and organizations for a more enhanced disaster management approach (Beaton et al., 2008). Communities train workplace-based emergency response volunteer teams who in turn educate individuals, families and work places and communicate disaster risks and disaster planning and management guidelines (Ripley, 2008).

### **State Level**

The state functions to provide guidance, assets, and resources to the local communities when they exceed their resources. These provisions support and sustain the locals during the disaster events and in the aftermath of the disaster (Beaton et al., 2008). The health departments and emergency management divisions in each state are responsible for the planning and preparedness efforts for major disasters in the state. The states also in collaboration with local communities and business partners provide training, education, and disaster exercises to the communities. These collaborative efforts between state and businesses, and communities ensure appropriate disaster response (Beaton et al., 2008).

**Federal Level**

The federal government responds to disaster relief calls from the state when disaster relief efforts exceed the local and state's level capabilities (Beaton et al., 2008). The president at the state governor's request may make disaster declarations and needed federal resources are disbursed to the communities impacted by the disaster (FEMA, 2015). At this level, the National Response Framework and National Incident Management spearhead the integration of federal, state, and local community disaster response into a collaborative and unified command system (Department of Homeland Security [DHS], 2008). The framework allows for a quicker and comprehensive response that is unified and synchronized activities (DHS, 2008).

**Global Level**

A disaster like the Indian Ocean Tsunami of 2004 is an example of a global level response given its catastrophic effects. According to Beaton et al., (2008), disasters of such a magnitude receive aid from the World Health Organization and other non-government organizations such as the International Red Cross. Like all the other levels, flexibility, perception, and being insightful are key elements of disaster response and recovery at the global level. In addition, global level responses require collaboration and cooperation between responding global agencies and the government of the affected county (Beaton et al., 2008).

### **Use of Theory in Similar Studies**

The ecological model of disaster management was used in the study, “Psychosocial responses to a disaster in the Caribbean: A case study of a Barbados cave-In”. The framework used the ecological model of disaster management to understand the psychosocial responses of the Arch Cot cave-in disaster in Barbados. Assessment was done on the interconnectedness of the multiple levels of the Barbados disaster management system, communications, collaborations, and partnerships. The findings indicated that there were communication challenges, poor coordination of services, and inadequate disaster preparedness for the agencies and workers. These challenges made it difficult to meet the needs of those affected effectively (Phillips, Ring, and Hackett, 2011).

Johnson (2011) used the model, “An ecological model of workplace bullying: A guide for intervention and research,” to understand the origin and outcomes of workplace bullying. The model assumes that the workplace is a series of interconnected layers within a society, and that there are elements at each level that influence bullying and response to bullying. According to Johnson (2011), the need, therefore, is to consider these elements when targeting interventions for workplace bullying. She further recommended that the model could be used to guide intervention planning and evaluation for workplace bullying initiatives (Johnson, 2011).

Radhakrishman and Jacelon (2009) used the ecological model of disaster management to determine strategies for chronic disease management during disasters in



their review “Synthesis of literature on strategies for chronic disease management post disasters.” The model was essential for the selection and synthesis of literature findings that focused on chronic disease management during disasters. Based on the findings, disaster relief efforts tailored to population characteristics are more beneficial. From the model, flexibility in disaster relief strategies is important for any response and recovery efforts (Radhakrishman & Jacelon, 2009).

### **Rationale for Ecological Model of Disaster Management**

Using this model for disaster preparedness among individuals with chronic diseases allows for addressing the individual influences that may hinder disease management and disaster preparedness. The model is cited as a useful tool to guide disaster preparedness at the various organizational levels and in identifying elements and processes that may be overlooked or underrepresented in the disaster management plans (Beaton et al., 2008). Given the inadequate disaster preparedness and management for individuals with chronic diseases, the model was useful in determining existing strategies that could be advanced through enhanced communications, collaboration and partnerships in all the levels from the individual level to the federal level. In addition, it could be used for future disaster planning and preparedness efforts by engaging the social environment of the target community and in advocating for policies that promote health.

### **Relationship of Model to Study**

The aim of the study was to develop strategies for improving disaster preparedness and management for communities with chronic diseases. The model used in

the study proposed that effective management, planning, preparedness, and response occurs at the individual/family level as well as the community, state, federal, and global levels. Integration and interactions among these levels enhance disaster preparedness and management for both individuals and organizations (Beaton et al., 2008). Using the above model enabled the development of appropriate and adequate disaster response measures for both chronic disease communities and disaster responders.

The model also helped in answering the research questions by exploring resources available to disaster relief workers during disaster response, utilization of the resources on chronic disease individuals, and in determining the ways in which individuals with chronic diseases were preparedness for disasters. Furthermore, it is a guide for developing disaster preparedness and management strategies fostered on collaborative efforts among all organizational levels for this population. The management and care of individuals with chronic diseases during a disaster, and how disaster relief workers address this population's needs are concepts explored in this study. The study also explored the disaster preparedness of individuals with chronic diseases. In addition, it guided the investigation on the effects of disasters on chronic diseases as well as seeking strategies for chronic disaster preparedness. The goal hence was to identify strategies that work following a disaster, and strategies that do not work to improve disaster outcomes for these individuals.

### **Literature Related to Key Variables and Concepts**

The key concepts explored in this study were the effects of disasters on individuals with chronic diseases, disaster relief workers' and disaster planners' approaches to chronic diseases before, during, and in the aftermath of disasters, and strategies for chronic disease management during and after disasters. The increased incidence of both disasters and chronic diseases in the United States and other parts of the world have prompted interest in the management and care of individuals with chronic diseases during disasters. This is because of increased health risks and injury susceptibility for these individuals above those of the general population (Owens & Martsolf, 2014). Additionally, there lacks disaster preparedness and health management for these populations during disasters, prompting concerns for the quality of their health maintenance during and in the aftermath of a disaster (Demaio et al., 2013).

### **Effects of Disasters on Chronic Diseases**

The vulnerability of Individuals with chronic diseases is reported especially in the setting of natural disasters given the increased health risks that lead to symptom exacerbation in addition to other effects (CDC, 2013; Demaio et al., 2013; Horn & Kirsh, 2018; Nomura et al., 2016; Owens & Martsolf, 2014). According to the findings of Ford et al. (2006) and Nomura et al. (2016), during disasters, there are adverse effects such as: destruction of infrastructure, loss of life, displacement of communities, injuries, and spread of infectious diseases. There is also great concern for those with chronic diseases given the threat to life and well-being after medical facilities are destroyed and access to

treatment severed (Ford et al., 2006; Nomura et al., 2016). In addition, the Katrina disaster of 2005 showed evidence of the great need for immediate treatment to those with diabetes, heart disease, hypertension, and kidney diseases (Ford et al., 2006).

Further evidence on the adverse health effects on individuals with chronic diseases was from a 2007 cross sectional study conducted by the International Committee of Red Cross on the 2004 Tsunami survivors. The study indicated that of the 1,188 cases presenting to the emergency room in the aftermath, 43.5% of the diagnoses were due to chronic diseases (Guha-Sapir, Van Panhuis, & Lagoutte, 2007). Additionally, over half of the consultations visiting the emergency department within the first week after access to healthcare services were reestablished were individuals with a history of chronic diseases who experienced acute symptoms. After the 2008 China earthquake, Chan and Kim (2011) assessed the health effects of a disaster on chronic illnesses as well as the post disaster health needs in a middle-income country such as China.

They carried out a cross sectional study in an emergency clinical setting on 182 patients presenting at the triage site after the disaster. The study conclusion was that 77% of all those requiring care had an underlying chronic medical condition compared to 54% who presented with trauma injuries (Chan & Kim, 2011). The main health needs identified were related to lack of chronic disease medications especially among the elderly population (Chan & Kim, 2011). It is evident that having an underlying chronic disease increases the risks of adverse effects and compromises further vulnerable populations during a disaster.

The overall health of individuals with chronic diseases is further compromised by disasters as evidenced in a study conducted 3 years after Hurricane Katrina. According to Jiao et al., (2011) a comparison done on hospital admissions 2 years pre-Katrina and 3 years post Katrina assessed for the presence of acute myocardial infarction (AMI). A total number of 418 patients out of 21,092 were admitted with the diagnosis post Katrina compared to 150 out of 21,079 patients before hurricane Katrina. In addition, those admitted post the disaster had a higher prevalence of smokers, non-insurance, medical non-compliance, multiple hospitalizations and history of coronary artery disease. The study concluded that the incidence of AMI onset age decreased from 62 years pre-Katrina to 59 years after the Katrina disaster (Jiao et al., 2011).

Extending further the research on the impact of disasters on chronic diseases, (Robinson et al., 2011) research on human immunodeficiency virus/ acquired immunodeficiency syndrome (HIV/AIDS) indicated that increased stress levels after a disaster aggravated chronic disease symptoms and exacerbated other illnesses among infected individuals. They found that such large catastrophic events affected those with chronic diseases such as HIV/AIDs as noted by the cluster of difference 4 (CD4) counts. They compared the CD4 count of AIDs patients before Katrina and after Katrina and discovered that the count severely dropped especially for those New Orleans residents returning after the disaster (Robinson et al., 2011). Most recently, researchers noted that there is greater morbidity and mortality for individuals with chronic diseases during and following a disaster. This is due to the vulnerability of these individuals in disasters,

exacerbation of symptoms leading to complications, and lack of appropriate care (Demaio et al., 2013; Horn & Kirsh, 2018; Nomura et al., 2016; Slim et al., 2016).

However, of greater concern is the lack of evidence-based guidelines and management for those with chronic diseases during and in the aftermath of disasters (Demaio et al., 2013 & Horn & Kirsh, 2016).

### **Approaches to Chronic Diseases in Disaster Events**

A few years following Hurricane Katrina, Arrieta et al. (2009) interviewed key informants who were healthcare providers and social workers at the hospitals, health centers, pharmacies, and HIV organizations on the management of chronic diseases during and immediately after the disaster. From their experiences, they highlighted the need for individual and community preparedness prior to disaster events (Arrieta et al., 2009). Individual preparedness meant awareness of medical information and having several days' supply of medications. The community and relief organizations on the other hand needed medication availability, awareness of chronic disease prevalence, better communication, and coordination of aid efforts for these individuals (Arrieta et al., 2009).

According to Banks, in a 2013 study, the greatest danger and challenge for older adults in disasters is the exacerbation of chronic diseases. He noted that much comorbidity among these individuals require multiple medications and specialized medical supplies and equipment for maintenance. During and after disasters, decline in their conditions occur due to interruption of supplies, lack of access to health providers, stress, and disruption of their daily eating and healthcare routines (Banks, 2013).

Approaches to chronic diseases during disasters according to Banks was noted to include personal preparedness, engaging neighborhood associations and community groups in evacuation plans, and having an updated medication list. In addition, home health services, clinics, and hospitals need to be included in community disaster planning to provide expert guidance and continued care to these populations (Banks, 2013).

Ochi, Hodgson, Landeg, Mayner, and Murray discussed another approach to chronic diseases during disasters in their 2014 study on disaster driven by evacuation and medication loss. They noted that individuals might survive the initial disaster; however, the aftermaths pose challenges when they are not adequately prepared, and relief workers have no resources for health maintenance. They discovered that medication availability for these individuals was paramount to continuity of care and health emergency risk reduction. It was also noted that preparedness actions such as having personal stockpiles, emergency kits, and the involvement of all stakeholders (patients, healthcare professionals, policy makers, and researchers) in preparedness actions and disease management during disasters would help minimize adverse health outcomes for these populations. Lastly, further research is needed to evaluate disaster risk reduction and identifying vulnerable populations for disaster preparedness (Ochi et al., 2014).

Medication procurement and access is continually identified as a major problem for individuals with chronic diseases during a disaster. Veenema, Rains, Casey-Lockyer, Springer, and Kowal (2015) further highlighted this problem in a 2015 study conducted on quality of healthcare services provided in disaster shelters. The authors noted that the

majority of the Katrina shelter evacuees with chronic diseases had only carried medications to last one to two days. The relief workers hence spent a lot of time filing prescriptions for these individuals. In addition, they assisted with medication management for those unable to self-medicate, a process that was difficult to coordinate (Veenema et al., 2015). They tried resolving the problem by grouping medications and using digital pictures to identify clients (Veenema et al., 2015). An approach to minimize medication shortage for those with chronic diseases is having individuals with chronic diseases obtain advanced prescriptions as a disaster preparedness measure (Radhakrishnan & Jacelon (2009).

Owens and Martsolf (2014) outlined other approaches to chronic diseases in their study on development of a framework on chronic diseases and disasters. They discovered that individuals minimally managed their health-related illness due to demands of evacuation, survival and reconstruction activities (Owens & Martsolf 2014). Strategies identified by their study participants regarding self- management of chronic diseases included use of media communications on preparedness prior to disasters, evacuation preparedness (searching for shelter availability and registration to special needs shelters for chronic diseases), and having preparedness items (medications, personal documents, water, and food). They echoed the findings of other researchers that preparedness activities for these populations prior to disasters improved response and management of chronic diseases during a disaster event. Response activities geared towards collaboration of resources, response at all levels, chronic diseases needs assessment, and consensus-



based protocols would lead to effective and timely management of chronic diseases during disaster events (Owens & Martsolf, 2014).

Another approach identified by Radhakrishnan and Jacelon (2009) is to have a system that identifies and registers patients in shelters and other relief areas during a disaster. Such a process would enable the relief workers to identify those with chronic diseases and hence allocate care expertise, medical supplies, and medications in a timely and appropriate manner. Lack of such a system was noted to delay distribution of resources and health services (Radhakrishnan & Jacelon 2009). Appropriate food distribution is another area easily resolved by having a registration system. Relief workers noted that inappropriate diets were given to the wrong people such as diabetics receiving sweetened foods.

A study conducted after the Hanshin earthquake of 1995 on 29 patients with rheumatism, diabetes, and chronic respiratory disease indicated that securing medication and being able to take them was of top priority (Mori et al., 2007). Other needs identified were ensuring correct room temperatures to avoid extreme cold or heat and having appropriate nutrition and diet. In addition, there was need for medical supplies, insulin syringes, and stress reducing strategies. The participants added that having volunteers and relief workers understand their physical limitations and capabilities was very important (Mori et al., 2007).

## **Disaster Planning and Management for Chronic Diseases**

The Missouri Health Department's Center for Infectious Disease Research and Policy (CIDRAP) developed a disaster preparedness plan for individuals with end stage renal disease (ESRD) who are on dialysis. In cases where individuals are sheltered in place and unable to access dialysis centers or the case of center destruction, the plan can sustain these individuals for three to ten days during a disaster event (CIDRAP, 2013). The plan includes a detailed three-day diet plan of meals and snacks that limit amount of waste in blood if dialysis is not available. It also includes forms that individuals can record their dialysis needs (dialysis location, frequency, dialyzers, medications), primary physicians, nephrologist, insurance, and other medical conditions (CIDRAP, 2013). This type of preparation may help individuals preserve health, help health practitioners and relief workers in directing and providing appropriate care during disasters.

The need to prepare and manage chronic diseases during and after a disaster remains evident. Bethel et al., 2011 concluded that it was less likely for vulnerable populations to be prepared for disasters than their counterparts were. In the study, individuals with three or more chronic diseases, disabilities and with reported poor health were less likely to have disaster preparedness plans and more than three days medication supply. The authors added that fostering partnerships with health care facilities, the government, non-profit organizations, and local businesses as a disaster preparedness strategy alleviates impact of disasters on the communities.

Lack of a population-based approach in the understanding of chronic diseases according to Radhakrishnan and Jacelon (2009) is among the top challenges that hinder management of chronic diseases during disasters. Having baseline knowledge of a population in terms of chronic disease prevalence would provide bases for disaster preparation and response especially immediately after a disaster. Specific needs such as medication and other medical supply donations would be guided by knowledge of disease prevalence. Another strategy is to ensure fast and accurate credentialing of volunteers providing care to chronic disease victims during a disaster. Having qualified people care for those with chronic diseases is an essential part of appropriate and effective relief efforts. Additionally, relief efforts need be coordinated through communication and collaboration with community-based organizations, institutions, and national aid agencies (Radhakrishnan & Jacelon, 2009).

According to Holt et al. (2008), the overall health status of a population, the extent of damage to the infrastructure, and public health assets of neighboring communities determine the impact caused by disasters. Therefore, assessing the presence of chronic health problems and resources available within a community is very important and needed to effectively plan for disasters and carryout effective responses (Holt et al., 2008). The Behavioral Risk Factor Surveillance System (BRFSS) is identified as a tool that can be used to identify populations with chronic diseases, their needs, and available resources for disaster preparedness. However, when combined with the geographical information system (GIS) the two could address the components of the recommended

surveillance tool (Holt et al., 2008). Using these tools could eliminate the existing concerns for public health practitioners regarding care and management of those with chronic illness in the advent of a disaster.

In planning for disasters, public health practitioners, the government, nonprofit organizations and other relief workers should incorporate strategies to deal with individuals who have chronic illnesses. According to Mori et al., (2007), health practitioners should plan and prioritize the needs of those with chronic diseases. Under consideration should be medication availability and other supplies, support for their physical daily needs given their limitations, stress management, appropriate diets, medical equipment to enhance mobility and prevent disease aggravation, and patient/family teaching (Mori et al., 2007). In addition, ensuring populations are well prepared is key to disaster response and management. Studies show that vulnerable populations such as those with chronic diseases do not have disaster preparedness plans compared to healthy populations (Bethel et al., 2011).

Mensah et al. (2005) recommended that public health practitioners should prepare for disaster response and management in disaster prone areas. The authors further noted that preparedness guidelines were needed to ensure appropriate disaster response and management especially for vulnerable populations. Recommended preparedness measures include disease surveillance to determine the prevalence of chronic diseases and daily management of chronic diseases. Additionally, they also suggested the need to

determine the health care capacity in disaster prone areas and neighboring areas to better plan for disaster events (Mensah et al., 2005).

### **Researchers' Approach to Problems**

This study highlights the adverse effects experienced by individuals with chronic diseases during and in the aftermath of a disaster. It also addresses the lack of preparedness and management of the chronic diseases when disaster strikes. There is limited literature on management of chronic diseases during disasters; however, there are some studies as noted above identifying strategies that relief workers used to manage chronic diseases. The various authors utilized different approaches to their studies and hence have varying strengths and weaknesses.

Owens and Martsolf (2014) conducted a grounded theory study on chronic diseases and disasters and developed a theoretical framework describing how individuals managed chronic illnesses during disasters. They interviewed individuals with chronic diseases and caregivers from Florida and New Orleans who had experienced a disaster. The results led to the development of a back burning model, a process whereby individuals shifted priorities from their health issues to address other needs they deemed important (Owens & Martsolf, 2014). A strength noted by the authors is the use of a qualitative inquiry, a naturalistic paradigm approach that brings out rich descriptions of experiences and processes by individuals with chronic diseases who actually experienced a disaster (Owens & Martsolf, 2014). A weakness noted by the authors in their approach is that the viewpoints were self-reported by individuals with chronic diseases and

caretakers who witnessed a hurricane hence the results could not be generalized in other instantaneous disasters such as tornadoes. In addition, although most participants were easily able to recall events of the disasters they had experienced, a retrospective study design could pose recall bias (Owens & Martsolf, 2014).

Ochi, Murray, and Hodgson (2013) reviewed literature on the health needs and relief activities of vulnerable populations at the time of the Great East Japan Earthquake disaster. The authors looked at studies that described experiences and interviews of rescue teams, assessed on-site health needs, and the prevalence of specific diseases at the time of the earthquake (Ochi et al., 2013). One limitation of the study that the authors described is that the available literature was from a short period from March 2011 to September 2012. Additionally, it was difficult to assess the full impact of health needs because there was little objective data such as in the epidemiological surveillance (Ochi et al., 2013).

In a study on disaster driven evacuation and medication loss, Ochi et al., (2014) identified one challenge in the data collection method. They noted the lack of comparative data and a standardized way of measuring the impact of bringing medication at evacuation and the use of convenience samples. In addition, they identified a publication bias given that the relevant articles reviewed in their studies were from the United States and specifically the Katrina disaster (Ochi et al., 2014). A strength used by these authors to overcome the data collection challenge was to include in their review, literature from a wide time period. They reviewed articles from January 2003 to August

2013, a process that allowed them to identify the extent and implications of lack of medication following disasters (Ochi et al., 2014).

Radhakrishnan and Jocelon (2009) highlighted limitations of their review study that identified strategies to manage chronic illnesses during disasters. They reviewed articles focusing on chronic disaster management during natural disasters and eliminated manmade disasters. In addition, the review lacked experimental studies although note worth is the challenge of manipulating study subjects during disasters to conduct an experimental study. Lastly, the authors eliminated studies other than in the English language (Radhakrishnan & Jocelon, 2009). The authors utilized the ecological model of disaster management to guide selection and synthesis of articles, a strategy that strengthened their study. In addition, they reviewed articles from January 2000 to May 2009 and used both computerized database search and manual reference search for relevant articles (Radhakrishnan & Jocelon, 2009).

### **Gaps**

It is evident that the existence of chronic illnesses in any given community is complicated by major stressful events such as disasters and especially when individuals are inadequately prepared (Davis, et al., 2010; Owens & Martsolf, 2014). The management and care of these populations by healthcare practitioners and other relief workers during and after disasters does not adequately address their healthcare needs (Davis et al., 2010; Horn & Kirsh, 2018). Despite these findings, there are inadequate data identifying the health needs of individuals with chronic diseases, availability of

resources such as medical equipment and medications, and access to healthcare after a disaster (Davis et al., 2010; Holt et al., 2008). Additionally, even with the findings on the healthcare outcomes of individuals with chronic diseases, there is very little research and data available regarding how relief workers and healthcare practitioners minimize complications and symptom aggravation of chronic diseases during disasters (Davis et al., 2010; Icenogle et al., 2016; Shehab, Anastario, & Lawry, 2008).

Researchers and healthcare practitioners therefore need to address the gaps identified in the management of chronic diseases during and after a disaster. Several methods can be applied to ensure closure of the noted gaps. One is by ensuring that disaster preparedness and relief efforts include management of chronic diseases and availability of needed resources for continuity of care. Having policies and strategies for chronic disease preparedness and management during and in the aftermath of a disaster will help reduce the incidence of acute on chronic illnesses, reduce disease burden, disability, and mortality rates (Bethel et al., 2011; Icenogle et al., 2016; Owens & Martsolf, 2014).

### **Summary and Conclusions**

For this study, the main themes that emerged are the effects of disasters on chronic diseases, management of chronic diseases during and after disasters by healthcare professionals, relief workers and individual patients, and recommendations for management for this vulnerable population. In reviewing the literature, evident themes are unavailability of medical supplies, lack of medications, and inaccessibility to



healthcare providers, lack of individual and community preparedness, and communication among responders (Arrieta et al., 2009; Owens & Martsorf, 2014). In addition, notable is the need for knowing the prevalence of chronic diseases in a community, knowledge of medication and health information by individuals, education of relief workers on needs for chronic diseases populations, and medication procurement (Arrieta et al., 2009; Banks, 2013; Ochi et al., 2014).

The adverse effect of disasters on chronic disease individuals is well documented, so are the health consequences that follow when disaster strikes. As noted, the effects of disasters affect all communities, but more so the vulnerable communities who are further compromised by events such as disasters. Such adverse effects range from destruction of infrastructure, damage to residential homes and loss of properties, economic and political impacts, disability and mortality, disruption of social life in communities, social and psychological disorders, and spread of diseases. In addition, there is the most pertinent disaster consequence addressed in this study, which is the exacerbation of chronic diseases during and after disasters (Ford et al., 2006; Demaio et al., 2013; Owens & Martsolf, 2014; Pourhosseini, Ardalan, & Mehrolhassani, 2015).

The literature though saturated with studies on the adverse effects, devastation, and health consequences of communities and especially those with chronic diseases lacks evidence or adequate information on management of chronic diseases after disasters. Researchers have focused less on how disaster relief workers and health practitioners manage chronic diseases during and in the aftermath of a disaster. There is scarce

research on disaster plans and preparedness strategies by relief workers and health practitioners that minimize chronic disease complications and symptom aggravation during and after disasters. The literature also indicates that there is inadequate data identifying the health needs of individuals with chronic diseases, the availability of resources such as medications and medical equipment (Holt et al., 2008), and access to healthcare after a disaster (Davis et al., 2010). Such information would be useful in disaster planning for this vulnerable population.

This study focused on identifying and developing strategies for disaster planning and management derived from the experiences of disaster planners and relief workers before, during and after a disaster. Having policies and strategies for chronic disease management during and after disasters would allow for appropriate interventions that could potentially reduce the incidence of acute on chronic illnesses, reduce disease burden, mortality rates, and other consequences of disasters on those with chronic diseases. The next chapter will discuss the study methodology used to develop strategies to improve the disaster preparedness and management for communities with chronic diseases.

## Chapter 3: Research Method

### **Introduction**

This study using the qualitative research design used the grounded theory approach. The purpose of the study was to improve disaster preparedness and management for individuals with chronic diseases. By exploring how disaster planners and relief workers plan and address the needs of individuals with chronic diseases during and in the aftermath of a disaster, I aim to develop strategies that will improve disaster preparedness and management for those with chronic diseases. In this chapter, I describe in a detailed manner the research methodology that I used to carry out this grounded theory research.

This chapter will start with an overview of the research design where I restate the research questions, define study concepts, and provide a rationale for the study's methodology. Next will be definitions and explanations of my role and any potential ethical issues. I will then discuss the methodology of this study in details to include the study participants' recruitment and sample size, sampling strategy, selection criteria, data collection instrument, and data analysis plan. Lastly, I will discuss issues of trustworthiness (validity and reliability) and ethical procedures, and provide a chapter summary.

### **Research Design and Rationale**

#### **Research Questions**

For this qualitative study, the primary research question was:

*RQ*: How do disaster relief workers and disaster planners address the needs of chronic disease individuals during and in the aftermath of a disaster? From the primary question, the following sub questions were derived:

*SQ1*: How do disaster planners and disaster relief responders manage chronic disease exacerbations?

*SQ2*: In what ways are individuals with chronic diseases prepared during disasters as reported by disaster relief responders and planners?

*SQ3*: In what ways were the disaster communities prepared for the response and management of individuals with chronic diseases as reported by disaster relief responders and planners?

*SQ4*: What strategies for chronic disease preparedness work following disasters as reported by disaster relief responders and planners?

*SQ5*: What strategies for chronic disease preparedness do not work following disasters as reported by disaster relief responders and planners?

### **Qualitative Method and Grounded Theory Design**

This study used the qualitative research methodology with a grounded theory tradition approach. Qualitative research, as explained by Taylor et al. (2015), is a research method that is inductive, flexible, has a holistic approach, puts emphasis on validity, and has a naturalistic outlook. The qualitative approach allows the researcher to investigate and describe phenomena of interest in detail, providing a deeper understanding of the issue. Data in a qualitative inquiry can be obtained through in-depth

interviews, direct observations, or written documents (Trochim, 2006). This study used interviews.

The flexibility of qualitative research means that data collection tools and methods can be adjusted as the research progresses. It is a method in which concepts, insights, and understandings are developed from patterns in the data and not preconceived theories or hypothesis (Creswell, 2009; Taylor et al., 2015). Qualitative research has four main approaches that explicitly explain the purpose of the research, role of researcher, stages involved, and data analysis method. These are ethnography, phenomenology, grounded theory, and field research. This study used the grounded theory approach.

Grounded theory was originally developed by Glaser and Strauss in the 1960s with the sole purpose of developing theory about a phenomenon of interest (Trochim, 2006). In this approach, the researcher begins with general questions that help guide the research and as data are collected, concepts are identified which leads to more data collection (Trochim,2006). In grounded theory, data are analyzed through coding, a process for categorizing data and describing implications of the data. Memoing, another analytic strategy, involves recording the ideas and thoughts of the researcher regarding a core concept throughout the study. The significance of grounded theory is that it provides sequential guidelines for conducting research, has specific strategies for managing the analytical phase of inquiry, integrates data collection and analysis, enhances qualitative

data analyses, and enables the legitimization of qualitative inquiry as a scientific inquiry (Charmaz, 2014; Hussein, Hirst, Salyers, & Osuji, 2014).

### **Design Rationale**

This study explored the experiences of disaster planners and relief workers in planning for and managing care for individuals with chronic diseases during and in the aftermath of disasters. The aim was to understand strategies and methods used by these responders and providers to address needs of individuals with chronic diseases during and after disasters. The goal is to develop strategies for disaster preparedness and management of chronic diseases for those individuals. Using the grounded theory approach enabled me to determine the participants' experiences and perspectives on managing individuals with chronic diseases.

The qualitative design is an inductive process that allows the researcher to carry out the study based on the interpreted data unlike the deductive nature of a quantitative approach (Creswell, 2009). In addition, the qualitative design enables the researcher to learn and understand deeply an individual's perspective and feelings regarding a particular subject while obtaining quantitative data is useful for measuring attitudes in a large sample (Taylor et al., 2015). I therefore opted for a grounded theory approach so as to understand the experiences of relief workers and healthcare practitioners with individuals with chronic diseases during disasters.

Prior to settling on this qualitative design, I researched and contemplated other quantitative methods for my study. According to Creswell (2009), the quantitative

method would be best in measuring attitudes across a large sample, require pre structured questions for the data collection, and the outcomes used to recommend a final course of action and the results generalized to a population of interest. I therefore settled for a qualitative grounded theory design that would provide an in-depth understanding of the processes of managing chronic diseases during disasters. Given that the grounded theory is an inductive method, it allowed me to direct the study through collected data to develop strategies for improving disaster preparedness and management for individuals with chronic diseases. This is not like the quantitative method, which is deductive in nature and starts with a hypothesis derived from an existing theory to guide research (Charmaz, 2014; Creswell, 2013).

The decision to use grounded theory methodology as my approach is because of its characteristic that offers flexibility to pursue themes that emerge from the data collection and during analysis process. The sampling process is an explicit continuous task of characteristics and meaning of categories until no new insights emerge (Charmaz, 2014; Creswell, 2013; Hussein et al, 2014). If new insights emerge, they may be a reflection of new categories that require further investigation, or they may contribute to existing categories that enrich the outcome (Charmaz, 2014). With this research design, I had to understand my role in the process to ensure compliance with research guidelines and ethics.

### **Role of the Researcher**

A qualitative researcher has the responsibility to bridge and integrate the development of research design, data collection, data analysis, and emerging categories in to propositions, models, or theories (Charmaz, 2014). Grounded theory researchers should demonstrate critical thinking skills and ability to facilitate the analysis of complex interrelationships and meaning. In addition, grounded theory researchers should be able to embrace different participant perspectives and be sensitive as they interpret meanings (Chamarz, 2014; Corbin & Strauss, 2014). Watt (2007) also puts emphasize on the need for qualitative researchers to be reflexive. He described reflexivity as the ability of a researcher to reflect on personal behavior, thoughts and the phenomena under study in order to become a better researcher.

My role as a researcher for this study called for an understanding of the grounded theory method to be able to carry out a successful study. In qualitative research, a researcher is a primary instrument for data collection (Creswell, 2007); therefore, an integral part of the study. Designing a study in which the study participants feel comfortable and safe sharing their experiences and recommendations is one of the goals for the study. As a researcher, there is need to recognize personal biases, values, and personal interests that may arise and address them accordingly (Creswell, 2009). My professional background as a registered nurse experienced in managing individuals with chronic diseases called for maintaining a clear boundary in the data collection and analysis process.



My primary role in this study was to interview participants and interpret data collected and to understand the process and the perspectives of the participants. A task in hand was ensuring ethical issues that could arise were addressed prior to collecting data. Addressing such ethical issues included obtaining permission to carry out the study from the International Review Board at Walden University, ensuring participant confidentiality, clearly explaining and providing information about the study to the participants, and ensuring participants signed a consent form. After the data collection and analysis, an important undertaking is to disseminate to readers and to share findings with the participants (Creswell, 2009).

## **Methodology**

### **Study Participants**

The grounded theory methodology was used to guide the data collection, analysis, and development of strategies for improving disaster preparedness and management for individuals with chronic diseases. The study participants were adult disaster relief responders/workers who have been involved in disaster response and care management of individuals with chronic diseases during and in the aftermath of a disaster. Also included were disaster planners who have specifically been involved in chronic disease planning and preparedness. The participants were recruited through snow balling, public postings within disaster relief organizations (Red Cross), health departments, community bulletin boards, and individual disaster responders by use of flyers, phone calls, and use of social media such as Facebook, WhatsApp, and LinkedIn.

The study participants meeting the previously stated criteria were affiliated with a government organization, non-profit organization, individual disaster responders, or healthcare workers. They also had responded to a disaster or cared for chronic disease individuals during disasters or in the aftermath of a disaster. In addition, individuals responsible for planning and policy making in disaster preparedness and management efforts for these populations were included in the study. These criteria ensured the selected participants best answered the research questions and enhanced the understanding of the phenomena (Sargeant, 2012). The use of open-ended questioning encouraged participants to tell their stories in their own words and descriptions.

### **Sampling Strategy**

Qualitative research uses non-probability sampling methods for which the investigation of a phenomenon focuses on a specific population. With these methods, the chance that an individual will be selected to participate in a study is unknown. However, having the appropriate sampling strategy ensures the focus of the study can be appropriately researched (Lopez & Whitehead, 2013). The method used for this study was the snowball sampling method, a participant-based referral method. It is a common sampling method used in various disciplines such as social sciences and medical science where a study participant refers another individual who meets the study criteria to the researcher (Kirchherr & Charles, 2018). Atkinson and Flint (2018) explained that snow ball sampling has a wider applicability in sociological research, and that it takes

advantage of the social networks of study participants to provide researchers with referrals for potential recruitment as study participants.

Snowball sampling can be a quick method of producing in-depth results, locating participants to fill in knowledge gaps in a phenomenon under study, and enabling access into hard to reach populations (Kirchherr & Charles, 2018). In addition, snowball sampling allows the development of trust given that the referrals are made by acquaintances or peers. The participants usually have experienced the phenomenon under different conditions therefore enriching the data and allowing the researcher to explore the various dimensions that emerge (Starks & Trinidad, 2007). The phenomenon in this study was trying to understand how individuals with chronic diseases are cared for and managed during and after disasters. Having such an understanding of what works in such instances will allow the development of preparedness and disease management strategies for these populations.

Unlike quantitative methodologies, the qualitative method does not have a preset sample size, but the number depends on the goal and purpose of the study (Starks & Trinidad, 2007). The qualitative researcher continually adds participants until a theoretical saturation point is reached. Theoretical saturation is when addition of participants to the study does not yield further insights or perspectives (Charmaz, 2014; Creswell, 2013; Starks & Trinidad, 2007). This study interviewed individuals who have responded to or cared for individuals with chronic diseases during and in the aftermath of a disaster, involved in disaster preparedness for chronic disease individuals, or healthcare

personnel who have managed the care of such individuals after a disaster. These varying experiences provided multiple dimensions on how to better manage chronic diseases in disasters. I continually recruited participants while concurrently analyzing the data and was able to determine data saturation when new themes no longer arose (Sargeant, 2012).

### **Participant Recruitment**

The aim of qualitative research is not to produce a statistically representative sample or for statistical inference but to understand a phenomenon. The method used to recruit participants puts emphasize on the individual characteristics hence highlighting the diversity and breadth of the sample population and enriches the phenomenon under study (Creswell, 2009). To answer the research questions, this study capitalized on the experiences of participants responding to different disasters in varying geographical areas. In addition, the care and management of chronic disease individuals after disasters in different settings further enhanced the phenomenon under study.

The recruitment plan for this study was to use a combination of methods to reach potential study participants. First, I identified and contacted organizations and healthcare facilities that respond to disasters and inquired about flyer distribution among their staff and volunteers. I, then, contacted local community sites such as fire houses, grocery stores, businesses, and community halls and requested the same. All the sites I contacted verbally confirmed that they had open access to their community bulletin boards. Once I received this confirmation, I distributed and posted the flyers with information about the study, eligibility criteria, and my contact information. To recruit individual participants, I

reached out through my social networks, colleagues, co-workers, and Walden's participant pool. Another recruitment effort was snow balling, where at the end of each interview, I requested participants if they could refer a potential participant in addition to sharing the study information and participant requirements with their friends and networks.

After potential participants reached out to me and identified themselves through initial phone calls, I ensured that they met the eligibility criteria through a screening questionnaire and confirmed their willingness to participate in the study. The use of phone calls was the main avenue by which I recruited participants for the study and a few face-to-face contacts. Once eligibility to participate was confirmed, I discussed in details the purpose of the study, the need for informed consent, confidentiality, and then scheduled an interview time. The interviews lasted anywhere between 33-80 minutes for the phone interviews depending on individual experiences and time availability. The face-to-face interviews lasted approximately 35 minutes.

### **Data Collection**

The data collection strategy in qualitative research can be a mixture of interviewing, observation, and review of documents (Creswell, 2009). For my study, I utilized interviews as the form for data collection. With grounded theory interviews, the researcher aims to elicit the participant's story with the assumption that their words will be understood as spoken and intended (Starks & Trinidad, 2007). A semistructured phone interview format with probing questions enabled the participants to provide detailed

accounts of their experiences in caring for individuals with chronic diseases during disasters and provided clarity on unclear matters.

The target participants were disaster planners and disaster relief workers who have planned for or managed care for individuals with chronic diseases in a disaster or in the aftermath. Prior to the beginning of each interview, I ensured that I received consent from the participants to continue with the interview process and provided an overview of the research study making sure I articulated the goals clearly. The data collection process followed an interview protocol that began with basic demographic questions and on to in-depth open-ended interviewing. The questions and answers process was audio recorded to ensure that answers were interpreted as intended. According to Creswell (2009), use of a digital recorder is the most common method of recording interviews as it preserves the entire interview for data analysis.

Data collection sample interview questions were (a) what types of disasters were you involved in, (b) did you encounter individuals with chronic diseases during your disaster response, (c) what were the most common chronic diseases noted, (d) how prepared were the individuals with chronic diseases, and (e) what preparedness measures did those with chronic diseases have in place? Additional areas that were addressed were the preparedness measures from the organizational perspectives, strategies that worked, strategies that did not work, and recommendations for improvement for both individuals and organizations. Finally, I reached out to the participants to provide a copy of the interview transcript to review for accuracy prior to final analysis to ensure data validity.

This strategic line of data collection will potentially improve disaster planning for individuals with chronic diseases.

### **Data Analysis**

The analysis of qualitative data begins during the data collection process as the researcher identifies concepts and themes that help understand the phenomenon under study. As data are collected, the researcher uses notes to identify important information and develops ways to code the data (Creswell, 2009). The most common method for qualitative data analysis is the inductive approach. The Inductive approach analyzes data with no predetermined structure or framework and uses the actual data collected to determine the structure of the analysis (Burnard, Gill, Stewart, Treasure, & Chadwick, 2008).

In grounded theory, data are constantly compared through the coding and analysis of data in three stages: stage one is open coding that involves examining, comparing, conceptualizing, and categorizing data; stage two is axial coding when data is re-assembled and grouped into patterns and the categories identified in the data; stage three is selective coding that identifies and describes the phenomenon (Starks & Trinidad, 2007). Using this three-stage method of analysis for my study allowed the separation and organization of the data into similar concepts and categories, development of relationships between the categories, and in grounding the experiences. My initial plan was to use NVivo for the data analysis; I however ended up using Atlas ti8, a type of Computer-Aided Qualitative Data Analysis Software (CAQDAS) tool. Atlas ti8 allows

researchers to develop and modify codes, identify categories and themes, create memos and notes, and determine the frequency and depth of codes (Frieese, 2014; Ricardo, 2015).

This study aims to use the analyzed data to develop strategies for disaster preparedness, planning, and management and care for individuals with chronic diseases. These strategies will potentially improve the quality of care and disease maintenance for the target population and hence influence social change among health providers, relief workers, first responders, regulatory agencies, non-profit organizations, communities, and individuals.

### **Issues of Trustworthiness**

Study validity or trustworthiness determines whether study findings are deemed accurate by the researcher, participant, and the reader, and is considered one of the strengths of qualitative research (Creswell, 2003). When a researcher addresses issues of trustworthiness, it is an indication that the true picture of the phenomena under study is presented. I utilized several strategies to ensure trustworthiness in my study. Creswell suggests using more than one strategy to check accuracy of findings and hence increase study validity (Creswell, 2003). The strategies I utilized were member checking, triangulation, and clarifying researcher bias.

Triangulation is a strategy where the researchers examine multiple and different data sources to provide corroborating evidence and justify themes (Creswell, 2003; Creswell, 2007). By interviewing participants from different backgrounds who have either responded to a disaster or cared for individuals with chronic diseases, I was able to



corroborate emerging themes therefore enhancing the credibility of the study. In addition, use of documented literature confirmed the themes and perspectives. The other method that I used was the clarifying researcher bias method, a self- reflection process by a researcher that creates open and honest narratives acceptable to readers (Creswell, 2003). Allowing self-reflection throughout the study process ensured that I maintained objectivity in my encounters with the participants and in analysis of the data.

Member checking on the other hand cross checks the collected data during the interview process and at the conclusion of the study. The participants are given a chance to review the paraphrased and summarized information for accuracy (Creswell, 2009). I was able to review the collected and analyzed data with eight of the study participants who were available to do that. The rest of the participants opted not to complete the review due to time constraints and stated the assurance that they were confident the analysis was a true reflection of their narrations and experiences.

To ensure the transferability of the study results, I provided rich and detailed descriptions of the data collected to ensure a solid framework for any researcher or reader interested in transferring information to other settings (Creswell, 2003; Creswell, 2007). With this strategy, the participants and the study settings were described in detail enabling others to determine transferability (Creswell, 2007). Dependability is the consistency and stability of a participant's account and the researchers' ability to collect and record data accurately (Noble & Smith, 2015). By use of the triangulation strategy, this study collected evidence from different sources to enhance dependability of the study

results. The confirmability of this study was achieved by triangulation to reduce the effects of researcher bias, audit trails, and in-depth description of the methodology to allow scrutiny of the research results (Noble & Smith, 2015).

### **Ethical Procedures**

The first step in safe guarding the rights of the participants and minimizing ethical issues for the study was to develop a consent form for the participants. An informed consent form signed by the participants prior to collecting data acknowledged the fact that their rights would be protected in the study process. The participants' rights included: the right to withdraw from study participation at any time without coercion, having detailed information on the study purpose, data collection process, and the right to a copy of the study results (Creswell, 2003). Prior to data collection, this study was submitted to Walden University's Institutional Review Board (IRB) and approval was granted (approval #10-11-17-0326419). The IRB review ensured that the study procedures protected the study participant's rights.

The privacy and confidentiality of study participants is very important therefore the telephone interviews were conducted in a private office setting at home to ensure privacy during the audio recording. Written material was kept locked throughout the data collection process and I used pseudonyms in place of any personal identifying information. In addition, measures to ensure that the data collected remained confidential were taken, and this included storing the audio recording and written material in a safe locked location and removing all identifying information. The plan for the collected and

analyzed data is to remain locked for 5-10 years after which I will destroy it as recommended by Creswell, 2003.

### **Summary**

This chapter explained in detail the grounded theory methodology chosen for this study. The chapter started with a restatement of the study purpose and the research questions followed by specifics on the grounded theory method and the role of the researcher. To carry out a good qualitative study, I provided details on the various components of the chosen methodology such as study participants and selection criteria, the sampling strategies, and the data collection and analysis process. I also addressed the issues of trustworthiness and strategies used to establish such, and lastly I addressed potential ethical issues during the data collection process and ways to minimize them. Chapter 4 focuses on the data collection process and the data analysis.

## Chapter 4: Results

### **Introduction**

The purpose of this qualitative grounded research study was to explore the strategies that disaster relief responders and workers used to manage the needs of individuals with chronic diseases during and in the aftermath of disasters. Targeting disaster relief workers and responders provided a platform to explore their lived experiences in caring for individuals with chronic diseases during disasters. In addition, their experiences allowed for the development of strategies for disaster preparedness and the management of chronic diseases during disasters. The goal of this study was to develop strategies that would improve disaster preparedness and disease management for individuals with chronic diseases before, during, and in the aftermath of disasters.

The qualitative approach used to address the research questions for this study was the grounded theory approach. The data collection method was in-depth firsthand interviews of participants involving insights and experiences of disaster relief responders and workers. The primary research question of the study was:

*RQ:* How do disaster relief responders and workers address the needs of chronic disease individuals during and in the aftermath of a disaster? From this primary question, five sub questions were in addition to an interview protocol with secondary questions focusing on the phenomena under study (see Appendix A):

*SQ1:* How do disaster planners and relief responders manage chronic disease exacerbations?

*SQ2:* In what ways are individuals with chronic diseases prepared during a disaster as reported by disaster relief responders and planners?

*SQ3:* In what ways were the disaster communities prepared for the response and management of individuals with chronic diseases as reported by disaster relief responders and planners?

*SQ4:* What strategies for chronic disease preparedness work following disasters as reported by disaster responders and planners?

*SQ5:* What strategies for chronic disease preparedness do not work following disasters as reported by disaster relief responders and workers?

This chapter focuses on the data collection method, data analysis process, and study results. I start by discussing the study participants' setting and demographics, as well as the methodology used to collect data. Next, I discuss data analysis while noting identified codes and emerging themes and provide evidence of trustworthiness. Finally, I conclude this chapter by addressing the research question and provide a summary of the research and a transition to Chapter 5.

### **Setting and Demographics**

The total number of individuals screened for the study was 19; however, not all individuals met the criteria for the study. The actual number of disaster relief responders and workers and planners who met the criteria and participated in the study was 15. Four individuals did not meet criteria for various reasons; one had not managed the care of individuals with chronic diseases but was a support personnel for responders, another was

in-charge of logistics at an offsite shelter and never managed any care, the third experienced a natural disaster but was not a responder, and another was involved in disaster planning but not for individuals with chronic diseases.

All 15 participants met the recruitment criteria as listed: They were disaster responders or relief workers, had participated in a natural disaster and managed the care of individuals with chronic diseases or planned for the same, and were noninstitutionalized adults over 18 years of age. To ensure confidentiality of the participants, any information that could easily identify them was removed from the analysis. The participants also received an alias name and these names are used throughout the study. Participants included four males and 11 females, 11 registered nurses/disaster planners, a firefighter, a logistics manager, a chronic disease coordinator, and one paramedic; six of the participants were recruited through snowballing, four from social media, two were college acquaintances, and three were conference acquaintances. Lastly, there were six participants who had responded to only one disaster while the rest had responded to two or more disasters. Table 1 illustrates the demographics of the study participants.

Table 1

*Study Participants' Demographics*

Name of Participant	Gender	Occupation	Recruitment Method	Disasters that the Participants Responded To
Anna	Female	Registered Nurse	Snow Balling	Hurricane Katrina, Harvey, Irma, and Maria
Betty	Female	Registered Nurse	Snow Balling	Hurricane Harvey
Cathy	Female	Registered Nurse/Disaster Planner	Social Media	Hurricane Maria
Dorothy	Female	Registered Nurse	Acquaintance	Hurricane Charley, Wilma, and Irma
Esther	Female	Registered Nurse/Disaster Planner	Social Media	Hurricane Harvey
Florence	Female	Nurse Practitioner/Disaster Management Team	Snow Balling	Hurricanes Sandy, Irma, Maria
Grace	Female	Nurse Practitioner	Snow Balling	Hurricane Maria
Henry	Male	Paramedic	Social Media	Hurricane Maria
Isaac	Male	Logistics Manager	Snow Balling	Matthew, Harvey, Virgin Islands, Irma, Maria
Sharon	Female	Chronic Disease Coordinator	Colleague Referral	Katrina, Matthew, Harvey, Irma
Katherine	Female	Registered Nurse	Conference Acquaintance	Hurricane Maria
Moffat	Male	NASA-Satellite Engineer	Snow Balling	Hurricane Katrina and Maria
Nancy	Female	Nurse Manager/Disaster Planner	Social Media	Hurricane Harvey
John	Male	Fire Fighter/Disaster Planner	Conference Acquaintance	Hurricane Katrina, Sandy
Lillian	Female	Disaster Planner	Conference Acquaintance	Hurricane Sandy and Irma

### **Data Collection**

Data were collected from 15 participants with the primary data collection method being 11 phone interviews, three face-to-face interviews, and one self-recorded response to the interview questions. The 11 phone interview participants and the one who self-recorded the responses were in different parts of the country; therefore, I had between two to four initial brief phone contacts with them during which time I explained the purpose of the study, screened for criteria requirements, reviewed the consent form, and made arrangements for phone interviews. With the face-to-face interviews, I had brief phone contact with one participant for introductions and arrangements to find an interview time and location, whereas for the other two I only had one meeting that covered all aspects of the interview. The phone interviews lasted between 33 and 80 minutes whereas face-to-face interviews lasted approximately 35 minutes each. For the majority of participants, although I made the initial calls, they had the freedom to make the follow-up calls at their convenience mainly, because of their challenging time and work schedules as well as allowing them autonomy to decide if they wanted to continue with the study or not.

I audio recorded the phone interviews after first notifying the participants of the need to record and after receiving their consent to do so. In addition, I took notes to later compare and clarify inaudible parts of the audio recordings. For face-to-face data collection, I wrote notes as participants answered the questions through narratives, and in the process I stopped and asked for clarification. At the end of the face-to-face



interviews, I reviewed the transcripts with the participants to make sure I had correctly captured their experiences.

### **Data Analysis**

The data analysis process according to Creswell (2009) begins during data collection as the researcher identifies important information and develops ways to code the data into concepts and themes. This process allows a researcher to have a better understanding of the phenomenon under study (Creswell, 2009). I utilized inductive coding, termed the most common method for qualitative data analysis that analyzes data with no predetermined structure or framework and uses the actual data collected to determine the structure of the analysis (Burnard et al., 2008). Inductive analysis ensures that extensive raw data are condensed into a summary format, establishes clear links that are transparent and defensible between the study objectives and summary findings, and develops a model or theory from the experiences or processes evident in the raw data (Thomas, 2006).

According to Thomas (2006), the expected outcome of using inductive coding is to highlight the study objectives in three to eight summary categories. He outlined a process to carry out inductive analysis as: (a) preparing raw data files in to a common format (font size, margins, and backing up each raw data); (b) familiarization of the raw data (the researcher becomes familiar with the content of raw data and identifies themes and events); (c) creating categories and themes (the researcher identifies and defines the themes and categories); (d) using overlapping codes (same text may be coded in to more

than one category as needed) and un-coded text (leaving out text irrelevant to the study objectives); and (e) revising and refining the categories by combining or linking similar categories.

To successfully generate large themes and develop a theory based upon the data derived from the lived experiences of the study participants, I used the three phases of coding: open coding, axial coding, and selective coding. Phase one which is open coding involves taking a part of an observation or interview and reading carefully line by line while applying a label or paraphrase (code). The codes represent different perspectives such as emotions, interviewee impressions, and values that a researcher considers important from the observations or interviews (Gale, Heath, Cameron, Rashid, & Redwood, 2013). During the open coding phase, I analyzed the interviews, sentence by sentence and created codes based on how I interpreted the sentences and placed the codes in similar categories.

According to Kolb (2012), axial coding is the second phase of coding and involves putting together the open coded data in new ways to allow connections between categories and subcategories. It also entails the researcher taking a detailed look at the categories and identifying the conditions that give rise to them (Kolb, 2012; Saldana, 2013). Charmaz (2014) explained that axial coding helps to answer questions such as why, who, when, how, where, and what, hence allowing the researcher to fully describe experiences under study. The last phase is selective coding which involves identifying the

main category and connecting it to the other categories in a systematic manner, validating similarities, refining, developing, and completing codes (Kolb, 2012).

I used Atlas ti8 for my data coding and analysis. Atlas ti8 is a type of Computer-Aided Qualitative Data Analysis Software (CAQDAS) tool used in qualitative data analysis process. It was originally developed as a tool for organizing data however does much more than that with advancement in technology (Friese, 2014). In using Atlas ti8, researchers are able to develop and modify codes, categories and themes, create memos and notes, and determine the frequency and depth of codes (Friese, 2014; Ricardo, 2015). With the Atlas ti8 software, I was able to identify the emerging themes by using the codes, memos, code categories, and evaluating the transcribed interviews multiple times.

After having an external transcriptionist transcribe the recorded interviews into Microsoft word, I reviewed the transcript comparing it to the recorded interviews for accuracy, and also, had participants review the transcripts for accuracy. I then uploaded the documents in to Atlas ti8 for coding and analysis and was able to identify 98 codes through the coding process. After reviewing the codes several times, re-reading the transcripts and referencing the interview questions, I noted some similarities with certain codes and therefore, I combined them. This process led to a total of 89 codes, which I grouped into categories of similar content areas and ended up with 17 categories.

In the process of identifying the codes and categories while using the inductive process, the themes started to emerge, reflecting the phenomenon under study. The research participants presented a wealth of lived experiences given their diverse

backgrounds. Their experiences differed based on the number of years they had responded to natural disasters, the magnitude and extent of the disasters, the disaster locations, and their professional backgrounds. Despite these differences, there were commonalities in the lived experiences of these participants that put emphasis on the phenomenon. Some of the recurring themes included health, disease, sympathy, empathy, preparedness, survival, mental health, resources, collaboration, resilience, and humane acts.

### **Evidence of Trustworthiness**

To ensure the trustworthiness, credibility, transferability, dependability, and confirmability of the study, I employed a number of strategies during the data collection process. The strategies used to ensure credibility were triangulation, member checking strategy, and the clarifying researcher bias strategy. I triangulated the data by interviewing disaster response participants who had varying differences in their background, type of disasters they had responded to, location of disasters, and the time that the disasters took place. This allowed for corroboration of the themes that emerged. To clarify researcher bias, I underwent a self-reflection process to ensure that I remained neutral and objective minded as I carried out the study.

Using the member checking method, I reviewed the collected and analyzed data with eight of the participants. The participants were able to confirm the accuracy of the transcripts and clarify any additional questions that I had. A preference for four of the participants involved in the member checking process was an over the phone review of

their analyzed data. I reviewed the data with the face-to-face participants as I collected it and prior to concluding the interviews while one of the participants sent their hand written responses. The rest of the participants were not available to participate either because they were unreachable or opted not to have the review due to time constraints stating that based on the interviewing process they were confident that the analysis reflected their views and perceptions.

To ensure that the study results are transferable, I provided rich and detailed descriptions of the data collected (of the participants, settings and their experiences). This created a solid framework for any researcher or reader interested in transferring information from this study. I also used a digital audio recorder to record the interviews and uploaded the interviews into Atlas.ti8 for coding and data analysis. Another strategy that I used was to establish the study context by providing the background data and a detailed description of the phenomena under study therefore allowing comparisons to be made.

In triangulating the data, I managed to minimize my bias as a researcher and highlighted the participant's perceptions hence ensuring confirmability of the study. In addition, I provided a detailed and in-depth methodology of the study allowing the study results to be scrutinized. Lastly, I employed an audit trail of the research process. This included maintaining a notebook with the dates and times I conducted the interviews, transcribed the interviews and when I uploaded the interviews in Atlas.ti8. I also kept

notes on verbal and written feedback that I received from my committee chair, colleagues, and peers.

I ensured the dependability of the study by use of the triangulation strategies in the data collection phase. Another strategy was to provide an in-depth description of the methods used in collecting data, analyzing data, and in interpreting data. Having my colleagues, peers, and methodology advisor review the study plan, process and interpretation of results also enhanced dependability of the study. Ensuring dependability of a study is important as it establishes that the study findings are consistent with the collected data (Creswell, 2009).

### **Results**

Throughout the process of my research, I sought to answer the primary research question through exploring the five sub questions. After conducting the data analysis, themes and sub themes emerged from the interviews that further enhanced an understanding of the phenomena under study. A theme as described by Vaismoradi, Jones, Turunen, and Snelgrove (2016) is an attribute or concept, the main product of data analysis that allows a researcher to answer the study question. It contains codes that generally unify ideas in the phenomenon under study (Vaismoradi et al, 2016). The themes are organized according to the research questions and the participant's responses (quotations and perceptions) are used to support the identified themes.

In reviewing the interviews, it is evident that the primary research question was addressed by all the study participants as evidenced by the various common keywords

and expressions that they identified. This question looked at the holistic approaches applied by disaster responders and planners to address chronic disease needs during and after disasters. Some of the interviewees admitted that they did not specifically single out the concept of chronic disease management while responding to disasters; however, they were able to relate to their practices and observations upon reflecting on their experiences during the interviews. Some of the key words and expressions noted were: information technology, the goodness of all the people (responders, victims, and the community), patient triaging, color coding patients, presence of healthcare personnel, presence of Walmart pharmacy, family support, disaster victim resilience, ability of the victims to handle stress, and special needs shelters for chronic diseases.

The emergent themes and corresponding questions are summarized in the table below, descriptions and discussions on how they relate to the phenomenon under study are provided.

Table 2

*Research Questions and Emergent Themes*

Research Questions	Theme(s)
RQ1: How do disaster relief responders and workers manage chronic disease exacerbations?	Theme 1: Disease management techniques: The means to managing chronic disease exacerbations in disasters.
RQ2: In what ways are individuals with chronic diseases prepared during a disaster as reported by disaster relief responders and workers?	Theme 2: Perceived individual disaster preparedness
RQ3: In what ways were the communities prepared for the response and management of individuals with chronic diseases?	Theme 3: Assessing the preparedness of disaster communities Sub Theme A: Community preparedness and immediate response during a disaster Sub-Theme B: Disaster response organizations and preparedness Sub Theme C: Responder training and preparedness
RQ4: What strategies for chronic disease preparedness work following a disaster as reported by disaster responders and workers?	Theme 4: Strategies, approaches, and practices: Advancing disaster preparedness and response for individuals with chronic diseases
RQ5: What strategies for chronic disease preparedness do not work following a disaster as reported by disaster relief responders and workers?	Theme 5: Ineffective strategies for chronic disease management in disasters.  Theme 6: Mental Health  Theme 7: Greatest good for the greatest number of people  Theme 8: Resilience



*SQI*: How do disaster relief responders and planners manage chronic disease exacerbations?

**Theme 1: Disease Management Techniques: The Means to Managing Chronic Disease Exacerbations in Disasters.**

The research participants in this study reflected on their disaster response experiences putting emphasis on the various approaches and practices that they employed to manage the chronic disease exacerbations. They recognized the approaches, efforts, and challenges that they and their team members experienced during the disaster response. They addressed what they observed and practiced as well as highlighting guiding concepts of accountability, responsibility, coordination, and collaboration as driving forces behind these practices. The following descriptions and comments from participants reflect this theme that answers the question: How do disaster relief responders and workers manage chronic disease exacerbations?

Almost all study participants expressed that generally the shelters were well set up with basic resources and they had an adequate supply of nurses, pharmacists, medical providers, and respiratory therapists. They however encountered great challenges when faced with inadequate or scarce essential resources such as medications, electricity, generators, water supply, and medical supplies. To manage the chronic diseases, the participants stated that they just made do with what they had. Betty explained that this involved strategies such as substituting unavailable medications to control exacerbations and utilizing capable individuals who were ‘walkie-talkies’ (stable and able to move

around) to assist other victims. Nancy also added that due to inadequate resources, they borrowed supplies such as insulin from family members or victims who had extra supplies and used the vial as a multi dose vial while ensuring patient safety by not reusing needles.

Anna, a seasoned disaster responder was involved with Hurricane Katrina, Harvey, Irma, and was awaiting deployment to Puerto Rico at the time of this interview. She described that, “When you have individuals in shelters, you're basically at the mercy of whatever resources that shelter has available. Even with several generators, you are still not able to meet all the respiratory and IV pumps needs”. Katherine emphasized the stated situation by describing the approaches that majority of the responders practiced in order to manage chronic diseases by saying that:

With the lack of electricity, we had to end up bagging a lot of the patients who were on vents. The power outages were a major challenge in keeping the place running and in taking care of all those patients... We just ended up doing manual nursing 101. For the vent patients, we just manually took turns to bag them to provide the oxygen and for IV needs we were counting the IV drips and just hanging them to gravity for the medications. For the insulin, sometimes we tried to rescue some of the insulin that was in the refrigerators, we kept the refrigerators closed so that we can keep them nice and cold, to be able to use them. Although we had a backup generator that still went out.

Just like in a clinical setting, the participants noted that in order to adequately manage the chronic disease symptoms, they had to prioritize the presenting symptoms in order of severity. In addition, managing the symptoms also meant they had to engage their critical thinking skills for appropriateness and timeliness. This as they explained was to ensure they managed everyone's symptoms the best way they could with the resources they had. The goal for disaster response as the study participants indicated was health improvement and maintenance for all.

Nancy and Anna discussed critical thinking and prioritizing strategies. Nancy explained that in her experience, managing chronic diseases required patience, critical skills, and speed as time was of essence. Her team triaged patients as they were brought in to the clinics and they managed those with stable symptoms with medications while the more serious ones were transported to close-by open hospitals. Anna described the prioritization and critical thinking strategy by explaining a color-coded triage system they used to gauge, prioritize, and determine how to provide care and ensure they were doing the greatest good for the greatest number of people. She explained:

The color-codes are either green, which means they're walkie-talkie patients and they can wait to receive treatment for multiple hours; If they're yellow...they need to receive care within two hours, then you have like red and black...some of these unfortunately, you cannot provide care to so you have to do the best you can with what you have.

To adequately manage chronic diseases, 93% of participants stated that success depended on collaboration among all responding units; between departments, disaster organizations, local organizations (faith-based organizations, churches, and hospitals), local businesses, police force, as well as individual responders. They acknowledged the presence of Walmart's mini mobile pharmacies and stores as key to curbing symptom exacerbation due to availability of medications and other necessities. They stated that the collaborative efforts were evident in the sharing of resources and manpower (health providers) among responding units to provide appropriate and timely disease management. Isaac a seasoned disaster responder recalled that in his experience, the collaboration between FEMA, American Red Cross, and the army was vital to the management of chronic disease symptoms both at the emergency response locations and by airlifting the victims out to nearby or to the appropriate hospitals. In Henry's experience, hurricane Maria was a devastating, out of control and severely destructive disaster however, the challenges were minimized through collaborative efforts between different responding organizations, the federal government and the local communities who reached out with loving arms and said:

You're here to help us...How can we help you? Churches, in general, reached out like did FEMA... You need food, we will find you food. You need clothes for the patients, we will find some clothes...A local laboratory, just a normal blood-testing laboratory generously came in and set up equipment and said, 'We will work for free to help you'...The local Coca-Cola bottle company reopened their

facility, worked on filtering water and supplied it across the island. Without collaboration with others, there would be no success during disasters.

Two of the participants described working for organizations that catered only for chronic disease individuals during disasters. Dorothy, one of the participants shared that to manage exacerbating symptoms; they had a pool of doctors, nurses, and non-licensed staff to manage symptoms and an onsite pharmacy for those individuals who did not have their chronic medications with them. They also collaborated with nearby hospitals where they transferred the patients with deteriorated symptoms. To accomplish this, there were Emergency Medical Technicians (EMT) and local police on standby to assist with the transfers. These collaborative efforts as Dorothy explained contributed to the success of the chronic disease shelters.

Another strategy noted by participants as an integral part of chronic disease management was teamwork. Teamwork was described by many as “coming together regardless of their backgrounds to save lives.” Katherine, another first-time responder with hurricane Maria emphasized that she felt encouraged at the amount of team work and collaboration she witnessed as responders ensured that even with few resources, exacerbating symptoms were managed. She said that, “We all worked as a team, helped each other out, trouble shoot problems together, and had solutions to help us manage under the circumstances.” She also added that in the spirit of teamwork, “A couple of my friends who were nurses went to the community, knocking at the doors to check on people that may have needed care because a lot of the people were barricaded.”

Several other strategies were used by the participants in order to manage individuals with chronic diseases. One of these strategies was using home medications brought by the victims to the shelters after the physicians had reviewed and consented to the use. This according to Betty reduced some challenges and ensured that the individuals continued with their regular medications in a timely manner. Another strategy utilized in most of the shelters was the presence of a documentation system (manual paper process) that tracked patient symptoms, interventions and progress and this allowed for continuity of care even with the challenging disaster circumstances. The participants also discussed that they had shift communications between outgoing and incoming shifts as another means to ensure continuity of care.

Cathy, a dialysis nurse and disaster preparedness planner managed care of dialysis patients in a rescue site during Hurricane Harvey and Maria. She noted that renal diet compliance was a major challenge for these individuals because of lack of finances after evacuating from their homes and the high costs of healthy foods. This then led to exacerbations of symptoms such as high blood pressure, edema, high glucose levels, and imbalanced electrolytes. The availability of physicians who assessed and wrote prescriptions, and a pharmacy that had most of the needed medications were necessary in managing the chronic disease symptoms exacerbations. However, in order to manage symptoms through diet control and to encourage diet compliance, Cathy said:

I can tell you, we came together as employees and just felt we could donate our own money for particular patients that were from Houston and you could tell they

wasn't ready with funds to be able to buy healthy foods, so we would donate some money and say, Okay, here's your money for lunch for a week. This really helped them buy appropriate food and their symptoms were not as bad.

Those participants who volunteered or worked for the veteran administration (VA) system gave a recount of their experiences in managing chronic diseases. This was mainly because they alluded to the availability of resources that enhanced the care management. In almost all the disasters, they were noted to have an adequate number of volunteers as well as family members who all worked together to manage those individuals with chronic diseases. Grace, a first-time responder added that the set up/organization within the shelter (makeshift pharmacy, supply area, respiratory, social worker area, and clinic area) all made it easier and organized in caring for those who had chronic diseases

Sharon and her husband run a chronic disease telemedicine management company in partnership with physician clinics. Some of the disasters they participated in were Katrina, Matthew, Harvey, and Irma with one of their major roles being to ensure continuity of care for their patients affected by disasters. They accomplished this by locating the patients during and after disasters and monitoring and managing their chronic diseases. Once contact was established, they managed their conditions through remote assessments, prescription filling or connecting them with primary physicians and hospitals for symptom management. Their patients have access to a phone or tablet and can be located as long as there is Internet or hotspots. The nurses make assessments

through video conferencing and from that they make recommendations for symptom management or referral to a hospital or medical shelter.

The participants reported that often the management of chronic diseases depended on the availability of resources and it required the responders to be creative and use of all possible options to get these resources. Moffatt, a contractor with FEMA, responded to both hurricanes Katrina and Maria and he recalled managing individuals who required essential resources such as oxygen to control symptoms of Chronic Obstructive Pulmonary Diseases (COPD) and asthma. His team's primary role was individual/family rescue and placement in rescue trailers, but these trailers caused symptom exacerbation for some due to odors, dust, and new materials from the trailers. Their conditions were also exacerbated by lack of medications, electricity, and clean water supply. To manage the above, Moffat recounted how they supplied oxygen tanks to those who needed them going into great lengths to get bigger oxygen tanks to meet the increasing demand, relocated others to more appropriate trailers, and when conditions seemed to deteriorate, the medical responders took over.

As the participants indicated, there were numerous challenges encountered in the effort to manage chronic disease exacerbations during disasters. The responders however developed strategies that enabled them to overcome most of the challenges giving the disaster victims a chance at survival. Managing chronic diseases was not an area that the majority of the responders reported as having prepared for; however, they did the best they could to safeguard the lives of the disaster victims. According to the participants, the



success in managing symptom exacerbations was because of engaging concepts of accountability, responsibility, coordination, and collaboration in to their practices.

*SQ2:* In what ways are individuals with chronic diseases prepared during a disaster as reported by disaster relief responders and planners?

## **Theme 2: Perceived Individual Disaster Preparedness**

Individual disaster preparedness is constantly a topic of discussion among public health practitioners and the general public before, during and after a disaster strikes (CDC, 2016b). The call for individuals to be prepared is to ease evacuations, for health maintenance, and ensure available resources are utilized on the most vulnerable individuals or communities (Banks, 2013). The participants expressed concerns at the widespread lack of individual preparedness despite the public forewarning information reminding citizens to prepare and evacuate pending a disaster. The study respondents narrated incidents of inadequate individual preparedness, a factor that failed to advance disaster response experiences.

In Texas, Anna explained that there were a lot of hurricane warnings to evacuate but many people chose to stay behind and yet still were unprepared. She added that in Florida, the majority of the communities were retirees with multiple comorbidities and they were not at all prepared for the devastation that followed. According to Nancy and Isaac, with the type of information available to the public regarding preparedness and evacuation they noted that, “Individuals should have been able to go to their pharmacies and get an extra 10-day medication supply, purchased generators, and packed some

drinking water and canned foods.” Moffatt additionally described that in his experience, the disaster victims did not seem to have prepared for the disasters, not the Katrina disaster or the Maria disaster. He summarized by saying, “Nobody was prepared, barely.”

Cathy explained that chronic dialysis patients receive a packet that contains their medical history, medical prescriptions, dialysis prescriptions, and most current laboratory test results. The idea is for the patients to have the packet with them wherever they go in case of dialysis needs and other medical needs. However, Cathy shared that in her disaster response experience; only one individual had the medical packet available. She explained that “the lack of medical history really delayed care especially in providing dialysis for the patients.” Other participants who managed care or encountered dialysis patients shared similar experiences.

There was another aspect of preparedness brought up by Betty and Florence who responded to hurricane Maria. Betty explained that in her experience, patients who had their families with them were more prepared and majority had a supply of their home medications. Florence noted that the family members were very involved and provided needed medical information, provided basic care like bathing patients, administered home medications, and provided moral support. The presence of family members as noted with the Texas and Puerto Rico disasters was greatly appreciated by the responders as their families provided significant information about their loved ones that helped the medical teams manage their chronic conditions better.

The rest of the participants encountered the same experiences as individuals who were not prepared but also some who were somewhat prepared. Cathy and Grace explained that in their experience; the victims had to flee the disaster area and hence had no time to evacuate with any necessities and hence the unpreparedness. The other participants said it was a combination where some individuals had medications and other items and others did not have anything, not even medications. This, as the participants explained was a challenge for the responders as they tried to manage chronic diseases without medications or medical records. They voiced their concern and frustration at the widespread lack of individual preparedness, a factor that hindered disaster management and impacted on the wellbeing of the disaster victims.

*SQ3:* In what ways were disaster communities prepared for the response and management of individuals with chronic diseases as reported by disaster relief responders and planners?

### **Theme 3: Assessing the Preparedness of Disaster Communities**

The general perception from respondents regarding local community preparedness was that more needed to be done. Some participants noted that the presence of the local Red Cross, non-profit organizations, and faith-based organizations alone was not adequate to manage the care for those with chronic diseases. What lacked in preparedness was the absence of basic resources, organization of the response efforts, and adequate collaboration/ communication among the responding organizations. However, they stated that community preparedness varied depending on location and severity of the disaster.

As the respondents reflected on their experiences, some of them gave personal accounts of what they witnessed. Anna said:

I would say, as long as the community healthcare organizations are up and running, they are almost able to pretty much stand on their own. But just an example with the hurricane Harvey; a lot of the businesses were closed because they had no electricity, and they were flooded. If an individual needed their medication, they couldn't just drive to CVS and get their medication, because the business had no electricity, no computer access, they couldn't pull up records... It almost throws you back in the Stone Age.

Florence, a three-time disaster responder, shared about individuals with diabetes. She indicated that food was a major component in managing individuals with chronic diseases and therefore considerations are needed when planning for food relief. She said:

It was tough because of especially limited resources for food. We got food but it was dependent on what we could get from local donations or the Red Cross, some days it wasn't a great meal and it was really dependent on their preparedness for people with diabetes. Not many community organizations or people were out there, so they couldn't get consistent carbs or somewhat regular diabetic diet...and it was hard.

Cathy said:

For the dialysis patients, there was no community preparedness at all.

Transportation was a challenge and likewise the food supply. The responders had

to do a lot of coordination to ensure they maintained compliance with scheduled dialysis days and ensure they had needed resources.

Katherine, Grace, and Henry explained that prior to the Puerto Rico disaster, chronic diseases were managed by public health clinics/hospitals and hence during the disaster, most family members had medications and health history available. However, they were amazed that large facilities did not have generators to cater for the vent/oxygen dependent patients. John and Lillian also voiced concerns that in their respective disaster response areas (Katrina, Sandy, and Irma), the major hospitals did not have ready-to-go generators and this delayed chronic disease management hence the exacerbating symptoms. At least 60% of the responders verbalized that the health organizations within the disaster areas were not adequately prepared especially with dealing with an influx of disaster victims and in resource allocation.

Approximately 80% of the responders appreciated local businesses that stayed open as long as they could to assist the communities. Nancy and other participants praised the Walmart store for setting up little stores in various disaster areas and for donating food stuff, new clothing and other items. In Betty's experience, she recalled that Walmart had set up a pharmacy on site to ensure free medication availability for the disaster victims. In various disaster areas, the presence and efforts of local faith-based organizations was noted according to the participants, what lacked however was adequate coordination and resources. The participants voiced that there needed to be good

communication between donors and receivers so as to better inform the communities about available resources.

### **Subtheme A: Community Response Immediately Following a Disaster**

The collaboration between and presence of local businesses, organizations, and individuals was dependent on the severity of the disaster. The participants shared that the response strategies utilized by the local communities were dependent on the type and magnitude of preparedness prior to the disasters. Almost all the participants shared that when present, the locals provided food, shelter, transportation, and managed donations. They expressed that the basic activities of disaster response were mainly carried out by the local communities. Esther said:

During Hurricane Harvey, I witnessed different churches going out and collecting clothes and other items from communities and bringing them to this one big warehouse for distribution to the victims. There were people who just came to help; nurses, policemen, and paramedics... Walmart was there too, and they had a small pharmacy.

The study participants recognized the efforts made by local communities to collaborate with disaster organizations in order to enhance disaster response for all individuals. In his experiences, Moffat remembered the presence of the local Red Cross, faith-based organizations, and Salvation Army. However, during Katrina, they had to close down a shelter due to lack of funds to support the individuals. Despite the challenges, the participants described the community response as togetherness. Isaac said:

We see a lot of participation by the community, by the mayor, by so many organizations and businesses that try to aid and help out as much as possible when a disaster hits. They do their best as much as possible to help out in any way they could help us out because they understand that we're there for a reason and that's to help out their communities...They take us in like we're family and help up to the best of their ability to help each survivor to what they need as much as possible...

### **Subtheme B: Preparedness of Disaster Response Organizations**

Success of disaster response and recovery is attributed to the preparedness of responding organizations (Arrieta et al., 2009; Banks, 2013). FEMA for example is one of the disaster response agencies and has been part of coordinating the federal government's disaster preparedness and response efforts. The agency also plays an integral part in encouraging and educating individuals, communities, and organizations about disaster preparedness (FEMA, 2019). All the study participants agreed that their organizations were in some way prepared to respond to the disasters and that what differed was specific preparation for the chronic diseases. In order to determine the management of care for individuals with chronic diseases, below are discussions and examples derived from the disaster responder interviews and indicate the preparedness levels of the responding organizations.

In the study, 67% of the participants noted that their organizations had some sort of preparedness to manage chronic diseases. The preparations ranged from medical

personnel at the disaster site to availability of resources and collaborations with other organizations. Of these participants, 40% were very confident that their organizations had specifically prepared for chronic disease management. In their responses, they noted the presence of emergency response ambulances and personnel, collaborations with local or nearby hospitals, adequate staffing/volunteers, availability of necessities such as food, water, medication, blankets, and the presence of the shelters. Anna a seasoned disaster responder with the same organization stated that, “because we know ahead of time what we're going into and we have local, state, and national resources, we tend to do pretty well”, and Betty added that, “what I experienced with my organization was preparedness and good planning, at the shelter, there were nurses from different hospitals in the Dallas metroplex area, the VA, and others.”

The rest of the participants who responded to other disasters shared experiences where the responding organizations were generally prepared however specific preparations for individuals with chronic diseases were inadequate. They reported that it was a work in progress that requires more preparedness efforts towards individuals with chronic diseases. There was consensus that preparedness depended highly on disaster location, magnitude, and duration; in Florida, the interviewees and noted increased and improved preparedness over the years compared to places such as Puerto Rico and Virgin Islands. One preparedness effort that stands out in Florida according to Dorothy is the presence of special needs shelters exclusive for individuals with chronic diseases. The



patients had to pre-register prior to the disaster and the main criterion to register was the presence of a chronic disease.

An indication of the need for improved disaster preparedness for individuals with chronic diseases was Moffatt's notable comparison of FEMA's response during the Katrina and Maria hurricanes. He said that, "During Katrina, FEMA did not have appropriate and adequate staff to manage the disaster, but was somewhat better prepared during hurricane Maria, yet still inadequate." He also noted that during and after disasters, it is often difficult to get people settled in temporary homes, shelters, hotels, and trailers due to government red tape and the lack of clear cut collaboration with other response organizations. Just like most of the study participants, Isaac said, "the disaster organizations were pretty much planned, well-planned in terms of tools, equipment, personnel, and medical needs. What lacked is the chronic disease planning." The lack of adequate disaster preparedness especially for individuals with chronic diseases is hence still a problem despite the progress made since hurricane Katrina.

Other organizational preparedness efforts according to the participants were gauged through the communications observed between the organizations and the responders prior to deployment. Majority of the participants voiced that communications regarding disaster response did not include the management of chronic diseases but was geared towards travel, accommodation, and team assignments. Allocation of duties was mainly determined once the responders were on site as well as any orientation or training that was deemed necessary. Sharon, Lillian, and Dorothy however explained that most

organizations have a medical disaster response team, both local and national that manages acute and chronic diseases and may explain the lack of focus on chronic disease response management. Sharon said, “They look at our skills to see if we are going to be able to meet the needs of the patients before they even send us in.”

Another aspect of organizational preparedness is planning for community sustainability and rebuilding after disasters. It is a process that allows communities to heal physically, mentally, and economically, as many study interviewees noted. In relation to this, Moffat said, “Building relationships helps create stability in communities and sustains recovery efforts.” To accomplish this, John, a disaster planner explained that after the acute disaster phase organizations make efforts to exit an area systematically:

It's a slow process but teams are steadily moved out depending on what the needs of the communities are. Typically, it's a slow process; they're not all just pulled out at one time, because that would be a big shock to a community. If you sent 5,000 nurses to Puerto Rico and they're there on a Monday and then the next day on Tuesday, everybody's gone, it would be another disaster.

### **Subtheme C: Responder Training and Preparedness**

The study participants had varying experiences regarding responder training and preparedness prior to deployment. Participants from major disaster response organizations were more likely to confirm some form of chronic disease training ahead of a disaster response event. Some of the seasoned participants felt that they were well prepared to manage the victims during disaster response. For instance, in terms of

personal supplies such as stethoscopes, the responders had their own supplies, or the organizations provided them with them. Katherine and Anna discussed that their organizations carried out responder training several times in a year, held conference calls to discuss issues and needs prior to deployment, and debriefed responders with adequate information that they were able to handle whatever situations they encountered.

Like some of their colleagues, Dorothy and Henry confirmed that their respective organizations provided responder training prior to deployment. According to Dorothy, prior to individuals responding to disasters in the special needs shelters, they had to undergo simulation training on managing the chronic disease needs. Henry on the other hand shared that responder training for his organization was an ongoing process prior to deployment, during, and after exiting the disaster site. He described a hot wash, “where the teams get together to identify strengths and weaknesses so as to determine areas that needed improvement.” The participants who confirmed responder training for chronic diseases within their organizations reported that the process enhanced the disaster response experience as well as the health outcomes of individuals with chronic diseases.

Isaac, a FEMA responder reported that prior to deployment, a lot of preparation and training took place through debriefs and PowerPoint presentations however, most were generalized to the rescue and recovery efforts without specifications on management of chronic diseases. Florence, a three time disaster responder said that, “we get survey questions at the end of every disaster response...general questions really, kind of an open-ended like what will you do better? What did you learn? Not really specific to

anything.” She stated that through the surveys, suggestions have been made for more preparedness and training on individuals with chronic diseases prior to getting to a disaster site. These surveys she says have been important in the improvement she and her colleagues have witnessed over the years especially in resource/supply availability and patient triaging in the shelters, however, more training and preparedness is still required.

The general consensus among all respondents was that their organizations could have prepared them better by providing training on chronic disease management during disasters. Grace, for example, described feeling confused just prior to deployment and immediately after arriving at the disaster site because there was inadequate communication, debriefing, and lack of organization. Some other participants shared that supplies such as diabetic testing equipment were not always in adequate supply leaving the responders to make do and be creative with what they had and with no advanced preparation or training on what to do in such circumstances. Regardless of the experience with organizational training, the participants all verbalized that they would like to see more focus on chronic disease response preparedness.

*SQ4:* What strategies for chronic disease preparedness work following disasters as reported by disaster responders and planners?

#### **Theme 4: Strategies, Approaches, and Practices: Advancing Disaster Preparedness and Response for Individuals with Chronic Diseases**

Having strategies and plans that are effective is the key to success in disaster response and recovery according to the participants. They all collaborated that there are

strategies that were in place in the various disasters they responded to and were effective as planned. In addition, the responders applied various approaches and practices that helped advance the disaster response experience. Anna verbalized that “I think encouraging people and organizations to have an emergency plan is a strategy that is very effective when disaster actually strikes.” Other responders echoed Anna’s call for continued public and organizational encouragement to have an emergency plan.

The interview participants all pointed out that for almost all the disasters they had responded to, the number of workers and volunteers available was adequate to address immediate disaster needs. They stated that the planners made sure to include various professions such as doctors, nurses, pharmacists, information technology, EMT, and the police. They also noted that most of the organizations planned for a rotational schedule where their responders are at the disaster site for a period of time and then replaced by another group. Having the rotations helped to minimize lethargy and enhanced productivity among the responders. Having enough personnel to deal with disaster rescue challenges is a strategy that many of the study participants applauded.

Another strategy noted by the participants to be effective is the use of traditional pen and paper charting system. They reported that the medical personnel are still able to document and maintain records of their assessments, medication orders and administration, and other treatments and interventions even when electricity is scarce and use of generators is limited. In addition to the above, a number of respondents explained how they triage patients to determine the acuity of their symptoms and illnesses by using

color codes. They explained that, “the triaging strategy is very effective in ensuring that those who need immediate medical care are assisted without delay and that resources are distributed accordingly.” The interviewees reported that triaging patients can be an emotional roller coaster however there is an assurance of doing the greatest good for the greatest number of people.

For Dorothy, an effective strategy during disasters is Florida’s implementation of a special needs shelter that caters for only individuals with chronic diseases. According to Dorothy, when there is an impending disaster, citizens who meet certain criteria for chronic diseases are reminded to pre-register in one of the special needs shelters. The shelters are open just prior to the disaster and stay open until it is safe for the citizens to return to their homes or an alternative location. The aim of the shelters is to take care of their medical needs hence they are staffed by medical personnel, have pharmacies attached to them, and have ready to go generators in case of the loss of electricity.

For communities and organizations that provide disaster preparedness education to the public, it is an encouragement when the public takes heed and prepare. Lillian noted that, “I think that's one of the strategies, education before disasters...its key for those persons and making sure that they go to their doctor's appointment before the disaster strikes.” Katherine said:

You have a wound, you want to make sure that it is dressed couple of hours before you enter into a shelter because you don't want to go there with a weeping wound, and it may fester, and it may turn out be worse than what it was.

Esther also shared a strategy that was effective in managing chronic diseases during the disasters in the rescue shelters. She discussed the importance of having an electronic medical record (EMR) and referenced a system used by the VA to ensure their members receive the care they need regardless of the location. In her experience, the VA used the EMR system to verify their member's identity, medical history, medications, and other pertinent information. This she said allowed for prompt and appropriate care. She summarized by saying that the use of EMR, allows continuity of care with the primary providers after a disaster.

In times of disasters, communities, nonprofit organizations, and faith-based organizations have traditionally responded and united to offer humanitarian aid to the victims. This disaster response strategy was noted by the participants as very effective in alleviating fear, anxiety, and anger through their presence and counsel, and in providing basic essentials to the victims through their donations. In many of the disasters, the participants noted the presence of the local faith-based organizations, the American Red Cross, some businesses, and also individual responders who donated their time and resources. Isaac said that, "No matter what the devastation, the communities come together."

Some participants also noted that in their experiences, there was collaboration and communication amongst various organizations and this aspect helped to advance the disaster response experience for both the responders and disaster victims. Grace said that, "You have to have really good communication so you can know what resources are

available and really good communication between senders and receivers.” Henry agreed that the success of disaster response was “largely a community effort, all the different organizations coming together to do some good.” Communication can be a challenge even within the same organization especially when phone lines are cut off. Moffatt explained that his organization ensured ongoing communication internally and with those other organizations by use of a two way radio.

The participants who responded to the Texas, Florida, and Puerto Rico disasters described warehouses that were utilized as the receiving centers for donations from local donors as well from around the country. Lillian said that, “People would donate clothing and stuff...all these churches basically pick up all these collections and donations in the community to bring it to a big center.” She explained how in every shelter, there were people stationed to communicate their needs...we need men's underwear, socks, things like that.” Other participants confirmed too that there was ongoing communication between shelters and the warehouses, a strategy that enabled a better process in caring for the disaster victims.

Another strategy that seemed effective according to the participants was the presence of Walmart mini stores within some of the rescue shelters. Individuals who came in without clothes or basic necessities received a hundred dollars gift vouchers and used that to purchase items from the mini stores or they purchased with their own money. In addition to the stores, they had pharmacies set up and this became an integral part of chronic disease management. Majority of individuals with chronic diseases do not



prepare for disasters especially when it comes to the medications, they were however able to get their prescriptions filled in the mobile pharmacies.

*SQ5*: What strategies for chronic disease preparedness do not work following disasters as reported by disaster relief responders and workers?

**Theme 5: Ineffective Strategies for Chronic Disease Management in Disasters.**

There are some strategies that were not as effective in managing chronic diseases as planned. The participants of this study described strategies that hindered chronic disease management or posed challenges. These strategies were in relation to the shelters, donations, and preparedness efforts. Anna said:

If you take a look at like these mega-shelters that were put up in Houston or the one in Dallas, they're usually equipped to handle about 1,700 people. This last event with Hurricane Harvey, there was close to 5,000 people. When you put 5,000 people all with different-- some are healthy, some are very sick and you put them all in one congregated area, you create additional problems.

Betty and Florence made their observation about the shelters and voiced concerns that there were too many individuals in one small enclosed area, no adequate isolation areas for the many contagious illnesses, and no partitions or privacy for personal hygiene care. In addition, they verbalized that the bathrooms were not enough, and the food and medical supplies were stored in the same area. Isaac however made the observation that the shelters will always be a good solution for displaced individuals; however, proper planning and considerations are needed. He said:

When you have a natural disaster, there is no setting where this section is going to be on diabetes section, this section is on mental health section, or this section is CHF. There is really no separation of the conditions. It's get as many as you can into a safe shelter. Again, you are throwing all of these different mentalities and comorbidities, and it can be chaotic sometimes...sometimes it is okay to take safety over comfort!

In his experience, Moffatt felt that having the plans to relocate victims in to trailers was a great idea; however there were no clear guidelines or plans on how to manage the supply of electricity, water, garbage disposal, and sewage drainage. In addition, there were victims who could not move to the trailers due to their asthmatic conditions which was exacerbated by odors, dust, and new materials used in the trailers. He also mentioned that the disaster planners had overlooked the use of trailers by individuals with disabilities hence lengthening the relocation process and causing heightened anxiety amongst the citizens in need. He said, "People refused to leave their homes, some were sleeping in cars due to the trailer space constraints for their families."

Another strategy that was not effective according to Anna and John was the distribution of money or gift cards to the disaster victims during the active phase of disasters. They noted that some organizations offered monetary gift cards to the disaster victims however there was no access to shopping locations. They made it clear that it could potentially be a great strategy but only dependent on the circumstances surrounding the disasters, the timing, and the location. In regards to gift cards, Anna explained:

It is not effective during disasters; any time there's a natural disaster, you have these agencies that try to help these individuals monetarily. I think their focus should be more on having those supplies on hand and being able to distribute those supplies.

In addition to this, John said:

There are things that you have to purchase with money but giving someone at least a card with \$250 on it, like a lot of the emergency organizations do is really not going to help when banks are closed and ATMs are out of cash, and businesses are closed. They can't really do too much with a visa card.

A major challenge noted about the shelters according to Katherine, Sharon, Cathy and other participants was the rule on smoking. They explained that the no smoking rule kept many individuals away who had health needs that could be addressed in the shelters thereby increasing their health risks. They deemed it counterproductive having rules in a community setting that were more appropriate for individuals in an inpatient setting.

Katherine said:

Smoking is a source of stress release for many people and if it's going to keep people calm and if it's going to take away stress it is okay because they are already in a stressful situation. Allowing them to go outside and have that one cigarette, these are individuals that have probably smoked for 20 or 30 years, it's not going to do as much harm to them as if you try to take that little bit away from them.

Katherine also explained about the futility of health promotion on smoking cessation during disasters. She said, “You want to promote wellness behaviors but now is not the time to address that. There is a time and a place for everything. You have to be able to recognize that.” One of the goals for health care providers is to promote the health of citizens at given opportunities. The study participants however indicated that it is not appropriate to try and influence behavior changes in individuals who are undergoing a life changing event such as disasters. Sharon said that “Allowing them a moment to have a cigarette also gives them a sense of control as they handle their stress, remember, most have lost it all.”

Safety was a major concern for the participants in the disaster zones but especially in and around the shelters. Lillian, Isaac, John, and Grace discussed about trying to maintain order in the shelters and situations that prompted police involvement to diminish some stress or tensions. Henry added, “We've had instances where people have been attacked or gotten in fights in these shelters because of the crowdedness and anger.” In addition to this, Esther said:

Then you have single women that may have been sexually traumatized and you're putting them in with men that have mental problems and again, you are already packed in these places. You have those fears that come up and it can be chaotic sometimes.

There were other challenges identified by the participants as hindering effective responses. Cathy stated that with the Maria disaster, some organizations restricted

volunteers to only those who spoke Spanish, a strategy that may have hindered qualified individuals from volunteering. She felt that it was an unnecessary hindrance given that there were locals who were readily available to interpret the language when needed.

Dorothy also discussed that with the special-needs shelters, one of the requirements was to have a family member or caretaker stay with the individuals who had chronic diseases:

Well, some of the problems were caregivers left them. The caregivers would drop them off and leave them at the special needs shelter, and the special needs shelter is not geared to take care of their personal needs. Their caregivers should have been with them, but some of them, the caregivers, did not come. They just dropped them off and expected the medical team to take over personal care. The medical team was there for medical care.

This as Dorothy explained strained the medical personnel as they had to manage the medical needs as well as personal needs such as hygiene and feeding assistance.

Food was an essential main item donated by responding organizations and the communities during disasters but in some instances, the food donated turned out to be a major challenge for those requiring special or restricted diets. Cathy, Esther, and Florence expressed the challenges on managing the exacerbating symptoms of individuals with diabetes, high blood pressure, and renal diseases after consuming foods high in fats and sugars. Cathy said that, "A lot of people that were diabetic complained because the foods were mainly high fat, high salt and high carb. They didn't have a lot of fresh meat, fruits, or vegetables." For dialysis patients, Florence said, "the labs don't lie, and you can see the

potassium shooting up, blood sugar very high, you know they are not complying. At that time, they are doing what they can, the best they can with what they have.”

### **Theme 6: Mental Health**

There are some themes that emerged during the interviews as general observations and experiences that were not directly related to the interview questions. One of the themes was mental health and the aspect of prevalence among the disaster victims, the approaches, and the availability of resources to manage those with mental health issues. The participants shared that they encountered individuals with mental health issues either as a history or acute presentation due to the effects of the disasters. To many, it was an area that was neglected with inadequate preparedness by majority of the disaster organizations and an area that required some form of interventions to ensure success in the disaster response efforts.

A few of the participants acknowledged the presence of mental health providers however stated that they were inadequate to meet the needs of the disaster victims. Anna expressed that during hurricane Harvey, there were only four counsellors and three social workers for thousands of patients or people who had been affected and concluded that most of them had to wait for weeks before their needs were addressed. She said, “these people are dealing with these mental...loss of life if they have lost a loved one, loss of their possessions, their belongings...A couple that were together 45 years lost everything, they were devastated and not handling it well.” Anna continued: “You want to tell them that all will be okay, but it is little comfort when you have lost everything. As a nurse,

they teach us to help people improve their health but no training to address the mental impact.” Anna’s experience resonated among other study participants who noted the inadequacy of resources to address the mental health concerns.

The lack of preparedness for individuals with mental health was expressed by the participants when they noted that individuals with mental illnesses such as schizophrenia, bipolar, anxiety, and manic depression were placed together with the general population in the shelters. Their symptoms were often aggravated by being in crowded situations which happened to be the case with the shelters. Anna said that in such situations, “individuals with a mental illness may feel threatened and they may lash out.” The situations were complicated by the lack of individual preparedness as most of the victims did not have their maintenance medications with them and the shelters lacked the same.

Besides individuals who had previous mental illness diagnosis, there are those who had acute presentations given the effects of the disasters. Cathy discussed individuals who were “shocked, stressed, depressed, and emotionally broken because they had lost everything and because of what they had witnessed.” She explained that as they managed their chronic diseases, they tried to provide some sought of counseling to alleviate their pain and grieve. According to Cathy, the most challenging individuals were evacuees from Puerto Rico because:

They were sick but had to go through dialysis to sustain their lives; however, they were very sad because they were constantly worried about the people they left

home, their loved ones, and the total loss of their properties. They felt like they had abandoned their loved ones to come so far away for treatment.

Esther and other participants noted the absence of mental illness medications even in the pharmacies that had set up temporary sites. She said: “The things that the pharmacies did not have is any kind of anti-depressants, anti-psychotic, there were no drugs for any mental health condition.” She continued that in her experience, there was a small section of the tent set up for a social worker or counselor and that was it. Florence explained the challenges of not being able to help someone with mental illness. She said: “You would tell it would be nice to have people talk to them further. We couldn’t spend that time mental health-wise as much as we wanted. We did what we could then move on to the next patient, unfortunately.”

There were a couple of shelters that had the presence of mental health counselors, especially in Florida. Dorothy said that, “we had persons that had mental illness, whether they came in with mental health is not quite sure, but we did have people exhibiting mental health illness, but there were mental health counselors that were assigned to the shelters.” Florence also stated that in her experience, there was a volunteer priest who acted the part of a mental health counselor but after he left, her team was left to deal with situations the best way they could. In Sharon’s experience, the availability of mental health practitioners was dependent on identified needs where her organization called in trained personnel from their organization after reaching out to the local mental health



providers as the need arose. Meanwhile, the medical personnel did the best they could with the limited training they had to address acute need.

### **Theme 7: Greatest Good for the Greatest Number of People**

Another general theme that emerged during the interview process was doing the greatest good for the greatest number of people. The participants made a reference to this in relation to the availability of resources, manpower, severity of symptoms, and severity of the disaster. The idea or practice according to the participants is to ensure responders rescue and safe guard the lives of as many people as possible despite the presenting circumstances. To most of the disaster responders, it is a concept that is in-grained in times of disaster rescue and requires critical thinking skills, prioritization, speed, and often detaching oneself emotionally from the victims.

The study participants all verbalized that to do the greatest good for the greatest number of people during disasters, disaster responders should be able to perform with fewer resources or work in unfavorable conditions yet perform at their very best. Such situations as they described required teamwork, patience, and control over emotions and having the right mind set to overcome challenges. They described situations where they had to make tough decisions during the distribution of scarce resources, where they had to use the police presence to control unruly crowds, or to restrict an obviously agitated individual from smoking in the presence of others. For medical personnel who often have to make splitting decisions when prioritizing medical emergencies or conditions, Anna,

one of the participants described it as “an emotional turmoil and emotionally draining.”

She said: Anna said:

I'm one of the triage nurses and you have about a five-second timeframe to make a decision on what color you're going to give an individual. That keeps you from, I don't want to say getting too emotionally involved because you really cannot at that point when you're triaging be emotionally involved. It's hard. You have to almost detach yourself because these are individuals' lives but again, they're human beings. As a nurse, you don't ever want to lose a patient. When you're a nurse, you're not thinking, “Okay, this one is red, this one is blue, and this one is green, whatever.” You're not thinking that. You're thinking, “I'm a nurse, my job is to help them and make them better.” Well, sometimes you can't make them better. That's why you have to detach yourself when you're triaging. You have to look at what's going on with that individual and make a decision within five seconds as to what color they're going to be...again it is the greatest good for the greatest number of people.

Cathy said:

What we did as staff, we worked longer hours; we did our regular people. Mostly they come in the morning and by 4:30 PM, we are finished. We had a third shift which would start 5:00 PM to the evening-ish. That's what we ended up doing. We also brought in extra staff to-- We didn't have a lot of staff, did not have so many...but we worked on working longer, the clinic had to pay longer...even

without insurance or any of that stuff, they sorted all that later...so yes, even if the dialysis hours were short sometimes, everybody managed to get their three-days-in-a-week dialysis...we tried doing the greatest good for the greatest number of people.

Grace said:

But I do think it is the way that the staff worked together in general I think it was the best for the patients there. Everybody worked there as a team. Like I said, you had social workers, you had respiratory, you had nursing staff and patient families... even with little privacy, and we did the best that we could. We provided good care whether you have this equipment, or that equipment, or whatever you had. We just kind of made it work and did the best we could. I think the patients knew that; they knew you were working hard for them...because of the continuity of care, because you had staff that worked well together.

The study participants shared that with the many challenges that face communities in times of disasters, the spirit of team work and empathy enabled them to overcome some of the challenges. As Florence stated, "In order to make it, we found different ways to manage the best way we could." Many of the participants were very emotional while sharing the challenges that the communities faced during the disasters. They however all agreed that having disaster responders on site gave the communities a sense of belonging, love, and hope for a better day.

**Theme 8: Resilience**

In conducting the interviews, the participants elicited an admiration for the communities because of their determination to rebuild, to remain positive, to join and help each other out, and to not give up despite the devastation from disasters; the communities were resilient. Resilience is the last theme that emerged from the participant interviews and the theme resonated across majority of the participants. For communities to go through severe devastation and destruction and yet remain positive was an aspect that most participants credited for enlisting multiple times for disasters response. In addition, they said that the support and presence of relief organizations and individuals made it easier and possible for these communities to bounce back. Isaac described resilience among communities that had taken in so much destruction, families with no homes, no clothes, and no food and yet they were able to walk away from that with hopes of rebuilding.

The study participants' descriptions involved experiences of individuals who were strong, positive, and shared their stories amidst their pain. According to Florence:

A lot of these people--a majority of these people were amazing. Whether it was in Florida or Puerto Rico, they were absolutely amazing and some are awesome. There was a couple and they were just so thankful. You would never know that they went through the disaster, had lost so much. For the most part people were just happy to be somewhere and happy for someone to be taking care of them to tell you the truth.

With Hurricane Maria in Puerto Rico, Sharon said:

Our organization worked with the local companies to rebuild and reconstruct from water filtration to the sewer system. So, literally everybody on the island chipped in the best they could. Sometimes the best way they chipped in was just to go back to work. They didn't sit around on their butt and they moan... They didn't weep or cry. In fact, one of the biggest things to come out of this is the phrase, "Puerto Rico se levanta," which translated from Spanish means Puerto Rico will arise.

Lillian said:

I came across individuals who said that, "we are not going to be down, and we are not going to be finished by this, we are going to work." Everybody chipped in to help any way they could and one of the biggest things they could do for us was to provide food and they appreciated our presence there.

As noted by the study participants, resilience can be challenging for many, however it is evident that determination, self-worth, togetherness, and humanitarian efforts are key factors to enabling communities and individuals to become resilient even after devastating life changing events.

### **Discrepant Cases**

During the data analysis for this study, there were no discrepant cases noted. The data collected from all participants conformed to the set standards as indicated in the literature review. There were some notable differences in terms of the way disaster

responders addressed the needs of individuals with chronic diseases; however, no discrepancies arose from any of the interviews. The data analysis was consistent with the explanations and experiences outlined by the study participants with no conflicts or inconsistencies.

### **Summary**

The purpose of this study was to explore how disaster relief responders and workers addressed the needs of individuals with chronic diseases during and in the aftermath of a disaster. In this chapter, I discussed the study participant's demographics, the data collection process, and on how the data was analyzed. There is a section that reviews measures taken to ensure the trustworthiness of the data by addressing credibility, transferability, dependability, and confirmability. Within the chapter, I addressed the research questions as well as the themes that emerged in relation to the questions and the responses from the study participants.

The following are themes that emerged from the data analysis in relation to the research questions. They represent the lived experiences of the study participants.

**Theme 1:** Disease management techniques: The means to managing chronic disease exacerbations in disasters.

This theme emerged in relation to the research question (How do disaster relief responders and planners manage chronic disease exacerbations?). The participants of this study reflected on their disaster response experiences in managing chronic diseases by sharing that they had to apply certain principles such as accountability, responsibility,

coordination, and collaboration as driving forces behind their practices. Their main challenge was not having adequate resources, and this was resolved by collaborating with other responders and stakeholders. To manage the chronic diseases, the participants stated that they just made do with what they had. This involved strategies such as substituting medications, safe sharing of home medications, having stable patients and family members assist sicker patients, and triaging patients to prioritize medical needs.

**Theme 2:** Perceived individual disaster preparedness.

The research question related to this theme is: In what ways are individuals with chronic diseases prepared during a disaster as reported by disaster relief responders and planners? The participants expressed concerns at the widespread lack of individual preparedness despite the public forewarning information disseminated during disaster warnings. A majority of participants noted that very few individuals were prepared with an additional few who were inadequately prepared. However, the greatest numbers of disaster victims were completely unprepared, a factor that hindered the management of chronic diseases and impacted on the wellbeing of the disaster victims.

**Theme 3:** Assessing the preparedness of disaster communities.

This theme and the three subthemes (Local community preparedness and immediate response, disaster response organizations and preparedness, and responder training and preparedness), are in relation to the third sub question (in what ways were the communities prepared for the response and management of individuals with chronic diseases?). In answering this question, the emergent theme and sub themes were

intertwined together where the participants referenced them back and forth. The general perception from the respondents regarding preparedness by the disaster communities (local communities and responder organizations) was that more needed to be done. There lacked basic resources, organization of the response efforts, and collaboration and communication amongst the responding organizations and the local communities.

The collaboration and presence of local businesses, organizations, and individuals was dependent on the severity of the disaster. The participants shared that the response strategies utilized by the local communities were dependent on the type of preparedness efforts prior to the disasters and the magnitude of the disasters once they occurred. In terms of preparedness for the disaster response organizations, 100% of study participants agreed that their organizations were in some way prepared to respond to the disasters however, what differed was specific preparation for the chronic diseases, which mainly lacked. Training the disaster responders prior to disaster response emerged as one measure of preparedness and the study participants shared their experiences with their sponsoring organizations. Majority agreed that there was some sought of general training and communication regarding the disasters; however, the organizations could have better prepared the responders by providing specific training for chronic disease management.

**Theme 4:** Strategies, approaches, and practices: Advancing disaster preparedness and response for individuals with chronic diseases.

This theme was related to the fourth sub question (what strategies for chronic disease preparedness work following a disaster as reported by disaster responders and



planners?). As noted, the study participants shared various strategies that enhanced their disaster response for individuals with chronic diseases. One strategy reported by all participants to enhance disaster response was encouraging individuals and organizations to have an emergency plan; it was noted to be very effective when a disaster took place. Other strategies reported were ensuring availability of personnel and resources, use of pen and paper for documentation when electricity was scarce, and use of electronic medical records for continuity of care when electricity was available. Other strategies involved triaging patients by use of color codes to prioritize medical care and resource allocation, utilizing faith-based organizations for moral and emotional support, and one of the greatest strategies being collaboration and communication amongst responding organizations.

**Theme 5:** Ineffective strategies for chronic disease management in disasters.

This theme emerged from the question: What strategies for chronic disease preparedness do not work following a disaster as reported by disaster relief responders and planners? The participants expressed concerns about various strategies that did not enhance disaster response for individuals with chronic diseases. They described strategies that hindered or created challenges for chronic disease management. These strategies were in relation to the shelter (size, rules, and set up), donations (use of gift cards and money), and preparedness efforts (relocation in to trailers, resources, and collaboration between organizations). Other challenges identified were restrictions to Spanish speaking

only responders, attempts at health promotion to disaster victims, and unhealthy food supply not appropriate for individuals with certain diseases.

The last three themes (Mental health, greatest good for the greatest number of people, and resilience) all emerged during the interviews as general observations and experiences but were not directly related to the interview questions. The mental health theme emerged as the participants described disaster victims who presented with acute and chronic mental health issues in the wake of scarce mental health providers. The disaster responders verbalized that this was an area that was often neglected during disaster planning and preparedness. The theme on greatest good for the greatest number of people arose from the numerous descriptions of the creativity and critical thinking the disaster responders had to come up with so as to manage chronic diseases in the absence of resources and manpower given the severity of symptoms and severity of the disasters. Finally, the resilience theme emerged as the participants narrated the positive attitudes among the disaster communities, their determination to survive and rebuild, the spirit of togetherness, and the humane touch demonstrated by individuals.

Chapter 4 concludes with a summary description of the themes that emerged and related research questions. The themes that emerged provided insight into the phenomenon under study. In Chapter 5, I provide a summary of the key findings of the study and interpretations, limitations of the study, and recommendations based on participants' feedback. I discuss the implications of the study findings for social change.

## Chapter 5: Discussion, Conclusions, and Recommendations

### **Introduction**

The purpose of this qualitative grounded research study was to explore the strategies that disaster relief responders and workers used to manage the needs of individuals with chronic diseases during and in the aftermath of disasters. In using the grounded theory approach, this study sought to get firsthand lived experiences of study participants to understand their practices in managing chronic diseases during disasters. Available literature, though saturated with studies on the adverse effects, devastation, and health outcomes of individuals with chronic diseases, lacks adequate information on the management of chronic diseases during and in the aftermath of disasters. I conducted this study in response to the public health concern for health outcomes of individuals with chronic diseases during disasters and the lack of disaster preparedness for this population. With the knowledge derived from these participants, I was able to identify strategies that could enhance and improve disaster preparedness and disease management for individuals with chronic diseases, thereby improving their healthcare outcomes during and in the aftermath of disasters.

### **Summary of the Findings**

The study participants contributed to the main goal of the study through discussions regarding their practices and management of individuals with chronic diseases. The primary research question was: How do disaster relief responders and workers address the needs of chronic disease individuals during and in the aftermath of a

disaster? This question was addressed by all study participants as they answered the five sub questions. Eight themes emerged from the participants' experiences: (a) the means to managing chronic disease exacerbations in disasters, (b) how participants perceived individual disaster preparedness, (c) assessing the preparedness of disaster communities, (d) advancing disaster preparedness and response for individuals with chronic diseases, (e) ineffective strategies for chronic disease management in disasters, (f) mental health concern, (g) doing greatest good for the greatest number of people, and (h) community resilience.

The research questions explored holistic approaches applied by disaster responders and planners to address chronic disease needs during and after disasters. Some of the interviewees admitted that prior to and while responding to disasters, they did not specifically focus on chronic disease management; however, they were able to provide pertinent information as they discussed their practices, experiences, and observations on the management of chronic diseases. All study participants acknowledged the legitimate public health concerns involving health outcomes of individuals with chronic diseases, and through their experiences, they noted that lack of resources and lack of individual, community, and organizational preparedness played a major role in how chronic diseases were managed. They indicated that disaster responders make efforts to manage chronic diseases; however, an interdisciplinary approach is needed relating to the responsibilities and preparedness of individuals, local communities, and disaster response organizations.

According to the participants, the management of chronic diseases was dependent on the magnitude, duration, severity, and location of the disasters.

### **Interpretations of the Findings**

This study used the grounded theory research approach to better understand the perceptions and experiences of disaster responders in terms of how they managed individuals with chronic diseases. The grounded theory approach allowed participants to share their lived experiences, hence enriching the data and study findings. The study results confirmed and supported the literature review findings on disaster preparedness and management of chronic diseases. The study findings also extend current knowledge regarding disaster preparedness, response, and chronic disease management during and in the aftermath of disasters.

The use of shelters in disaster areas is indicated in this current study as well as in past literature as key to disaster response outcomes. An important finding is that the shelters in disaster areas were properly set up with basic supplies and staffed with various medical personnel, a strategy that seemed to enhance chronic disease management according to study participants. There was however inadequate and scarce essential resources such as medications, electricity/generators, water supply, and medical supplies in the disaster shelters. According to Mori et al. (2007), the lack of such essential supplies for individuals with chronic diseases hindered support for their daily needs, limited their mobility, aggravated their disease symptoms, and lessened efforts involving chronic disease management. The findings of this study and literature suggest that inadequate

resource availability continues to be a major concern for researchers as well as disaster responders.

In the absence of essential resources to manage chronic diseases, participants discussed various strategies that they used to manage symptom exacerbation. They employed critical thinking skills to prioritize the presenting symptoms and determine courses of action. They also triaged patients based on the severity of symptoms, and this assisted them in managing the most critical symptoms first as well as prioritizing resource allocation. The participants discussed situations where they made do with what they had to manage individuals with chronic diseases.

A major finding of this study was that vulnerability and increased poor health outcomes were experienced by individuals with chronic diseases during and after disasters. The study also highlighted the challenges encountered by responders during disaster response such as the lack of disaster preparedness for chronic disease management amongst individuals, communities, and disaster organizations. In addition, there were increased risks of adverse health outcomes for individuals with chronic diseases, especially in the absence of proper disaster preparedness and management efforts for chronic disease communities (Arrieta et al., 2009; Davis et al., 2010; Demaio et al., 2013; Holt et al., 2008). Disaster preparedness is vital for disaster response as it allows for an organized and collaborative process that leads to positive health outcomes not only for populations with chronic diseases but also for the general population.

The importance of having appropriate diets for the right individuals was part of the findings for this study. Compliance with renal and diabetic diets for victims was a notable challenge for the responders, as the food donors were not entirely prepared to ensure special foods were available for those with restricted diets. When the individuals on restricted diets consumed high fats, salts, and high sugar foods, this led to exacerbations of symptoms such as high blood pressure, edema, high glucose levels, and imbalanced electrolytes, making it difficult for symptom management. Radhakrishnan and Jacelon (2009) reported in their study that relief workers within the US stated that inappropriate diets such as sweetened buns were given to individuals requiring a diabetic diet making it difficult to control diabetic symptoms. The Missouri Health Department's CIDRAP developed a plan for individuals with ESRD and on dialysis that included a detailed 3-day diet plan of meals and snacks that limit amount of waste in blood to be used when dialysis treatments are not available (CIDRAP, 2013). This puts emphasis on the importance for food preparedness for individuals with chronic diseases prior to disasters.

Banks (2013) said that older adults with certain chronic diseases were in great danger of symptom exacerbation during disasters due to lack of medications and specialized medical equipment as well as other preparedness measures. Some of these diseases (congestive heart failure, diabetes, hypertension, asthma, chronic kidney disease, COPD, oxygen dependent, and mental illness) were identified in the literature as most prevalent during disasters and this study's findings concluded the same. Robinson et al.

(2011) also discovered that during disasters, increased stress levels among victims aggravated the symptoms of these chronic diseases, further compromising individual health outcomes. The participants in this study consistently indicated that the greatest challenges were managing these diseases, especially with scarce resources. The call to improve the health outcomes of individuals with chronic diseases after disasters through better disaster preparedness, planning, and management strategies is ongoing needed.

This study extends the public health knowledge in various ways. Radhakrishnan and Jacelon (2009) recommended that a system that could identify and register patients with chronic diseases was needed as a strategy for improving disaster preparedness for these populations. In my study findings, four participants discussed their experiences with shelters that primarily catered to individuals with chronic diseases. Preregistration was required so that the planners could better prepare with allocation of medical supplies, medications, and health practitioners. This practice was identified by the participants as one of the strategies that worked to improve the health outcomes of individuals with chronic diseases and they verbalized the need for more disaster planners to embrace the practice.

Another way that this study extended knowledge was that I acquired data about the effectiveness of disaster preparedness education to the public and media communication on preparedness prior to disasters. The communities and individuals with resources and evacuation preparedness had better chronic disease management and resource allocation. The use of electronic medical records in disaster areas that still had



electricity, or the use of generators was reported to enhance prompt, appropriate, and continuity of care among those with chronic diseases. According to the participants, in the absence of electricity or generators, the use of traditional pen and paper to communicate to other team members the patient needs, and the care provided seemed to have similar results.

Based on information available, researchers identified the need for enhanced communication and collaboration amongst disaster responders and disaster communities (Horn & Kirsh, 2018; Slim et al, 2016). The participants in this study expanded this knowledge by confirming that organizations that ensured effective communication amongst their responders and collaborated with other response organizations and the affected communities had better outcomes for those with chronic diseases. Other findings that expanded knowledge were information on strategies deemed ineffective in advancing disaster response such as futility of gift card donations to disaster victims with no access to shopping sites as well as overcrowded and un-partitioned areas within the shelters. Smoking restrictions in the shelters and smoking cessation education additionally, proved to be ineffective strategies in managing chronic diseases among disaster victims.

The participants discussed their encounters with new onset mental health illnesses and victims with previous mental health diagnosis. They shared that this was an area that was heavily neglected by response organizations in terms of preparedness, resource allocation, and management. Often, they lacked mental health medications, responder training to manage mental health illnesses, and lack of trained mental health providers or

counsellors. In some cases, the participants noted that faith-based ministers provided supportive counselling to the mental health victims to alleviate their anger, frustrations, anxiety, and depression. Results from this study identified the lack of mental health providers as a failure for disaster planners, a great challenge for the disaster responders in trying to manage the illnesses, a safety risk for other disaster victims, and a disservice to the mental health victims.

Having focused on a grounded theory approach enabled the focus to be on the lived experiences of the study participants. The participants were able to share firsthand how they managed the care of chronic diseases during disasters while struggling with inadequate resources or in some instances, scarce resources. They all shared that despite the challenges they faced, they were committed to doing the best they could for the greatest number of people. Team work was discussed as the greatest strategy amongst the responders that yielded the most results given the challenging situations the participants encountered. The participants disclosed that the drive, determination, and positive attitudes of the disaster victims enabled them to give their best and that the overall community resilience and positive health outcomes were the highlights of their disaster response efforts.

The theoretical framework that grounded this research study is the ecological model of disaster management. The model focuses on the interdependence of the various levels of disaster management during the whole disaster cycle. This framework was utilized in this study to better understand how the model's assumptions of planning,

preparedness, response, and recovery of disasters relate to the individual, community, organizational, state, and federal levels. The study results indicated that there is mutual interdependence and interaction between all the levels and they all influence the disaster management process and outcomes.

One of the findings of this study was the inadequate disaster preparedness and management of individuals with chronic diseases. Based on the participant's narratives, use of the model was useful in developing disaster preparedness strategies for chronic disease populations and determining existing strategies that could be advanced. In this study, the participants focused on communication and collaboration between disaster responders and organizations as an effective strategy for disaster preparedness and response. This was in alignment with the model's focus on the interrelationship and interconnectedness of all the different levels from the individual level to the federal level.

Another aspect of the ecological model for disaster management is the focus on engaging the social environment of a target community in advocating for policies that promote health in disasters. From the data collected in this study, I discovered that the participants alluded to the fact that disaster preparedness and response efforts were dependent on the magnitude, severity, and location of the disaster. As seen in the study, engaging the local businesses, hospitals, faith-based organizations, and individuals in disaster preparedness allows for the development of strategies that would be effective in managing the care of chronic diseases during disasters. The study participants concluded that disaster locations that had active local community engagement (individuals,

hospitals, churches, local businesses) had better experiences with the disaster response and more favorable health outcomes for all victims.

A finding in this study that every participant addressed was the scarcity of essential resources. They discussed that lack of resources was one major hindrance to an effective disaster response not only for individuals with chronic diseases, but also for the general population. There was consensus among all the participants that disaster response organizations and communities should plan and prepare to ensure availability of resources for disaster victims especially those with chronic diseases. Through the call for disaster preparedness and management, the ecological model puts emphasis on exploring availability of resources in communities to enhance the disaster response and outcomes for those with chronic diseases. Both the model and study findings focused on having partnerships with individuals, communities, and response organizations, flexible response strategies tailored to population characteristics, and dynamic interconnectedness and interdependence of all stakeholders to effective disaster response and disease management.

### **Limitations**

One limitation for this study is participant recall bias. At the time of the interviews, majority of the participants had responded to varying numbers of disasters that dated several years back. The experiences they shared were self-reported and although they were able to recall the events from the disasters, there was a possibility of forgetting actual and specific events leading to a recall bias. Recall bias could lead to

overestimation or underestimation of the study results. Two strategies that can minimize recall bias is the careful selection and articulation of the research questions and administering the interviews close to when the disasters happened.

For this study, I utilized snowballing and social media as some of the methods for participant recruitment, and they turned out to be limitations for the study because of the lengthy period that it took for the referred individuals to initiate contact and, to receive responses through the social media recruitment. In addition, after the initial contacts, the potential recruits did not follow up or return calls in a timely manner and therefore I had to send out reminders several times to the recruitment platforms hence limiting how fast I could move the interview process forward. This hence lengthened the data collection process. Researchers conducting future studies could probably collaborate with disaster organizations, local communities in disaster areas, and faith-based organizations for participant recruitment. The snowballing method however eliminated referrals that did not meet study criteria such as not having cared for chronic disease individuals during disaster response.

Besides the limitations, there were some challenges identified about the participants who were located in different time zones and states. This was evidenced by the challenges in scheduling interview times with some of the participants who were hard to get due to the time differences. Another challenge was the difficulty in recruiting the target population (disaster responders and planners) who turned out to be professionals but with time constraints. Besides time zone differences, it was challenging to get access

to participants who were on the same time zone due to their work schedules and personal time demands. This resulted in an interview process that carried on for a lengthy period between contacts and often several attempts to conclude on the interview or follow up time. Despite these challenges, this study however provided in-depth experiences of the study participants that added to the body of literature that seeks to develop strategies for disaster preparedness and chronic disease management.

### **Recommendations for Future Research**

According to the findings of my research study, the lack of disaster preparedness for individuals with chronic diseases continues to be a concern. Having communication and collaborative efforts among all levels of disaster organizational levels proved to yield positive health outcomes for the disaster victims as well as a positive experience for the disaster responders. Further research is needed to explore the barriers that hinder consistent communication and collaborative strategies among the organizational levels in disaster preparedness and management of chronic diseases. Knowing the barriers that exist could potentially inform disaster planners and allow for the development of strategies that could eliminate the barriers and foster communication and collaboration among disaster responders.

Additional research should also be conducted to determine specifically why individuals, communities, and organizations do not adequately prepare for disasters despite repeated warnings and reminders and vulnerability to disasters. Having specific reasons could lead and enable disaster planners to develop aligned strategies that

individuals and communities could more readily embrace in preparing for disasters. Another research recommendation that arose from this study is how communities can identify resources that would be available in a disaster for individuals with chronic diseases as a disaster preparedness measure. The participants pointed out that the lack of resources was the main hindrance to chronic disease management and identifying community resources prior to disasters could be a step towards chronic disease management.

The issue of mental health prevalence among disaster victims was reported as a major concern by the participants of this study. They discussed the absence of mental health providers at the disaster sites, the lack of disaster preparedness for individuals with mental health illness, and the lack of proper disease management. These findings indicated a need for further research to explore how chronic and acute mental health issues can better be managed during and in the aftermath of disasters. Lastly, the success of the special-needs chronic disease shelters in some Florida locations was evident and therefore, researchers can further investigate how they identified individuals with chronic diseases and the effectiveness of such shelters. They can then explore how such a strategy can be implemented in other disaster-prone areas to manage the care of individuals with chronic diseases during disasters and in the aftermath.

### **Implications**

The findings of my study have significant implications for social change on all social levels to have disaster preparedness for individuals with chronic diseases. The

results indicate that there are strategies that could be developed to enhance the health outcomes of individuals with chronic diseases through proper disaster planning and preparedness for this vulnerable population. The driving force behind the aim for social change is the need for positive health outcomes during and after disasters for populations with chronic diseases. All the stakeholders (individuals, communities, organizations, public health practitioners, health care providers, and the government) can use the findings of this study to serve the chronic disease population and enhance their health outcomes after disasters.

### **Individuals**

The findings of my study can help individuals with chronic diseases plan for disasters and ensure that they are equipped to manage their chronic diseases in the initial stages of a disaster and immediately in the aftermath. Personal preparedness is the first step in disaster preparedness and requires individuals to take responsibility for personal safety and health outcomes. The results outlined some strategies and recommendations that individuals with chronic diseases can adopt as an ongoing effort or prior to disasters to better manage their chronic situations during disasters. Individual preparedness has the potential to minimize challenges such as the inadequate resources and manpower often seen in disasters. The results could really empower individuals to take charge of their health and wellbeing by learning more about their illnesses and how to always maintain optimal health, be disaster ready with recommended medication and other resources,



having an evacuation plan, having their medical information and their doctor's information readily available to ensure continuity of care.

### **Communities**

The study results indicated that communities are an important influence in disaster preparedness and response and there was a certain amount of community engagement. They were identified as the first responders at a disaster site and hence their preparedness is vital for a successful disaster response. The study results could help communities be able to identify resources that could be made available for citizens during disasters, be able to identify individuals with chronic diseases, and better plan for a community wide disaster response. A major finding of the study is the lack of communication and collaboration among communities and disaster response organizations. Based on the findings of this study, communities can strengthen community preparedness and response by engaging in better communications and collaborations with individuals, local businesses, faith-based organizations, the government, and disaster response organizations for a more enhanced disaster management approach for those with chronic diseases.

### **Disaster Response Organizations**

The findings of this study can empower disaster response organizations to better prepare for individuals with chronic diseases given that majority of the disaster response organizations play a major role in responding to disasters especially if it is a high magnitude disaster. One suggestion was to ensure chronic disease responder training

prior to disaster response. The study findings identified the lack of/inadequate responder training as a hindrance to proper disease management by responders. In addition, the findings will direct these organizations into specific preparations for chronic disease disaster response. The findings also encourage the disaster response organizations to collaborate with local organizations such as hospitals, businesses, and non-profit organizations for a successful disaster response, not only for individuals with chronic diseases but for the general population.

### **Public Health Practitioners and Healthcare Providers**

The study findings will encourage public health practitioners and health providers to take active role in disaster planning, response, and in the management of chronic diseases. With adequate disaster planning and preparedness, there were positive health outcomes for individuals with chronic diseases during and after disasters. The results will influence practitioners and providers to become more engaged in mobilizing efforts for chronic disease disaster preparedness. Some of the strategies to minimize disaster impact on those with chronic diseases include teaching and encouraging citizens to prepare for disasters, ensuring timely communication and announcements of public disaster information that is precise and adequate, ensuring resource identification, and planning for continuity of care for these individuals. These study findings will also empower the practitioners and providers to influence the health outcomes of these individuals by implementing the strategies noted to be effective in managing chronic diseases during and in the aftermath of disasters.

## **Government**

Each state and federal government bodies play a vital role in disasters, especially the major disasters. Their roles in disaster planning and response are important in ensuring success of the whole disaster process. The findings of my study indicate that collaborative efforts between the local communities and these government bodies allow for favorable disaster response results. The results will influence these bodies in developing policies that will enhance disaster preparedness and response for individuals with chronic diseases. The implications for positive social change in this study are enormous and require all the stakeholders to embrace and make intentional efforts to improve the health outcomes of individuals with chronic diseases during and after disasters.

## **Conclusion**

The frequency of natural disasters here in the United States continues to rise every year leaving behind significant consequences such as loss of life, infrastructure and property damage, and economic loss (Chinen, 2017; Khan et al., 2014; Knap & Rusyn, 2016; Patterson et al., 2018). Additionally, the incidence and prevalence of chronic diseases have been on the rise especially in the aging population and some of them account for the leading causes of death in the United States (Arrieta et al., 2009; CDC, 2013; Demaio et al., 2013; Owens & Martsof, 2014; Raghupathi & Raghupathi, 2018). From a public health perspective, these two aspects continue to be of concern given vulnerability of individuals with chronic diseases and the poor health outcomes they

experience after disasters and the lack of disaster preparedness for this population (Horn & Kirsch, 2018). The purpose of this qualitative study was to explore the strategies that disaster relief responders and workers utilized to manage the needs of individuals with chronic diseases during and in the aftermath of disasters. Through the study results, I was able to develop strategies that could improve disaster preparedness and disease management for individuals with chronic diseases.

By focusing on disaster responders and workers who had lived the experience, the study results provide a good representation of the phenomena under study. The findings of my study also provided insight in to the strategies that disaster responders and workers utilize to manage the care for individuals with chronic diseases. This allowed for the development and enhancement of strategies that can be adopted by all stakeholders in the efforts of improving disaster preparedness for this vulnerable population. The study results highlighted the participants' efforts of 'doing good for the greatest number of people' as a way to manage chronic diseases in the absence of adequate disaster preparedness. This is an indication that the study findings of the need to have all stakeholders adequately plan and prepare for chronic diseases in the advent of a disaster are valid. The conclusion based on the study results is that all stakeholders must have some accountability and responsibility for individuals with chronic diseases and there has to be coordination and collaborative efforts between disaster response organizations, non-government entities, local communities, and individuals so as to ensure favorable health outcomes for individuals with chronic diseases.

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## Appendix A: Interview Guide

1. Would you please tell me if you have ever participated or responded to a natural disaster? If you have could you share some details about that disaster or disasters?
2. In your experience what was the disaster victims' presentation in terms of acute injuries or chronic diseases?
3. Please explain the types of chronic conditions you and your peers came across during disaster response?
4. Would you please share your experiences in managing the care for those individuals with chronic diseases?
5. How did other disaster relief responders and health practitioners manage chronic diseases during and after disasters?
6. In what ways are individuals with chronic diseases prepared during a disaster?
7. In what ways are disaster responders prepared to manage chronic diseases in a disaster?
8. In your experience, what strategies for chronic disease preparedness work following a disaster?
9. What strategies for chronic disease preparedness do not work following a disaster?
10. What suggestions would you share in regards to chronic disease management that may improve disaster response for these individuals?

## Appendix B: Interview Screening Guide

## INTERVIEW SCREENING QUESTION GUIDE

1. Are you 18 years and older?
  - a. Yes
  - b. No
2. Do you currently reside in a facility (such as; Nursing home, assisted living, prison...)?
  - a. Yes
  - b. No
3. Have you ever responded to or worked with a disaster relief organization during a natural disaster?
  - a. Yes
  - b. No
4. During the disaster response or after the disaster, did you manage the care of individuals with a chronic disease?
  - a. Yes
  - b. No
5. Are you a disaster preparedness planner or have you ever participated in disaster planning?
  - a. Yes
  - b. No
6. Have you ever participated in disaster planning for individuals with chronic diseases?
  - a. Yes
  - b. No
7. Which of the following statements best describe your involvement in disaster planning?
  - a. I have been involved in disaster preparedness planning for individuals with chronic diseases
  - b. I have been involved in disaster response planning and management for individuals with chronic diseases
  - c. I have not participated in disaster preparedness planning or response planning for individuals with chronic diseases

## Appendix C: Codes

The victim's helplessness  
 Lack of mental health providers/psychologists  
 The lack of resources-water, food, electricity, roads, hospitals  
 In-adequate supplies-medical supplies, personal hygiene items, medications  
 No medical history or information to help provide best and right care  
 Lack of social support  
 Empathy  
 Sympathy  
 Collaborations amongst disaster responders  
 Co-ordination of care and other disaster responses.  
 Family support system  
 Organizational/responder preparedness  
 Presence or the absence of NGOs, local businesses  
 Responder training prior to deployment  
 Availability of health practitioners  
 Public awareness of impending disasters  
 Information management and dissemination  
 The play of culture in overcoming stress, devastation, and loss of property and loved ones  
 The goodness of the people demonstrated in times of need surpassed that of businesses  
 Use of survival techniques to ensure safety of the disaster victims  
 Availability of social workers and the need for more  
 Transitioning victims back to society in after disasters  
 Triaging disaster victims to determine level of care and urgency  
 Tendency to ignore chronic disease individuals  
 The need for an enhanced communication system amongst providers  
 Medically dependent  
 Perseverance  
 Persons with disabilities  
 Public awareness,  
 Risk communication,  
 Social media  
 Accountability,  
 Responsibility,

Coordination,  
Availability of health practitioners,  
Impact on health,  
Water disposal and sanitation,  
Public health and safety,  
Information sharing and exchange  
Cultural aspects,  
Non- Government organizations,  
Local businesses,  
Community disaster response preparedness,  
Individual preparedness  
Communications systems and/or networks,  
Health facilities, 'lifelines',  
Power and energy, electricity  
Emergency evacuation shelters,  
Disaster preparedness,  
Disaster prevention,  
Disaster risk reduction plan,  
Policies and strategies,  
People-centered early warning system,  
The destruction of infrastructure, environment  
Mental health awareness  
Water and food supplies  
Accessible roads  
Personal hygiene items,  
Medications  
Dialysis  
Lack of medical history/information  
Social support  
Empathy  
Sympathy  
Family support system  
Organizational/responder preparedness  
Goodness of the people  
Humanity  
Safety  
Social workers

Transitioning victims back to society  
Triaging disaster victims  
Level of care  
The need for an enhanced communication system amongst providers  
Chronic diseases not addressed  
Greater good for the greatest people  
Survival tactics  
Impact of disaster  
Prevalence of chronic diseases  
Disaster response  
Disaster management  
Determination to manage the chronic diseases  
Making do with what is available  
Victim's feeling of helplessness  
Vulnerability of chronic disease disaster victims.  
Mental health incidence and prevalence  
Coping mechanism  
Loss absorption,  
Psychological impact



## Appendix D: Coding Categories

1. Magnitude of disasters
2. Information management
3. Vulnerable populations
4. Infrastructure
5. Early warning and preparedness
6. Disaster risk management
7. Governing disaster preparedness and response
8. Health outlook (Medically dependent; availability of health practitioners; impact on health; Lack of medical history/information; Hospitals/clinics; medical supplies; Prevalence of chronic diseases)
9. Chronic disease individual preparedness
10. Community and organizational preparedness
11. Management of information
12. Resilience (cultural aspects, coping mechanisms, loss absorption, psychological impact)
13. Media and networking
14. Societal responsibility (Presence of NGO's, local businesses)
15. Resource availability and inadequacy
16. Availability and the lack of supplies
17. Social impact