Barriers to the long-term recovery of individuals with disabilities following a disaster

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This study examines how pre-existing disabling conditions influenced the recovery process of survivors of Hurricane Katrina. It focuses specifically on the barriers that hindered the recovery process in these individuals. Focus groups were convened in four Gulf Coast states with 31 individuals with disabilities who lived in or around New Orleans, Louisiana, prior to Hurricane Katrina in August 2005. Qualitative data were analysed using grounded theory methodology. Five themes emerged as the most significant barriers to recovery: housing; transportation; employment; physical and mental health; and accessing recovery services. While these barriers to recovery were probably common to most survivors of the disaster, the research results suggest that disability status enhanced the challenges that participants experienced in negotiating the recovery process and in acquiring resources that accommodated their disabilities. The findings indicate that, when disaster recovery services and resources did not accommodate the needs of individuals with disabilities, recovery was hindered. Recovery efforts should include building accessible infrastructure and services that will allow for participation by all.

Keywords: disability, disaster, Hurricane Katrina, recovery

Introduction

The social vulnerability perspective posits that certain groups in society are disadvantaged by disaster risk and impact owing to the interplay of cultural, economic, and societal factors (Tierney, Petak, and Hahn, 1988; Morrow, 1999; Enarson and Morrow, 2000; Wisner et al., 2004; Phillips and Fordham, 2010). Research grounded in this perspective has included studies on children, the elderly, immigrants, and women, and suggests that the unequal disaster-related consequences experienced are because of disparities in the existing socioeconomic system. Individuals with disabilities often are among these vulnerable populations, yet empirical research on how disasters affect them are limited (National Council on Disability, 2009; Peek and Stough, 2010). The small amount of literature in this area is surprising given that slightly less than 20 per cent of the community-dwelling population of the United States reports having a disability (Brault, 2012) and an estimated one billion people worldwide have a disability (World Health Organization and The World Bank, 2011).

Studies that do exist on people with disabilities and disasters focus primarily on emergency preparedness and evacuation. In an early work, Tierney, Petak, and Hahn

(1988) determined that people with physical disabilities are at a particular disadvantage during earthquakes as the built environment exposes them to a higher degree of risk. Morrow (1999) states that older adults who are physically frail are especially at-risk during an evacuation. Building designs that require the ability to descend stairs, exit windows, or open doors create evacuation barriers for people with physical disabilities (Christensen, Blair, and Holt, 2007). In addition, few emergency managers have completed training regarding the needs of people with disabilities and emergency management plans often do not include them (Fox et al., 2007). Furthermore, evacuation behaviour is affected when a household member has a disability. During Hurricanes Bonnie (August 1998), Floyd (September 1999), and Dennis (July 2005), evacuations among households with people with disabilities were delayed and occurred less frequently than in households without a member with disabilities (Van Willigen et al., 2002). Most of these households identified a lack of transportation or of accessible shelter facilities as the main reasons for their reluctance to evacuate. A survey of 680 evacuees owing to Hurricane Katrina found that 38 per cent of those who did not evacuate before the storm of August 2005 either were physically unable to leave or were caring for someone who was physically unable to leave (*The Washington Post*, The Henry J. Kaiser Family Foundation, and Harvard University, 2005). Similarly, nine per cent of households with members with disabilities located near to a chemical weapons storage site in the US State of Alabama were identified as needing evacuation assistance in a time of disaster, but 60 per cent reported that there they did not have adequate help to do so and 59 per cent reported that they lacked suitable evacuation transportation (Metz et al., 2002). Research on levels of preparedness in households with disabilities found them to be both more and less prepared for disasters with respect to elements such as communication planning, disaster supplies, evacuation, and medication (see, for example, Eisenman et al., 2009; Uscher-Pines et al., 2009; Bethel, Foreman, and Burke, 2011).

People with disabilities are differentially affected both by the impacts of a disaster and during the response phase. For instance, households with a family member with a disability are more likely to live in a mobile home or on an island, and hence experience significantly more damage to their home during a hurricane (Van Willigen et al., 2002). Services that individuals with disabilities receive immediately after a disaster also differ: emergency personnel and voluntary service organisations frequently do not consider the support needed by individuals with disabilities in post-disaster exercises (Parr, 1987). Similarly, Byrne and Davis (2005) found that volunteers pretending to be wheelchair users or to have a visual impairment were passed over, ignored, or attended to inappropriately by emergency responders during a drill scenario. Case studies of Hurricane Katrina and the Indian Ocean tsunami of 2004 (Hemingway and Priestley, 2006; Priestley and Hemingway, 2007) found that people with disabilities were disadvantaged during the relief phase owing to multiple types of physical and social barriers. Studies on sheltering (see Twigg et al. (2011) for a review) suggest that the response to a disaster often fails to meet the needs of people with disabilities, presenting problems across multiple areas, including facilities, medication, needs

assessment, and physical access. In addition, individuals with pre-existing physical or mental health disabilities have been found to be at increased risk of acquiring additional disabilities or health conditions as result of a disaster (Reinhardt et al., 2011). However, one study (Ducy and Stough, 2011) following Hurricane Ike of September 2008 found that special education teachers were instrumental in meeting the educational needs of their students with disabilities post disaster.

Several social vulnerability theorists (see, for example, Peacock, Morrow, and Gladwin, 1997; Fothergill and Peek, 2004; Cutter et al., 2006) have suggested that socially marginalised groups are slower to recover from disasters. Virtually no studies, though, have examined the long-term recovery phase and individuals with disabilities. An exception was a study of 559 households following Hurricane Floyd of September 1999 in which households with a person with a disability were significantly more likely to report that their lives remained disrupted one year after the storm (Van Willigen et al., 2002). Specifically, 67 per cent of households without a member with a disability reported that their lives were completely back to normal one year later, whereas 58 per cent of households with a member with a disability reported that their lives were back to normal.

A growing number of disability researchers are evaluating how disasters affect people with disabilities. Similar to studies conducted by disaster researchers, these analyses have concentrated on preparedness and post-disaster issues, but usually have a decidedly activist flavour and include a call for policy change. As most of these studies were done following Hurricane Katrina (August 2005), they tend to focus on issues particular to large-scale disasters, such as mass evacuation and sheltering. For example, the *Report on Special Needs Assessment for Karina Evacuees (SNAKE) Project* by the National Organization on Disability (2005) detailed inequities in accessibility and communication in shelters in the US States of Louisiana, Mississippi, and Texas. Three weeks later, during Hurricane Rita (September 2005), Deaf evacuees encountered numerous communicational barriers when staying in large public shelters (White, 2006). During the wildfires in the US State of California in November 2008, which triggered the largest evacuation in its history, Kailes (2008) documented difficulties with transportation between shelters and disaster assistance centres experienced by individuals with disabilities.

Only a few peer-reviewed studies have used first-hand reports from individuals with disabilities as their primary source of data. Rooney and White (2007) collected online reports from 56 key informants with mobility impairments who had suffered a range of natural and man-made disasters. Informants reported six problem areas: a lack of worksite or community evacuation plans; being left behind during an evacuation; inaccessible shelters or temporary housing; unaware disaster relief personnel; inadequate infrastructure; and difficulties returning to daily routines owing to trauma, a lack of mobility, or the need to restore accessibility. Fox et al. (2010) interviewed 56 disaster survivors with disabilities over a six-month period following Katrina and found that disruption of accessible housing, communication channels, employment, essential medical care, and transportation severely compromised the

ability of persons to live independently post disaster. Six major themes emerged: blaming others or oneself; faith; family; adaptation and resiliency; incredulousness; and work and professional responsibility. Barile et al. (2006) interviewed 15 women who reported barriers and a lack of disability accommodation in shelters after the North America Ice Storm of 1998. Barbara White (2006) described her own experience as a Deaf professional social worker in a Houston, Texas, shelter following Hurricane Katrina, and her subsequent evacuation in anticipation of Hurricane Rita. Her narrative emphasises the effectiveness of disaster services when the disability community participates in disaster response efforts. Collectively, though, these studies concentrated on the evacuation and immediate aftermath of a disaster and did not examine long-term recovery.

Earlier work of the authors examined the long-term recovery of people with disabilities using reports from disaster case workers (Stough et al., 2010). According to these case workers, individuals with disabilities had the same post-disaster recovery needs as did individuals without disabilities, such as in relation to housing, medical services, and transportation. However, the case workers reported that they required additional support to obtain these services and that long-term recovery took longer and was more complicated. But the findings were limited in that data were procured from reports from case workers rather than from the direct reports of individuals with disabilities. As such, the results may not have reflected the complete extent of the lived experience of the disability community.

The authors' own opinions on disability have been shaped as family members of and advocates for people with disabilities and through the multiple disciplines of education, law, psychology, and public policy. Their work in the area of disasters began following Hurricane Katrina, in conjunction with participation in the national Katrina Aid Today programme. Consequently, analytical perspectives in this study have been moulded primarily by immersion in disability culture and research, rather than by disaster and emergency management viewpoints. The social vulnerability perspective aligns most closely with the authors' stance as disability advocates, given its focus on how the interactions between the environment and individual affordances give rise to vulnerability, as opposed to presenting vulnerability as a trait of an individual. The disability studies perspective, arising from cross-disciplinary literature, similarly draws from a social-contextual outlook. Disability studies' scholars conceptualise disability as not a medical diagnosis, but rather as the product of how cultures and societies respond to individual difference.

Purpose

The rationale for this study was to analyse the barriers to long-term recovery from Hurricane Katrina using the direct reports of individuals with disabilities. The intent was to evaluate how disability status interacts with barriers to successful recovery following a catastrophic disaster. The research started from the premise that individuals with disability are the best source of their own disaster perspectives. The objective

was to understand which parts of their lives were most affected by Katrina and specific hindrances to their recovery. Few studies have investigated the experiences of individuals with disabilities in a disaster. A focus-group technique was determined to be an effective means of gathering data from this population, as it 'create[s] concentrated conversations that might never occur in the real world' and is an appropriate data-collection method for learning about poorly understood groups (Morgan, 1998, p. 31). In addition, a focus-group methodology was selected as it would generate personal narratives from a population from which direct reports are seldom acquired in disaster research.

Method

Participants

Five cities in four different States—Atlanta (Georgia), Baton Rouge (Louisiana), Gulfport (Mississippi), Houston (Texas), and New Orleans (Louisiana)—were chosen as the sites in which to conduct the focus groups. These cities were selected since they each had a high number of resident Katrina survivors and were locations of disaster case management programmes that specifically served individuals with disabilities.

These disaster case management programmes were part of the Katrina Aid Today case management consortium, and offered services to all disaster survivors, regardless of socioeconomic status. The Katrina Aid Today initiative trained and deployed more than 3,000 case managers throughout the US post Katrina. These disaster case managers worked with households to obtain employment, furniture, housing, medical attention, and other needs following the event. Several dozen offices were staffed by disaster case managers with disability-related expertise and each was headed by a case management administrator.

Procedure

Recruitment

The case management administrator in the five target locations collaborated with the researchers to select a convenient location for the focus groups, as well as contacted potential participants. The administrators were asked to invite up to eight participants that met the following criteria: (i) had contact with their case managers during the previous 60 days; (ii) received at least six months of case management services; (iii) were over 18 years of age as of the date of the storm; and (iv) represented a wide range of disabilities. Case managers were given a brief description of the study to read to the potential participants as well as a copy of the Institutional Review Board's approved consent form. Between six and nine participants agreed to take part in each group. They were called and reminded of the upcoming focus group 24–48 hours before each one took place. Transportation to the focus group was paid for the participants and accessible transportation was provided by the research team when needed. Each participant received a USD 25 stipend for contributing.

Lunch was served at the beginning of each focus group, while the first author, who was also the moderator of the groups, introduced the purpose of the study, the rights of the participants, and the compensation conditions. Participants were asked to complete a brief demographic survey sheet. All participants had been displaced for at least three months following the storm and reported a disability that limited at least one activity of daily living (see Table 1) in accordance with the definition of disability in the US Americans with Disability Act of 1990. As defined by the Americans with Disabilities Amendments Act of 2008, a disability is a physical or mental impairment that substantially limits one or more major life activities, or an individual who has a record of such an impairment, or is regarded by others as having such an impairment. Most participants reported having more than one disability, such as a mobility impairment and a health-related disability, and were categorised as having 'multiple disabilities'. Income level was not elicited as almost all participants had either lost their jobs or had seen a change in their job status following the disaster. However, it is estimated that, of the people displaced by Hurricane Katrina, one-fifth were likely to have been poor and more than 40 per cent had income levels that were below two times the poverty line (Gabe, Falk, and McCarty, 2005).

As was the case with other individuals receiving case management through the Katrina Aid Today programme (see Stough et al., 2010), the participants were primarily female, Black, and middle-aged. These demographics were consistent with an earlier analysis that compared households who received disability case management and those receiving case management through other agencies (see Roberts–Gray and Stough, 2007). As with others receiving case management, almost all of the participants had experienced damage or loss of housing and displacement after the storm.

Table 1. Demographics of focus groups

Variable	Percentage	N*
Age		
Mean	51	
Range	31–74	
Sex		
Male	29	9
Female	71	22
Ethnicity		
Black (African-American)	84	26
Caucasian	13	4
Other	3	1
Marital status		
Married	45	14
Separated/divorced	23	7
Single	23	7
Widowed	3	1
No response	6	2
Education		
Less than high school	22.6	7
Completed high school	25.8	8
Some college	32.2	10
More than four years of college	13	4
Not reported	6	2
Disability category		
Multiple disabilities	51.6	16
Medical needs	22.6	7
Mental illness	13	4
Mobility	6	2
Learning disability	3	1
Visual impairment	3	1

Note: * Total N is 31.
Source: authors.

Focus-group questions

Focus-group discussions concentrated on questions presented by the first author, along with appropriate follow-up probes that were used to elicit further elaboration and participation. The questions centred on the supports and barriers that the participants had encountered during the recovery phase post Katrina. Most participants actively shared information throughout the meetings and the focus-group moderator ensured that each person had the opportunity to impart their experiences.

Data collection

Informed consent to audiotape the group was obtained from each of the participants. The first author moderated the focus group while the second author took notes during the session. Sessions lasted for an average of 110 minutes. Following each session, at least two members of the research team reviewed the session and the first author finalised field notes for each session. Transcripts were completed for each audiotape, resulting in a total of 258 pages of double-spaced narrative data. Memos were used to record initial impressions of the data collected. Responses to the following questions were the focus of the analysis in this study:

1. What has helped you recover from Hurricane Katrina?
2. What have been things that prevented you from recovering?

During the first focus group, participants bypassed the initial question and discussed barriers to their recovery, rather than supports received post disaster. In fact, they seemed unable to talk about their recovery process until after they had discussed thoroughly the barriers that they had encountered. The investigators thus reordered the questions to facilitate the flow of discussion in the remaining four focus groups. However, participants across all of the groups tended to deliberate barriers to recovery even when asked directly about what had aided their recovery process.

Analysis

Data analysis of the transcripts was performed using grounded theory analysis (Strauss and Corbin, 1990). This is an appropriate methodology when an area has not been investigated previously, as was the case in this study of the recovery of disaster-affected individuals with disabilities. Grounded theory methods principally use qualitative data and produce inductively derived concepts and theories wholly acquired from and grounded in the data. First-pass analysis of the focus-group transcripts was done using open coding (Glaser and Strauss, 1967; Strauss and Corbin, 1990), specifically by coding the transcripts line-by-line. Open coding involves taking raw data and raising it to a conceptual level (Corbin and Strauss, 2008). Specifically, the first three authors separately coded each focus-group transcript line-by-line and then met subsequently

to refine their coding labels. Once all five focus groups had been coded, the first three authors collapsed these open codes to form categories that represented themes present across the five focus-group discussions. The constant comparative method (Glaser and Strauss, 1967; Lincoln and Guba, 1985) was used to form systematically the categories. This compares new data to previous coded or categorised data, and any new information permits the formation of iteratively more precise evidence on the question of interest. Properties and dimensions of these categories were identified and a description of each category was written as part of the memoing process (Corbin and Strauss, 2008). Each category was examined to ensure that enough data had been collected for the described categories to reach saturation. These category descriptions and representative quotes were then reviewed by the fourth and fifth authors to reach concurrence and agreement on the categories presented in this paper.

A core category emerged from the data as a result of the constant comparative method. The core category was central, related to the majority of the other categories, and accounted for a large portion of the data. Axial coding (Strauss and Corbin, 1990) was employed by the first and third authors to understand the relationship between the categories and the central category as well as the relationships among the other categories. Other categories generated from the analysis were then conceptually placed in relation to the central category. Selective coding, involving a re-examination of the raw data and the categories, served to determine the overarching and subordinate categories. Selective coding was finalised after a continual return to the raw data and the data coded through open and axial coding. These categories were linked using the paradigm model described by Strauss and Corbin (1990). Those categories that represented intervening conditions (Strauss and Corbin, 1990) that constrained participant movement towards recovery are detailed below.

Results

Struggling towards recovery

The central category around which the focus-group discussions revolved was the participants' struggle for recovery following Hurricane Katrina. However, not one of the participants felt that they had 'recovered' from the disaster—their recovery remained unrealised. The participants identified a lack of resources as the prime reason for their stalled recovery, specifically the lack of housing, health care, transportation, and employment. These categories functioned as intervening, constraining variables that limited their recovery process. Most participants cited mental health as a health concern. Participants with mobility impairments or chronic medical conditions often mentioned durable medical equipment as a health-care need. Gatekeeping in different forms, including excessive paperwork and 'getting the run-around', was another significant type of barrier. For some participants, a dearth of information, or even conflicting information, added to their difficulties in accessing

services. As many participants had been relocated to new cities, unfamiliar environments made getting information even more difficult. These intervening categories were all enhanced by the dimension of disability: disability status heightened the barriers that these individual encountered. These barriers to recovery are the focus of the reporting of the study results.

In the following subsections, direct quotes, as well as summarised responses, are employed to substantiate and illustrate the thematic categories. Names and quotes that might identify participants have been modified or deleted to ensure confidentiality. Interpretation of these categories is included within each section as part of the theoretical analysis of the data.

Barriers to recovery

Barriers identified by the participants constrained their progress towards recovery, and, as such, functioned as intervening conditions in the grounded theory analysis of the data. Strauss and Corbin (1990, p. 103) describe intervening conditions as those that 'act to either facilitate or constrain the action/interactional strategies taken within a specific context'. During the focus groups, participants had difficulty in responding to the following question: 'What has helped you to recover from Hurricane Katrina?'. Instead, they concentrated on: 'What has prevented you from recovering from Hurricane Katrina?', and they found it much easier to list the barriers to their recovery rather than to pinpoint the factors that were facilitating their recovery. Variables mentioned that affected recovery negatively were categorised and then consolidated so that commonalities could be examined across the five groups.

The first overarching category, identified quite readily by the participants, concerned the lack of concrete resources that they believed would be helpful to their recovery. Participants returned repeatedly to this theme during the focus groups, even in response to prompts. They stated that they had received assistance soon after the storm but that these resources had diminished substantially by the time that the focus groups were held, two years after the disaster. Five issue areas were identified consistently across the five focus groups: housing; health; transportation; employment and financial status; and accessing services.

Housing

The majority of respondents reported a lack of adequate housing as the main barrier to their recovery. Housing is a concern for most individuals following a disaster, regardless of their health status or capabilities. Yet, post-disaster housing seemed to evidence special challenges for individuals with disabilities. Individuals with disabilities often require housing that accommodates their disabilities, but accessible housing post Katrina was in short supply. One participant who used a wheelchair and was living in a Federal Emergency Management Agency (FEMA)-issued trailer had to sleep in her living room:

You know, I have a trailer, and . . . I am uncomfortable in a way because the sofa is old. I am sleeping on top of a pillow because [in] the back bedroom the bed is so high I cannot get into it. And they got one air conditioning unit in there and it does not cover the whole trailer. Certain parts of the day it gets hot (Gulfport participant).

Despite assurances given to participants that their unique needs would be accommodated, follow-through frequently did not happen. In some cases, the housing provided was not appropriately accessible or was located where there was limited public transportation. One survivor waited for more than a year and still was not living in accessible housing:

I'm handicapped, [my case manager] gives me a trailer as big as this room here, it's not handicapped equipped. Okay, she promised me faithfully, oh . . . that you're here now, we gonna take care of this. Just give me about two weeks and we're gonna put you in a handicapped [accessible trailer]. So we spent two months, six months, eight months . . . now I'm getting ready to be kicked out of my trailer (New Orleans participant).

Most participants expressed uncertainty and anxiety about the future of their housing and almost all were living in rental properties or with other families. Exacerbating the housing challenges was that most participants' income decreased significantly after Katrina and participants frequently found that rental properties that had been affordable previously had become too expensive for them. One participant noted that, when she returned home, 'all of sudden apartment buildings I would see that were one bedroom that might have been say $400 dollars [before Katrina] now it's $700 dollars' (Gulfport participant). Katrina survivors were then frequently relocated into housing that did not fulfil their needs:

In a two bedroom, one bathroom house. Six adults, five children. And that is because we are not making it, we just are not making it. We are paying twice the rent and we [are] not making half the money we was making (Atlanta participant).

Housing costs are a common concern for people with disabilities: rents for modestly priced units often exceed the *entire* social security disability support received by an individual with disabilities, leaving no income for clothes, food, or other necessities (Cooper, O'Hara, and Zovistoski, 2011). In addition, following Hurricanes Katrina and Rita, although close to one-quarter of those affected reported having disabilities, only between one and two per cent of evacuees in Louisiana and Mississippi received accessible FEMA trailers (Davis et al., 2013). People with disabilities of working age tend not to desire supported housing options (Newcomer et al., 2002) and most accommodations that make housing accessible are tailored in accordance with the specific disability of an individual. Recreating these accommodations so that individuals can sustain living independently necessitates the construction of similarly designed supports in the post-disaster home setting.

Health

Health issues are a common concern after a disaster; however, many individuals with disabilities experience significant health limitations even before a disaster occurs. People with disabilities, in general, face poorer levels of health than the general population (World Health Organization and The World Bank, 2011). In addition, Bethel, Foreman, and Burke (2011) reported that vulnerable populations, such as those with disabilities, are at increased risk of poor health outcomes following a disaster. From a national sample, they found that those with disabilities or chronic health conditions were less likely to be prepared for a disaster in terms of having supplies such as food, water, and an emergency evacuation plan. Interestingly, though, they were more likely to have a three-day supply of medication to hand.

McGuire, Ford, and Okoro (2007) estimated that 31.6 per cent of older adults with a disability, and 16.6 per cent of older adults living in the general community, use special equipment such as hearing aids, service dogs, or wheelchairs that require accommodation during evacuation and sheltering. Members of the focus groups frequently mentioned the need for durable medical equipment, such as wheelchairs, and prescriptions. One pointed out that:

> . . . my baby needs medicine right now, but CVS [pharmacy] will not take his Medicaid card and he catch pneumonia. He has a respiratory disease, and he catch pneumonia like three times a year. And I got a prescription right now and they are like 'we are not taking that', you know, and it is just I am scared to transfer and then I am scared not to (Atlanta participant).

In addition, the Bethel, Foreman, and Burke (2011) study found that individuals who used durable medical equipment were less likely to have emergency supplies to hand. Another study on individuals displaced by Katrina similarly found a high level of need for durable medical equipment (Ridenour et al., 2007).

Many participants were quite candid about psychological effects that had affected their ability to seek out services post disaster. At least two participants in each group reported that they were currently experiencing depression. In response to the question about barriers to recovery, one participant replied:

> . . . mentally, I guess. [Name of case manager] has helped a lot with getting a down payment of the mobile home and getting furniture, but you have got to deal with the mental stuff. And you see all this stuff in the paper every day that Katrina is gone, get over it, and all this stuff. But it ain't gone for everybody (Gulfport participant).

This self-reported depression usually was mentioned in connection with an increasingly limited pool of options and the bureaucracy of applying for aid. Stress was described as leading to secondary health concerns. One participant said:

> I don't sleep. That was the first thing I have had to eat [referring to the lunch provided at the focus group] since yesterday. I don't really have an appetite, I eat once a day. I don't know why, I guess the stress has got me gaining weight, maybe the lupis is acting up, but I'm swelling (Atlanta participant).

In some cases, depression became in and of itself a barrier:

I don't know how to explain it but I have like a sadness in me that comes out every night and I get really, really depressed, I really do. Sometimes I be like that for weeks on. And the other people they won't know that I just get in a rut and I just can't get past it and . . . come home from work [and] just go to sleep (Houston participant).

Negative emotions at times led to maladaptive coping strategies:

The frustration of it all. I had quit smoking years ago, I started smoking again. I'm taking pills for depression. Her [wife's] hair's falling out. I mean it's, it's . . . I don't know you. . . . I don't know how to deal with it (Gulfport participant).

I was having a whole lot of issues as far as my thoughts were concerned, and at one point I was even thinking about suicide. I was thinking that if I would take myself out then people wouldn't have to worry (Atlanta participant).

The disaster literature demonstrates that groups that differ with respect to gender or social class or linguistically, or those that have experienced prior distress, are particularly prone to post–disaster stress (Morrow, 1999). In addition, resource loss has been found to correlate highly with psychological stress in a number of disaster studies with diverse characteristics (see, for example, Norris et al., 2002). Stough (2009), in a summary of research on the psychological impacts of disasters on individuals with disabilities, noted that researchers have virtually ignored the matter. However, participants in the current study confirmed overwhelmingly that they continued to experience considerable psychological stress two years after Katrina.

Transportation

Transportation emerged as another key challenge for the study participants:

Most of the thing that I am really looking for right now is to get me some transportation, some better transportation than what I got. Basically from there, I think I can make from there, but I know it is going to be a little rough up the road, but basically I just need transportation (Gulfport participant).

Not only did the lack of a form of transportation limit these participants, but knowing how to navigate around a new city presented difficulties:

I am originally from Wisconsin, but I knew New Orleans. Getting around is one of my biggest problems. Getting from point A to point B (Baton Rouge participant).

It is possible to surmise that other Katrina survivors also faced transportation difficulties, but for those with disabilities, accessible transportation was essential if they were to live independently in their new locations. Transportation is a critical public

infrastructure upon which people with disabilities typically rely. People with mobility disabilities may require accessible transportation, such as taxis that can accommodate wheelchairs or low-floor buses that have no steps between the door and the cabin of the vehicle. People with cognitive or physical disabilities often rely on public transportation when they are not able to drive themselves. Individuals usually cope with crises by utilising contingency plans, for instance, if your car breaks down, you take a bus, or if the taxis are not working, you walk. For individuals with disabilities, though, there are frequently a limited array of viable substitute options that support their functional needs (Batavia and Beaulaurier, 2001). Participants who had returned to New Orleans found the loss of city infrastructure made transportation less accessible, whereas other participants found their new towns to be less accommodating of individuals who needed accessible transportation alternatives.

People with disabilities also are more likely to depend on others for their transportation needs (Mohammadian and Bekhor, 2008). However, family members who had assisted before the storm by providing rides or assisting with chores, often were living in different places following the disaster and no longer could provide needed assistance. One participant commented that:

> If I could just get a place, get my house fixed and get some transportation so my daughter can carry me to where I need to go then I . . . She can drive, but I can't so if I had some transportation where she could take me (Gulfport participant).

In some instances, case managers became *in situ* family transportation providers, even though most organisations discouraged their employees from assuming this function:

> [Name of case manager] has helped me tremendously because I didn't have any transportation. Even when [disability support organisation] got me into [a] Section 8 program I had no way to find a house because I had no transportation. So when I did get in touch with [the case manager] they took me to look at houses, they took me for the inspection of the houses and just helped me (Atlanta participant).

Limited accessibility to transportation can influence negatively the ability to participate in community life, the quality of life, and the health of individuals with disabilities (Seekins, Arnold, and Ipsen, 2012). A lack of transportation can also discourage people with disabilities from seeking employment or obtaining health care (World Health Organization and The World Bank, 2011). Participants in this study repeatedly cited a lack of transportation as a significant barrier to seeking employment, medical services, or acquiring appropriate housing.

Employment and financial status

Many of the participants reported having had a job prior to Katrina and securing employment following the storm was an important goal for them. One underlined, for instance, that:

. . . they say I want a handout. All I want to do is go to work. All I want to do is pay my bills, put food on my table, put gas in my car. I want to be able to come and go like a human being (Atlanta participant).

Historically, gaining employment has been a challenge for people with disabilities. Only 20 per cent of individuals with disabilities over the age of 16 in the US are currently employed, as compared to 70 per cent of those without disabilities (Bureau of Labor Statistics, 2013). In the State of Louisiana, furthermore, jobs for individuals with disabilities typically were low paying; median earnings in 2005 were USD 18,200, in contrast to national median earnings of USD 28,779 (Rehabilitation Research and Training Center on Disability Statistics and Demographics, 2010). Consequently, most Katrina survivors had limited savings on which they could draw post disaster.

Finding new employment opportunities was difficult for all Katrina survivors. However, employment was particularly challenging for individuals with disabilities who had informal or sporadic jobs that were accommodating to their disability and perhaps were unique to southern Louisiana. One participant described her husband's and her own source of income prior to Katrina:

You know there is no professional doorman where you can just go and get another doorman job and then it is not going to pay as much as it did in New Orleans. You know what I mean—he was making 200–300 dollars cash sometimes. You just can't replace that. And then I had my hustle. I had my little sewing business where everyone in the school system wore uniforms so everyone needed their uniform altered and I had my little business going. Everything was just going swell and lovely and . . . you're back down to the bottom again (Atlanta participant).

Individuals with disabilities are over-represented in the percentage of people living in poverty in the US: 26.4 per cent as compared to 11.7 per cent in the general population (Rehabilitation Research and Training Center on Disability Statistics and Demographics, 2010). The poverty rate in Louisiana before Katrina, though, was even higher: 27.4 per cent. Many people with disabilities are eligible for social security income (SSI) benefits, which many of the study participants referred to as being 'on disability'. People with disabilities who rely on SSI as their primary source of income, however, are among the nation's poorest citizens: average SSI in Louisiana before Katrina was approximately USD 398 per month (State of Louisiana, 2014). One participant highlighted that:

Well, like with me, I am just staying in an old trailer that was there. I had no help to fix it, I am on low income, I am on disability. But I just don't have money to fix it. But I have not had any help from nobody so I am just doing the best I can, what can I do about it? (Gulfport participant).

Alba et al. (2008) found that people with lower income are also less likely to live in dwellings with modifications or adaptive features. Focus-group participants reported

that they had not only lost housing, but also that they had lost accessible housing that they had obtained and altered at considerable effort and cost.

Finally, participants who had been relocated felt social stigma owing to their non-working status. A number of them commented that their new neighbours seemed to think that Katrina survivors were lazy and did not want to work. One participant said that:

> *Everybody thought just because you came from New Orleans you didn't work or you weren't educated or whatever. That wasn't the case they had like what seven or eight universities out there that everybody came from all over the place you know so people didn't realize yeah we go to work a lot of people were entrepreneurs* (Houston participant).

> *In fact, most participants not only expressed eagerness to return to the workforce, but also demonstrated an openness regarding the type of employment that they would accept: 'any kind of job . . . a dollar is better than no dollar and that way you can make it in life'* (Baton Rouge participant).

Accessing services

Difficulty in accessing recovery services is a recurring issue for individuals with disabilities: the World Health Organization and The World Bank (2011, p. 9) note that 'poor coordination of services, inadequate staffing, and weak staff competencies can affect the quality, accessibility, and adequacy of services for persons with disabilities'. Some studies (see, for example, Beatty et al., 2003) have found that people with chronic or disabling conditions who have the poorest health and the lowest incomes also are the least likely to be able to access health services. Complicating access to services was that participants struggled to obtain disaster and disability services. Participants in this study frequently reported 'getting the run-around', gatekeeping of resources, and competing for limited resources. In the words of one:

> *It is the most frustrating thing is to call a number and they tell you they're going to be able to help you but then when you call that number, 'Right, but let me give you another number you can call', and then you call that number, 'Here's another number you can call,' and you're sittin' there with a list of numbers and you call that whole page [but] you still have nothing* (Atlanta participant).

Procuring services was seen by the study participants as a necessary precursor to achieving recovery. The possibility of obtaining recovery assistance through a case worker brought optimism and encouragement. One participant commented that: 'Having doubts for two years, just having doubts. And then our case worker . . . came along and she finally gave us a little bit of hope. She has been the only hope we have had since the hurricane' (Gulfport participant). Other disaster research similarly has found that social service providers expand their formal role to provide concrete resources and social support not available in the post-disaster environment (Stough

et al., 2010; Ducy and Stough, 2011). However, this initial positive outlook often gave way to doubt and frustration. Navigating a complex and confusing service delivery system was difficult. A Houston participant explained: 'I haven't received anything . . . [I] just got all this process'—a process described as involving an excessive and complicated application system with copious amounts of paperwork. A New Orleans participant remarked: 'Nobody knows what's going on and you're right there in the middle of this . . . you're already in all the confusion. You go there and guess what? They are like "Oh, well, here's the birth certificate" . . . then they still need more'.

These experiences were exacerbated by what participants presented as a disorganised and circuitous search that yielded little fruit. One participant stated that:

> . . . it's like a glass of cold, cold water when you deal with somebody who is there for you and [they] just . . . says 'Well, look, let me go to my supervisor and get back to you,' and . . . even if they got to say 'No' they have gotten back to you (New Orleans participant).

Most of the study respondents had received FEMA housing assistance at some time during the previous two years. The responses indicated, though, that ongoing FEMA assistance was fraught with uncertainties, required complicated and excessive recordkeeping, and was maintained only through repeated and sometimes stressful interactions. According to one participant:

> That's like that's how they do ya, they find all kinds of loopholes not to give you the money, you know 'You didn't cross your t's you didn't dot your i's.' . . . You know I'm in need—forget about that—give me what I need. 'I need it,' that's what I say but they don't see it like that (New Orleans participant).

In sum, the search for services became not only a barrier for participants with disabilities, but also it placed an extra burden on them as they struggled with recovery.

Recovery unrealised

What was apparent after all of the focus-group interviews was that, without exception, these participants felt that they were still recovering from the disaster—none saw themselves as having 'recovered.' Participants repeatedly stressed that they were unsure about the future, frustrated by the length of time their recovery was taking, and compared their current living situation unfavourably with that before the disaster. Frequently they made comments that illustrated that they were still struggling towards recovery. For instance, one participant noted that:

> It's not really a recovery moment you can't really say that you have actually recovered. It's not easy so it's like you're not there yet, you're still not there (Houston participant).

As the interviews took place two years after the disaster, participants repeatedly expressed frustration with the length of time that the recovery process was taking. Many reported hopelessness or depression about their status. In the words of one:

It is like we have lost our hope. No one answers our phone calls, no one calls us back, you know. We have been left out. By asking certain questions or asking for something that we need, desperately need, and it [is] just 'Call this number, well, call this number, call this number.' I had six in one day, different ones to call and nobody had any answers for me. So that has been a very long drawn out thing (Gulfport participant).

Most participants only made negative predictions about their recovery and some questioned whether their situation was ever going to change. One described feeling 'stuck': 'It is like a record scratching, you feel like you keep jumping back to the same point. Wherever you was at in New Orleans once that happened it just put everything on the halt, just stuck' (Houston participant).

Participants emphasised that they were not satisfied with the conditions in which they were living now and believed that their lives had been better 'before.' Not one felt as if their current living situation was settled or permanent, even those who had employment or who had returned to their home. Without exception, they longed for their pre-Katrina life, while simultaneously acknowledging that their lives would never be the same. One stated that:

I think it's more than money—it's . . . where you live, the ground that you walk on—and when you wake up you know where you are and . . . it's just your whole life has changed and I don't think you'll ever really recover because you'll never get back what you had. Everybody's lost friends and family [who are] scattered all around the country (Houston participant).

In some cases, the relocated participants felt unwelcomed or even discriminated against in their new cities. One pointed out that:

I go places sometimes and people see that I am from Louisiana and I have [been] getting a lot of nasty things said to me while I am driving. I just feel scared here, I don't feel secure or welcome (Atlanta participant).

The goal for these participants seemed to be to return to a previous level of life satisfaction, even if they were unable to return to their previous home. This goal, however, remained unrealised. As one focus-group member concluded: 'I don't know what recovery means—I don't know if I'll ever recover' (Houston participant).

Discussion

The social vulnerability perspective suggests that people with disabilities are disproportionately, and sometimes differently, affected by a disaster. However, reports from participants with disabilities in this study for the most part parallel those from individuals without disabilities in other works on Hurricane Katrina (see, for example, Angel et al., 2012; Weber and Peek, 2012). Participants discussed their need for tangible

resources and services, specifically housing, employment, transportation, and health care, to recover from the event. In addition, as has been reported in other studies on recovery (Dash, Peacock, and Morrow, 1997; Weber and Peek, 2012), difficulties in accessing resources and services were also highlighted here as a barrier to recovery. Participants described 'getting the run-around', excessive paperwork, and other forms of gatekeeping, as impeding their recovery. For some individuals, the lack of information on services or, in some cases, conflicting information on services, exacerbated their difficulty in accessing services. Compounding these barriers were mental health concerns, specifically depression, which was typically discussed in connection with the challenges identified above. Although many studies exist on disaster mental health, research on the mental health of individuals with disabilities post disaster is scarce (Stough, 2009; Stough et al., 2010). These findings suggest a linkage between a lack of resources and the mental health of individuals with disabilities following a disaster.

Despite parallelism in the *types* of barriers identified, the *nature* of these barriers for participants with disabilities differed from those reported previously. Participants spoke about difficulties in obtaining *accessible* housing, transportation, and jobs that would accommodate their disability. Housing frequently was not adapted adequately, such as in the case of a participant who received a FEMA trailer that did not enable her to transfer from her wheelchair to the bed. Participants with chronic health problems noted difficulties in obtaining durable medical equipment or home health-care aides that would allow them to live more independently. Fox et al. (2010) similarly found that a lack of accessible housing, transportation, employment, and medical care compromises the lives of people with disabilities post disaster.

The application and referral system for disaster services also did not adequately accommodate for disabilities. Participants in this study not only were negotiating the bureaucracy of the disaster service system, but also the bureaucracy of the disability service system. Participants reported problems with finding health-care providers knowledgeable about their disability, obtaining subsidised medications, and completing special education paperwork. Fothergill and Peek (2004, p. 98) note that 'the ease with which individuals are able to negotiate disaster recovery systems may dictate the success or failure of the recovery process'. This study posits that a salient difference in the disaster experience of individuals with disabilities is the considerable and unique complications that they confront in accessing disability-related services and resources after a disaster. Such findings support arguments that individuals with disabilities might benefit from specialised case management post disaster (see Stough et al., 2010).

Many parallels emerged between the needs of individuals with disabilities in this study and people living in poverty. However, Traustadóttir and Rice (2012) point out that there are factors specific to disability that create conditions of vulnerability that are not factors for people who are unemployed or receive low wages. For instance, people with disabilities require structural and environmental accommodations that enable them to live independently, such as accessible housing or information in Braille,

which are not needed by people living in poverty. In addition, people who require electricity to power their wheelchairs or respirators may experience life-threatening situations under disaster circumstances that most poor people will not. Although disability certainly intersects with poverty, poverty should not be used as a demographic proxy for disability when examining the impact of a disaster on vulnerable populations.

Reconceptualising disability in disaster

The results of this study warrant a reconceptualisation of the barriers people with disabilities experience post disaster. The social model of disability (Oliver, 1990, 1996) asserts that existing social policies, practices, and institutions, rather than the individual impairments of people with disabilities, generate barriers and inequitable access. Similarly, the reports of the focus-group participants challenge the perception that impairments negatively affect disaster recovery: rather, the participants described the social and structural factors that produced barriers for them. While the vulnerability of people with disabilities often is attributed to their cognitive or physical inabilities, the participants described barriers created when transportation was inaccessible, housing did not accommodate their disability, or service systems were difficult to navigate. Other researchers (see, for example, Hemingway and Priestley, 2006; Priestley and Hemingway, 2007; Peek and Stough, 2010;) have previously connected the social model of disability to the social vulnerability theory of disaster. They conceptualise the societal vulnerability of people with disabilities as the result of preexisting barriers and exclusionary social practices, which parallels arguments made by disaster social vulnerability theorists. Priestley and Hemingway (2007, p. 25) contend that: 'Just as disability is not the inevitable consequence of physical or cognitive impairment, disaster is not the inevitable consequence of natural hazard'. The reports of the focus-group participants similarly concentrated on barriers and exclusions rather than on their own characteristics as problematic in the recovery process.

These findings also illustrate how the recovery barriers for individuals with disabilities were multi-layered. Phillips and Morrow (2007, p. 62) point out that, while research on vulnerable populations has tended to focus on single demographic factors such as age, sex, or income level, individuals actually 'experience vulnerability through overlapping, intersected dynamics'. Certainly, the individuals with disabilities in this study, as they themselves reported, had limited access to resources and services and were displaced from family, friends, and their home. A lack of accessibility and accommodation were additional layers of vulnerability that heightened these barriers to recovery. These reports highlight that 'disability' is not simply a demographic characteristic: disability encompasses complex socioeconomic factors such as health care, physical infrastructure, social capital, and social networks previously identified by disaster researchers (Morrow, 1999; Cutter and Emrich, 2006).

Living with a disability engenders structural considerations, such as the need for accessible infrastructure and accommodation, so that full participation in the workplace and community is possible. In this aspect, the recovery of individuals with

disabilities also appears to differ: people with disabilities often are reliant on infrastructure such as accessible housing, in-home health care, or transportation systems to live independently. When these social and structural systems are not rebuilt or are not accessible, therefore, the recovery of individuals with disabilities can be anticipated to take longer, be more costly, and require more intensive social support. Irshad, Mumtz, and Levay (2012) reported on the protracted long-term recovery of women who acquired a disability during the Kashmir earthquake of 2005. Similarly, participants with disabilities in this study felt that their recovery was lingering a full two years after Katrina made landfall. Disaster recovery services and resources must be inclusive so that they address the needs of those across the entire human spectrum.

Limitations

First, as with most qualitative studies, the number of participants in this study was relatively small and not randomised. Quantitative studies will answer more appropriately the question of whether or not a disaster affects individuals with disabilities disproportionately. Second, participants self-identified themselves as having a disability rather than being selected from a population of known cases. All participants, though, were receiving case management services from a disability-related organisation and there was no reason to believe that any of the participants falsely claimed to have a disability. Third, the sample was a cross-categorical representation of disability as opposed to a single disability category, such as mobility impairment. The results, therefore, did not identify how particular barriers intersected with specific functional needs. Fourth, the authors were informed primarily by their experiences of US disasters and hence acknowledge that the particularities of the US context shaped interpretations of the findings. Fifth, the focus groups were mixed with respect to age and gender, which may have obscured the role that these factors played in the recovery process. Finally, in keeping with the homogenous nature of samples typical in grounded theory qualitative studies, the sample was composed entirely of individuals with disabilities. As such, the design does not allow for direct comparison of these results with those from a sample without disabilities.

Conclusion

The study findings represent one of the few systematic accounts of the long-term impacts of a disaster on individuals with disabilities. Direct narrative reports from individuals with disabilities were employed here, rather than observational, survey, or proxy methodologies, to illustrate the post-disaster recovery period. The analysis produced thematic categories that any participant might list as a barrier to disaster recovery, including employment, housing, and transportation. Disability status influenced these categories principally when there was a need for disability-related resources or services. Furthermore, the reconstruction of or access to transportation and disability and medical services appeared to be critical, as participants stressed that, without

accessible infrastructure, they could not live as independently or productively as they did before the disaster. For people with disabilities, recovery must include accessible infrastructure that will enable independence and full participation in society.

Although this study focused on human recovery, it has implications for physical reconstruction post disaster. Housing and public infrastructure should be designed not only so that they reduce vulnerability to a disaster but also so that they accommodate and can adapt to the needs of people with disabilities. Recovered communities should also be inclusive communities; an inclusive design promotes an environment that fulfills the needs of diverse members of society. As asserted by Cutter and Emrich (2006), greater consideration of the needs of vulnerable populations must occur for socially-just recovery and reconstruction of the Gulf Coast. Failure to consider these needs will result in a rebuilt infrastructure that perpetuates the inequalities that make people with disabilities vulnerable to disasters, as well as the barriers reported here during the recovery phase of a disaster.

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