


# Caregiving in U.S. Gulf States During Natural Disasters and COVID-19

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## Abstract

**Objectives:** To ascertain common experiences and needs of a diverse group of caregivers challenged by hurricanes/floods and COVID-19.

**Methods:** In-depth interviews with unpaid caregivers in U.S. Southeast/Gulf Coast states who had experienced caregiving during a natural disaster and during COVID-19.

**Results:** Caregivers report challenges including daily living disruption, altered social supports, complicated health management, additional disaster planning, and emotional/financial impacts. Caregivers suggested helpful resources, policy options, and preparatory tools at individual, local, and health system levels to mediate discontinuity.

**Conclusions:** Our data describe combined caregiver experiences of hurricanes/floods and the pandemic. Caregivers experience unique burdens related to care recipient diagnosis, location, and veteran status. Access to community supports varies as they manage the tasks required for care recipients' health and safety. Our findings indicate the need for public health reinforcement of caregiving through caregiver pre-planning and targeted support. Bolstering understanding of communities' caregiving capacity through first responder trainings and caregiver registries may enhance health and safety.

## Keywords

caregivers, COVID-19, qualitative methods

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## What This Paper Adds

- First-hand descriptions of stressors faced by a diverse group of caregivers during natural disasters and COVID-19
- Recommendations for resources and preparatory tools that would benefit caregivers in these situations

## Application of Study Findings

- Highlights the need for public health reinforcement for caregiving
- Recommendation for illness-specific community disaster-management planning

## Introduction

Emergencies, including natural disasters and pandemics, are occurring at higher rates with more devastating

outcomes (Centre for Research on the Epidemiology of Disasters, 2020; Kossin et al., 2020). Older adults and individuals with serious illness are at higher risk for poor outcomes in the short and long term. During

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Hurricane Katrina, mortality rates were higher among older adults (Gibson, 2006) due to the unique vulnerabilities and evacuation challenges of this group, including health conditions, isolation, and high levels of poverty (Knowles & Garrison, 2006). Veterans with military service-related disabilities may be particularly vulnerable due to health conditions, including mental health concerns, that complicate transitions to new places or changes in routine (Oliva et al., 2013; Ramchand et al., 2014). Often, the brunt of managing these challenges falls to unpaid family caregivers who are underprepared for disasters (O'Sullivan et al., 2012; Pickering et al., 2021). For example, caregivers of people with Alzheimer's disease during a 2015 flood in South Carolina discussed how caregiving limited their ability to plan or evacuate (Gibson et al., 2018). Another study showed late-stage versus early stage patients living with dementia (PLWD) expressed less resistance to evacuation, but caregivers experienced an increased workload given the greater care needs (Christensen & Castañeda, 2014).

The COVID-19 pandemic again highlighted the breakdown of systems protecting vulnerable groups and resulting stressors for caregivers. A scoping review examining PLWD during COVID-19 highlighted caregiver burnout and fatigue, and pervasive lack of access to services and supports (Bacsu et al., 2021). In a national survey of 400 caregivers, 83% reported increased stress related to caregiving since pandemic start (Rosalynn Carter Institute for Caregivers, 2020a). Key sources of stress included isolation, finances, resource insecurity, increased burden (Sousa et al., 2021), coordinating health services, and supporting the care recipient's emotional needs (Irani et al., 2021).

There are an estimated 26.4 million unpaid family caregivers in the U.S. (AARP and National Alliance for Caregiving, 2020; Sawhill et al., 2020), of whom, an estimated 5.5 million provide care to Veterans (Ramchand et al., 2014). These family caregivers are the backbone of home-based long-term care and handle the majority of health care, social care, and service coordination. Therefore, supporting caregivers should be a high public health priority in the context of disaster management (Rosalynn Carter Institute for Caregivers, 2020b). Family caregivers are a heterogeneous population engaging services across systems at multiple levels, which makes defining clear plans an important, but elusive, policy goal.

The objective of this study was to explore the experiences and needs of family caregivers to identify commonalities to inform policy. We captured the experiences of a variety of caregiver types, including caregivers of Veterans and non-Veterans, of care recipients from different disease groups and stages, and with differing relationships to the care recipient. We explored across multiple emergency situations—natural disasters and the COVID-19 pandemic. Our goal is to generate an understanding of lived experiences and recommended resources to inform approaches to support family caregivers during emergency situations.

## Methods

### *Study Design and Participants*

A qualitative descriptive study using in-depth interviews (IDIs) was conducted (Sandelowski, 2000, 2010). Study participants were English-speaking adults, who provided unpaid care to another adult during a recent hurricane or flood, and during the COVID-19 pandemic. A 5-year look back was chosen to capture a wider group of potential candidates; recalling experiences from this timeframe is supported by previous literature (Fivush et al., 2004; Krishnan et al., 2019). The majority were recruited from the U.S. Gulf Coast states via social media, newsletters, support groups, prior interaction with the Rosalynn Carter Institute for Caregivers, or participant/team member referral. Participants were provided \$25 gift cards upon completion.

### *Data Collection*

Trained qualitative interviewers conducted IDIs with caregivers by telephone between July 6, 2020 and February 2, 2021. COVID-19-related questions focused on challenges pertaining to healthcare, daily living, social supports, and caregiving-specific impacts of the pandemic. Hurricane/flood-related questions included describing (1) experiences in the days leading up to, during, and after the disaster, (2) effects of the disaster on daily living, including on the care recipient's access to medical or home healthcare, (3) disaster specific impacts to caregiving, (4) resources they utilized, or needed but did not have, and (5) recommendations for improving assistance offered by local governments or aid organizations. All interviews were audio-recorded with participants' permission.

### *Data Analysis*

Descriptive statistics summarize participants' demographic characteristics. Interviews were transcribed verbatim using a transcription protocol (McLellan et al., 2003) and analyzed using applied thematic analysis (Guest et al., 2011). NVivo 12 (QSR International) software was used to organize the data and apply codes to the transcripts (Saldaña, 2013). Two analysts independently applied structural codes based on the interview guide, segmenting participants' interview narratives into broad categories related to the overall objectives. Inter-coder reliability (ICR) was assessed on 12% of transcripts (O'Connor & Joffe, 2020), discrepancies in code application were resolved through discussion, and any necessary structural coding revisions were made. Next, analysts identified content codes reflecting specific caregiver experiences within each structural code, applied these to the text, and assessed ICR arriving at agreement on 12% of transcripts. The remaining 22 transcripts were divided evenly between 2 coders, and were coded independently. The two interviewers, who were also the coders, assessed informational redundancy.

**Table 1.** Sociodemographic Characteristics of Caregivers.

	Caregiver characteristics (%)
Total sample	25 (100)
Age (years), n (%)	
<40	6 (24)
40–49	7 (28)
50–59	5 (20)
60+	7 (28)
Median; range	49; 18–78
Education level, n (%)	
Less than college degree	8 (32)
Completed college (B.A., B.S.)	7 (28)
Completed graduate school	10 (40)
Gender, n (%)	
Female	20 (80)
Male	5 (20)
Race/ethnicity, n (%)	
White	15 (60)
Black or African-American	6 (24)
Multiple, other, unanswered	4 (16)
Spanish/Hispanic/Latino origin	6 (24)
Disaster type	
Flood	3 (12)
Hurricane	22 (88)
Care recipient is the caregiver's <sup>1</sup> :	
Spouse	15 (65)
Parent	5 (20)
Child	2 (9)
Sibling	1 (4)
Grandparent	1 (4)
Friend	2 (9)
Length of time caring for this recipient <sup>2</sup>	
<1 year	2 (4)
1–3 years	6 (21)
3–5 years	5 (21)
More than 5 years	13 (54)
Living arrangement <sup>3</sup>	
Caregiver lives with recipient	21 (84)
Recipient lives independently	3 (12)
Recipient lives in a care facility	3 (12)
Caregiver time spent providing care <sup>4</sup>	
<10 hours/week	0 (0)
10–20 hours/week	4 (20)
20+ hours/week	16 (80)
Difficulty in paying for basic needs in the last month	
Hard/very hard	7 (28)
Somewhat hard	7 (28)
Not very hard	11 (44)
Type of care tasks provided to care recipient <sup>5</sup>	
Transportation	17 (68)
Personal care (bathing, food)	20 (80)
Emotional support	24 (96)
Supervision	19 (76)
Behavioral or communication support	22 (88)
Schedule/attend health appointments	22 (88)
Medication management	21 (84)
Other	4 (16)

<sup>1</sup>One caregiver was caring for two people during the disaster.

<sup>2</sup>One caregiver indicated a different length of time for two separate care recipients.

<sup>3</sup>Two recipients had different living arrangements for the disaster versus the pandemic and are counted in both categories.

<sup>4</sup>Not all caregivers provided a response to this question.

<sup>5</sup>Categories are not mutually exclusive.

## Ethics Board Review

The Duke Health Institutional Review Board reviewed this study and provided an exempt determination. Participants were provided written information regarding voluntariness, data security, and other pertinent study details, and verbally acknowledged its review prior to enrollment. Participants were assigned a coded study ID, and sensitive information was not included within the transcribed interviews.

## Results

Table 1 describes caregiver characteristics. Three caregivers experienced a flood while 22 experienced a hurricane. Results are organized in four parts: I) *Experiences related to COVID-19*, II) *Experiences related to natural disasters*, III) *Resource needs*, and IV) *Recommendations for assistance from government or aid agencies*. Supplemental Tables S1 to S4 contain illustrative quotes.

### Experiences Related to Covid-19

Experiences related to COVID-19 primarily included challenges related to healthcare, homecare services, and social support. Caregivers were frustrated with aspects of telemedicine, including loss of hands-on diagnostic ability, lack of ability to measure vitals and check bloodwork, and difficulties using the Internet. However, some caregivers preferred telehealth visits to minimize COVID-19 exposure. Other stressors included delays in specialty care, difficulty obtaining medications without lab testing, increased hospitalizations resulting from delayed routine testing, and separation of caregiver and recipient during hospitalization.

Access to home healthcare and respite care was constrained, due to caregiver concerns about COVID-19 exposure and service discontinuation resulting from aide shortages and lockdown. Decisions regarding care were adjusted given visitation restrictions:

*Ultimately, I knew that he belonged in a long-term care facility. His issues had progressed to a point that, even with aides coming into the house, I was having a real struggle trying to take care of him. I even had my daughter here with us for several months and, between the two of us, we were having trouble. His needs were relentless and 24/7. . . .but the idea of placing him in a facility when you couldn't go see him was a terrible decision to make especially to someone who doesn't understand. . . . ultimately, we had to do it, but he only lived 17 days [after moving to facility].*

For caregivers who contracted COVID, caring was a challenge. In our sample, two caregivers contracted COVID and one spent a week in ICU. The impact on the household could be dramatic:

*I was really violently ill. And it made it impossible for me to do anything and take care of anyone. And when I was put on isolation and told to stay home for 14 days, it ended up with a situation that we had no way to even access food.*

*There was no way to get food because I couldn't do the shopping, and I couldn't cook. And it was just an absolute disaster. And we had no resources whatsoever.*

Some caregivers perceived that they might have been better positioned to handle quarantine/social isolation than non-caregivers, as one caregiver explained:

*Most caregivers are pretty isolated anyway. I think there's a level of social isolation amongst caregivers that is different than the regular population, and I've never just been able to at a whim go out and do anything I wanted, so I haven't really felt the impact of [social isolation due to COVID].*

However, a few caregivers were used to interacting online with peers and support personnel, which was a welcome source of support:

*[The caregiver coaching] program . . . that is a lifesaver. [ . . . ] I think that saved my sanity because you're speaking to a live person, she's giving you some tips on how to de-stress, or how to manage the COVID situation. I look forward to it. She gives me nice resources, and it's just like someone holding your hand saying, "It's gonna be okay. Things are a little bit rough, but try doing this."*

One major social support challenge was being separated from care recipients who were hospitalized, or in long-term care, or dying—virtual visits with care recipients were emotionally difficult for the caregivers.

Despite these challenges, two positive aspects emerged: 1) online peer networks, particularly for veterans, were an important source of emotional support for caregivers (during both the natural disaster and COVID-19), as other caregivers understood their challenges. 2) Some caregivers appreciated having extra time to spend with the care recipient during COVID-19.

### Experiences Related to Natural Disasters

While caregivers undertook many of the same *pre-disaster* preparations for weather events as non-caregivers (in their estimation), they also faced unique considerations. Advance medical preparations included obtaining medication refills and special nutritional items, ensuring availability of battery power for medical devices, planning evacuation logistics for non-mobile or complex care recipients, and locating accessible alternative lodging. One caregiver expressed the risks they faced after deciding not to evacuate:

*My husband's a quadriplegic, so temperature regulation is a problem for him. His sweat glands don't work, so if the A/C's not working, that is life-threatening for him. And . . . that was one thing we realized was that we don't have a generator because you have a medical bed that needs power. We do have a portable A/C, but we don't have any way to run it if the power goes out.*

Those whose care recipients had post-traumatic stress disorder (PTSD) or PLWD needed to continually manage the care recipient's perceptions of their surroundings

and their emotions. Caregivers living separately from their care recipient worried about getting care recipients through the storm safely, while managing needs of their own households.

During the disaster, caregivers discussed challenges managing care recipients' mental state during an evacuation. Two caregivers noted care recipients with dementia or traumatic brain injury were prone to wander, necessitating constant vigilance by the caregiver. The latter caregiver described her "very stressful," experience, adding:

*I had to focus on my [newborn] daughter, and I had to focus on him because he can get lost. That happened many times. Even here, the police had to help me to find him one time. [ . . . ] And if he gets out to the bathroom in the gas station or whatever, I have to park in the front because I have to keep my eyes looking at him. [ . . . ] The hotel was hard, too. Because he wanted [to go from] the hotel. [ . . . ] If I don't be there watching him, calling him, he can go.*

During the *post-disaster* period, effects on medical care were notable. Interrupted prescription access was stressful; some caregivers expended substantial time and effort locating an open pharmacy or getting replacement prescriptions. One caregiver explained:

*It was just frustrating versus if you had a pharmacy you could drive up to and say, "I need this filled," that would've been helpful. But we use the VA mail system, and the mail got lost, and there was a hurricane.*

Three caregivers lost community-based care, including adult day care, home healthcare, and in-home physical therapy. One caregiver described serving as primary mental health support for a care recipient who was without access to mental healthcare. In all cases, caregivers had to perform these functions. Temporary loss of home healthcare was particularly impactful for one caregiver who relied on the service to free up time to take care of her children's needs and the home.

*. . . every day, there's a nurse aide that comes in to help him to get ready for the day, [ . . . ] so that I can focus on getting the kids and whatever things need to be handled first thing in the morning, I don't have to split between the two, and he can still make all his appointments because all of that has to happen before he can get out and going. So yeah, the fact that we lost our home health aide until things started getting back to normal was a big, big impact.*

Nearly all caregivers reported that they had experienced negative emotions, including stress, anxiety, exhaustion, confusion, sadness, and worry. Caregivers worried about the care recipient's physical and mental health during and after the storm and expressed anxiety about their ability to meet health needs. Caregivers described guilt—for example, related to their ability to briefly step away from the situation when the care recipient was unable to do this. One caregiver described the wide array of emotions:



*Stress. I don't think that really covers it. I was really sad. . . . We moved here with a lot of excitement and hope, and it was kind of crushing to have [the hurricane] happen within the first two months of living here. Fear. I won't lie, I was scared. I felt so much like it was all up to me to handle it all, which I mean, you feel that sometimes a lot as a caregiver, especially when you have to take care of another adult, so it's a hard dynamic.*

On a positive note, caregivers appreciated having both physical help and emotional support during and after the event. Neighbors' assistance with cleanup and obtaining supplies was particularly reassuring for caregivers.

### Disaster Resources Needed

One area of expressed caregiver need was help with transportation and shelter services, including assistance transporting a disabled recipient, providing fuel for evacuation, or helping evacuation under special circumstances—such as one caregiver with an infant who was caring for a veteran with PTSD and a history of fleeing when not closely watched.

Some caregivers described how standard shelters are not designed for care recipients who cannot handle lots of stimulation or being around large numbers of people. One suggested to:

*have shelters that were easier for people who are older or incapacitated [because] to take somebody who's having difficulty with rational thinking and putting them into a gymnasium full of people would be something you would only do if you absolutely had no place else to go.*

Some also described unattended medical needs, requesting a way to ensure continued access to medical care during evacuation, facility shut down, or emergency room overcrowding. A caregiver for a homebound care recipient wanted some means of securing specialized home health care services throughout the course of the disaster event.

Some caregivers also requested caregiving-specific information leading up to, during, and after the disaster, such as how to evacuate someone with disabilities, mental health conditions, or those that relied on medical equipment. Caregivers noted that advanced preparation was most helpful for managing needs during disaster, including pre-arranging for help during the storm and using Veterans Affairs (VA) or locally provided preparation checklists. One caregiver provided questions that needed answering:

*Where do you go with a handicapped person that is on a breathing machine, has a wheelchair, needs a Hoyer lift to lift, needs a hospital bed to go to, needs a roll-in shower—all the types of things that a handicapped person needs? Where are those available in another location?*

These caregivers voiced a preference that information about available resources be proactively provided to

them instead of having to seek it out. One caregiver commended the VA for having great communication approaches, but they noted that those channels were not utilized to provide disaster planning information:

*I felt if there could've been what to know during a hurricane and beyond the just normal storm preparation stuff but for caregiving, like make sure you have the medication, and if you are worried that it will get lost in the mail, maybe pick it up at the VA, or use My HealtheVet to communicate any concerns about behavioral changes or increased symptoms, especially for post-traumatic stress or other mental health challenges, anxiety, etc. [ . . . ] Maybe a blast about what time might look like for veterans and what the VA can do in the dynamic of a hurricane.*

A caregiver also mentioned the potential utility of having a dedicated resource, such as a case manager, reach out to assist with preparation efforts.

### Additional Support Recommendations

Many caregivers provided recommendations for local governments or organizations to better support caregivers and their loved ones in future events. A common suggestion was a service to check on those in need either before or after a storm to ensure that they were prepared and had resources to deal with the after effects. One caregiver suggested a service to formally register a caregiver/care recipient's needs in case problems arise:

*Number one, have a center—whatever. You can call and then [say], "My husband cannot move. He's homebound. This storm is coming. We have history of flooding around [here]. We just need you to be aware if something happens, I'm gonna contact you to help me with this. If I don't have electricity, you need to know that my husband is on ventilator."*

Other caregivers described a post-disaster check-in that gave priority to those with circumstances that made them more susceptible to disaster impacts. Direct support for caregivers was also mentioned, such as a caregiver support hotline and resources helping caregivers take better care of themselves. One caregiver suggested creation of a registry with utility companies to ensure that power is not cut off for any reason (e.g., those relying on oxygen/ventilators).

Some caregivers highlighted a need for specialized training, such as training first responders to assist triggered veterans or for dealing with specific rare diseases, such as ALS. The latter was informed by a vivid encounter:

*When my dad was hospitalized a number of times [ . . . ] I would be in the ambulance with these paramedics who don't know how to deal with ALS patients, and they're trying to use the suction machine, but they're doing it way too forcefully. Later, when he had the tracheostomy, at one point, I'm shouting at them, "You can't put it in that hard because you could damage his lung and have bleeding!" I'd have to fight with people who just don't know about ALS.*

Additional suggestions included making sure that caregivers can accompany care recipients during visits with medical providers, having dependable home health personnel that can speak the same language as the care recipient, and Medicare and Medicaid expansions to cover some of the types of care needed during and after a disaster. Several caregivers felt that the VA needed more flexible policies or exceptions for securing extra medications as part of a disaster plan.

Also mentioned were recommendations for enhancing the relay of accurate, current information during disasters. One caregiver described her experience getting inaccurate info:

*One thing that was unfortunate during Hurricane Harvey is I was relying on the chat of my town on Facebook, and a lot of the information I was getting was really wrong, and I didn't know that at the time. But I'm trying to learn from people who have lived in this community and people who have gone through hurricanes before, but I would say at the community level, there wasn't a whole lot of emphasis on getting information out, and I would love official channels—not like, "Hey, check out our Facebook page for information about this."*

This information should be dispersed in ways accommodating people unfamiliar with virtual means of communication, such as a call service or "snail mail," and newsletters with disaster preparation advice. Some also suggested an informal "buddy system" with someone in their community, or the provision of linkages to caregiver networks, to enhance social supports.

## Discussion

This paper describes collective caregiver experiences during hurricanes/floods and the 2020 to 2021 COVID-19 pandemic, querying the *same* caregivers who experienced both events. Overall, our findings mirror some of the literature regarding caregiver stress and challenges with either phenomena. Caregivers need psychological support (Elizarrarás-Rivas et al., 2010) as increased caregiving accountability and responsibility during emergencies heightens caregiver burden and stress (Chiang et al., 2005; Cohen et al., 2021; Sawa et al., 2013). Our findings also align with a recent scoping review identifying stress related to obtaining medications and supplies (Pickering et al., 2021).

Both the pandemic and natural disasters evoked similar experiences regarding access to supplies and support resources and general caregiver stress. While caregivers experienced elevated levels of anxiety during both events, the source of their anxiety was different—for example, worry about risk of infection during the pandemic versus complete disruption of medical services during disasters. Timelines were also different; natural disasters curtailed more services and supports for less time while the pandemic limited services and supports less so, but for longer.

Caregivers of veterans discussed support resources that could serve as an example for other communities. For example, the VA provides support through formal programs during disasters—some of them mental health-specific—that attempt to maintain continuity of care to veterans (Wyte-Lake et al., 2021). VA also has a National Caregiver Support Program, and offers informal online veteran communities which research suggests are commonly used by caregivers of veterans with neurological or psychological conditions (Friedman et al., 2018). Being part of a supportive group with shared experiences might provide strength during difficult times.

Additional community-based supports ideas proposed by caregivers included: 1) An evacuation process addressing the unique challenges of caregiving, including transportation and shelters designed for care recipients with various medical and mental health conditions (e.g., reduced stimuli); 2) Specialized emergency preparation and management services that span public health, medical, and social services to avoid service disruptions and address acute issues; 3) A caregiver registry for first responders and utility companies, disaster case managers, and implementing technology systems enabling local officials to quickly connect with families with medical needs in all phases of a disaster; and 4) Proactive dissemination of disaster-related planning information tailored to the needs of caregivers and recipients.

Regarding limitations, we had difficulty recruiting caregivers from the U.S. Gulf Coast states during COVID-19 and an active hurricane season, such that available participants may have self-selected, or our recruitment pool may have been limited. The study focused primarily on Gulf Coast states, but similar natural disaster circumstances exist in other American Southeast coastal states. Lastly, the sample had a high education level despite our attempts to recruit a diverse sample.

## Conclusions

Our findings indicate the need for reinforcement of caregiving at the federal, state, and local levels and we present actionable suggestions to support community caregivers. Future research is needed to address cross-sector disaster preparation systems that place caregivers at the center of the emergency. We also need better understanding of the unique caregiver experiences dealing with climate-related emergencies elsewhere in the U.S., to meet needs in these specific contexts.

In conclusion, continued recognition, inclusion, and support of caregivers is necessary for community health in all communities in the inevitable next natural disaster or pandemic. Bolstering and maintaining the health and abilities of caregivers is critical during emergency situations so they can continue caregiving work when there are few additional resources to support them.

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## Declaration of Conflicting Interests

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## Human subjects protections

This study was reviewed by the Duke Health IRB and determined to be exempt (Pro00105250).

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## Supplemental material

Supplemental material for this article is available online.

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