“You Get Three Different Hats on and Try to Figure It Out:” Home-based Care Provision During a Disaster

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Abstract

Background: Home-based care is a vital, and growing, part of the health care system that allows individuals to remain in their homes while still receiving health care. During a disaster, when normal health care systems are disrupted, home-based care remains a vital source of support for older adults. The purpose of this study was to describe the experiences of home-based care providers in providing care to older adults during a disaster in order to inform future disaster planning.

Methods: Using qualitative inquiry informed by the social ecological model, five focus groups were conducted with home health nurses (n=25) in two settings affected by Hurricane Irma and Hurricane Harvey. An open-source database of home health agencies participating in Centers for Medicare and Medicaid Services programs was used to identify participants. Data were manually coded and larger themes were generated from recurring ideas and concepts using an abductive analysis approach.

Results: Twenty five participants were included in one of five focus groups. Of the 22 who responded to the demographic survey, 65% were registered nurses, 20% were Licensed Vocational Nurses (LVN), and 15% were other types of health care providers. 12% of the sample was male and 88% was female. Seven themes were identified in the analysis: *the importance of the community in preparedness and response, government and corporations were viewed as unreliable, disasters exacerbate inequalities, the role of the family bond, the breakdown of preparedness is at implementation, the tension between caring for self and family and caring for patients, and the resilience and adaptability of home based care providers.*

Conclusions: While home-based care providers faced multiple challenges to providing care during and after a disaster, the importance of community supports and existing nursing models of care in the immediate period after the disaster were emphasized. This study informs the growing body of evidence on the value of home-based care in promoting safety and well-being for older adults during a disaster.

Background

The United States population is rapidly aging. Currently, more than 46 million Americans are aged 65 years of age and older.(1) According to Healthy People 2020, this number is expected to reach 98 million by 2060.(2) Aging comes along with its own set of unique challenges including an increase in chronic conditions such as diabetes, heart disease, and dementia, along with increased difficulty carrying out activities of daily living (ADLs). Given the unique needs that come with aging and the projected increase in numbers of older adults, it is imperative that older adult groups receive support that allows them to age optimally in place.

Healthy aging needs are compounded by disasters, such as hurricanes, where normal patterns of daily living are disrupted. Hurricane Harvey and Irma were two large-scale disasters critically affecting the coastal South of the United States in 2017. Responsible for an estimated 90 deaths and nearly \$200 billion in damages,(3) Hurricane Harvey is one of the most significant disasters of this century. During Hurricane Harvey, over 300,000 customers lost power lasting for some up to two weeks, and 20

hospitals closed temporarily.(4)(3) Hurricane Irma was similarly devastating, causing 6 million residents in Florida to be evacuated from coastal areas, and thousands of homes damaged.(5) These events not only have historic significance in terms of the amount damage and destruction, but they also have very personal effects on older adults, their caregivers, and their communities.

Alongside an increasing number of large-scale disasters and an exponential increase in aging populations, the spectrum of home-based care services is expected to grow as well.(6) Since home-based care in particular is one area where emergency preparedness and response interventions can have substantial effects, expanded training for this workforce is important. Home-based care is intended to continue to function during a disaster or community emergency, and home care agencies receiving Medicare and Medicaid funding are mandated to have emergency preparedness plans in place.(7) During a disaster, home-based care needs of patients continue, and home-based care providers (HBCPs) use existing care delivery models to support clients wherever they may be located, including in shelters and hotels. Every disaster presents unique challenges, and the unpredictable nature of disasters requires HBCPs to adapt rapidly to changing situations in order to provide minimal interruptions in care. HBCPs provide a vital lifeline for clients when their access to other types of healthcare may be restricted. Despite the importance of home-based care, we know little about the experiences of home-based care providers during a disaster, including the successful workarounds that are employed as well as the barriers to supporting clients that remain to be addressed. Therefore, the purpose of this paper is to qualitatively understand home-based care provision during a disaster through the lens of home care providers.

Methods

This descriptive, qualitative study was part of a larger study that explored home-based care providers' experiences providing care during a disaster, and was informed by the social-ecological model.(8, 9) Institutional review board (IRB) approval was received from the University of Michigan (HUM00132531). Participants provided written informed consent and were offered a \$50 visa gift card via email as an incentive for participation. This study adhered to the consolidated criteria for reporting qualitative research (COREQ) guidelines. Institutional review board (IRB)

Interview Guide

An interview guide informed by prior conceptual work on disasters, home care, and aging was developed. (10-14) This guide was refined through pilot testing with qualitative experts initially and then with a small group of registered nurses. The interview guide focused on barriers clients faced to health and healthcare access after the disaster, strategies to support preparedness before the disaster, and strategies after the disaster to support safety and aging in place. The final interview guide was constructed for a goal interview length of 45 to 60 minutes.

Study Sample and Recruitment

The study sample was recruited from counties with Federal Emergency Management Agency (FEMA) disaster declarations for Hurricane Irma and Harvey,(15) and further limited to counties that received individual assistance funding. Individual assistance provides support for individuals (rather than only for public assistance such as rebuilding roads) and was conceptualized in this study as a measure of the extent to which a disaster affected the community. We also considered county demographic statistics on socioeconomic status and race in our recruitment strategy. In order to include the perspective of the home-based care workforce on caring for historically underserved patient populations, counties with higher numbers of residents who identify as Black, Hispanic, Asian, and “other” were prioritized in our recruitment process, as were counties with a median annual income closest to 2017 Federal poverty guidelines. In order to reach saturation, a sample size of 25 was targeted a priori.

A two-stage sampling design was employed. First, we contacted the 164 home health agencies that met the study criteria. Each agency was contacted via telephone by a member of the study team up to five times. After a fifth unanswered call or request for a call back, the agency was removed from the study due to non-response. Once contact was made, the study was explained to the agency administrator or their representative, and study information was disseminated to potential participants, who then contacted the study team.

Focus Groups

Five focus groups were conducted in person in January, October, and November 2019 in greater Houston, Texas, and in Southern Florida. The focus group participants had provided care during hurricanes Harvey and Irma, both of which made landfall in the late summer of 2017. Each focus group was moderated by the principal investigator who has doctoral-level training in qualitative methods, with support from a trained research assistant, who was responsible for the audio recording, informed consent and incentive documents, and note-taking. Focus groups lasted approximately 60 minutes and started with an introduction, during which participants were encouraged to speak openly, written informed consent was obtained, and then followed by the semi-structured interview itself.

Analysis

After the study team reached an agreement that data from the focus groups had reached saturation, the processes of coding and analysis were initiated. Focus group conversations were recorded digitally and transcribed by an IRB-approved transcription service. After removing identifying information from the transcripts, including the mention of a specific facility, other clinicians, or family members, the transcripts were formatted for coding. Data was analyzed using an abductive analytic approach.(16) This method combines inductive and deductive approaches thereby allowing for a purposeful examination of a range of explanations, which reduces the likelihood of bias. Using an iterative process, two research assistants independently generated codes in light of existing theory, here using the social-ecological model(17) applied to the disaster life cycle of mitigation, preparedness, response, and recovery (figure 1). Coders met face-to-face weekly in order to review and arbitrate differences in each other’s codes. The final codes and their agreed upon definitions were then entered into a codebook. These codes were presented to the

larger research team, and after systematic analysis and collective deliberation, eight larger themes emerged from the data that represented larger over-arching concepts extracted from the focus groups transcript data. These themes represent common strategies used by participants and the barriers they faced in providing care for older adults during disasters.

Results

Demographics

A total of 25 participants were included across five focus groups. Of the 22 who responded to the demographic survey, 12% were male and 88% were female. The majority (84%) identified as White/Caucasian, followed by 12% who identified as Hispanic, and 4% as Black. Registered nurses made up 65% of the sample, 20% were Licensed Vocational Nurses (LVN) and 15% were other healthcare professions. The average length of time participants resided in their profession at the time of the focus group was 16.5 years, with a range of 3.5 to 39 years.

Themes

Seven themes were generated from the analysis. These themes represent the experiences of home care providers during two hurricane disasters, and addresses the barriers they faced in providing care for older adults during these events and the successful strategies they employed.

1) *Preparedness and response must be in tune with community.*

Participants described mixed reports about the quality of support provided by formal community organizations that provide disaster services. In contrast, community support from faith-based organizations, university or school groups, and informal volunteers were reported to have held up the community effort in assisting those affected by the hurricane.

“They could come in and get toiletries, clothing, whatever they needed. They were able to come through there because that was more like a donation station because they were one of the churches that didn't flood. So people could go through and get things.” (D4)

“Facebook had a whole app, and so the whole app was Hurricane Harvey assistance or whatever for [name omitted] County. And so people were constantly posting on there if they needed help and people were just volunteering.” (B3)

“This was, I feel like it was much more of a community effort than it was an organized effort. There became this saying called [name omitted] County strong. And it was just anybody and everybody that could do, and they did whatever needed to be done. People took people in, strangers. I don't know you but I have two bedrooms. You can come stay at my house till we figure out what's going on. Large groups of people just going through neighborhoods and literally mucking out, starting at one end and just mucking out and taking out furniture and things like that.” (B2)

Furthermore, participants described a sense of reliance on supports coming from their own community. Community members took on front-line roles in the response, providing valuable insight on response efforts due to their knowledge of community intricacies.

"I mean really the only positive thing is that people that were here and really the community all looked out for each other and was very helpful even if they weren't in the medical field." (A4)

"At the end of the day, it was a community, helping community. They realize that government was not going to be their solution." (D4)

2) Perceived unreliability of government and corporations.

Participants expressed an overwhelming consensus that federal resources (such as FEMA) and insurance companies were viewed with mistrust by their clients. A primary barrier to clients receiving disaster support was the application process, which they described as challenging to decipher, and even once completed, there was no follow-through about the status of the application. They also described poor communication in the event they were able to speak in-person to representatives.

"I think the other thing about that is that the application process was very complicated. We tried to pull a lot of community information for people because the County would publish, go here for FEMA help, go here to access. You've got to fill out these forms, you got to talk to these people. But it's a very complicated process." (B6)

"Many people told me the FEMA people got mad at them, which with some of our elderly people, you get mad at them, they're done, they shut down, they're done. They're not going to be disrespectful. They're just done. And so that's an issue in my opinion." (E4)

"And yet they paid in to their insurances all this year, never missed a payment, and are not getting any help either on that end." (E6)

3) Disasters exacerbate inequalities.

Participants described how the disaster disrupted the way their clients access essential services and information, where such disruptions were described to have a greater impact on those living with disabilities, limited literacy, and/or low socioeconomic status. Many participants reported having clients who stayed home, were reluctant to evacuate, or lacked an acceptable place to evacuate to, citing mobility issues or poor experiences in previous evacuations.

"He didn't have to evacuate from his home, so his home was okay. It's just that he couldn't get the supplies that he needed to live basically." (B3)

"The other thing I wanted to say is our elderly population here, a large percent do not write. They don't write. They don't know how to write because of their education level. Or read. So the FEMA program has to have people that can understand that to help these people." (E4)

"What am I going to do? Where am I going to stay? I can't afford a hotel, I don't have any family anywhere else. This is where all my family is at. And so what they typically find is they find the family member who they think has the most sound structure. And that's typically what they'll do to ride out the storm and they'll suffer through heat and humidity and mold if they have to, just to make sure that everybody's safe." (E2)

Participants also stated that for limited education around health and safety in the aftermath of disasters was also an issue. They described how this lack of education contributed to unsafe living conditions.

"If you have floodwaters in your house, you can't be walking around with your bandaged foot, and there's so many people doing that. So many people. Well first of all they didn't have tools but also just not aware of the danger of doing that." (B5)

4) Importance of Family.

Study participants described a multi-generational family-centric value system for many of the populations they serve. Relying on family members for preparedness and support in times of crisis is a part of this. They described how their patients will look to family members to assist with communication, continuation of care, and participation in an active role in caring for the patient. Being displaced after a disaster was a source of stress and care interruption; having family to rely on during times of crisis alleviated some of those effects. However, family caregivers experienced additional burdens as a result of their role as caregivers.

"We have a lot of patients that their husbands or wives are elderly as well and very sickly. We would see some of our patients that were extremely sick trying to take care of their loved ones that were also sick." (B5)

"The people that I saw, two, three people, they're elderly, they didn't have insurance on their house so they got relocated to children's house. And of course then you have the emotional and all the issues and the conflict and all that." (E3)

"Write down your wound care instructions for you because your family is going to have to do it wherever you're taken to." (B4)

"Some of them had to leave their animals because the one lady that I told you about that couldn't walk and now she is, she had a dog. But thankfully, she had family that was able to tend to him while she was going through all this and he's back at the house with her." (D4)

5) Barriers to implementing preparedness plans.

Home health agencies participating in Centers for Medicare and Medicaid programs are required to have disaster preparedness plans, which are communicated to clients upon admission into home health services. These tailored plans are designed specifically for a client's care needs and also provide

information on community resources and education for them. Components of this disaster preparedness plan may include evacuation planning, triage, storm and flood preparation planning, wound care education, resources and literature, alternative dialysis sites, specialized diet education, and communication with the home care agency at the time of a disaster.

"We do all this on admission. We get the emergency plan put in place for each patient. It's individualized. Everything's on there, if they're tube feeding, if they have a CPAP. I mean everything, how they walk, how they communicate, the whole works. We register them with [redacted] if they weren't registered. Or we put on there if they're wanting to be evacuated by family or whatever. Everything's on this one, on the one stop sheet...Everything's on that plan. Then, we also give them emergency management packages which is information packages. Everything from hurricane tracking information, all the way through to what to have as emergency storage, foods, things like that. All in this little booklet that we give them. It comes in multiple different languages. It comes from the Office of Emergency Management. We put that in there for them." (C3)

"We confirm what their evacuation plan is, and talk with them about, okay, you have to leave, where you going to go? What are you going to bring with you? How are you going to get there? What are you going to do?" (B3)

However, despite the efforts of study participants to prepare their clients, a breakdown in the actions required by their patients was described. They cited reasons for this such as financial concerns, lack of transportation, and health and mobility issues, but participants also held the view that many believed the storm would not cause substantial damage.

"And so those types of preparations, I don't know that we could do any better just because of the way the world works. You tell people to have two weeks extra of their medicines, but there's really no way to do that. That's a real problem." (B4)

"Then, like I said, you'll get the call from the family. It's like, 'We just don't know what to do.' 'Really? We've been at you for a week... giving you information. We've prepared you since admission.'"(C3)

6) *Balance between caring for self and family and caring for patients.*

HBCPs described experiencing multiple stressors as they juggled patients' disaster-related needs with those that they and their own families were experiencing. Participants cited challenges with ensuring their patients' well-being as well as that of their own families. Participants reported the critical importance of having personal preparedness plans in place for their own families to make sure they were taken care of while the provider was working with patients. They reported feelings of helplessness because they were not able to help patients regain lost possessions or provide answers while simultaneously caring for the same issues for themselves and their own families.

"So we're calling all of our staff because one of the first things that we've got to make sure is that our staff is prepared in getting their family taking care of... So that they don't have to worry about them, while

they're taking care of our patients.” (C2)

“You need to understand your own personal plan and you need to understand who's responsible for your family while we need you here, so we have designated who's at the beginning of the disaster, who comes back at the end of the disaster and how that works.” (B3)

“And the mother of the patient kept asking me, “Have you heard anything? Do you know when the power's going to come back on?” And I just had no answers for them and that was difficult too.” (E4)

“Because it impacts their health for sure. Our goals and stuff, everything because of what they're dealing with personally. And then it's frustrating because I don't know where to go....I can see what they need and I'm like, I have no idea where to start.” (E4)

“I was considerably more concerned about my patients than I was my family. I knew my family was basically okay, but my patients were not. My son lost everything in Hurricane Harvey but I knew that physically he was okay, and I knew that we would be able to help him and he was going to be okay. So for that reason I didn't worry as much about my family, but my patients, I can't fix those kinds of problems for them. And maybe when I grow up I'll get to the point where I don't feel like I should.” (B2)

7) Resilience and adaptability of home-based care providers.

Home-based care providers reported numerous instances of supporting their clients beyond providing health care. Whether it was helping with disaster relief applications or navigating insurance websites on the internet, clients often had no other options for assistance with these tasks. HBCPs stated they viewed these types of support for their clients as out of their expected role, but also a necessary part of keeping their clients healthy and in their homes.

“So then when you see the patients, you're there to deal with their medical concerns and we're supposed to be doing our wound care, whatever but you're also having to deal with all the other stuff because that's part of what they're dealing with right now so then that gets thrown on you and so then you're dealing with that right now because you don't want to just leave them there with no type of solution or help. So then you get three different hats on and try to figure out how to take care of them.” (B5)

“She (the HBCP) brought him diapers because she wasn't sure whether they took them with them, when they evacuated. So she just brought diapers with her, just in case. She stopped off at a grocery store that was open and bought them herself. I mean, so, everybody... It was everything from just whoever was looking after the patient, jumped in. (C3)

Discussion

This study provides qualitative evidence on both the challenges HBCPs face and on the effective practices they used when providing home-based care in disaster-affected settings. Our findings underscore the importance of informal community supports in supporting individual and community-level

recovery, especially relative to formal supports. HBCPs themselves are a part of this community expertise as they live in the disaster-affected communities where they work. Family, friends and neighbors, as well as informally organized response and recovery efforts from faith-based organizations and other community groups were seen as vital to community recovery. Our findings echo those of past studies on disaster-affected communities, which have shown that social connectedness and trust in relationships were vital aspects of community recovery.(18, 19)

Conversely, participants in this study observed barriers around formal supports by their patients, particularly insurance agencies and governmental resources. The associated complexities and delays seen with these formal supports were a source of frustration, and even despair, for the patient population served by HBCPs. Notably, reducing complexity was a major stated goal in FEMA's 2018 strategic plan. (20) Progress on actions to reduce complexity at the community level will benefit from both continuous evaluation and ongoing community stakeholder involvement. Mistrust of the government is not a new challenge, but is a place for still-needed intervention.(21, 22)

In keeping with our use of the social-ecological model alongside the disaster management cycle of mitigation, preparedness, response, and recovery, a significant effort at the policy level is needed to improve trust in order to better serve populations affected by disasters. Formal support agencies can focus on building relationships with local community leaders as a mitigation strategy. This could include strategic efforts on how to best support members of the community, and then on disaster response and recovery service delivery. To further capitalize on local resource networks, formal support agencies can focus on how to work alongside community organizations, including having these local organizations take the lead on response and recovery, perhaps with financial support from formal agencies.

We also saw the importance, and value, of the relationship between the home-based care provider, the client, and the community in this study. HBCPs often provided support and assistance to clients outside of expected clinical practice, including help with filling out forms or navigating resources on the internet. HBCPs had to adapt their practice after the disaster to address concerns outside of health, doing so with the knowledge that without this assistance, clients would be at risk for social issues that would ultimately affect their health. Given that HBCPs often have established and trusting relationships with their clients, formal organizations could coordinate with home care agencies to understand the needs of their clients and develop shared strategies to support clients in promoting response and recovery.

Our study highlights the need for an ongoing focus on equitable solutions to support structurally marginalized communities. Despite existing efforts by organizations targeted towards these communities, our study found that many still reported experiencing inequities as a result of the disaster. Participants identified a need for strategies to reach low-literacy populations or hidden populations (such as seasonal farmworkers or undocumented individuals). An area also identified as a need is for focused interventions around evacuation education for those who cannot or will not evacuate. Many participants observed clients reluctant to evacuate due to past experiences, financial concerns, or mobility issues. As part of the emergency preparedness planning routinely done with patients, HBCP providers can work to

identify the barriers around preparedness actions, such as why their patients do not plan to evacuate, and work with them to develop a safe plan. On top of this, research is needed that critically analyzes the effectiveness of current preparedness and response planning, including how to better support those whose reported intention is to not evacuate.(23, 24)

Limitations

This study does have limitations that prevent the findings from being widely generalizable. First, this study is set in two hurricane affected areas, and included only 25 home care providers. Second, the majority of participants were white women, and therefore this study does not represent the diverse perspective that is needed to better understand and support structurally marginalized communities. Also needed is the study of a large scope of types of disasters and communities with differing sociodemographics. However, this study is one of few that gives voice to the important insight of home care providers during disasters and community emergencies.

Conclusion

Home-based care fulfills an essential need during a disaster, where providers continue to support their clients through all phases of a disaster to maintain minimally-interrupted care. Our study provides insights on how home-based care providers and other stakeholders can address disaster-associated health challenges. We call for an emphasis on the importance of community supports, and a sustained focus on supporting structurally marginalized individuals and communities.

Abbreviations

ADLs: Activities of daily living

HBCPs: Home-based care providers

IRB: Institutional review board

COREQ: Criteria for reporting qualitative research

FEMA: Federal Emergency Management Agency

LVN: Licensed Vocational Nurses

CPAP: Continuous Positive Airway Pressure

Declarations

Ethics approval and consent to participate

All authors have abided by appropriate ethical standards and attest the research has been approved by the University of Michigan's Institutional Review Board ethics committee. (HUM00132531) All authors confirm written informed consent was obtained from all participants.

Consent for publication

All authors of the manuscript have read and agreed to its content and are accountable for all aspects of the accuracy and integrity of the manuscript in accordance with ICMJE criteria, as well as attest that the article is original, has not already been published in a journal, and is not currently under consideration by another journal. All authors agree to the terms of the BioMed Central Copyright and License Agreement, and Open Data policy. All authors confirm consent from participants was given for the usage of direct quotes from their interviews to be published in this manuscript. All authors confirm participants gave consent for direct quotes from their interviews to be published in this manuscript.

Availability of data and materials

The datasets generated and/or analyzed during this current study are not publicly available due to ongoing use of data set but are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

Each author contributed substantially to this manuscript and take responsibility for all work reflected in this analysis. S.B. conceptualized the study, conducted focus groups and data analysis and led the authorship of the manuscript, S.D. contributed to the data analysis and manuscript preparation, and M.R. supervised the methods and contributed to writing the manuscript. Those authors being S.B., S.D., and M.R., have approved the submitted version of this manuscript. Each author has agreed both to be personally accountable for their own contributions and ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the manuscript.

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Figures

Figure 1

Theoretical Framework