



'More stressful than cancer': Treatment Experiences Lived During Hurricane Maria among Breast and Colorectal Cancer Patients in Puerto Rico

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Background

In September 2017, Hurricane Irma affected the Caribbean region, including Puerto Rico (PR), followed by the devastating category 4 Hurricane Maria, which caused thousands of deaths and massive infrastructure and economic loss. Cancer patients are highly susceptible to disruptions, caused by natural disasters, from diagnosis through treatment and survivorship.¹ For example, it has been estimated that for CRC every four-week delay in chemotherapy decreases overall survival in 14%.²⁻³ Few studies have assessed the impact of natural disasters on chronic diseases such as cancer⁴⁻⁵, since it remains uncertain how such a disruption will affect access to treatment especially those patients with breast (BC) and colorectal cancer (CRC), two of the most common cancers in incidence and mortality in PR.⁶ Since Puerto Rico is in a very susceptible area for disasters, it is imperative to find cancer patients needs to diminish their treatment disruptions, in future disasters.

Objectives

This is the first part of the 'Mixed Methods Study to Explore the Effects of Hurricanes' Irma and Maria on Cancer Care in Puerto Rico', which aims to evaluate factors associated with cancer care disruption and time since continuation of care in the aftermath of Hurricanes Irma and Maria. The focus group explore the following factors: (1) experiences of cancer diagnosis, and knowledge of treatment plan; (2) disruption and time to resume continuation of cancer care after the Hurricanes impact; (3) drug and supplies needed; (4) transportation barriers; (5) communication and coordination of services with physician or treatment facility; (6) medical insurance communication and assistance before, during and in the aftermath; and (7) physical and emotional stress during the storm and its impact on continuation of treatment (e.g. evacuation planning and assistance, provision of accessible shelter, adequate power, food and water).

Methodology

Participants

Inclusion criteria:

- 1) ≥40 years
- 2) CRC or BC patients diagnosed between March 2017 and September 2017
- 3) Being under active cancer treatment before, during and/or after September 2017.
- 4) Living and receiving treatment in Puerto Rico during the aftermath of the events.

Procedures

The PR Central Cancer Registry (PRCCR) provided to the research staff, a list of patients who met the inclusion criteria. A random sample of 40 CRC patients and 40 breast cancer patients were obtained (Figure 1), to coordinate 4 Focus Groups of 10 participants each. Then, the staff followed the Case Ascertainment Protocol established by PRCCR to contact participants (Figure 3). The participants were assigned based on the cancer type and the zone assigned to their county of residence at cancer diagnosis (Figure 2). A modified grounded theory approach was used for data collection and analysis. Focus group interviews were recorded and transcribe by staff. Atlas.ti was used to code and analyze the transcriptions.



Figure 1. Selection of the potential participants for Focus Groups

Figure 2. Zone selection for participants in Focus Groups

Case Ascertainment Protocol (CAP)

The CAP is used by the Central Cancer Registries for contacting cancer patients. The PRCCR modified the protocol to Puerto Rico. The staff contacted the physician to receive a passive consent for contacting the patients, after one week, the letters to the patients were sent. After two weeks of sending the letters to the patients, the staff called them for screening. If the possible participants were eligible and accepted to participate, the staff inform about the assigned Focus Group, and where is held.



Figure 3. Focus Groups Recruitment Procedure (Case Ascertainment Protocol)

Results

Three focus groups were held on summer 2019, with a total of 10 participants. All participants started their cancer treatment before hurricane Maria, and forty percent of the participants interviewed reported that their treatment was interrupted (or delayed) due to the disaster.

The most prevalent themes observed were (a) barriers and facilitators related to their cancer treatment, (b) experiences in treatment post-disaster, and (c) stressors related to the hurricane. Most participants had comorbidities diagnosed before the disaster, 80% had Hypertension and 40% had Diabetes. We gathered some of the quotes from these themes as follows:

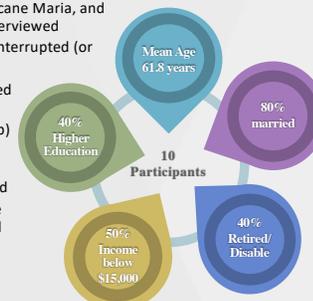


Figure 4. Demographics characteristics

- The study participants commonly mentioned a lack of preparation at the time of the hurricane. Most of them were only were prepared with canned food and water, some of them had a gas stove, and very few had electric generators or water cisterns:

"As for my condition well that caught us by surprise, because after the operation, remember that I got operated on September 8th. During Maria, I was discharged from [hospital] the same day that Maria came." – BC participant

- Participants discussed different experiences in the delay in their cancer treatment and how they were resilient and conformed with what was happening with their treatments:

"No, because my chemo was every 3 weeks. Every 3 weeks I would take my chemo. It took a few days, but we have to understand that it was because of the hurricane. But I'm done, thank God." – BC participant

"my sister had an electric generator, what she did was she took my insulin and put it in the fridge and I kept the bottle [insulin] I was using at the time." – CRC Participant

- Difficulties reaching out to health care providers or facilities, as well as lack of electricity where treatment took place, were among the most common codes identified:

"chemotherapy was not available, and my physicians did not have their facilities ready for treatment." – CRC participant

- Participants showed the hurricane related stressors affected more than the possible delay of the treatment:

"I would say that, comparatively, the most stressful for me, but has nothing to do with me, the most stressful was seen other families without homes..." – CRC participant

"No, because since I had a long time in conversation with the doctors, well I said, a bit more of waiting, because right now with the hurricane I can do nothing. That (delay of treatment) was not stressful." – BC participant

Conclusions

Participants discussed struggles regarding their experience with treatment and access to care during and after the hurricane and how household limitations due to lack of electricity and water, deter their intention to continue their treatment. It is imperative the need to address the patients' limitations or stressors due to a disaster, which can lead to treatment delays. Participants recommended a more specific preparation for disasters in terms of continuing treatment.

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