



'More stressful than cancer': treatment experiences lived during Hurricane Maria among breast and colorectal cancer patients in Puerto Rico

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Keywords Puerto Rico, Colorectal and breast cancer patients, Health services, Natural disasters, Emergency preparedness, Hurricane María, Qualitative study

addressing frequently asked questions (FAQ) about cancer studies (e.g., ‘Why are members of this research study contacting me?’). The letter explained the study’s objectives and invited the participants to join the research.

The PRCCR letter addresses the purpose of this registry and explained to the potential participant how our research staff have this information. After two weeks of certified mail confirmation of receipt, we called the participants to discuss the study, assess their interest in participating in the study, and assess their eligibility. Research staff can attempt to contact potential participants up to a maximum of 8 times.

Three focus groups were conducted between May and

Hurricane Maria, with 40% reporting that their treatment was interrupted or delayed due to the hurricane.

Analysis of the focus group identified (a) barriers and facilitators related to their cancer treatment, (b) experiences in treatment during the disaster, and (c) stressors related to the hurricane, as the themes most emergent.

Barriers related to their cancer treatment

Difficulties in reaching healthcare providers or facilities, as well as limited or no access to basic needs at treatment sites or in their homes, were among the most common codes identified. Participants described the continuous calls and efforts they had to make to access care and resume treatment (particularly among participants from rural areas); to reach for sufficient phone coverage and contact their providers. It was also discussed how participants traveled to the metropolitan area to assess provider's and treatment facilities' availability or find out if drugstores were open. Participants mentioned how these barriers led to weeks (sometimes months) in determining and having plans regarding the next steps of their cancer care treatment. ***“chemotherapy was not available, and my physicians did not have their facilities ready for treatment.”*** — CRC participant.

The majority of the participants discussed how the hurricane delayed their scheduled mastectomies and other treatments (e.g., chemotherapy, radiotherapy), mainly due to lack of electricity in the institutions, which led to a postponement of their treatment by months. Some participants also discussed the potential impact of rescheduling their cancer treatment, as they show hesitation to initiate treatment due to their household situation (e.g.,

lack of electrical plant, lack of water). Participants also expressed fear due to the instability of the electric system at the provider's institution, which would affect their treatment. ***“Radiotherapy was then scheduled for October. It was the partial mastectomy in August, then in September, the ovaries [oophorectomy], and the radiotherapy in October. Everything was postponed. When [the institution] finally had electricity, they called me in October, and I said no, because I work in the metropolitan area and here half the island [shutdown] every day.”*** — BC participant.

The discontinuation of the special health coverage was another topic discussed with the participants related to economic availability. The government provides special health coverage to patients with specific complex diseases, such as cancer. This special coverage aims to facilitate the management and treatment of these conditions among the population with the government health plan. Special coverage under this provision begins upon confirming a cancer diagnosis and ends after cancer treatment is completed. Some participants argue that the discontinuation of the special coverage after completing the chemotherapy affected follow-up services. ***“I still***

referrals and they told me, you no longer have the catastrophic [special coverage], you do not have the coverage, I had to pay for it and since I didn't have the money, I didn't do it, and it's been a year and I haven't done it yet. — CRC participant.

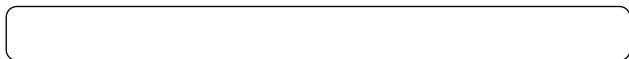
Facilitators related to their cancer treatment

and supplies was also mentioned. is was heightened by the limitation to use the Food Stamp Program card, as lack of communications impeded the use of the Electronic Benefit Transfer (EBT) cards system.

preparedness strategies and cancer center protocols in areas most affected by hurricanes, flood, and electric and power outage, to ensure timely reentry and access to cancer care while mitigating the impact of future disruptions on vulnerable patient populations, particularly in areas most affected by hurricanes, flooding, and power outages.

Abbreviations

BC Breast cancer
CRC Colorectal cancer
IRB Institutional Review Board
PR



18.