

Original Research

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Medical Access and Care Continuity: Qualitative Assessments of Patients with Breast Cancer and Family Members' Experiences Following the 2011 Triple Disaster in Fukushima, Japan

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Abstract

Objectives: While studies have examined the effects of large-scale disasters on disaster-vulnerable individuals, these analyses may not capture the full impact. This study qualitatively explored the impacts of the March 2011 Fukushima triple disaster on patients with breast cancer and their families, aiming to highlight the importance of incorporating family narratives to grasp the full effect of large-scale disasters.

Methods: Utilizing the medical records from two hospitals, deceased patients with breast cancer from the disaster period were identified. Relatives were interviewed using a semi-structured approach. Thematic analysis was conducted via the Braun and Clarke method and Taguette transcription software.

Results: Interviews with seven family members of six patients revealed three main themes: the family's caregiving burden and their deepened bonds with the patient, the patients' extensive medical challenges and their physical and mental decline, and the shared confusion during the disaster due to resource shortages and evacuation dilemmas.

Conclusions: This study uncovered significant infrastructural issues such as reduced medical support and the heavy caregiving load on families, amidst some strengthened relationships during a time of crisis. Future research should investigate these issues across various disaster contexts, and proactive measures should be implemented to prevent exacerbation of these challenges.

Large-scale disasters (both natural and nuclear) often result in the disruption and delay of health care services, as health care infrastructures are often vulnerable worldwide.^{1,2} Furthermore, health care is impacted as necessities such as food and medication often cannot be delivered to hospitals.³ This phenomenon leaves disaster vulnerable populations, like patients who are immunocompromised or diagnosed with cancer, at highest risk of suffering.³

The Great East Japan Earthquake of March 2011, along with the ensuing tsunami and nuclear disaster at Fukushima Daiichi Nuclear Power Station, exemplifies the profound impact such events can have on health care infrastructures.^{4,5} This disaster, also known as the triple disaster of 3/11, highlighted the implications that primarily affect disaster vulnerable populations. Infrastructure damage, evacuation protocols, overcrowded hospitals, and system disturbances impose issues particularly for cancer screening and treatment.¹

Cancer care has emerged as a critical area, susceptible to significant upheaval during catastrophic events.^{4,6,7} Recent investigations, such as those exploring the challenges faced by patients with gynecologic cancer following Hurricanes Irma and Maria in Puerto Rico, or the

impact on cancer care in Nepal after a devastating earthquake, underscore the vulnerable position of individuals battling cancer amidst such crises.^{4,6,7} The scarcity and delay of delivering medicine, such as chemotherapy, especially for those who may need treatment every day poses a fatal risk to many people.⁴ Delays in treatments and screenings have severe consequences on disease remission and survival chances.¹

During the Great East Japan Earthquake, the lives of patients with cancer and their families were irrevocably altered.⁸ The evacuation led to the separation of numerous evacuees from their family members and their well-established community network, exacerbating both physical and psychological distress.^{8,9} Studies have shown that social isolation, particularly affecting the elderly, was a significant factor contributing to patient care delay, suboptimal treatment courses, and adverse medical outcomes.^{8,10} That being acknowledged, it is important to emphasize that the cohesive functioning of families assumes a pivotal role in the recuperation of physical, mental, and economic wellbeing in the aftermath of a disaster.¹¹ Moreover, it contributes substantially to broader societal resilience and sustainability.¹¹

Breast cancer, given its significant disease burden globally and in Japan, is particularly important to consider.¹² However, there is still a notable gap in understanding how the events of 3/11 impacted these patients in Fukushima.¹³

To bridge this gap, qualitative studies are valuable for examining the personal impact of the disaster on breast cancer patients and their families.¹⁴ This study positions itself as a continuation of Kaneda's foundational work, which emphasized the need for qualitative approaches to understand the intricate implications of such catastrophic events.¹⁴ By extending the scope to include family members through additional interviews, this research study seeks to offer a more nuanced and comprehensive understanding of the

multifaceted repercussions, particularly in the realms of treatment continuity, family-patient relationships, and medical access, for local patients with breast cancer in Fukushima, Japan.

Methods

Settings and Participants

The study sites were Minamisoma Municipal General Hospital and Watanabe Hospital in Minamisoma City, 23 km and 25 km north of the Fukushima Daiichi Nuclear Power Station, which experienced a hydrogen explosion during the 2011 triple disaster (Figure 1). Previously, the database was developed for patients with breast cancer who were diagnosed both before the disaster and visited the hospitals from 2006 to 2016.¹³ This secure database included information like the patient's age at medical examination, gender, occupation, home address, and clinical information like diagnosis, stage of breast cancer, subtype, relapse status, breast cancer screening results, medical treatment, date of doctor's visit, and date and cause of death. For patients who had passed away, their family members informed the research staff about their passing. This information was recorded and the research team reached out to the patients who were alive, which led to an initial qualitative study targeting the patients themselves.¹⁴ In this latest work, their family members were reached, following an informed consent process, and a call was scheduled with them when they agreed to join this study. Seven interviews were done via phone call or online video conferencing by Zoom with the family members.

Data Collection

The survey process began with an informational letter sent to family members' addresses, outlining the study's purpose. AO discussed

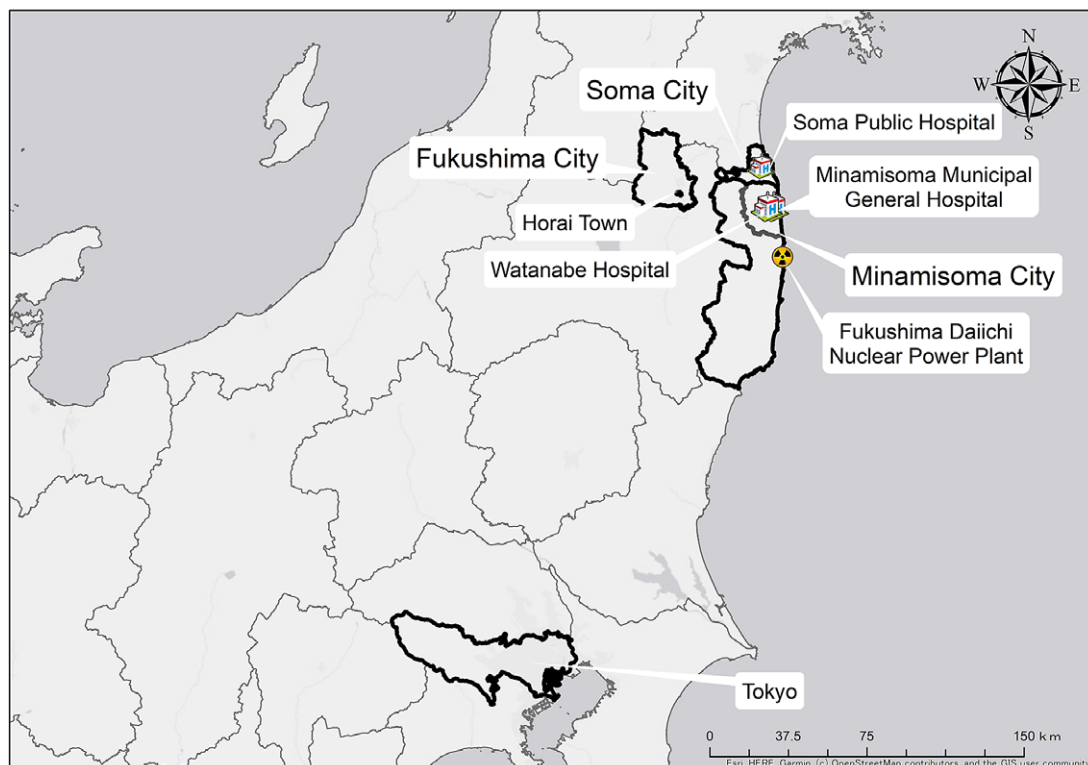


Figure 1 Map of locations mentioned

the study format and obtained consent via phone. Interviews were scheduled, and consent forms were returned via pre-addressed envelopes. Anonymity and confidentiality were assured, and participants were informed of their voluntary participation and right to withdraw. Semi-structured interviews lasting 20 minutes to 1 hour were conducted by AO, PS, and SM, covering topics like living arrangements, occupation, medical experiences, evacuation experiences, and the impact of the disaster on treatment continuity and support. The main questions asked were:

- Were you living with the patient at the time they were diagnosed? What was your occupation at the time? What was the experience of the medical examination like for the patient and for you? How about when they were treated?
- What was your experience like at the time of the 3/11 evacuation? What was the patient's experience like?
- For those diagnosed pre-disaster, what was the general impact of the disaster on the patient's continuity of treatment? Do you think how their disease progressed was related to the earthquake at all?
- What were the difficulties you faced in supporting the patient? How about during the disaster?

Data Analysis

Interviews were transcribed from recorded audio and translated from Japanese to English using DeepL (Linguee, Cologne, Germany). The translated text was reviewed by a Japanese researcher (AO) for clarity. Inductive thematic analysis followed the six-step Braun and Clarke approach, involving data familiarization, initial coding, theme identification, theme review, defining and naming, and result production.¹⁵ AO ensured the accuracy of the summary content with participants, while PS, SM, RY, and CK reviewed transcripts to identify keywords, codes, themes, and subthemes. Taguette, an online qualitative data analysis tool, facilitated the analysis process.

Institutional Review Board

The Institutional Review Board of Minamisoma Municipal General Hospital approved this study (5-8) in October 2023, adhering to the guidelines established by the Ministry of Health, Labor, and

Welfare (MHLW) and the Ministry of Education, Culture, Sports, Science, and Technology (MEXT), Japan.

Code of Ethics

The survey process included an informational letter sent to family members' addresses, outlining the study's purpose. The study format was discussed with each family member and verbal informed consent was obtained via phone call for anonymized participant information to be published in this article. Interviews were scheduled and written informed consent forms were also returned via pre-addressed envelopes. Anonymity and confidentiality were assured, and participants were informed of their voluntary participation and right to withdraw.

Results

Table 1 outlines patient and family member characteristics. The study included 6 breast cancer patients, 4 diagnosed before the disaster and 2 after. Seven family members were interviewed, with one patient's family members interviewed separately. A total of 129 codes were condensed into 3 themes and 16 subthemes, detailed in the text. Table 2 provides a summary of these themes and subthemes.

Theme 1: Family Experience (n=96, 43.8%)

A family member's role in a breast cancer patient's life was multifaceted, involving active caregiving, emotional support, and decision-making. While some families established strong rapport and open communication, others faced challenges due to distance or reserved patient attitudes.

Family member involvement (n=33, 34.4%)

Family members were often involved in the patients' lives in some capacity, especially after their diagnoses. One of the patient's daughters recounted, "Well, I was able to stay home quite a bit, so my father was able to stay home, and so was I, and my husband and children were able to stay with us" (1b). Another family member stated that she "[gave] her [the patient] medicine every day to prevent her dementia from progressing" (3).

Table 1. Characteristics of patients with breast cancer and interviewed family members

Transcript #	Family Member Relationship to Patient	Family Member Age	Patient Age at Consultation	Diagnostic Stage	Subtype	Recurrence	Patient Evacuated
1a*	Husband	–	67	Stage 4	HR+ HER2+	Yes	Yes
1b*	Daughter	52	67	Stage 4	HR+ HER2+	Yes	–
2	Daughter-In-Law	72	87	Stage 2A	HR+ HER2-	No	No
3	Daughter-In-Law	65	77	Stage 1	HR+ HER2-	No	Yes
4	Daughter-In-Law	60	63	Stage 2	HR+ HER2-	No	Yes
5	Husband	81	64	Stage 4	–	Yes	–
6	Wife	67	82	Stage 3C	HR+ HER2+	–	Yes

*1a and 1b were interviews with family members of the same patient

Table 2. Themes and subthemes identified

Themes	N = 219 Total Quotes (% Appeared in Transcript)	Subthemes	N = 219 Total Quotes (% Appeared in Each Theme)
Theme 1. Family Experience	N = 96 (43.8%)	a. Family Member Involvement	N = 33 (34.4%)
		b. Lack of Family Member Involvement	N = 28 (29.2%)
		c. Burden of Caregiving	N = 23 (24.0%)
		d. Family Member and Patient Rapport	N = 12 (12.5%)
Theme 2. Medical Issues	N = 91 (41.6%)	a. Range of Medical Problems	N = 30 (33.0%)
		b. Physical and Mental Deterioration	N = 22 (24.2%)
		c. Course of Medical Problem	N = 16 (17.6%)
		d. Handling of Diagnosis	N = 13 (14.3%)
		e. Role of Aging and Dementia	N = 8 (8.8%)
		f. Communication about Medical Problem	N = 2 (2.2%)
Theme 3. Evacuation and Earthquake	N = 32 (14.6%)	a. Evacuation after Disaster	N = 9 (28.1%)
		b. Post-Evacuation Life Different	N = 7 (21.9%)
		c. Lack of Impact of Earthquake on Health	N = 6 (18.8%)
		d. Confusion about Evacuation	N = 4 (12.5%)
		e. Lack of Resources after Disaster	N = 3 (9.4%)
		f. Issues with Transport	N = 3 (9.4%)

Lack of family member involvement (n=28, 29.2%)

Some family members were not as involved because of distance or work commitments. One family member mentioned he wasn't home very often, given his job as a security guard (1a). Other patients simply did not share their symptoms or diagnosis with family members. A daughter-in-law of one of the patients mentioned, "She [the patient] was not a very detailed person... I felt that she was a little uncomfortable living with me, and I felt that she had some kind of discomfort" (4).

Burden of caregiving (n=23, 24.0%)

Many family members struggled to provide adequate support or serve as a caretaker. One of the patient's daughters-in-law stated, "She [the patient] had a serious head injury a long time ago, so she had to go to the neurosurgeon about once a month... but it was very difficult. It really took about two days to get there" (4). Another patient's daughter had to quit her job to take care of her family members. She said, "I quit to take care of my family. I had to go to various hospitals for breast cancer and other things like that" (1b).

Family member and patient rapport (n=12, 12.5%)

Some family members were able to build strong rapport with the patients and have good communication. The patients would seek advice from their relatives about their health. One of the patients asked her daughter-in-law if she "thought it would be better to have [her] boobs removed" before the surgery (4). Another family member stated, "My mother, you know, whenever there was something strange, she would talk about it. When she was tired, she would go to the doctor and ask for an IV. If she had any questions, she would talk about it, so she never hid anything from me" (3). Some family members discussed the patient's cancer diagnosis collectively within the family, not just one-on-one. For example, one of the patient's wives said, "We were able to talk about it together as a

family, and we were able to talk about things like not prolonging her life" (6).

Theme 2: Medical Issues (n=91, 41.6%)

Beyond breast cancer diagnosis, patients grappled with a range of medical challenges, including dementia, depression, and physical deterioration. Coping mechanisms differed, emphasizing the need for personalized health care strategies. Communication within communities proved crucial as family members took advice and support in navigating complex medical scenarios.

Range of medical problems (n=30, 33.0%)

Many patients had various medical issues, alongside their breast cancer diagnosis. Some illnesses included dementia, acute injuries, arthritis, progressive supranuclear palsy, and depression. One family member noted that, "she never moves, or she doesn't talk much anymore. The way she speaks has also become slower... she gradually became unable to eat or swallow" (4). Some of the patients also developed "various metastases from breast cancer" (5).

Physical and mental deterioration (n=22, 24.2%)

Patients experienced physical and mental deterioration, and some patients felt depressed. One family member said, "He was depressed, so he didn't want anyone to know about it [the cancer diagnosis] ... he also didn't want his children to worry" (1b). Another family member said, "when [the patient] had breast cancer, [she] started to lose [her] energy" (4). It was also difficult for family members to communicate with the patients if they had neurodegenerative diseases. One of the family members said, "In short, their minds are already in completely different directions. So even if I talk to them, they can't understand me. Because their brain is damaged" (1a).

Course of medical problem (n=16, 17.6%)

The patients had varied symptom onset to their diagnosis of breast cancer. It “took about a year” for one of the patients to see a doctor and his symptoms progressed to being unable to “move [his] hand properly” thus eventually having to “undergo irradiation” (1b). Another patient went to a hospital and was “admitted to the Soma Public Hospital in Soma for 20 days” (6).

Handling of diagnosis (n=13, 14.3%)

Each patient handled their diagnosis of breast cancer differently. After receiving her diagnosis, one of the patients “went for regular checkups... and took care of things herself” (3). Some patients suffered from depression after their diagnosis, so they did not want to leave their home or go to work (1b).

Role of aging and dementia (n=8, 8.8%)

Aging and dementia played a challenging role for many patients. One patient “started to fall down a lot” and the family member suspected that “she [the patient] was a little different from before” (4). Other patients had slowed mobility (3).

Communication about medical problem (n=2, 2.2%)

Some family members would try to seek advice from people in their immediate communities on how to support the patient. One of the family members said, “After all, we are here, my friends are here, and my father’s daughters are in Tokyo, so it was rather easy for me to talk to them...and get information about what to do in such a situation” (3). Some family members also advised the patients on how to proceed if they were feeling symptoms. One family member said, “I talked to people around me about various things, and... I told him that this was not good and that he should go to the hospital” (1a).

Theme 3: Evacuation and Earthquake (n=32, 14.6%)

Evacuation decisions lead to changes in living arrangements and daily routines. Some perceived no direct impact of the earthquake on health, while some experienced confusion about evacuation procedures and limited post-disaster resources.

Evacuation after disaster (n=9, 28.1%)

Some patients and family members had evacuated after the triple disaster. One recounted “So we evacuated voluntarily...we evacuated to a place called Horai in Fukushima City. After that, my mother evacuated alone to my own sister’s place in Tokyo” (3). Another family member had difficulties finding an appropriate place to stay after the disaster: “The town hall introduced me to various hot spring resorts and other places, or rather, gave me information about them...The hot springs were a bit too mountainous, and it was very difficult to get there, so we went to a hotel a bit further up the mountain, where there were more people, and we were taken care of there again” (4).

Post-evacuation life different (n=7, 21.9%)

Many of the family members and patients felt that their lives had changed after the disaster. One of the patients had a business and her family member said, “Until then, our employees were always around, but since they were evacuated from place to place, it was difficult for us to reopen the restaurant” (3). Some family members also felt that the patients were drastically different people post-earthquake. For example, one person said, “Compared to the time

before the breast cancer surgery or before the earthquake, she has gradually become a different person” (4).

Lack of impact of earthquake on health (n=6, 18.8%)

Meanwhile, some family members and patients felt like the earthquake had no impact on the patient’s health. One person said, “[She] got sick regardless of the earthquake or anything like that” (1a). Another family member said, “As a family, we don’t really feel that the earthquake had a huge impact on us or anything” (4).

Confusion about evacuation (n=4, 12.5%)

Some were confused after the earthquake about what to do or if they needed to evacuate. For example, one family member said, “Immediately after the earthquake, I think I was at home for a few days. I didn’t know what was going on at all. I was not sure how long it would last after the nuclear power plant accident” (4). Another family member said, “We left Haramachi late, and, you know, we couldn’t even fill up the gas tank. That kind of thing happened. Where should we evacuate to? It was a little bit like that. So I asked everyone to go ahead of me” (6).

Lack of resources after disaster (n=3, 9.4%)

After the disaster, there were not many medical resources available in affected areas and “all the doctors, like the big city hospitals, were closed” (6). Another person said, “There are not many people here at the hospital” (1b), so this served to be a barrier for patients who needed care at the time of the disaster.

Issues with transport (n=3, 9.4%)

Some family members and patients also struggled with transportation and traveling to doctor’s appointments or procedures. One family member said, “I was in the hospital for two weeks, and then I was told to come back one month later, on March 15... I was not able to go [back] to the hospital because of the earthquake” (6). Another family member said, “After the earthquake. At that time, the medical care system here was not normal. Because of that, I don’t think he went to the medical checkups or anything after that” (3).

Discussion

This study explored the profound impact of the Great East Japan Earthquake on breast cancer patients and their families in Fukushima, Japan, focusing on care continuity, family dynamics, evacuation, and medical access. Through semi-interviews with family members, three main themes emerged: (a) Family Experience, highlighting caregiving dynamics, (b) Medical Issues, revealing health challenges, and (c) Evacuation and Earthquake, detailing post-disaster life changes.

In investigating the impact of 3/11 on patients with breast cancer and their families, this study employed a comprehensive approach, incorporating family members as proxies. While patient interviews remained crucial, this study primarily relied on insights gleaned from family members, recognizing their potentially critical roles in patient care. Supported by Kaneda et al., family members emerged as valuable contributors to disaster research, offering nuanced perspectives often overlooked in patient-focused studies.¹⁴ A reliability study conducted by Schless and Mendels on a life events questionnaire emphasized the important contributions of “significant others” (family members, partners, or friends), adding approximately 29% of new information, specifically offering more detailed insights into the cancer patients’ health

status.¹⁶ This finding highlighted the unique insights provided by family members, serving as witnesses to the physical and emotional toll of disasters on patients.¹⁷ Additionally, Sandén *et al.* underscored the varied influence of cancer on individuals and their families, highlighting that the disease manifests differently for each patient and their family members.¹⁸ Acknowledging cancer as a relational disease,¹⁸ this study recognized the complex patient-family dynamics, investigating a comprehensive exploration of the intricate implications for individuals and their families affected by breast cancer and the disaster. The exploration of Family Experience, the first theme, revealed critical insights into the dynamics within patients' families affected by the Great East Japan Earthquake. Family Member Involvement emerged as a predominant aspect, with 33 instances in the text (34.4%), highlighting the active roles played by family members in the care process. This importance resonates with existing literature emphasizing the multifaceted nature of caregiving, including providing transport to medical care establishments and offering emotional support.^{19,20} Additionally, these findings highlighted the emotional Burden of Caregiving (24.0%), aligning with studies on the challenges faced by family caregivers in the context of cancer.¹⁹ The intricate dynamic of Family Member and Patient Rapport (12.5%) was integral to the experience, reflecting the emotional support provided by family members during times of uncertainty and fear.²⁰ However, this study also revealed instances of Lack of Family Member Involvement (29.2%), shedding light on potential challenges and social isolation. This aligned with the broader challenge faced by cancer patients in the aftermath of disasters, contributing to delays in medical treatments.⁸ Notably, with 38% of Japanese households being one-person households in 2020, the role of families became crucial, especially when older individuals became frail.^{21–23} The multifaceted nature of caregiving, encompassing emotional support and alterations in family roles adds depth to this study, emphasizing the need for flexible family structures to navigate the challenges imposed by cancer and disasters.^{19,20} Moreover, the impact of the disaster and subsequent evacuation into unfamiliar environments contributed to psychological distress, adding an additional layer of complexity to the experiences of families in the aftermath of the disaster.²⁴ Medical Issues, the second theme, intricately explored the pivotal role of family members in supporting patients grappling with various medical challenges. Notably, the prevalence of Range of Medical Problems (33.0%) emphasized the effect of health issues beyond cancer, including dementia, acute injuries, arthritis, progressive supranuclear palsy, and depression. These findings agreed with Kaneda *et al.*'s emphasis on the nuanced nature of patient care.¹⁴ The impact of Physical and Mental Deterioration (24.2%) shed light on family members' support for patients navigating the toll of the disaster on their overall well-being, with instances where patients experienced depression and loss of energy. Research suggests that depression and anxiety could impede cancer treatment, recovery, and overall quality of life.²⁵ Additionally, chronic illnesses, exacerbated by disaster conditions such as lack of food, clean water, extremes of temperature, stress, injury, and exposure to infection, further amplify the complexity of health care challenges amidst disaster situations.¹⁷ Conversely, elevated family cohesion has been shown to mitigate anxiety and support individuals' physical and mental health specifically in times of disasters.¹¹ This study highlighted the need for tailored strategies in health care following disasters. Evacuation and Earthquake, the third theme, uncovered the transformative impact of disaster-related decisions on patients and their families, some of which

likely were universal experiences of all evacuees. Evacuation after Disaster (28.1%) prompted significant relocations, reflecting the challenges faced by those voluntarily evacuating to places like Fukushima City and Tokyo. Post-Evacuation Life Different (21.9%) represented the lasting changes experienced by families, from altered living environments to challenges reopening businesses, exemplified by one patient's struggle with a restaurant. Notably, Lack of Impact of Earthquake on Health (18.8%) portrayed varying perceptions, with some asserting no significant health effects from the earthquake. The intricacies of evacuation procedures created Confusion about Evacuation (12.5%), as some were unsure when or where to evacuate, highlighting the complexities faced by families. Lack of Resources after Disaster (9.4%) amplified difficulties in accessing health care, as city hospitals closed, leaving patients with limited medical resources. Issues with Transport (9.4%) compounded the challenges, hindering patients from attending crucial doctor's appointments or procedures due to disrupted medical care systems and transportation issues. These findings aligned with Mokdad *et al.*'s paper, emphasizing the critical role of access to routine health care, particularly during post-disaster evacuations.¹⁷ Additionally, Kaneda *et al.* highlighted the challenges in health care access, detailing how patients hospitalized during disasters faced obstacles due to the destruction of medical facilities and limited amenities, further highlighting the importance of maintaining health care services during such crises.¹⁴

Limitations

It is important to note that this study included several limitations. Firstly, the sample size was relatively small, with six patients and seven family members, potentially limiting the generalizability of the findings. Additionally, the reliance on retrospective interviews with family members may introduce recall bias, as memories of events can distort over time. Moreover, conducting interviews years after the disaster may further affect the accuracy of recall and understanding of health care challenges post-disaster. Furthermore, solely interviewing family members may provide an incomplete picture of the individual experiences of breast cancer patients. Lastly, focusing solely on the Fukushima region may restrict the applicability of the findings to other disaster-affected areas.

Conclusions

This study contributes to the evolving discourse on the aftermath of the 2011 triple disaster on patients with breast cancer in Fukushima, Japan. By incorporating family perspectives and delving into the intricate medical challenges and evacuation experiences patients experienced, this study offers a nuanced understanding of the multifaceted repercussions of large-scale disasters on vulnerable populations. The insights gained from this study can inform future disaster preparedness and response strategies, emphasizing the importance of tailored health care, comprehensive family support, and efficient evacuation protocols for individuals battling not only breast cancer, but cancer in general in disaster-prone regions.

Institutional Review Board. The Institutional Review Board of Minamisoma Municipal General Hospital approved this study (5-8) in October 2023, adhering to the guidelines established by the Ministry of Health, Labor, and Welfare (MHLW) and the Ministry of Education, Culture, Sports, Science, and Technology (MEXT), Japan.

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