災害時における疾患や障がいをもつ人の体験と支援
― 東日本大震災に焦点をあてて ―

Experience and Support of People with Chronic Illness and Disability during the Great East Japan Earthquake

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I. Introduction

1. Research Motive and Background

The Great East Japan Earthquake, that occurred on March 11th, 2011, caused unprecedented damages in the disaster areas. Especially, the difficult situations of people with chronic illness and disability, known as 'the disaster vulnerabilities', were extensively quoted in the mass media, and various problems in disaster support have become apparent. Researchers who specializes in the adult nursing science had taught the support that should be given for people with chronic illness and disability, however they didn't cover the disaster nursing for such people sufficiently. Reviewing the textbooks of adult nursing science, the reference to disaster care to people with chronic illness and disability is hardly seen thus further exploration in this area should be made in the future.

2. Purpose of the Research

The purpose is clarify the disaster experience of people with chronic illness and disability in the Great East Japan Earthquake and the support provided for such people at the time of disaster.

3. Significance of the Research

Clarifying actual problems and difficulties that people with chronic illness and disability experienced in the disaster situation can provide a clue in examining ideal disaster support. The results of this research should also promote the inclusion of 'disaster support for people with chronic illness and disability' into the textbook of adult nursing science and should be fully utilized for the education given for nursing students.

II. Methods

1. Research Outline

This research intended to grasp experience of people with chronic illness and disability, mainly focusing on chronic illness in the Great East Japan Earthquake, and the

support provided for them by utilizing the database of newspaper articles. Also, it aimed to summarize the necessary information for the support from the past research results, the guidelines or proposals on disaster support that had been presented by the related academic societies, or the information provided on the webpage for people with various diseases during disasters.

2. Methods of the Research

(1) Searching of newspaper articles

Utilizing the retrieval database 'NIKKEI TELECON 21', the searching was targeted at five national newspapers (Asahi Shimbun, Sankei Shimbun, Nihon Keizai Shimbun, Mainichi Shimbun, Yomiuri Shimbun), six local newspapers in disaster areas (Too Nippo, Iwate Nippo, Kahoku Shimpo, Akita Sakigake Shimpo, Yamagata Shimbun, Fukushima Minpo), and the comprehensive medical information magazine 'Nikkei Medical'. By combining the term 'earthquake' with each core keyword for chronic illness such as 'hypertension', 'diabetes' 'dialysis' 'respiratory disease' 'intractable disease' 'heart failure' 'cerebral infarction', articles that include any of these keywords in its headline or texts were searched. The scope of searching was that published for one year since Mar 11th, 2011, and the qualitative analysis was made for descriptions that illustrate the disaster experiences of people with chronic illness and disability and the support provided for them at that time.

(2) Searching of references

The searching of references was made with the JDream III's MEDLINE + JMEDPlus, a database for science technology academic dissertation. A keyword 'nursing' was added to the keywords used for the searching of newspaper articles such as 'hypertension', 'diabetes' 'dialysis' 'respiratory disease' 'intractable disease' 'cardiac failure' 'cerebral infarction' and combining with 'earthquake', the reference that were published from 1995 to 2013 were searched and examined to see if there were any changes in the number of references or the contents after 2011, when the Great East Japan Earthquake occurred.

(3) Searching of information offered by academic societies or public institutions

The searching was made for guidelines or proposals on disaster support that were provided by academic societies or public institutions whose activities are related to the keywords used for the newspaper article searching, or webpage information provided for people with chronic illness and disability at the time of disaster, and summarized the contents that are required for nursing support.

3. Research Period

From December 2011 to December 2013

4. Ethical Considerations

It is important to accumulate experiences in the past disasters and knowledge about supports and activities implemented on that occasions in order to take appropriate responses to future disasters. For that, conducting interview survey with disaster victims is vitally important, however the victims seem to carry a tremendous burden from the similar researches or surveys on the Great East Japan Earthquake. Therefore, this research chose not to conduct direct interviews with the victims but to collect data from newspapers or webpage of academic societies and public institutions about the disaster experience of people with chronic illness and the support provided for them. We gave sufficient attention like removing the real name of patients or supporters if they are included in the collected articles or information, so that the person cannot be identified. The references were quoted according to the copyright law, the personal information protection law, or the privacy policy. Also, this research was implemented upon obtaining an approval from Research Ethics Committee at the Japanese Red Cross College of Nursing (Approval No. 2011-81).

III. Results

1. Number of retrieved newspaper articles

The searching of newspaper articles was made by combining the term ‘earthquake’ and

seven keywords of diseases (respiratory disease, diabetes, dialysis, hypertension, intractable disease, cerebral infarction, heart failure), and 1,780 articles were retrieved in total. In details, both respiratory disease and diabetes had over 400 articles, 412 for respiratory disease and 406 for diabetes respectively, and 375 articles for dialysis, 248 for hypertension, 165 for intractable disease, 111 for cerebral infarction, and 63 for heart failure (Table 1). There were lots of descriptions about the experience of people with chronic illness and disability.

Table 1 Number of retrieved newspaper articles

Keyword	Number of retrieved articles
earthquake disaster & respiratory	412
earthquake disaster & diabetes	406
earthquake disaster & dialysis	375
earthquake disaster & hypertension	248
earthquake disaster & intractable disease	165
earthquake disaster & cerebral infarction	111
earthquake disaster & heart failure	63
Total	1780

2. Changes of references

1,972 references in Japanese were retrieved in total by combining the term 'earthquake' and disease names or disability, in order of respiratory, dialysis, diabetes, hypertension, intractable disease, heart failure, and cerebral infarction (Table 2). Since major earthquakes such as the Great Hanshin-Awaji earthquake and Niigata Prefecture Chuetsu earthquake had occurred for fifteen years, 1995 - 2010, many references related to these earthquakes were found. For 2011-2013, two years from the Great East Japan Earthquake, the number of references increased 3.5 times and most of them were about the Great East Japan Earthquake. Especially, references about

heart failure sharply increased 8 times, followed by respiratory disease of 4.7 times and hypertension and cerebral infarction of 3.8 times.

Table 2　Number of retrieved references by keyword and period (Japanese)

Keywords	1995-2010	2011-2013	Total(case)
earthquake disaster & respiratory (or respiration)	134	633	767
earthquake disaster & dialysis	183	414	597
earthquake disaster & diabetes	50	184	234
earthquake disaster & hypertension	36	138	174
earthquake disaster & intractable disease	18	65	83
earthquake disaster & cardiac failure	8	65	73
earthquake disaster & cerebral infarction	9	35	44
Total(case)	438	1534	1972

(ascending order)

For English references, 168 were retrieved in total, in order of hypertension, respiratory, dialysis, diabetes, heart failure, cerebral infarction, and intractable disease (Table 3). What increased after 2011 was only heart failure.

Most references on the Great East Japan Earthquake published after 2011 were meeting minutes, regarding the fact-finding survey of diseases, factor analysis for symptomatic worsening, or the mechanism of the development of hypertension after the earthquake, known for 'disaster hypertension'. Also, there were reports that oral medicines or medicine notebooks were washed away in tsunami, they had difficulties

in receiving necessary medicines as the roads were shut off or in securing necessary power for medical equipments due to lack of power.

References about respiratory diseases included descriptions on respiratory tract infection and allergic respiratory difficulties in addition to patients who uses artificial ventilator for their illness or disability. Therefore, there were references for preventing the development of new illness after the disaster.

Table 3　Keywords and searched number by term (English)

Keywords	1995-2010	2011-2013	Total
earthquake disaster & hypertension	36	23	59
earthquake disaster & respiratory (or respiration)	27	21	48
earthquake disaster & dialysis(or hemodialysis, or peritoneal dialysis)	30	6	36
earthquake disaster & diabetes	9	3	12
earthquake disaster & heart failure	2	7	9
earthquake disaster & cerebral infarction	2	1	3
earthquake disaster & intractable disease	1	0	1
total	107	61	168

(ascending order)

3. Contact of academic societies (webpage, etc.)

Immediately after the earthquake, various academic societies whose activities are related to chronic illness started to provide information and opened counseling window via webpage in various forms. This research started from around 10 month after the Great East Japan Earthquake and had limitation in collecting the past data as the webpage had already many updates. Based on the limitations, Table 4 shows the number of consulting service or proposals in each area such as hypertension, diabetes, respiratory disease, cerebral infarction, heart failure, dialysis, or intractable disease.

There was correlation in information provision about hypertension and heart failure. Also, since a new problem called 'disaster hypertension' was pointed out and newly-development or symptom worsening of heart failure or cerebral infarction that are related to hypertension were seen after the earthquake, suggestions were made as cardiovascular disease measures.

For diabetes or dialysis for which medical treatment such as insulin is inevitable, the main academic society summarized information, delivered them, and implemented a cooperative system as the entire medical team. As the respiratory diseases range from various respiratory diseases, infectious diseases, pulmonary embolism to the use of artificial ventilator, the related academic societies or organizations were responsible for providing information on warnings or prevention. For intractable disease, the Japan Patient Association, collaborating with Ministry of Health, Labour and Welfare, requested the support to the ruling party and related industries.

As the cross-sectional form for all seven areas, the nursing professionals in chronic illness, who have sub-specialty in various areas, opened the counseling service on the Japan Society for Chronic Illness and Conditions Nursing, and Japan Society of Disaster Nursing or the nursing colleges which are engaged in disaster nursing is delivering disaster nursing information.

As above, in terms of the support in disaster areas, medical professionals proactively encouraged the public by providing questions & answers on the webpage of each academic society, developing a cooperative assistance between medical persons, and submitting proposals from the professional groups to the government.

Table 4　Contact of academic societies (webpage, etc.)

	Contact of Related Academic Societies	Suggestions/ Request	Nursing
earthquake disaster &respiratory (or respiration)	8	0	
earthquake disaster & dialysis (or hemodialysis, or peritoneal dialysis)	1	1	
earthquake disaster & disabetes	1	2	
earthquake disaster & hypertension	3	2	3
earthquake disaster & intractable disease	1	1	
earthquake disaster &heart failure	2	3	
earthquake disaster & cerebral infarction	1	1	

4. Experiences of people with chronic illness and disability

In the Great East Japan Earthquake, the damages caused by earthquake as well as tsunami and the subsequent power blackout and so on had a great impact on the experiences of people with chronic illness and disability.

There were cases that people who cannot evacuate by themselves with intractable disease or paralysis were washed away in tsunami as they couldn't receive evacuation support immediately after the disaster. Although such people were designated as those who need the disaster support, this disaster caused damages in unexpected scale and people who were supposed to provide support were also involved in the disaster, thus the support to those people were not appropriately delivered.

People who need dialysis for their kidney disease or medical equipments such as artificial ventilator for their intractable disease or respiratory disease reported the blackout-related experience that they couldn't secure necessary power for their equipments, rushed around to secure power, or had almost dead experience.

Diabetes patients reported that oral medicines, insulin injection, or medicine notebook were washed away in tsunami which was characteristic event in the Great East Japan Earthquake, and they were too panicked to bring them out when they rushed out from home, therefore they had difficulty in continuing treatment or controlling blood sugar level.

As for the difficulties in the shelter life, diabetes patients reported that they felt the fear of death as the ill-balanced food life caused worsening of their illness. Also, there were cases that people with hypertension or heart failure experienced aggravation of their symptoms or in some cases it resulted in fatal death in the severe environment such as frequent high-salinity retort foods, cold regions, and lack of exercise.

People with cerebral infarction similarly pointed out the severe environment, the decline of ADL without the self-help devices, or worsening of illness under stress. People who need dialysis reported the cases that they were taken to the emergency hospital in the night to receive the emergent dialysis treatment as the necessary food control (protein, salt, potassium restricted diet) could not be implemented in the shelter.

5. Experiences of people who developed illness after the earthquake

In the Great East Japan Earthquake, some people developed illness during their life as evacuees.

In the prolonged life at the evacuation center after the earthquake, lots of people experienced disorder of lifestyle habits such as excessive intake of salt or calorie from distributed foods, stress, fatigue, physical inactivity, deficiency of water in the group living. Besides, environmental factors such as shortage of medicines or flaws of treatment circumstances caused development of cerebral infarction, hypertension, heart failure, etc.

The Great East Japan Earthquake had more people who developed heart failure compared to those in Kobe Earthquake or Niigata Chuetsu Earthquake. It is believed that this was related to the fact that most disaster victims of this earthquake were the elderly who were more vulnerable to the change of life and treatment environment. In addition, the increase of pregnant hypertension syndrome or the case of medical person who had provided utmost support to victims developed cerebral infarction. Also, it was suggested that mental stress like fears to ongoing aftershocks or anxiety to unclear future prospect can trigger the development or aggravation of cardiovascular diseases such as cerebral infarction or heart failure.

As for the development of respiratory illness after the earthquake, there were cases where respiratory infectious disease such as flu have developed due to underlying factors such as group living in the evacuation centers, severe cold weather, environment where hand wash or gurgle cannot be done sufficiently. Also, pulmonary embolism was reported due to limited drinking water as the bathroom of the shelter was at distant locations, long-time cramped postures in cars or evacuation centers, or bruises during evacuation. However, drawing lessons from past earthquakes, preventive actions for respiratory tract infection or pulmonary embolism were taken from the early stage such as repetitive warnings on newspapers about cares for infants

and the elderly.

The aspiration pneumonia of the elderly were also seen and factors such as insufficient mouth care from shortage of water, chewing difficulty caused by the loss of artificial dentition in the tsunami, or aspiration unnoticed by people around them were cited.
It was reported that a child developed allergy as they ate normal foods from hunger as allergy-safe foods could not be easily achieved.

Further, future health problems of people who were engaged in the reconstruction supports were pointed out such as effects of dust (asbestos) caused by removal of debris or internal exposure of people engaged in the post-cleaning of nuclear accident due to aspiration of radioactive materials.

6. Supports for people with chronic illness and disability

(1) Supports in the disaster areas

Since the lifeline was disrupted and it took so long to recover them, persons who need medical equipments or caretaker were placed in a chaotic situation. For person under dialysis treatment and their family, the disaster information network had been established based on the experience of The Great Hanshin-Awaji earthquake, and they were collectively moved to a distant place to receive appropriate treatment at a relatively early stage. On the other hand, the evacuation support were not reached out to people who need artificial ventilator for intractable disease or respiratory disease as caretaker also became victims and communication means were all disconnected.

Also, observation by experts or residents, traveling clinic by medical professions who were dispatched from various places, or mental care were systematically implemented for people with hypertension, cerebral infarction, or diabetes, etc.
Supports such as careful hearing about background or disease history of each person, self-managing instruction with distributed medicines, early detection of basic illness or complications or preventive intervention, instructions on hygiene situation, continuous

psychological care by the same person were reported, which significantly supported persons with chronic illness.

(2) Supports through information communication

As a preventive support for illness or disability caused by prolonged life in evacuation center, the enlightenment information on prevention or early detection associated with hypertension, cerebral infarction, venous thrombus, or respiratory tract infection were continuously delivered through local papers in disaster areas.

Also, medical professionals had engaged in support activity while sharing information through earthquake-related questions and answers on webpage of various academic societies. Further, medical professionals have taken actions to disclose information from their own professional positions, for example professional groups such as academic society had submitted proposals to the government.

IV. Discussion

1. Supports for people with chronic illness or disability and their family members

In the Great East Japan Earthquake, earthquake and the subsequent tsunami and loss of power had significant impacts on the lives of people with chronic illness and disability. When they lose their medicine under such disaster situation, it is necessary to instruct about where people with chronic illness and disability and their family members can get medicine.

Also, considering the fact that the occurrence rate of pressure sore had increased as the electric bed became useless due to loss of power, it is important to provide support to people with chronic illness and disability and their family members from ordinary times so that they can learn multiple applicable skills that can substitute electric equipments in case they became useless. Although 'self-care' is defined as caring oneself (Orem, 2001/2005), we view that providing visionary supports that allows people with chronic illness and disability to improve their own skills so that they can self-care at an ordinary times as well as at disaster times.

It became obvious that illness and disability can be newly developed due to the poor living environment or excessive stress after the earthquake. In the Great East Japan Earthquake, information on prevention of hypertension or cerebral infarction was provided on newspaper or from various academic societies. For the future disaster too, it is inevitable to deliver information to the general public from the viewpoint of preventing new illness or disability.

2. Establishment of the evacuation center

Since the environment where barrier-free or self-help devices were not available caused the decline of ADL or resulted in the aggravation of illness or disability, we need to examine the promotion of barrier-free evacuation center or the installment of self-help devices. As for the nutrition in a time of disaster, Yamamoto (2011) points that 'the ill-balanced nutrition and the excessive intake of salt under the disaster situation are always pointed out' (p.424). The results in this research suggested that the increase of salt intake and ill-balanced nutrition has a serious risk for people with chronic illness and disability, aggravating their medical condition and developing complications, or causing a new chronic illness. In order to avoid such serious risk, we need to consider the stock of low-salinity food or with appropriate calories and nutrition for each disease. Since breathing disorder caused by allergy was seen in the Great East Japan Earthquake, it is necessary to make it visible so that anyone can easily get the idea about what type of allergy materials are included in the stocked foods.

3. Network among medical professions and access to information during disasters

In the Great East Japan Earthquake, supports between medical professionals were given through setting the questions & answers page on the webpage of various academic societies. For future disasters, we need to examine what type of information the academic societies can deliver at a time of disaster by taking advantage of their own specialty. At the same time, we medical workers need to acquire knowledge from

ordinary times about where necessary information can be obtained.

4. Teaching to nursing students

For nursing students, it is essential to provide the course in which they can learn from actual disaster experiences of people with chronic illness and disability. Ozaki (2011) made it clear that he had surveyed experiences of nursing students who had been involved in the Great East Japan Earthquake and they requested that the 'disaster preparation' or 'behavior as disaster victims' should be included in the course contents (p.47). As such, it will be important to offer the course that makes nursing students realize that disaster could happen to themselves and encourages them to get prepared for disasters. In addition, learning beforehand in the course about 'experiences of people with chronic illness or disability, like what was achieved in this research, will provide students a clue in examining what support would be available for people with chronic illness and disability, allowing them to make preparation by themselves for disaster.

We want to change the course contents so that nursing students would be encouraged to get prepared to protect themselves and to make creative efforts to provide support that allows people with chronic illness and disability to get prepared for disasters as well. For example, the adult nursing science has the instruction time about the support to people with chronic illness or disability. To start with, we want to include the 'disaster experiences of people with chronic illness and disability' or 'teaching of skills that are applicable in the disaster to patients or their family members from ordinary times into the course.

V. Conclusions

1. It is essential to instruct skills that are applicable at the time of disaster to people with chronic illness and disability and their family members from ordinary times.
2. It is necessary to establish a disaster stock system or shelters based on the needs of people with chronic illness and disability such as the barrier-free evacuation

center or the food stock of low salinity foods.

3. It is important to build a network between medical professionals and to be prepared for the disaster from ordinary times. In case of disaster, proactive delivery of information is needed to prevent worsening of illness or disability or newly-development of illness or disability.
4. It is necessary to adopt disaster experiences of people with chronic illness or disability into the course curriculum or the texts intended for nursing students, and spread the knowledge to people who will take responsibility for future nursing.

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This project is the Supported Program for the Strategic Research Foundation at Private Universities of Ministry of Education, Culture, Sports, Science and Technology.