

Development of Disaster Pamphlets Based on Health Needs of Patients with Chronic Illnesses

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Abbreviations:

NTT = Nippon Telegraph and Telephone Corporation
PTSD = post-traumatic stress disorder
PTSS-10 = Post Traumatic Stress Symptom
10

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Abstract

The aim of this research was to develop a pamphlet that would enable patients with diabetes, rheumatic diseases, chronic respiratory disease, and dialysis treatment to be aware of changes in their physical conditions at an early stage of a disaster, cope with these changes, maintain self-care measures, and recover their health.

Illness-specific pamphlets were produced based on disaster-related literature, news articles, surveys of victims of the Great Hanshin-Awaji Earthquake Disaster and Typhoon Tokage, and other sources.

Each pamphlet consisted of seven sections—each section includes items common to all illnesses as well as items specific to each illness. The first section, “Physical Self-Care”, contains a checklist of 18 common physical symptoms as well as symptoms specific to each illness, and goes on to explain what the symptoms may indicate and what should be done about them. The main aim of the “Changes in Mental Health Conditions” section is to detect post-traumatic stress disorder (PTSD) at an early stage. The section “Preventing the Deterioration of Chronic Illnesses” is designed to prevent the worsening of each illness through the provision of information on cold prevention, adjustment to the living environment, and ways of coping with stress. In the sections, “Medication Control” and “Importance of Having Medical Examinations”, spaces are provided to list medications currently being used and details of the hospital address, in order to ensure the continued use of medications. The section, “Preparing for Evacuations” gives a list of everyday items and medical items needed to be prepared for a disaster. Finally, the “Methods of Contact in an Emergency” section provides details of how to use the voicemail service. The following content-specific to each illness also was explained in detail: (1) for diabetes, complications arising from the deterioration of the illness, attention to nutrition, and insulin management; (2) for rheumatic diseases, a checklist of factors indicating the worsening of the illness and methods of coping with stress; (3) for chronic respiratory disease, prevention of respiratory infections and management of supplemental oxygen; and (4) for patients requiring dialysis, conditions of dialysis (such as dry weight, dialyzer, number of dialysis treatments, and dialysis hours) and what to do if a disaster occurs during dialysis.

It is expected that these pamphlets will be useful to patients with chronic illnesses, and will be used to prepare for disasters, thereby helping the patients cope with the unusual situation that during a disaster and recover as soon as possible.

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Introduction

In Japan, the Great Hanshin-Awaji Earthquake of 1995 made people aware of the necessity of being able to cope with disasters, and led to discussions of more concrete measures for this purpose. Between two weeks and three months after the Great Hanshin-Awaji Earthquake, medical institutions resumed their functions little by little, but first-aid stations lacked sufficient examination facilities and medical supplies to be able to cope adequately with chronic illnesses. In addition, people living in temporary housing found that they were too busy to pay sufficient attention to their illness, or that the way they coped with their chronic illness was affected and altered by changes in their nutritional habits and living environment, or due to the fact that the hospital was far away and difficult to access. The effects of the earthquake on patients with chronic illnesses were seen not only in the stoppage of medications or the stream of patients whose colds had deteriorated to pneumonia due to poor living conditions, but also the existence of a chronic illness itself proved to be a major risk factor in the emergence of psychosomatic disorders, such as insomnia and fatigue.¹⁻³ In terms of disaster nursing support, the above factors not only suggest the need for better physical and psychological mental care, but also the importance of self-management by individual patients. There was a necessity for the development of pamphlets that could be used before an event to nurture the ability of patients with chronic illnesses to cope with and recover from a disaster independently. Therefore, the aim of this project was to develop pamphlets for patients with chronic illnesses to use to prepare for a disaster, so that they would be able to maintain self-care and recover their health against an unexpected event.

Methods

The first pamphlets were for patients with diabetes, rheumatic diseases, and/or chronic respiratory disease, and these were followed by a fourth pamphlet for use by those receiving dialysis. The reasons for choosing these particular illnesses as representative of patients with chronic illnesses were: (1) diabetes is difficult to control in situations of stress and departure from normal routine; (2) rheumatic disease, while not life-threatening, requires preparation and support due to the enormous effect it has on one's lifestyle as a result of the lack of freedom in movement; and (3) chronic respiratory disease is accompanied by the danger of respiratory infection.⁴ The pamphlet for patients on dialysis was added later, in view of the fact that a large proportion of dialysis patients are diabetic, in order to highlight the importance of consideration of dealing with dialysis patients during a disaster.⁵

Based on literature on disaster preparedness for diabetic patients⁶ concerning the Great Hanshin-Awaji Earthquake of 1995,⁷⁻¹⁴ and results of a semi-structured interview survey investigating the health needs of victims of this disaster suffering from one or more of the three chronic illnesses, the draft of the pamphlets was completed. The draft was revised by a team of 15 members, using the literature related to the 2004 Mid-Niigata Prefecture Earthquake, where deep venous thromboembolism became an issue,¹⁵ and a

semi-structured interview survey of the specific care needs of chronic respiratory disease patients who were victims of flooding after Typhoon Tokage in 2004.¹⁶ This process resulted in the publication of the current pamphlet. The pamphlets are available in Japanese and English, with the English version especially aimed at foreign residents in Japan. A summary version is available in Chinese. These pamphlets also can be downloaded from the Internet, making them available whenever necessary (<http://www.coe-cnas.jp/english/index.html>). Copies of the pamphlets were printed and distributed to elderly people, who may be less likely to use the Internet. Pamphlets also were distributed to victims and on-site volunteer staff after the Niigata Prefecture Chuetsu-oki Earthquake in 2007, and the Noto Hanto Earthquake in 2007. The various surveys conducted in the process of developing the pamphlets were approved by the Research Ethics Committee of College of Nursing Art and Science, University of Hyogo.

Results

The above process resulted in the completion of the *Overcoming Disasters* pamphlets, which consist of the following seven sections: "Physical Self-Care", "Changes in Mental Health Conditions", "Preventing the Deterioration of Specified Chronic Illnesses", "Medication Control", "Importance of Having Medical Examinations", "Preparing for Evacuations", and "Methods of Contact in an Emergency".

Sections of the "Overcoming Disasters" Pamphlets

Physical Self-Care—It has been widely reported that many patients experience some form of health problems in the wake of disaster, due to factors such as not being able to see their doctor or lapses in medication.⁷⁻¹⁷ The effects on patients with chronic illnesses are particularly long-term, as evidenced after the Great Hanshin-Awaji Earthquake, when there was a stream of patients developing pneumonia after deterioration in their condition due to the discontinuation of medication or the experience of poor living conditions.¹⁻³ Furthermore, it seems that the existence of a chronic illness is a major risk factor for developing physical and mental symptoms, with many patients suffering psychosomatic conditions such as insomnia and/or easily becoming fatigued.^{1-3,18} Based on this research, a checklist of "physical disorders" that could be recognized at an early stage by the victims of a disaster was created. The 18 common items, which were adapted and revised partially from the literature regarding disaster symptoms,⁷ include symptoms such as "stomachache", "stiff shoulders", and "tire easily and feel weary" (Table 1). These are supplemented by items specific to each illness (Table 2). The items are designed in a format that is simple for patients to understand and check. Both of the lists are designed to be used repeatedly from immediately after the precipitating event, with the number of items checked offering an easy visual indication of the level of physical problems being experienced. The list is followed by detailed explanations of the four categories of physical disorders that may be signaled by specific groups of checklist symptoms: (1) stress-related problems; (2) problems caused by overwork; (3) problems that

1. Stomach ache
2. Stiff shoulders
3. Headache or heavy-headedness
4. Poor appetite
5. Tire easily and feel weary
6. Thumping heart
7. Diarrhea or constipation
8. Shortness of breath or trouble breathing
9. Often catch a cold
10. Fever
11. Nausea or vomiting
12. Joint pain
13. Low back pain
14. Trembling hands/feet or numbness in hands/legs
15. Dizziness
16. Hot flushes or ringing in ears
17. Swollen hands and feet
18. Canker sores

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Table 1—Checklist of general physical condition

may signal illness such as infections; and (4) problems that may indicate deterioration in each specific chronic illness. An example of the content of explanations is “If you marked (3) headache or heavy-headedness, (15) dizziness and/or (16) hot flushes or ringing in ears, please measure your blood pressure, as it may be high. If you have high blood pressure, you should try to reduce your salt intake and take measures to deal with stress”. In this way, the aim is to make patients aware of their own physical condition, understand what is happening to their bodies, and propose ways of coping with the problems.

Changes in Mental Health Conditions—One paramount lesson of the Great Hanshin-Awaji Earthquake Disaster for the medical field was the recognition of the importance of coping with mental health problems. Therefore, the Post-Traumatic Stress Symptom 10 scale (PTSS-10)¹⁴ used after the Great Hanshin-Awaji Earthquake disaster to screen for post-traumatic stress disorder (PTSD), was incorporated in the form of a checklist to help patients monitor their state of mental health.

Preventing the Deterioration of Specified Chronic Illnesses—One of the health needs elicited from surveys of patients with each of the illnesses,^{4,16} especially from patients with chronic respiratory diseases, was the vital need to prevent infectious diseases. For this reason, an item was included on cold prevention, advising patients to wear masks, wash their hands and gargle, take their temperature if they suspect that they may have a fever and be vaccinated against influenza. Advice also was included about nutritional balance and maintenance of daily routine, along with explanations of how disaster-induced sleep disorders, reduction in appetite, and changes in activity levels can disturb ordinary daily routines. After the Mid-Niigata Prefecture Earthquake in 2004, deep venous thromboembolism became a problem among people who slept in their cars to avoid living in evacuation shelters where there was no privacy.¹⁵ Thus, the pamphlet encourages people not to stay in one position for a long time, but to move their legs every 1–2 hours if possible, and to ensure sufficient fluid intake within restric-

Diabetes	Dry mouth	
	Increased urine volume	
	Decreased urine volume	
	Rapid weight gain	
	Rapid weight loss	
	Cold sweats	
	Altered consciousness	
	Rheumatic diseases	Joint pain
Slightly worsen		
Remains unchanged		
Slightly better		
Better		
Number of joints with pain		Increased
		Slightly increased
		Remains unchanged
		Slightly decreased
		Decreased
Joint stiffness		Worsen
		Slightly worsen
		Remains unchanged
		Slightly better
		Better
Difficulty in walking		Became more difficult
		Became slightly more difficult
		Remain unchanged
		Became slightly easier
		Became easier
Activities in your daily life	Became more difficult	
	Became slightly more difficult	
	Remain unchanged	
	Became slightly easier	
	Became easier	
Sitting up or tossing about in bed		
Going up and down the stairs		
Putting on and taking off outdoor shoes		
Putting on and taking off clothes		
Washing your face and hair		
Chronic Respiratory Diseases	Yellow or brown phlegm	
	Cough	
	Altered consciousness	
	Hands and feet feel hot	
Undergoing Dialysis	Weight gain	
	Altered consciousness	
	Numbness around the mouth	

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Table 2—Checklist of type-specific physical condition

Name of medication	Instructions for taking medication
Allergic reactions to medication (I have had a rash or itch after taking medication.)	
Medications to be stored with care	Name of medications
Amount of oxygen	At rest () liters In motion () liters
Duration of oxygen cylinder	() hours

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Table 3—Medication control table (e.g., chronic respiratory disease)

tions. It was clear from the surveys of health needs^{4,16} that stress was widespread, with comments such as, “There’s no choice but to push myself when there is so much to do”, “I don’t want to cause trouble to my family and other people”, “I can’t cope with the changes in my health”, and “I hate having to be dependent on other people”. Stress not only abets the deterioration of chronic illnesses, but also is a risk factor in the emergence of new associated diseases. In easily understandable terms, this section encourages caution on the part of those who suffer chronic illnesses, emphasizing that everyone is susceptible to the deterioration of their illness not just because of the changes in lifestyle, but also because of the stress caused by the difficulty of maintaining normal medical care. Explanations concerning the benefits of involvement in community affairs, consultations with medical personnel, and participation in leisure activities in reducing stress also are provided.

Medication Control—It was clear from the survey on health needs,⁴ that for all patients with the three chronic illnesses, “being able to ensure the supply and use of medication” was important in controlling the disease.

During a disaster, it is quite common for the shock to cause people to forget the names or ways of taking medications, even if they usually remember, and it can be difficult to obtain medications and medical goods, so it is necessary to have a thorough understanding of the functions and names of medications as well as how to take them. Moreover, it is unrealistic for patients

with chronic illnesses to expect full medical care immediately during a disaster. As it is necessary for patients to recognize and prepare for the actual situation by knowing what medications they need to carry in an emergency and how to manage them, a medication control table was included (Table 3). Patients also are advised to prepare at least a week’s supply of spare medications. Space also is provided in the pamphlet to list names of any medications that have caused allergic reactions, and methods of storing medications.

Importance of Medical Examinations

Among patients with chronic illnesses who experienced the Great Hanshin-Awaji Earthquake, there were those who pushed themselves too far without realizing it and did not notice that they had caught respiratory infections or were in poor physical condition.⁴ This was why information was included in the pamphlets about the importance of continuing with regular hospital appointments amid the hectic lifestyle during a disaster. A space to record the physician’s contact details and patient identification card number also was provided in order to facilitate contact with the home doctor in an emergency. As it is not always possible to see the home doctor in such conditions, a recommendation to patients to ask nearby medical staff for advice about any concerns was included.

Preparing for Evacuations

The pamphlet includes a section on what to prepare in advance for evacuation, for others to avoid panicking dur-

Treatment-Related Items	Check	Everyday Items	Check
Medications		Cash and valuables (bankbooks, etc.)	
Insulin self-injection kit		Cell phone	
Blood sugar level measuring device		Flashlight and batteries	
Drinking water		Portable radio	
Emergency provisions, and food containing sugar and glucose		Changes of clothes/towels	
Clinical thermometer		Notepad and writing utensils	
Gargle		Toilet paper	
Disinfectant		Wet tissue paper	
Adhesive bandage		Sanitary products	
List of food exchanges		Dentures, glasses, cane, etc.	
Mask		Outdoor shoes and room shoes	
Patient ID card, patient handbook, and health insurance card		Plastic wrap	
Shawl or other items that help keep you warm		Large-size waste bags	
		Work gloves	

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Table 4—List of evacuation items (e.g., diabetes)

ing an emergency. The list of items to prepare was made with reference to the Chitwood *et al* checklist of useful items to prepare for a disaster for diabetic people.⁶ The list is divided into everyday items and treatment-related items (Table 4). The list of everyday items was based on information gained from the survey on health needs,⁴ taking account of what patients themselves can prepare to carry in an evacuation; for example, replacing a heavy blanket by a light shawl, and paying attention to such factors as the heightened risk of stumbling when wearing slippers, so preparing indoor shoes instead.

Methods of Contact in an Emergency

Following a major event, such as an earthquake, the huge surge in phone use by people trying to check the safety of others or request information, can make it difficult to contact others by phone for several days. From March 1998, NTT (Nippon Telegraph and Telephone Corporation) introduced the “Disaster Emergency Message Dial 1-7-1” service that can be used anywhere in Japan, to enable people to check the safety of friends, family, and acquaintances in an emergency. This Disaster Dial service is a voice message board that uses the phone numbers of households in

the disaster area as mailboxes to record and play back voice messages concerning personal safety and other information. This Section of the pamphlet provides information about how to use the “Disaster Emergency Message Dial 1-7-1” service to make contact with family members without panicking in an emergency, and also includes a space to record mobile phone numbers of family members.

Description of Features of Pamphlets Specific to Each Condition

Diabetes

For people with diabetes, the stress of a disaster itself has effects on the secretion of insulin, and this, combined with various complicating factors such as diet, exercise, and medication compliance, makes blood sugar control during a disaster difficult.¹⁹ Accordingly, in the physical self-care checklist, of abnormal blood sugar levels, such as thirst, changes in urine volume, weight changes and altered consciousness were included, as these may indicate a deterioration of diabetes or complications (Table 2). Together with the common items, the inclusion of these items was intended to help people avoid hypoglycemia, diabetic coma, diabetic nephropathy, brain infarction, myocardial infarction,

and so on. It is clear both from the literature and from the survey on health needs⁴ that many people even with Type 2 diabetes in Japan are dependent on insulin, and so space was in the “medication control” section for patients to record the name of the type of insulin used and how to use it, and included an insulin self-injection kit and blood sugar level measuring device in the list of items for evacuation. Information about the use of glucose and glucagon injections to deal with hypoglycemia also was included.

Rheumatic Diseases

In the checklist of items which may indicate the deterioration of rheumatic diseases, items on the degree of joint pain, number of joints with pain, degree of joint stiffness, and level of difficulty in walking and daily life activities were included (Table 2). As keeping warm is especially effective in preventing the deterioration of rheumatic diseases, advice on making even greater efforts than usual to keep warm, and added pocket warmers and shawls to the list of evacuation items was included. The pamphlet also included an explanation on the importance of re-establishing a daily routine and moving joints as much as possible as a way of continuing rehabilitation. Many people with rheumatic diseases easily become stressed during or after a disaster due to worries about whether they will be able to cope with everyday life or receive adequate medical care.²⁰ This is a major factor in the deterioration of the condition, so advice about talking to family members about stress, consulting a physician or other medical personnel, and participating as much as possible in community events as ways of avoiding the accumulation of stress also were included.

Chronic Respiratory Disease

As respiratory infections such as colds and influenza, are a menace to persons with chronic respiratory diseases,^{4,16} the physical self-care checklist includes symptoms related to respiratory infections and respiratory functions such as the production of yellow or brown phlegm, coughing, altered consciousness, and hands and feet feeling hot (Table 2). In order to prevent a respiratory infection, patients are advised to have had an influenza vaccination in the winter if possible, and the list of evacuation items includes gargle medicines. Attention also is drawn to the importance of wearing a mask to avoid the inhalation of dust, molds, and mites, and of keeping bedding clean and sanitary.

For patients suffering respiratory failure, the procurement of oxygen during a disaster is a priority. However, the supply of oxygen may be adversely affected during a disaster by the disruption to transport and communications systems, power cuts, and other unforeseeable factors. Therefore, the pamphlet advises patients to prepare portable oxygen cylinders ready for easy evacuation,⁴ and provides a space to record the amount of oxygen required at rest and in motion, and the duration of a portable oxygen cylinder (Table 3). Based on this knowledge of how long one cylinder of oxygen lasts, the pamphlet advises patients to make sure they have at least 2–3 days' supply of oxygen cylinders. It also provides a space to write contact details of the oxygen equipment company, so that patients are able to contact the company independently in an emergency,

inform the company of their condition and evacuation location, and thereby ensure a stable supply of oxygen.

Dialysis

As there was a problem with dialysis patients being unable to receive dialysis treatment at their usual hospitals during a disaster,⁵ items on weight gain, altered consciousness and numbness around the mouth (Table 2) were included on the physical checklist. The pamphlet for dialysis patients was created by adapting the pamphlet for people with diabetes and adding characteristics associated with dialysis patients. The pamphlet includes a table in which to record dialysis treatment conditions (dry weight, dialyzer, number of dialysis treatments, dialysis hours, blood flow, dialysate solution flow, shunt area, anticoagulant, drugs used during dialysis and problems during dialysis), to facilitate response should a disaster occur during dialysis. The pamphlet also stresses the importance of dialysis patients being aware of the potential impact of a disaster in their everyday lives, and being prepared to help each other should they encounter an emergency situation.

Discussion

It is clear from the literature and from the surveys conducted on health needs, that people with chronic illnesses are unlikely to be able to receive the same treatment or the same level of treatment during a disaster as they are used to. In other words, there is a need for people with chronic illnesses and their families to be able to cope independently with the extraordinary situation caused by a disaster.

In concrete terms, the importance of “being able to obtain and use medication” as a health need for people with diabetes, rheumatic diseases and/or chronic respiratory disease was delineated, and the pamphlets were designed to enable patients to have a portable record of details of their medications, thus facilitating a secure supply in an emergency. Relative to Hurricane Katrina, patients with chronic illnesses reported to have experienced problems in accessing treatment, due to damage to medical facilities and disruption of transport networks. Diabetes patients without access to treatment found it difficult to obtain insulin and hypoglycemic agents, and experienced problems controlling their diabetes. The lessons drawn from this disaster were the necessity of cooperation between government and medical companies in times of disaster and emergency situations, forming a network to support patients with diabetes and enable them to maintain management of their own health condition in times of disaster.¹⁸ The Great Hanshin-Awaji Earthquake disaster led to a re-appraisal of the supply of medication and medical supplies, and provision was made to enable chemists to sell necessary prescription medicines to patients in cases where patients were unable to see a doctor or get a prescription dispensed in times of a large-scale disaster. However, in the case of elderly people, who often are coping with multiple chronic illnesses, it is difficult to manage multiple prescriptions without being treated at a general hospital. This is why it was considered necessary to create a system whereby people with multiple chronic illnesses could use the list of medications in the pamphlet in case of a disaster. In order to promote such a

system, it is necessary for both patients and medical personnel to be aware of the significance of such a list of medications before any disaster, and the pamphlets have potential to serve a role in developing this kind of function. Methods of using the pamphlets are a topic for focused investigations.

It can be assumed that different types of events, such as earthquakes or floods, will result in differences in patients' health needs, and this is another issue that must be examined further.^{4,16} It is necessary to increase the range of disasters under consideration and analyze each one in greater detail. In addition, these pamphlets were intended to be used within the context of Japanese culture and the Japanese medical system. The basic aim of the pamphlets, "to enhance the ability of patients to care for themselves in preparation for a disaster," is a prevention education strategy that is applicable to any national context. However, modifications must be made to allow for different cultures and medical systems when these pamphlets are used in other countries. Further research is planned to use the pamphlets with a greater number of patients with chronic illnesses, and to improve the content by examining the usefulness of the pamphlets.

Conclusions

A series of pamphlets, entitled *Overcoming Disasters* was created for four chronic illnesses (diabetes, rheumatic diseases, chronic respiratory disease, and dialysis treatment), designed to help patients to deal with the health needs experienced by victims of disasters who have chronic illnesses, emphasizing especially the importance of "being able to obtain and use medication" and "coping with stress". The pamphlets are intended to be read and filled in by patients with chronic illnesses before disaster strikes, so that during a disaster, producing what patients will be able to cope with unaccustomed situations and quickly recover their state of health.

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