

# Questionnaire Survey about Disaster Preparation for Users of Long-term Oxygen Therapy

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**Background** : Disaster preparation measures have come under review since the Great East Japan Earthquake in 2011. Users of long-term oxygen therapy (LTOT) are predominantly elderly, and there is some concern that disaster preparation measures for LTOT users may be insufficient, making it difficult for them to move in an evacuation. This study was performed to clarify disaster preparedness among LTOT users and to determine how they can best be supported by medical workers.

**Materials and Methods** : We conducted a survey of LTOT users visiting several outpatient clinics.

**Results** : The responses of 106 LTOT users (18.3 % response rate) were analyzed. Less than 40 % of the respondents had received information on disaster preparation. The number of preparedness items for disasters was significantly different among “with explanation”, “with counselor” and “with disaster registration”.

**Conclusion** : Medical professionals should repeatedly explain the necessity of preparation in a way that is suited to the individual situation, such as the physical condition and the living environment, provide consultations, and work with LTOT users to improve self-reliance in the event of a disaster. *Shinshu Med J 67 : 407—416, 2019*

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**Key words** : long-term oxygen therapy, measurements for disaster, disaster registration, self-management, the role of medical profession

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## I Introduction

The Great East Japan Earthquake in 2011 prompted reviews of disaster preparation measures all over Japan<sup>1)2)</sup>. According to a survey of long-term oxygen therapy (LTOT) users performed by a research group belonging to the Ministry of Health, Labor and Welfare in 2014<sup>3)–5)</sup>, less than 50 % of LTOT users had received an explanation of disaster preparation measures and only about 20 % of the respondents had received an explanation from medical staff about disaster preparation. The survey also revealed that patients prescribed LTOT at higher flow rates tended to fear that their physical condition would be ad-

versely affected by inability to receive supplemental oxygen in the event of a disaster. LTOT users are predominantly elderly, and there is growing concern that disaster preparation measures are insufficient, which may result in difficulties in the event of evacuation being necessary during a disaster. Based on the results of the survey conducted in 2014, we administered a questionnaire survey among LTOT users who visited outpatient clinics in Matsumoto City and the surrounding area to clarify the situation regarding disaster preparedness and to consider the support that medical staff can provide.

## II Materials and Methods

### A Subjects and protocol

The survey was conducted among patients prescribed LTOT at the outpatient clinic of the respiratory and cardiovascular divisions of Shinshu University Hospital, respiratory division of Matsumoto

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Kyoritsu Hospital, Marunouchi Hospital, and Shinshu Ueda Medical Center, and cardiovascular division of Saku Central Hospital Care Center. Six respiratory physicians and cardiovascular physicians were asked to recruit outpatients prescribed LTOT for the survey. The purpose of the survey was explained to the physicians, and they were asked to provide each LTOT user with a package containing a survey request letter, a self-report survey form, and an individual reply envelope. The physicians asked each LTOT user to distribute survey forms and individual return envelopes. The study period was from May to December 2016.

Consent of the survey participants was obtained passively, i.e., the survey-request statement indicated that returning the survey form signified consent to disclose information and to publish research based on the survey results. The subjects answered anonymously and of their own free will, and there was no potential disadvantage to the target population in not responding to the questionnaire. The survey was conducted after receiving approval from the Committee for Medical Ethics of Shinshu University School of Medicine (approval number : 3424).

There are no conflicts of interest to disclose related to this report.

## B Questionnaire

Seven items on disaster prevention were taken up with reference to brochures distributed by oxygen companies and medical professionals<sup>6)7)</sup>. In addition to basic information on age, gender, duration of LTOT use, flow rate of supplied oxygen and oxygen supply device type, disability class, nursing care certification, other usage of medical services, activities of daily living (ADL), basic disease as cause of LTOT and institution prescribing LTOT were also inquired about (**Table 1**). Questions regarding whether LTOT users recognized having received an explanation of disaster preparation measures and whether they had encountered a consultant or evacuation collaborator or registered the need for a support person in the event of a disaster were included. Furthermore, respondents were asked to provide a free response describing worries or concerns related to evacuation.

To increase its relevance, we received advice from medical professionals and disaster prevention experts on the contents of the survey.

## C Statistical analysis

Descriptive statistics were calculated. The average number of items related to disaster preparation was calculated. Recognition of receipt of an explanation, the presence or absence of a consultant, the presence or absence of accreditation for long-term care, the presence or absence of disaster registration, age, period of use, oxygen flow rate at the time of exertion and the number of items prepared for use in the event of a disaster were examined using the *t* test. To determine the relevance of region, residential areas were divided into three areas based on postmarks on the return envelopes. The relationships between the numbers of items and the residential areas, age, duration of LTOT use, flow rate of supplied oxygen were analyzed by one-way ANOVA. SPSS v22.0 was used for statistical analyses. Values are expressed as means  $\pm$  standard deviation. In all analyses,  $P < 0.05$  was taken to indicate statistical significance.

## III Results

580 copies of the survey form were distributed in total and 106 replies were obtained (response rate 18.3 %)

### A Basic attributes

The respondents included 68 men (64.2 %), 35 women (33 %), and 3 of unknown gender. The average age was  $75.1 \pm 10.4$  years old (median 76 years old). The average period of LTOT was  $5.63 \pm 4.77$  years (median 4.46 years). 80 patients (75.5 %) used a combination of oxygen concentrator and portable oxygen cylinder, and the mean oxygen flow rate during exertion was  $2.37 \pm 1.41$  L/min. The most common causative disease was chronic obstructive pulmonary disease (COPD,  $n = 70$  patients [66 %]), followed by interstitial pneumonia ( $n = 15$  patients), heart disease ( $n = 12$  patients), and cancer ( $n = 8$  patients). With regard to ADL, 32 patients (30.2 %) could go out alone, 36 patients (34.0 %) could go out alone only within their neighborhoods, 20 patients (18.9 %) required assistance

Table 1 Questionnaire

We asked patients prescribed long-term oxygen therapy about their preparations for a disaster.

Please check the box most applicable to you for each of the following items from 1 to 8.

Q1. Please check the following items that you are going to prepare for a disaster.

- ☐ I have prepared an oxygen cylinder and confirm residual quantity.
- ☐ I have placed the oxygen cylinder in a location where it can be reached immediately.
- ☐ I can calmly change oxygen supply to an oxygen cylinder from an oxygen concentrator.
- ☐ I have prepared a dry battery or flashlight for use in an emergency.
- ☐ I am thinking about the use of an oxygen concentrator with a built-in battery or have changed to one.
- ☐ I have prepared drinking water and food for approximately 3 days in the event of an emergency.
- ☐ I have written information, such as medications and urgent contact details, in a patient card or pocket notebook.
- ☐ When I go out, I carry the pocket notebook or card mentioned above.
- ☐ Emergency contact information of the oxygen supplier is located where it is easy to find.
- ☐ I have learned breathing methods, such as pursed lips breathing or abdominal breathing.
- ☐ Others

**Q2. Have you received explanations about preparation for a disaster?**

- ☐ No
- ☐ Yes → From whom? Please check the following boxes that are most applicable to you.

☐ spouse
 ☐ family member
 ☐ attending physician
 ☐ nurse

☐ oxygen provider
 ☐ care manager
 ☐ ward mayor
 ☐ friend

☐ neighborhood resident
 ☐ public health nurse
 ☐ government employees

☐ others (

**Q3. Is there a person with whom you can consult about preparation for a disaster?**

- ☐ No
- ☐ Yes → Who? Please check the following boxes that are most applicable to you.

☐ spouse
 ☐ family member
 ☐ attending physician
 ☐ nurse

☐ oxygen provider
 ☐ care manager
 ☐ ward mayor
 ☐ friend

☐ neighborhood resident
 ☐ public health nurse
 ☐ government employees

☐ others (

**Q4. Please provide details regarding any anxiety or problems you may have concerning preparation for a disaster.**

**Q5. Have you participated in a disaster drill in your district?**

Please check the following boxes that are most applicable to you.

- ☐ None
- ☐ Yes → How many times did you participate? (                      times)
- Have you participated after starting home oxygen therapy?   ☐ No                      ☐ Yes

**Q6. Have you enrolled in a municipal registration requesting assistance in the event of a disaster?**

Please check the following boxes that are most applicable to you.

- ☐ Already registered  
→ Was there safety confirmation at the time of a disaster drill? ☐ No ☐ Yes
- ☐ Not registered  
→ With regard to the reason why you have not registered, please check the following boxes that are most applicable to you.
- ☐ Do not know ☐ No need for me ☐ Do not want personal information to be known
- ☐ Others (

**Q7. With regard to the measures for a disaster in the area of Matsumoto City and neighboring cities and villages (3 cities and 5 villages), please check the following boxes that are most applicable to you.**

- (1) Do you know where the refuge nearest to your home is? ☐ No ☐ Yes
- (2) In the event of an earthquake with seismic intensity more than 6, do you know that the LTOT center will be opened temporarily for the patients who are usually treated with oxygen at a flow rate < 3 L/min? ☐ No ☐ Yes
- (3) Do you know where the LTOT center will be opened? ☐ No ☐ Yes
- (4) In the event of an earthquake with seismic intensity more than 6, do you know that the family should bring patients treated with oxygen at a flow rate ≥ 3 L/min by car to the appointed hospital? ☐ No ☐ Yes
- (5) Please provide details of any anxiety about problems concerning disaster measures.

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**Q8. Finally, please check the following boxes or enter the numbers and words most applicable to you.**

- 1) Age : \_\_\_\_\_ years old.
- 2) Gender : ☐ Male ☐ Female
- 3) How long have you been prescribed LTOT? \_\_\_\_\_ years \_\_\_\_\_ months
- 4) Oxygen flow rate  
     At rest : \_\_\_\_\_ L/min  
     On effort : \_\_\_\_\_ L/min      While asleep : \_\_\_\_\_ L/min
- 5) What kind of oxygen supply device do you use?  
☐ Only stationary oxygen concentrator  
☐ Stationary oxygen concentrator and portable oxygen cylinder  
☐ Portable oxygen concentrator  
☐ Liquid oxygen
- 6) Do you have a physical disability certificate?  
☐ No ☐ Yes → What class? \_\_\_\_\_ Class
- 7) Have you received certification of long-term care insurance?  
☐ No ☐ Yes → Please check the following boxes most applicable to you.  
☐ Support grade 1 ☐ Support grade 2 ☐ Care grade 1  
☐ Care grade 2 ☐ Care grade 3 ☐ Care grade 4 ☐ Care grade 5
- 8) Do you use any service? Please provide details.

( )

- 9) What is your daily life situation. Please check the following boxes most applicable to you.  
☐ Almost independent in daily life and able to go out alone using means of transportation.  
☐ Almost independent in daily life and able to go out alone in the neighborhood.  
☐ Almost independent in daily life at home, but can not go out without support.  
☐ Require some kind of assistance in daily life at home.
- 10) Which of the following illnesses do you have? Please check the following boxes most applicable to you.  
☐ Chronic obstructive pulmonary disease (COPD), emphysema, or chronic bronchitis  
☐ Asthma  
☐ Interstitial pneumonia, pulmonary fibrosis, or diffuse lung disease, etc.  
☐ Heart disease, cardiomyopathy, or other cardiac diseases, etc.  
☐ Neuromuscular disease  
☐ Cancer  
☐ Others ( )
- 11) Which of the following medical facilities prescribes home oxygen? Please check the boxes most applicable to you.  
☐ General clinics (Respiratory)  
☐ General clinics (Other than respiratory department)  
☐ Respiratory division of general hospital (private or public)  
☐ Divisions other than respiratory division of general hospital (private or public)  
☐ Respiratory division of university hospital  
☐ Divisions other than respiratory division of university hospital  
☐ Others ( )

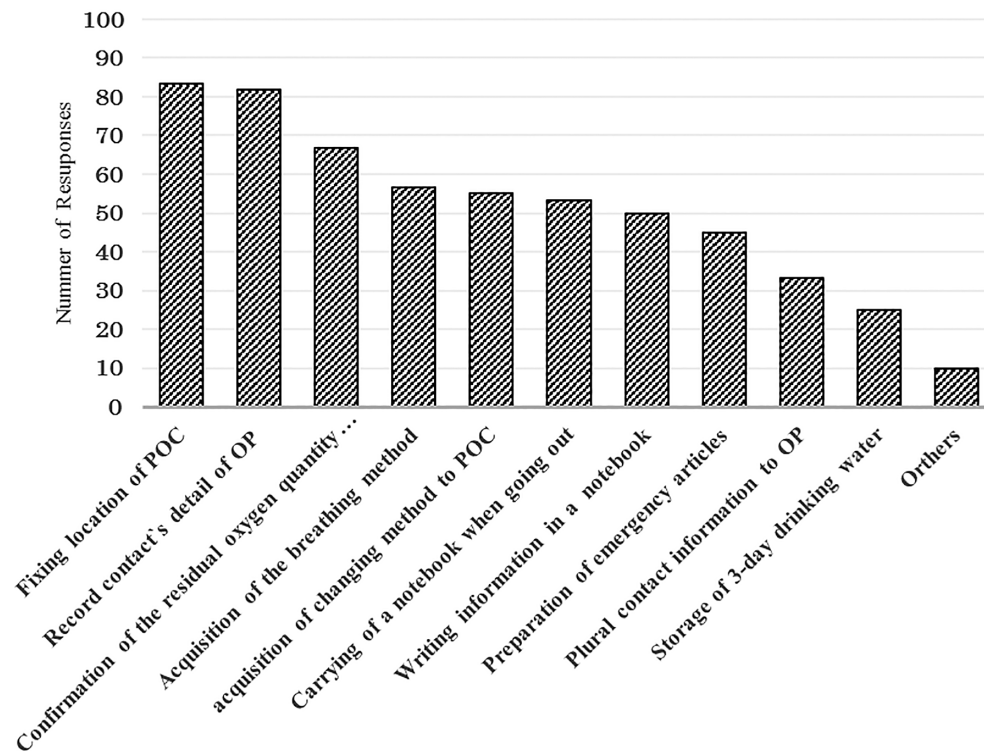


Fig 1 Items prepared for the event of a disaster by patients prescribed long-term oxygen therapy (LTOT) and their family (multiple answers,  $n = 106$ )

Others included the preparation of private power generators and booster cables.

POC, portable oxygen cylinder ; OP, oxygen provider

to go out and 13 patients (12.3 %) required assistance even when at home. 43 patients had received nursing care certification, and 42 patients used a day service, visiting nursing care, daycare, visiting rehabilitation, and/or loan of welfare equipment.

#### B Disaster preparedness (multiple responses were allowed)

With regard to making preparations for a disaster, 88 patients (83.0 %) responded that they placed a portable oxygen cylinder in a location where they would be able to access it immediately, 84 patients (79.2 %) responded that they had prepared contact information for an oxygen supplier for use in an emergency, 72 patients (67.9 %) responded that they consistently checked the amount of oxygen remaining in the portable oxygen cylinder, 64 patients (60.4 %) responded that they had learned breathing methods, such as pursed lips breathing or abdominal breathing, 58 patients (54.7 %) responded that they could calmly change their oxygen supply to an oxygen cylinder from an oxygen concentrator and 55

patients (51.9 %) responded that they carried a notebook containing information, such as medications and urgent contact details, when they went out (**Fig 1**). The average number of items prepared for use in the event of a disaster was  $5.6 \pm 2.6$  items.

#### C Explanation and consultation about preparedness for a disaster (multiple responses were allowed)

21 patients (35 %) answered, "I have never received an explanation about preparedness for a disaster". Of the 44 patients who had received such an explanation, 21 patients (36.8 %) had received an explanation from an oxygen provider, 15 patients (14.2 %) from an attending physician, 15 patients (14.2 %) from a nurse, 7 patients (6.6 %) from their spouse and 7 patients (6.6 %) from a family member (**Fig 2**).

81 patients (82.1 %) had access to an assistant with whom they could talk and think about disaster preparedness. Among these 81 patients, the assistants were reported to be their spouse for 48 patients (45.3 %), family members for 48 patients (45.3 %), oxygen

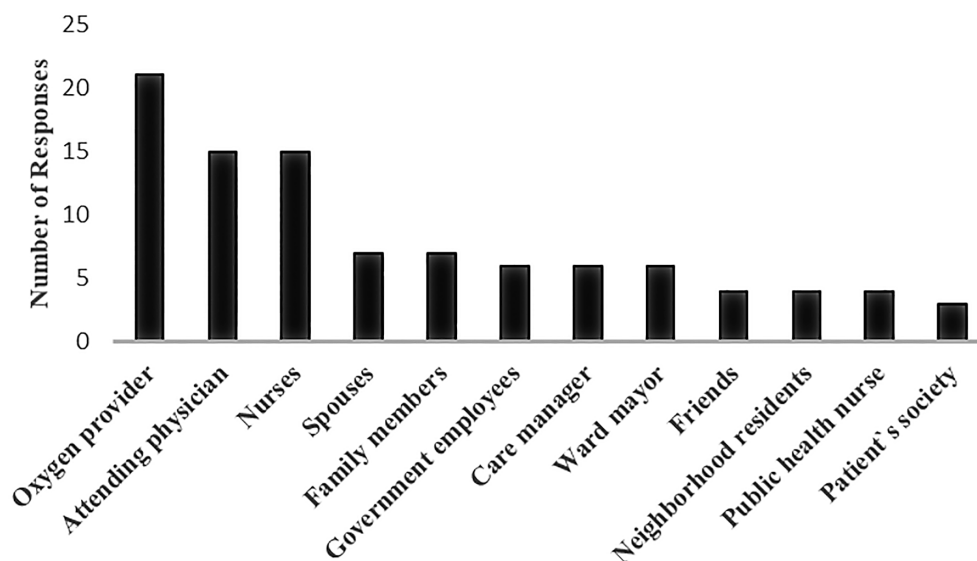


Fig 2 People who explained measures for a disaster (multiple answers,  $n=44$ )

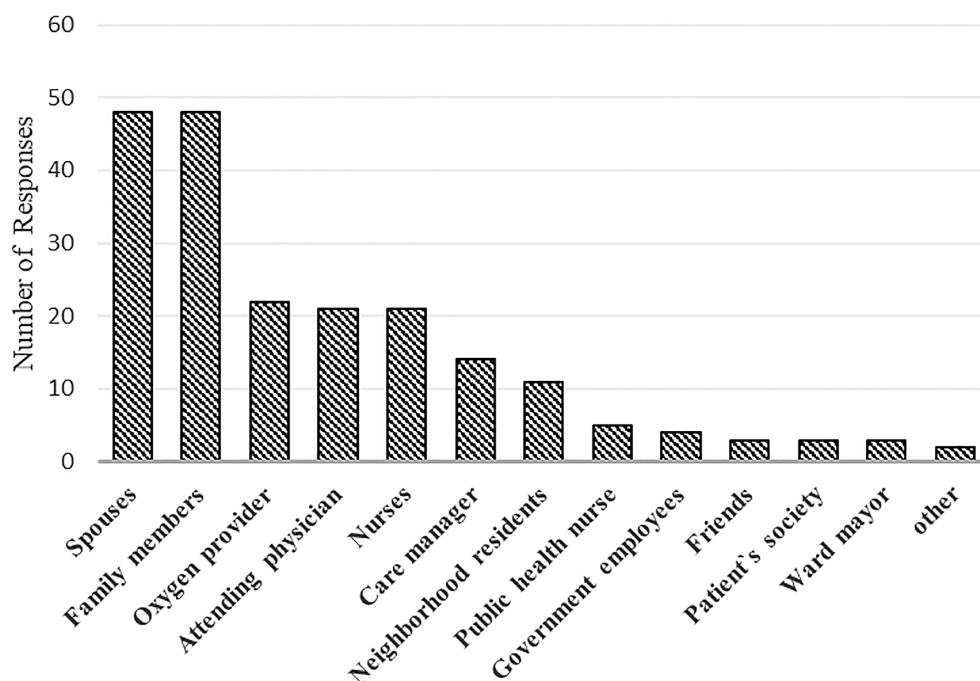


Fig 3 Persons who think about preparations for a disaster with patients prescribed long-term oxygen therapy (multiple answers,  $n=87$ )

providers for 22 patients (20.8 %), an attending physician for 21 patients (19.8 %) and nurses for 21 patients (19.8 %) (**Fig 3**). The average number of such assistants with whom respondents could talk and think about disaster preparedness was  $2.0 \pm 1.6$  people. 29 patients (27.4 %) answered that they had already registered as people who will need assistance in the event of a disaster with the municipal city or

village office, while 35 (33 %) answered that they had not yet registered, and 35 (33 %) answered that they did not know about the system. Other responses included that there was no system in their residential area, they had not yet registered because they had not joined their neighborhood group and that they hesitated to register because they did not wish to reveal their illness.



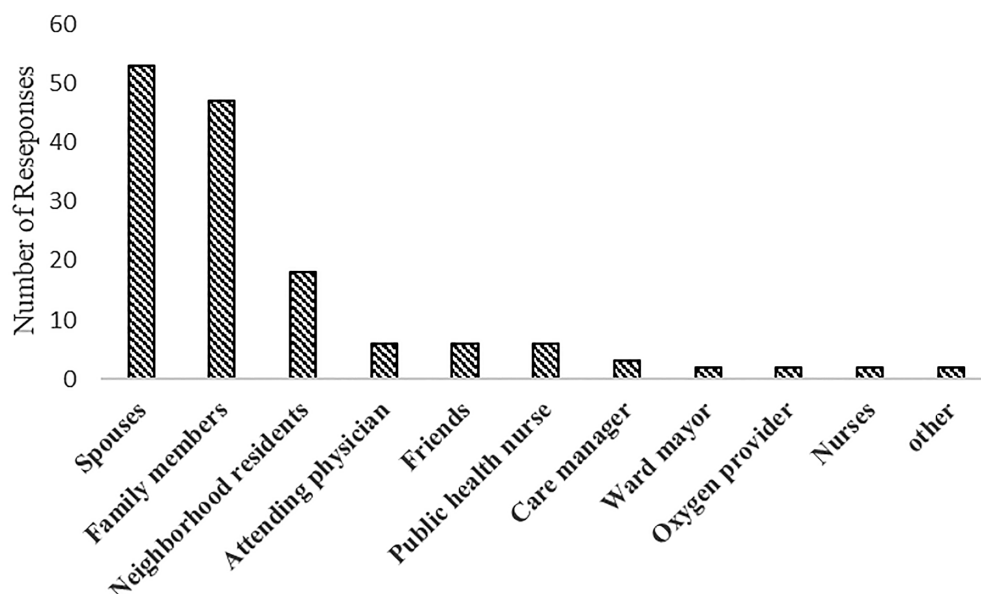


Fig 4 Assistants who will support patients prescribed long-term oxygen therapy (LTOT) in a disaster (multiple answers,  $n = 83$ )

#### D Cooperation during evacuation

Of the survey participants, 85 (80.2 %) knew about evacuation places close to their homes. 83 patients (78.3 %) reported that they would receive assistance in the event that evacuation became necessary, with 53 patients (50 %) receiving help from spouses, 47 patients (44.3 %) from family members and 18 patients (17.0 %) from neighborhood residents (**Fig 4**). On average, each LTOT user reported being able to rely on receiving assistance from  $1.3 \pm 0.9$  people.

#### E Factors related to the number of items prepared for use in the event of a disaster

The number of items prepared for use in the event of a disaster was significantly related to the presence or absence of an explanation regarding disaster preparation measures ( $P = 0.002$ ), presence of a consultant ( $P = 0.019$ ), and presence or absence of disaster registration ( $P = 0.016$ ). On the other hand, there was no significant difference with age, duration of LTOT use, or flow rate of supplied oxygen (**Table 2**).

#### F Anxiety and fears in the event of evacuation

LTOT users expressed concerns about the difficulties they might face in the event of a disaster. Most of these concerns focused on oxygen supply, such as having only enough for half a day or having an uncertain supply of oxygen cylinders if roads

were impassable. The next most common concerns were those related to transport in the event of evacuation, such as worries that they could not walk quickly and for extended periods, the evacuation centers were far away, and that they could not carry heavy objects or drive. Other concerns were related to the environment and support system, such as worries about whether their neighborhood could support LTOT users because they would not have additional coverage for support due to the elderly, whether they could request support and aid, and whether they would panic in the event of a disaster.

## IV Discussion

According to the Oxygen Therapy Guidelines of the Japanese Respiratory Society, it is important for doctors to provide their patients with explanations about coping methods and preparations for emergency situations, such as a disaster<sup>8)</sup>. Ohara et al. mentioned that it is fundamental for disaster prevention for individuals to be able to protect their own life by themselves, and that self-help, mutual assistance, and public assistance are indispensable at the time of a disaster<sup>9)</sup>. LTOT patients will also need to take responsibility to prepare for emergency situa-

Table 2 Factors related to the number of items prepared for use in the event of a disaster

Question	Answer	Number	Mean number of items for disaster preparedness	P-value
Explanation <sup>1)</sup>	Yes	<i>n</i> = 44	6.41 ± 2.13	0.002**
	No	<i>n</i> = 58	4.86 ± 2.74	
Consultation <sup>1)</sup>	Yes	<i>n</i> = 87	5.84 ± 2.51	0.019*
	No	<i>n</i> = 16	4.19 ± 2.76	
Certification of long-term care insurance <sup>1)</sup>	Yes	<i>n</i> = 43	5.47 ± 2.70	0.912
	No	<i>n</i> = 54	5.41 ± 2.42	
Registration for requesting assistance <sup>1)</sup>	Yes	<i>n</i> = 28	6.36 ± 2.15	0.016*
	No	<i>n</i> = 70	5.00 ± 2.58	
Age <sup>2)</sup>	below 65 years	<i>n</i> = 11	4.64 ± 2.62	0.296
	65 to 74 years old	<i>n</i> = 33	5.30 ± 2.71	
	over 75 years old	<i>n</i> = 62	5.84 ± 2.50	
Period of use <sup>2)</sup>	less than 1 year	<i>n</i> = 15	5.07 ± 2.63	0.723
	less than 1 to 3 years	<i>n</i> = 15	5.00 ± 2.73	
	less than 3 to 5 years	<i>n</i> = 21	6.00 ± 2.55	
	less than 5 to 10 years	<i>n</i> = 26	5.81 ± 2.88	
	over 10 years	<i>n</i> = 29	5.51 ± 2.29	
Oxygen flow rate at the time of exertion <sup>2)</sup>	less than 2 L	<i>n</i> = 35	5.77 ± 2.54	0.139
	less than 2 to 4 L	<i>n</i> = 53	5.77 ± 2.66	
	over 4 L	<i>n</i> = 18	4.44 ± 2.33	
	C region	<i>n</i> = 27	4.15 ± 2.30	
	D region	<i>n</i> = 19	6.53 ± 2.48	
Activities of daily living <sup>2)</sup>	go out alone	<i>n</i> = 32	6.31 ± 2.78	0.194
	go out in the neighborhood alone	<i>n</i> = 36	5.61 ± 2.46	
	require support for going out	<i>n</i> = 20	4.90 ± 2.43	
	require support at home	<i>n</i> = 13	4.92 ± 2.13	

Values are means ± SD. \**P* < 0.05, \*\**P* < 0.01, and \*\*\**P* < 0.001. 1), *t* test; 2), one-way ANOVA.

Annotation: Relationship between the mean number of items for disaster preparedness and the responses to questions about whether an explanation of countermeasures had been received, presence or absence of persons with whom to consult, having certification of long-term care insurance, having already registered as requiring assistance, and activities of daily living.

tions. However, according to a survey in 2014<sup>4)5)</sup>, more than half of the respondents reported that they did not recognize whether an appropriate explanation of countermeasures for a disaster has been received. In the latest results, less than 40 % had not received such explanations. On the other hand, the number of items prepared for disaster by LTOT patients was

more than those who received explanation, consultation, or with disaster registration.

HOT users have opportunities to explain, confirming that preparations are progressing, and taking a consultation, and considering them together the possibility that stockpiling for HOT users in the case of a disaster will advance. The details can be related to



HOT users at the time of admission and departure, at the outpatient department, at home visits, etc, and because it is a medical profession, We think that we can be involved in explanations, consultations, or thinking together according to individuality such as physical condition and background of life. In addition, it seems to be important to actually collaborate with families, oxygen companies, and many types of occupations.

In the free description of worries and difficulties concerning evacuation, the respondents expressed a wide range of opinions on various issues, such as oxygen supply, transportation in the event of evacuation, and support systems. Therefore, regional support through mutual assistance as well as self-help is extremely important for disaster-vulnerable people, such as LTOT users living in the community, who are highly dependent on medical care.

The Revision of the Basic Law for Disaster Countermeasures 2013 obliges municipalities to prepare full lists of those who will require assistance during evacuation<sup>2)</sup>. There are also areas where the heads of residential districts and other civil servants are establishing systems to ensure the safety of vulnerable individuals through self-declaration of vulnerable persons themselves. It would be useful to have regional connections during emergencies, such as district activities civilian committee members, reaching out on a daily basis to understand the characteristics and dependencies of LTOT users.

Safety confirmation, information transmission, and evacuation guidance are also frequently mentioned<sup>10)</sup>. An increasing number of municipalities have initiated such systems, so medical staff have easy access to information on countermeasures for the disaster-relief staff in residential areas, including LTOT users, exits from the hospital, outpatient visits, and other measures; this will assist in patient self-help and mutual assistance. Some differences in awareness and preparation for a disaster were found according to residential area, such as the Matsumoto area and other areas. It is important to continue the establishment of region-appropriate systems to assist in problems caused by regional natural disas-

ters. To promote the development of a regional support system in cooperation with the public administration, it is important to collaborate with multiple occupations and multiple institutions, such as hospitals, oxygen providers, and home nursing providers. While acknowledging the anxiety of LTOT users, it is desirable to continue studying what can be done as medical professionals in collaboration with various professional occupations involved with LTOT users, institutions, and areas of residence.

In summary, about 40 % of people did not recognize that they received an explanation. The number of preparedness items for disasters was significantly difference among “with explanation”, “with counselor” and “with disaster registration” Among concerns about evacuation, there were a wide range of opinions such as concerning oxygen supply, things concerning evacuation movement, living environment and support system. Medical professionals can engage in LHOT users with explanations, consultation, and attitudes to think together, according to individual physical conditions and living background. It is also desirable to continue to consider support systems while collaborating with multi-occupations/multi-institutions and regions.

### Limitation

Since the response rate was very low this time, it can not be said that the result reveals the situation as a whole. As distribution to HOT users was considered to be a reliable method but was regarded as unacceptable, the doctor requested patients to distribute the survey form at the time of outpatient care. However, it has not been confirmed whether it was distributed reliably at the time of complicated medical care. It is important to reflect on the fact that the doctor did not request confirmation or confirmation of distribution again when the number collected was low.

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