

Summary

# Japanese White Paper on Home Respiratory Care

Editors

The Japanese White  
Paper on Home  
Respiratory Care  
Production Committee  
The Japanese  
Respiratory Society



The Japanese Respiratory Society

# Policy and statement on home respiratory care

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## I. Principles of home respiratory care based on the White Paper

1. Improve the quality of care for long term oxygen therapy (LTOT) and home mechanical ventilation (HMV) in continuity based on the evidence clarified in the White Paper.
  - Improvement in patient education and pulmonary rehabilitation at an early stage.
2. Search and confirm the scientific evidence for future medical issues in home respiratory care.
  - Early implementation of LTOT, noninvasive positive pressure ventilation (NIPPV).
3. Increase public awareness and the importance of respiratory home care in community, both by close collaboration between the Japanese Respiratory Society and the Japan Federation of Patient Organizations for Respiratory Disease.
  - Improvement in the health care environment and welfare conditions.

## II. The health care environment that must be established

1. Make equipment more convenient and safe: ambulatory equipment (oxygen concentrators, tanks), low-cost pulse oximeters, remote monitoring systems, establishing systems for handling emergency situations and disasters.
2. Acquiring and training human resources.
  - Training of nurses specializing in the care of patients with chronic respiratory diseases (in concert with the Japan Nursing Association, the Japan Respiratory Society, and the Ministry of Health and Welfare).
  - Provide information on welfare and strengthening liaison connections.

In order to achieve a high quality of home respiratory care, it is necessary to deepen the understanding of those responsible for providing health care and of the patients, and to promote disease management. It is essential to propagate this thinking in order to achieve a society and health care system that will provide reliable health care.

The Japanese Respiratory Society, Japanese White Paper for Home Respiratory Care Production Committee

# Demands regarding the needs of patients summarized in the White Paper

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## I. Improve the education and support for self-management for respiratory care patients

1. Education and support for the prevention of exacerbation and the improvement of QOL.
  - Implementation of pulmonary rehabilitation from an early stage.
  - Increase of institutions providing pulmonary rehabilitation.
2. Detailed examinations when assessing the indications of LTOT.
  - Implement evaluation of hypoxemia in daily life, including during exercise and sleep.
  - Consideration of early implementation in patients with severe shortness of breath.

## II. Approaches to welfare

1. Designation of physical handicap.
  - Fair evaluation of internal physical disability designation, establishment of a 2nd class disability category\*.
2. Long-term care insurance.
  - Evaluation of respiratory symptoms (shortness of breath) in determining the need for long term care.
  - Liaison between health care insurance institutions and long term care insurance institutions.

## III. Creating a system of safe and anxiety-free home respiratory care

1. Monitor the quality of service provided by home respiratory equipment providers.
2. Establish the action plan for emergencies.

## IV. Increase public awareness of respiratory diseases and patients with respiratory disabilities

1. Increase public awareness.
  - Provide lung help consultation program and lung health classes in the community.
2. Education concerning home respiratory care for health care professionals other than physicians specializing in respiratory care.
  - Provide information to those working in local health organizations and those in service providing institutions related to long-term care insurance.

By the Japan Federation of Patient Organization for Respiratory Diseases  
From the Presidential Symposium Report, the 45th Japan Respiratory Society Annual Conference

\* [http://www1.mhlw.go.jp/english/wp\\_5/vol1/p2c4s2.html](http://www1.mhlw.go.jp/english/wp_5/vol1/p2c4s2.html)

## Results of Physician Survey

Survey Targets : institutions accredited by the Japanese Respiratory Society, institutions related to the Japan Physicians Association (mainly general practitioner), and randomly-selected general hospitals (internal medicine, neurology)

Period of survey : July 1, 2004 - July 31, 2004

Survey method : questionnaires were sent and returned by postal mail

### Study design and results

	Questionnaires sent	Questionnaires returned	Return rate
Institutions accredited by the Japanese Respiratory Society	534	286	54%
Randomly-selected general hospitals (internal medicine, neurology)	2,307	425	18%
Institutions related to the Japan Physicians Association (GPs)	1,500	306	20%
Total	4,341	1,017	23%

### [1] LTOT (long term oxygen therapy)

	Abbreviated title	Valid responses	Institutions implementing LTOT	Response rate
Institutions accredited by the Japanese Respiratory Society	Accredited institutions	278	275	99%
Randomly-selected general hospitals (internal medicine, neurology)	General hospitals	404	253	63%
Institutions related to the Japan Physicians Association (GPs)	Clinical internists	289	142	49%
Total	Total	971	670	69%

### [2] NIPPV at home (noninvasive intermittent positive pressure ventilation)

	Abbreviated title	Valid responses	Institutions implementing NIPPV	Response rate
Institutions accredited by the Japanese Respiratory Society	Accredited institutions	264	208	79%
Randomly-selected general hospitals (internal medicine, neurology)	General hospitals	398	153	38%
Institutions related to the Japan Physicians Association (GPs)	Clinical internists	246	19	8%
Total	Total	908	380	42%

### [3] TIPPV at home (tracheostomy intermittent positive pressure ventilation)

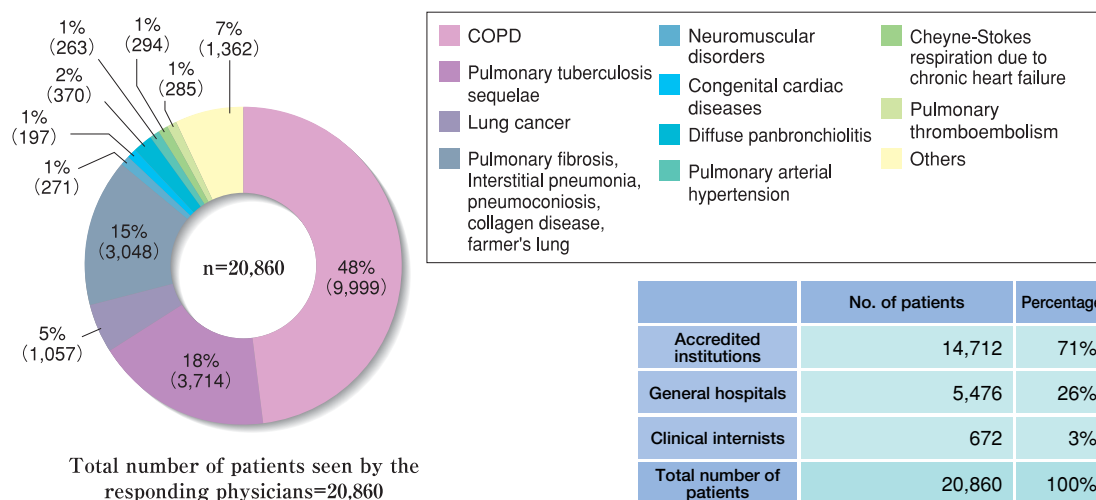
	Abbreviated title	Valid responses	Institutions implementing TIPPV	Response rate
Institutions accredited by the Japanese Respiratory Society	Accredited institutions	255	74	29%
Randomly-selected general hospitals (internal medicine, neurology)	General hospitals	387	82	21%
Institutions related to the Japan Physicians Association (GPs)	Clinical internists	243	8	3%
Total	Total	885	164	19%

## [1] Long term oxygen therapy

### A Implementation conditions and breakdown of the patients undergoing LTOT

- Of the total responding institutions, 69% were implementing LTOT. According to category, 99% of accredited institutions surveyed implemented LTOL compared to 63% of general hospitals, and 49% of clinical internist.
- The five most common diseases among patients receiving LTOT were chronic obstructive pulmonary diseases (COPD) 48%, pulmonary tuberculosis sequelae 18%, pulmonary fibrosis 15%, lung cancer 5%, and diffuse panbronchiolitis 2%.

#### Breakdown of patients receiving long term oxygen therapy according to disease



### B Indication criteria for LTOT, examinations, and prescriptions

- In each institution, the main complaints requiring the implementation of LTOT were dyspnea at rest, dyspnea on exertion, marked decrease in the level of activities of daily living (ADL) and cyanosis.
- More than 50% of accredited hospitals and general hospitals pointed out the need for reevaluation of the health insurance reimbursement criteria for indications under conditions at rest.
- Among patients receiving LTOT, 28% had a  $\text{PaO}_2 > 60$  Torr (room air) at rest (3,422/12,375), 92% of responding institutions (288/313) had patients who required LTOT with a  $\text{PaO}_2 > 60$  Torr (room air) at rest and in more than 3/4 of those patients, their dyspnea or hypoxemia on exertion or during sleep were shown to be improved after the implementation of LTOT.
- Pulse oximetry at rest was used extremely widely to determine the indications. However, the evaluation of hypoxemia during the field exercise test or while sleeping was made only in 42% and 40% of all the institution, respectively.
- Although 94% of institutions considered the pulse oximeter to be effective in self-management for daily living, only 16% of patients had one (2,745/16,905).
- The three most commonly prescribed administration flow rate at rest in LTOT patients were  $\leq 1\text{L}/\text{min}$  in 45%,  $1\text{L}/\text{min} <$  and  $\leq 2\text{L}/\text{min}$  in 34%,  $2\text{L}/\text{min} <$  and  $\leq 3\text{L}/\text{min}$  in 14%.
- Concerning the type of stationary equipment used, 94% used oxygen concentrators and 6% used liquid oxygen. Of the patients who used the oxygen concentrators, 69% used cylinders with intermittent flow oxygen conserving devices.
- The cylinders with intermittent flow oxygen conserving device were used, in descending order of frequency, by accredited institutions, general hospitals, and clinical internists.

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## **C** Patient education for LTOT

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- More than 60% of all responding institutions gave a comprehensive patient education at the time of induction and, among the various types of institutions accredited institutions provided the highest rate of patient education.
- The average time spent on patient education for induction of LTOT for all institutions was approximately 2.5 hours. Accredited institutions spent the longest amount of time for this. Three categories requiring the longest time for instruction were the breathing retraining, exercise training, and oxygen equipment guidance.
- The patient education at the time of induction was done by multidisciplinary professionals.
- 64% of institutions provided all categories of patient education necessary for respiratory care throughout the outpatient clinic management.
- 49% of accredited institutions had pulmonary rehabilitation programs; indicating pulmonary rehabilitation is becoming more widespread especially among the accredited institutions. A total of 45% of LTOT patients were receiving pulmonary rehabilitation.
- While 94% of institutions recommended influenza vaccine, only 59% of institutions recommended pneumococcal vaccine.
- 27% of patients were prescribed to receive home visiting nurse service, and 46% of patients used the long-term care insurance service.
- A total of 63% (9,857/15,621) had obtained physical disability certification.

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## **D** Clinical care system for LTOT

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- Concerning the clinical care system in their local practice area, 51% of institutions replied "almost completely available" and 43% replied "not very well established".
- Local care networks were established by 36% of institutions and the most frequent liaison contact point was the visiting nurse station.

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## **E** Evaluation and requests concerning LTOT equipment

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- 15% of the institute were satisfied with stationary oxygen concentrators and 9% with stationary liquid oxygen systems.
- Only 6% of all institutions replied that they were satisfied with ambulatory oxygen (cylinders and intermittent flow oxygen conserving device) , and 8% with ambulatory liquid oxygen systems, respectively.

## [2] Noninvasive intermittent positive pressure ventilation (NIPPV) at home

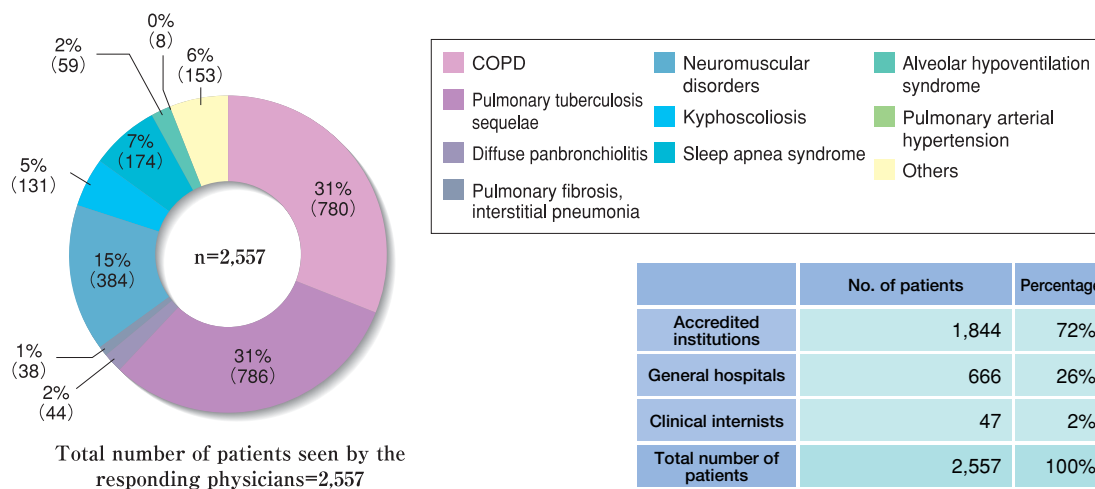
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### **A** Implementation conditions and breakdown of patients undergoing home NIPPV

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- Of all the responding institutions, 42% were implementing home NIPPV. Of the home NIPPV patients, 70% were using LTOT.
- The five most frequent diseases among home NIPPV patients were pulmonary tuberculosis sequelae 31%, COPD 31%, neuromuscular disease 15%, and sleep apnea syndrome 7%, and kyphoscoliosis 5%.

## Breakdown of patients receiving home NIPPV according to disease



### B Indication Criteria for NIPPV at home, examinations and prescriptions

- Institutions employing PaCO<sub>2</sub> for the indication criteria of home NIPPV were 41% and 39% in COPD and pulmonary tuberculosis sequelae, respectively. Most of the institutions used PaCO<sub>2</sub> level of greater than or equal to 60 Torr, followed by PaCO<sub>2</sub> ≥ 55 Torr.
- 82% of the institutions took into account the SpO<sub>2</sub> monitor results obtained by pulseoximetry in evaluating the indications of home NIPPV.
- The most common symptoms leading the implementation to home NIPPV were dyspnea, headache or head heaviness on awakening, and somnolence during the day.
- Arterial blood gas analysis was employed by 99% of institutions when assessing the indications of home NIPPV. In addition, 78% of institutions performed overnight SpO<sub>2</sub> monitoring
- 43% of home NIPPV patients had started their NIPPV when they were admitted to hospital due to exacerbation.
- In 37% of the institutions, mask fitting was mostly done by nurses.

### C Patient Education for NIPPV at home

- Comprehensive patient education was given by more than 70% of all institutions.
- The average time spent on patient education for induction of home NIPPV for all institution was more than 3 hours and the 3 categories requiring the longest time for instruction were breathing retraining, exercise training and equipment guidance.
- Pulmonary rehabilitation was received by 55% of home NIPPV patients.

### D Clinical care system of NIPPV at home

- Institutions replying that the home NIPPV clinical care system in their local practice area was either "not very well established" or "almost completely lacking", totaled 69%.
- Less than 20% of institutions took a positive attitude to referral of home NIPPV patients and, unlike the questionnaire for LTOT, the reason that they did not have a positive attitude to referral was because they were worried about the management that patients would receive at the facilities to which they were referred.

### E Evaluation and requests concerning home NIPPV equipment

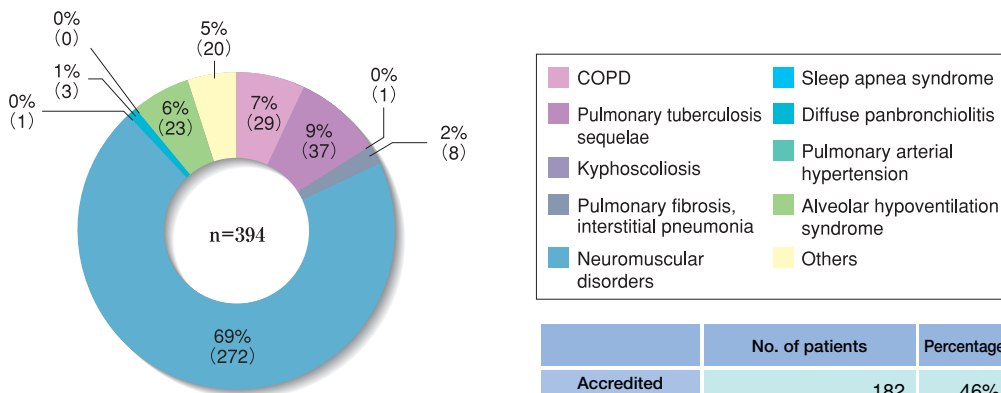
- Evaluation of equipment and masks as "satisfactory" was 7% and 4%, respectively.

## [3] Tracheostomy intermittent positive pressure ventilation (TIPPV) at home

### A Implementation conditions and breakdown of patients undergoing home TIPPV

- Home TIPPV was implemented by 19% of all replying institutions. In 46% of patients, they were also employing LTOT.
- The five most common diseases among patients receiving home TIPPV were neuromuscular diseases 70%, pulmonary tuberculosis sequelae 9%, COPD 7%, alveolar hypoventilation syndrome 6%, and interstitial pneumonia 2%. The total number of patients was 394.

#### Breakdown of patients receiving home TIPPV according to disease



Total number of patients seen by the responded physicians=394

	No. of patients	Percentage
Accredited institutions	182	46%
General hospitals	196	50%
Clinical internists	16	4%
Total number of patients	394	100%

### B Prescription of TIPPV at home

- A prescription for 24-hour TIPPV was given to 69% of patients.

### C Patient education for TIPPV at home

- The average amount of time for comprehensive patient education for home TIPPV was 219 minutes. The category requiring the longest amount of time was education concerning the equipment, followed by breathing retraining, exercise training, diet and nutrition, and prevention of infection. During the education, nurse played an important role in education.
- Of patients undergoing home TIPPV, 39% received pulmonary rehabilitation (96/244).
- Patient home visits by a doctor were made by 64% institutions. Number of patients' home visits per month averaged 2.5 and 27% of responding physicians made four or more home visits per week.
- 91% of patients were prescribed with home visiting nurse service and 78% of patients were certified for the long term care insurance. A total of 97% had obtained physical disability certification, and 80% made use of helpers or public health nurses.

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## **D** Clinical care system of home TIPPV

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- The total of 66% of institutions replied that in their local practice area, the home TIPPV clinical care system was not sufficiently established.
- Institutions taking a positive attitude towards referral of patients to other institutions totaled 21%. The reason that those who did not have a positive attitude to the referral was because they were worried about the management that patients would be given at the institutions to which they were referred, or the patients did not desire it.
- Long term hospitalization of TIPPV patients of 3 months or more were reported by 103 institutions for the total of 598 patients. The three most common patient conditions for the long-term hospitalization patients were neuromuscular diseases (67%), COPD (12%), pulmonary tuberculosis sequelae (6%). The reason for not being able to be discharged was lack of stability of the family or refusal to accept the patient, in 85%.

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## **E** Evaluation and requests concerning TIPPV equipment at home

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- Requests were expressed for making home TIPPV equipment smaller, portable and especially to make the tube more difficult to be dislodged.



## Results of Patient Survey

Subjects : Patients belonging to the Japan Federation of Patient Organizations for Respiratory Diseases

Period of survey : November 15, 2004 to January 31, 2005

Survey methods : Sent by postal mail in the newsletter of the Japan Federation of Patient Organizations for Respiratory Diseases and affiliated associations and returned anonymously by postal mail.

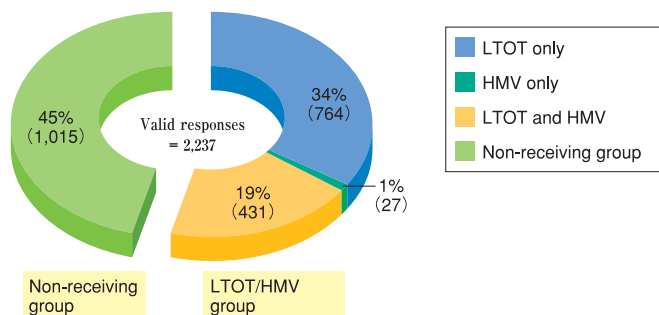
Patient Organizations to which the questionnaire was sent : NPO-J Breath, Iwate Advocacy Group of Lung Impairment (Iwate teihai no kai, Zenkoku Teihaikinousha Guruupu), Tohoku Public Advocacy Group of Lung Impairment Patient (Zenkoku Teihaikinousha Guruupu Tohoku Hakucho Kai), National Advocacy Group of Lung Impairment Patient (Zenkoku Teihaikinousha Dantai Kyougi Kai), Japanese Network of Polio Survivors (Zenkoku Polio Renraku Kai)

Survey results : returned questionnaires 2,237, return rate: 44%

### [1] Background

- Of the 2,237 people who returned questionnaires, 55% were receiving LTOT and/or home mechanical ventilation (LTOT/HMV group), and 45% were receiving neither LTOT nor HMV (non-receiving group).
- The three most common conditions were COPD (39%), pulmonary tuberculosis sequelae (35%), and post-polio syndrome (15%).
- Reason for joining the patient advocacy group and things they thought were good about joining was "because they could get information about their disease and treatment" (75%), and they "could study about their disease" (81%).

Presently receiving respiratory care



### [2] Activities of daily living

- Of the responders, 87% went outside of their home, apart from going to hospital. 21% of the patients in the LTOT/HMV group were restricted to home.
- The reasons for not going out of the home were problems with the portable oxygen in 68% followed by fear of becoming breathless (63%), lack of confidence in being alone (50%).
- Concerning present enjoyments, the LTOT/HMV group replied watching television or reading books, but in the non-receiving group, going outside and travel were equal to watching television and reading books.
- Concerning wishes for daily living, the LTOT/HMV group stated that their greatest wish was "life without breathlessness" (76%), which was more than double that of the non-receiving group.

### [3] Scheduled outpatient clinic attendance

- The ratio of patients who frequently (twice a month or more) visit outpatient clinics was the largest (51%) in the LTOT only group.
- The most common means of transportation going to the outpatient clinic was their own car, in 55% cases.
- For patients in the LTOT/HMV group, 45% required somebody to accompany with them to the outpatient clinic, and in 87% of those cases, the person accompanying them was a family member.

### [4] Treatment, education, and support

- Among the LTOT/HMV group, 33% had been hospitalized once in the past year compared to 14% in the non-receiving group.
- The most common symptoms that patients decide to make emergency visit to the institution clinic were "worse-than-usual breathlessness", "fever", and these were recognized as indications of exacerbation. The average fever that was considered necessary to visit a physician was 38°C.
- The patients who received pulmonary rehabilitation accounted for 49%. Among those in the LTOT/HMV group, 63% received pulmonary rehabilitation and in the non-receiving group, it was 30%.
- The total of 55% of patients had educational books or pamphlets concerning their treatment. Of those who did not have such materials, 84% replied that such materials would be useful.
- Various reasons were given concerning why they did not have a pulse oximeter. In the LTOT/HMV group, 49% said it was too expensive for them to buy. In the non-receiving group, the most common reason (48%) was that they did not feel the necessity.
- Concerning requests to medical staffs, the most common reply, in 80%, was they wanted to be taught more about the skills for self-management. The three most common concrete examples of this concerned pulmonary rehabilitation (management of breathlessness).

### [5] Economic burden

- In 26% of cases, personal economic burden was more than 12,000 yen per month. In 46% of those receiving both LTOT and HMV, and 31% of those receiving only LTOT, the monthly personal expenditure was more than 12,000 yen.
- The monthly expenditure not directly due to medical costs (transportation to and from hospitals, electricity cost for equipment, purifying water, etc.) were more than 10,000 yen in 36% of those receiving LTOT and HMV.

### [6] Use of physical disability welfare

- 83% had obtained physical disability certification.
- Among the LTOT/HMV group, Class I handicapped were 36% and Class III were 52%\*.
- Among the recipients, 30% expressed dissatisfaction with the results of their physical disability classification.
- The three most common services they received using physical disability certification were subsidy of personal costs for medical expenses (51%), reduction of tax (45%), reduction of travel cost (43%).

\* [http://www1.mhlw.go.jp/english/wp\\_5/vol1/p2c4s2.html](http://www1.mhlw.go.jp/english/wp_5/vol1/p2c4s2.html)

## [7] Long-term care insurance service

- 32% applied for long-term care insurance.
- Those requiring long-term care level 1 or less (minimal long-term care) were 66%\*\*. Those satisfied with the result of their long-term care classification were 46%, and those dissatisfied were 31%.
- Despite the utilization of long-term care insurance, 48% of patients replied that their long-term care conditions had not changed or had worsened. The main reason for that was other people did not understand the disability due to breathlessness, in 56% of cases.
- Of 1,518 patients, 71 had expressed their wish to be hospitalized in the long-term care insurance facility, of those only 20 were accepted.

## [8] Long term oxygen therapy

- Through LTOT, 89% of patients hoped for "lessening of breathlessness". This was followed by "heart protection" in 54% and "mental comfort" in 46%.
- Concerning the improvement of symptoms since beginning LTOT, 85% said that their breathlessness had lessened. In 26%, they said that they are now able to go outside and 22% said that their sensation of head heaviness had become more tolerable.
- The strongest worry or dissatisfaction since beginning LTOT was about electrical blackouts or natural disasters (57%).
- Of the total number of cases, 52% replied that they had received explanations from the institution concerning use of the equipment in an emergency, while 49% replied that they had received explanations from the institution concerning the LTOT providers system of conservation management.
- Concerning the ambulatory oxygen cylinders, 8% of patients expressed satisfaction, 62% said it should be improved, and the main point of improvement desired was improvement of portability and weight.
- The three most common demands concerning LTOT were a wish for subsidy of electricity cost of the stationary oxygen concentrator, a wish for distribution or rental of pulse oximeters, and better explanation of the response of the LTOT providers in the event of a natural disaster.

## [9] Home mechanical ventilation

- Concerning the implementation of HMV, 6% (14 people) were receiving it via tracheostomy, and 83% (204 people) were receiving it via a nasal mask.
- Most common improvement in symptoms due to HMV was relief of breathlessness, in 67%.
- Explanations concerning emergency response to the use of the equipment had been received from the institution by 49% of the respondents. 46% replied that they had received explanations from the institution about the LTOT providers conservation management system.
- Concerning the ventilator, 15% replied they were satisfied, and 6% replied they were satisfied with the mask.

\*\* <http://www.mhlw.go.jp/english/topics/elderly/care/>

## **Japanese White Paper on Home Respiratory Care : Summary**

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First published 2006

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Nitinai Kaikan 7F, 3-28-8, Hongo, Bunkyo-ku, Tokyo, 113-0033, JAPAN

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The survey reported in this white paper was conducted with cooperation of the Japan Federation of Patient Organization for Respiratory Diseases

This study was partly sponsored by the research grant to the Respiratory Failure Research Group (chair: Keishi Kubo, The First Department of Internal Medicine, Shinshu University) from the Ministry of Health, Labor and Welfare in Japan

### **Published by**

The Japanese Respiratory Society  
Nitinai Kaikan 7F, 3-28-8, Hongo, Bunkyo-ku, Tokyo, 113-0033, JAPAN  
<http://www.jrs.or.jp/>

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**Acknowledgement:** The translators are indebted to Dr. Jun Ueki of School of Health Care and Nursing, Juntendo University and Dr. Yasuhiro Setoguchi of the First Department of Internal Medicine, Tokyo Medical University for their assistance with their translation.

### **Printed by**

Bunkodo Co., Ltd.  
6-7-1, Hongo, Bunkyo-ku, Tokyo, Tokyo, 113-0033, JAPAN