

Toward the harmonization of work with treatment and prevention for patients with chronic respiratory failure

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Abstract: Home oxygen therapy (HOT), also known as long-term oxygen therapy, is prescribed to patients with chronic respiratory failure (CRF) due to advanced respiratory diseases, as it has been shown to improve the prognosis of patients with chronic obstructive pulmonary disease (COPD). However, the therapeutic impact of HOT does not fully reflect the “socialization” of patients, which is one of the final goals of “comprehensive pulmonary rehabilitation”, proposed by the Japanese Respiratory Society. Since working is one form of socialization, we evaluated a 55-yr-old worker prescribed with HOT for the management of advanced COPD to elucidate and assess the social barriers experienced by HOT users. This case demonstrates a variety of factors affecting patients, respiratory physicians, occupational physicians, and management teams, which prevents patients from working. By elucidating these factors and seeking solutions, the promotion of the “harmonization of work with treatment and prevention” will both improve working environments and encourage CRF patients to continue working, leading to better socialization. Thus, the “harmonization of working with treatment and prevention” for CRF patients is a core goal for the promotion of both “health and productivity management” and “comprehensive pulmonary rehabilitation.”

Key words: Chronic respiratory failure, Long-term oxygen therapy (LTOT), COPD, Pulmonary fibrosis, Tuberculosis, Lung cancer, Socialization, Comprehensive pulmonary rehabilitation

Introduction

The recent launch of the “harmonization of work with treatment and prevention” initiative in Japan, begun for the support cancer patients, will presumably be applied to patients with various diseases and pathologic conditions, including chronic respiratory failure (CRF). CRF

is an advanced condition of respiratory diseases, such as chronic obstructive pulmonary disease (COPD), pulmonary fibrosis, and lung cancer. The Japanese Respiratory Society (JRS) defines respiratory failure as the hypoxic condition determined by a partial oxygen pressure (PaO₂) <55 mmHg or a PaO₂ <60 mmHg accompanied by a serious decline in PaO₂ levels during sleep or exercise¹⁾. CRF is subsequently defined as the prolonged and persistent condition of respiratory failure, which can continue for months or more¹⁾. The condition is associated with severe dyspnea or breathlessness, especially on exertion, which results in impaired quality of life (QOL) and daily activities.

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Home oxygen therapy (HOT), also known as long-term oxygen therapy (LTOT), is one therapeutic choice for patients with CRF. HOT has been shown to significantly improve the prognosis of patients with CRF due to advanced COPD^{2, 3)}. However, the Japanese White Paper on Home Respiratory Care, published in 2010 by JRS, showed that the proportion of CRF patients who underwent HOT and continued working was 10%, compared to 30% without HOT who were able to continue working⁴⁾. This raises an issue regarding HOT: while severe disease in most cases may drive patients to stop working, there is a possibility that HOT itself limits their ability to work, whereby HOT becomes a barrier to its users as a part of the working environment. Thus, the prognostic improvement of CRF patients as a result of HOT does not seem to be reflected in the maintenance and opportunity of work at the individual level. We focused on the factors affecting the ability of CRF patients prescribed HOT to continue working because working is a form of socialization.

In this case-based report, we present a CRF patient undergoing HOT due to advanced COPD, and discuss the difficulties and social barriers to his ability to work.

Case Report

A 55-yr-old man was hospitalized for exacerbation of COPD when this interview was conducted. He had a history of smoking 20–30 cigarettes a day in his 20s and most of his 30s, when he drove to work in a sales section of a company. At the age of 38, he was diagnosed with COPD after experiencing severe dyspnea while playing baseball. He stopped smoking and underwent treatment using bronchodilators, although the disease developed gradually. At the age of 50, he was further diagnosed with CRF and HOT was prescribed. He could continue working while undergoing HOT and started to commute by bus, following the suggestion to stop driving a car by his family and home doctor. He could afford two oxygen generators: one at home and the other at his workplace, and he carried a portable oxygen bomb while commuting. However, commuting and working while on HOT became difficult after the Great East Japan Earthquake in 2011. He was afraid that an electricity power outage might neutralize the oxygen generators, and that he might run short of oxygen during the commute if an unexpected traffic accident and/or delay occurred. These concerns led him to decide to leave his job. At the time of the interview, a wheelchair with portable oxygen bomb was required for travelling because of severe dyspnea and weakness. He was hospitalized for

treatment of exacerbation of COPD a few times a year.

The case described the difficulties of his continuing to work. Such difficulties included the limitation of oxygen supplementation and dyspnea, as well as his limited ability to attend business trips despite most oxygen suppliers in Japan arranging temporal oxygen generators at travel destinations upon request. He also required occasional or unanticipated absences from work due to COPD exacerbation or to attend regular respiratory physician appointments.

The case documented his difficult experience in travelling. For this, he had to carry an oxygen bomb to maintain oxygenation during commuting, which is heavy and occupies space, making it inconvenient to travel on a crowded train in Japan for nearly an hour.

The case later started travelling on wheelchair, which further modified the difficulty in travelling with HOT and referenced his requirement of a wheelchair to travel at the time of the interview. While transport hubs, such as busy terminal stations, provide many so-called “barrier-free ramps”, these may merely be a downhill slope. Mobile phones may narrow the sight of their user, so that they fail to notice him on a wheelchair directly in front of them. Furthermore, there are many small steps or narrow entrances that block wheelchair access in Tokyo, Japan.

Discussion

Summary of the case

We present the case of a patient with COPD who developed CRF and subsequently received HOT and required a wheelchair. Consequently, the patient ceased working because of difficulty commuting while on HOT. There are various factors associated with the CRF patients, respiratory physicians and occupational physicians, as well as the management team of firms and companies, that influenced the decision regarding whether or not CRF patients can continue to work (Table 1): for example, patients need to seek for the means of oxygen supplementation at home, at workplace and during commuting. Their symptoms can be limiting factors in their career. Furthermore, patients with CRF on HOT may need an understanding and support from the workplace, because they may, for example, be absent due to occasional sick leave and may reveal limited job activity. They thus have a risk of losing job and reduction in wages, in addition to the barriers on street in everyday life.

One of the reasons that enabled the patient to continue working for over 5 yr after commencing HOT was access

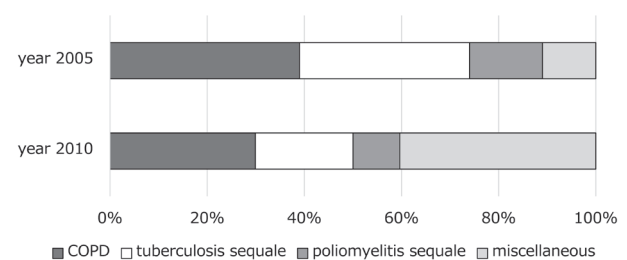
Table 1. Difficulties and barriers experienced by the case (a CRF patient on HOT)

Inconveniences	Patient factors	Workplace factors
Oxygen supplementation	Oxygen generator (bomb) Heavy weight Limiting activities as one hand is required to carry the bomb Occupying space (in a train)	Oxygen generator Occupying space (in working places) Needing for another oxygen generator Unsupported by social insurance Difficulty in long business trip
Symptoms	Dyspnea Limiting travel Slowing movement Expectoration	Limiting activities, due to symptoms and carrying HOT Difficulty in travelling by flight
Social issues	Inadequate barrier-free facilities Many slopes Many lifts Crowded train Possible loss of job Possible reduction in wages (modified by other conditions, such as using wheelchair and comorbidities.)	Needing for understanding in the workplace among colleagues or managers regarding: Occasional sick leave Job limitations Limited travel (length and altitude) Slow movement Oxygen use Smoking ban on workplace

to two oxygen generators, while the social insurance in Japan currently allows CRF patients to have only one, which is usually located at home. Another reason was that his managers facilitated his effort to work at the office while on HOT, and compensated for the inconveniences that arose due to his disease and its treatment. In this way, the patient was able to not only continue working, but also enjoy the clinical benefit of improved prognosis from HOT. However, CRF patients who were successfully treated with HOT and able to continue working, like the presented case, are rare⁴⁾ and the clinical impact of HOT is not usually reflected on the socialization of recipients. Confirming this, a small observational study suggested that 46% of CRF patients on HOT were socially isolated, as measured by the Lubben Social Network Scale (LSNS)⁵⁾, compared to 19.4% of the general population in Japan⁶⁾.

Factors regarding respiratory physicians

Previously, the main respiratory disorders leading to the development of CRF included advanced COPD and tuberculosis sequelae, as noted in the Japanese White Paper on Home Respiratory Care 2005⁷⁾. Patients with these disorders were possibly underweight or of retirement age. However, in the Japanese White Paper on Home Respiratory Care 2010, HOT was predominately prescribed to patients with lung cancer or interstitial pneumonia (categorized in “miscellaneous” in Fig. 1)⁴⁾, suggesting that many of the patients with these diseases were younger and not yet of retirement age. This shift in the distribution of the causative diseases emphasised the importance of

**Fig. 1. Respiratory Conditions leading to the prescription of HOT to CRF patients.**

“harmonization of work with treatment”.

Many respiratory physicians accept and attempt to practice the idea of “comprehensive pulmonary rehabilitation”, including not only pharmaco-therapy, patient education, oxygen supplementation, and physiotherapy, all of which are available at many middle or large sized hospitals, but also socialization.

However, assessing socialization can be difficult as it depends on the severity of the disease and family sub-culture. While there is no consensus on a scale regarding assessment of socialization or working environments, there are well established clinical and research assessment tools to evaluate respiratory symptoms and QOL, such as the modified Medical Research Council (mMRC) dyspnea score⁸⁾, Borg scale⁹⁾, Lung Information Needs Questionnaire (LINQ)¹⁰⁾, St George’s Respiratory Questionnaire (SGRQ)¹¹⁾, and COPD assessment test (CAT)¹²⁾. The SGRQ questions whether patients are working or not, but does not evaluate the work environment or access to the

Table 2. Questionnaires and categories of their assessment^{8–12)}

Generation	Items	Assessment
1st generation	Dyspnea, Hypoxaemia, PFT	mMRC (initial version in 1979) ⁸⁾ Borg scale (1989) ⁹⁾ oxygenation (SpO ₂ , SpO ₂), FEV ₁ , VC, etc.
2nd generation	Prognosis	Mortality (1980, 1981) Other prognostic index (hospitalization, exacerbation etc.)
3rd generation	QOL Patients' education	St. George's Respiratory Questionnaire (SGRQ) (1991) ¹¹⁾ LINQ (2008) ¹⁰⁾ COPD assessment test (CAT) (2009) ¹²⁾
4th generation	Socialization Work harmonization	(Job maintenance)

PFT: pulmonary function test; SpO₂: partial oxygen pressure; SpO₂: percutaneous arterial oxygen saturation; FEV₁: Forced expiratory volume in 1 second; VC: vital capacity; QOL: quality of life; LINQ: Lung Information Needs Questionnaire.

workplace. Based on the evaluation items, Table 2 classifies these assessment tools for respiratory patients into four-generation groups^{8–12)}.

The first generation of assessment tools includes the mMRC, Borg scale, PaO₂, and the forced expiratory volume in one second (FEV₁), to evaluate symptoms and pulmonary physiological conditions at the time of assessment. Second generation assessment tools evaluate therapeutic effect, using mortality and other prognoses, such as hospitalization and exacerbation-free periods. In the third generation, QOL and patient education are investigated using SGRQ or CAT, and LINQ, respectively, making patient-oriented medicine possible. Finally, in the fourth generation, socialization and work harmonization need to be emphasized and assessed, although they are not well established to date (Table 2).

In the super-ageing society of Japan, social isolation is a crucial social and medical issue. Since working provides opportunities for socialization in Japan, the “harmonization of working with treatment” of CRF patients will help these patients achieve better socialization. The establishment and improvements of “harmonization of working with treatment” of CRF patients will allow for its application not only to those working, but also to those with other physical and/or mental disorders, pregnant women and aged people. Therefore, fourth generation assessment tools need to be developed.

From the “harmonization of work with treatment and prevention” to health and productivity management of CRF patients

The patients with CRF who were prescribed with HOT

used to be diagnosed either with COPD or with tuberculosis sequale, and were usually as old as 60s or 70s, when they were already retired from working. As discussed above, the causative diseases for the prescription of HOT have shifted from COPD and tuberculosis to pulmonary fibrosis and cancer^{4, 7)}. In addition, the number of younger and working age patients on HOT will increase due to the currently high proportion of smokers seen after the World War 2 in Japan. Hence, the issue of CRF may likely become a crucial social and medical issue. To address this, Fig. 2 illustrates the approach for the health and productivity management (HPM) of this condition; the concept of which was proposed by the Japanese government¹³⁾, and is discussed in detail elsewhere¹⁴⁾.

When a worker suffers from CRF, he or she will likely to experience a loss in wage, while the company will lose their well-trained work force, resulting in a deficit for both parties (condition A). In instances where CRF patients and respiratory physicians work together to address treatment, symptom severity and physiological parameters, prognosis will be improved, as evaluated using the 1st and 2nd generation assessment tools (Table 2), and will be mainly beneficial for the patients (condition B). In instances of occupational physicians being involved, workers on HOT can continue to work and their QOL will be improved. In addition, the company can avoid losing their well-trained workers, leading to benefits for both workers and the company, which will be further promoted by the participation of the management team (condition C). In this process, occupational physicians may need to understand the clinical relevance of HOT for patients with respiratory diseases who want to work, and to provide special care for these

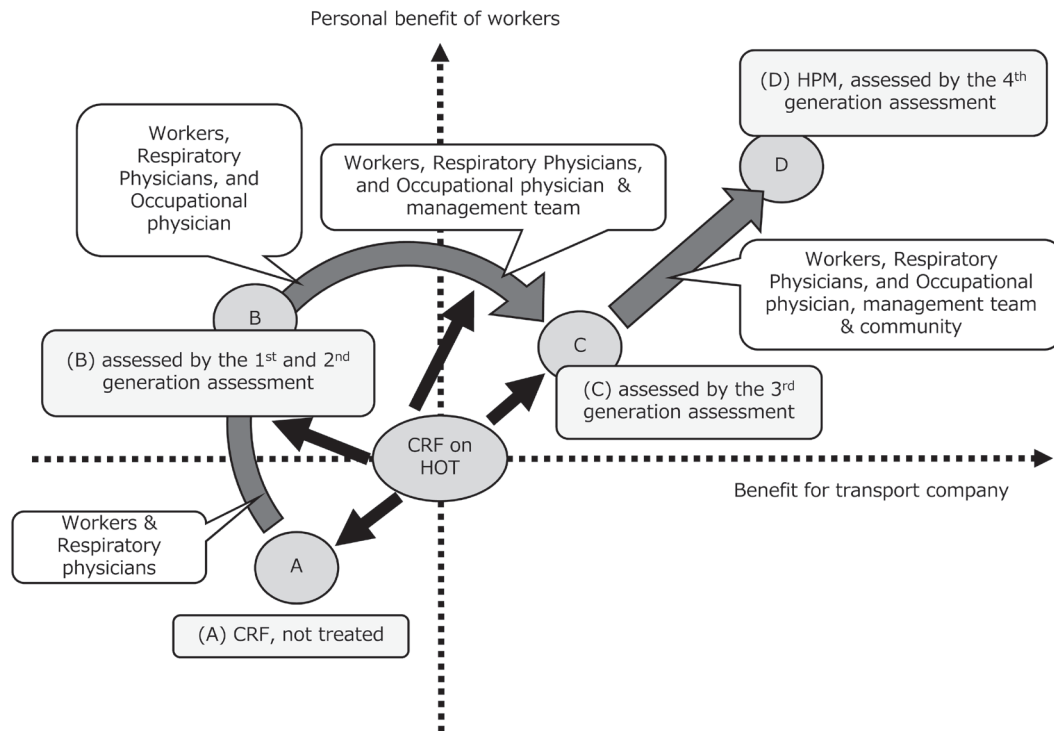


Fig. 2. Harmonization of working with treatment and prevention contributes to health and productivity management, benefiting both the worker and the company¹⁴.

patients, whilst respiratory physicians should take patient working conditions into clinical consideration. The process of promoting the “harmonization of work with treatment and prevention” of CRF patients can also help “comprehensive pulmonary rehabilitation” to be a co-operative strategy involving patients, respiratory physicians, and occupational physicians, as well as the management team.

Furthermore, CRF patients experience improved working lives and socialization with the intense involvement of the community and society, since it was shown in the previous discussion that commuting and travelling can be possible barriers to individuals on HOP. These barriers to CRF patients in the community and society are also barriers to those with other conditions or disorders, such as ageing and pregnancy. Thus, the elimination of these barriers will be beneficial, and subsequently improve both working environments and the community and society as well as lead to the promotion of the HPM (Fig. 2, condition D)¹³. Socialization is the final goal of “comprehensive pulmonary rehabilitation.” Therefore, the HPM and comprehensive pulmonary rehabilitation share a common idea of the “harmonization of working with treatment and prevention.”

Limitations

There are several limitations in the present study. Firstly, only one case is presented and discussed, which may introduce case-specific bias. Secondly, the need for the harmonization of work and treatment for CRF patients may be perceived as minimal, because patients were historically considered older or already retired. However, the recent trend suggests that the more patients on HOP suffer more pulmonary fibrosis and lung cancer than before, and that those patients are young and of working age.

In addition, COPD is regarded as an ageing accelerating disorder, because its co-morbidities (geriatric disease or conditions such as sarcopenia, osteoporosis, stroke, heart disease, pneumonia and cancer) are shared by individuals in their 80s or 90s. Thus, the experience of the present case, who required a wheelchair and portable oxygen bomb, can be generalized and applied to the super-ageing society of Japan. The limitations and the benefits provide the rationale for the future study on the cohort of CRF patients with HOP in association with working.

Conclusion

Patients with CRF on HOT have many issues that need to be addressed regarding inclusion in the workplace, as well as in the community and society at large. The “harmonization of working with treatment and prevention” promotes both HPM and comprehensive pulmonary rehabilitation by improving workplace conditions. It has also been suggested to be important in addressing the various issues of super-aging societies.

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