

Dyspnea management in Palliative home care: A case series in Malaysia  
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Managing dyspnea at home is a challenging task. Although a competent palliative home care team can assist a patient to live at home with better pain control, dyspnea is usually not as well managed. In the Asian context, there are few research studies in dyspnea management in palliative home care. This paper aims to illustrate the cultural context that has an impact on dyspnea management at home and the assessment and management of dyspnea in a community palliative care setting in Malaysia. This paper reports on a study of 5 dyspneic patients suffering from both cancer-related and non-cancer-related dyspnea. Its focus is on a unique Asian cultural belief system that affects communication about prognosis and the role of family in palliative home care. In addition, this paper also describes dyspnea assessment, the barriers to morphine use, benzodiazepine prescription, oxygen therapy, and nonpharmacologic intervention in this center.

## Introduction

Dyspnea is an awareness of uncomfortable breathing sensation and is a subjective individual experience. [sup][1],[2],[3] It results from the interplay between multiple physiologic, social, and environmental factors. [sup][4] The prevalence of dyspnea varies between 10% and 95% depending on the underlying disease and the disease severity. [sup][1],[2],[3],[4],[5],[6],[7] Comparing to pain, dyspnea management at home is poorly controlled. [sup][8] Moreover, community palliative care is given limited investigation and treatment facilities. This paper aims to illustrate the Asian cultural context, which impacts on dyspnea assessment and management at home in Malaysia.

## Materials and Methods

### Setting

The Malaysian organization at which the observation occurred is a charitable organization. The service provides a hospice home care service, after-hours telephone emergency consultation, hospice day care, and a palliative bereavement service. [sup][9] The multidisciplinary team included 7 palliative care nurses, 4 palliative care doctors, one pharmacist, and one occupational therapist. There are nearly 700 home visits per month with more than 1000 individual cases per year. After-hours telephone consultation with palliative care nurse is available for emergency situations. In the case of any emergency hospital admission, palliative care nurses would follow up the person in the hospital.

## Methods

The first author undertook a clinical attachment from November to December 2010, to observe the clinical management of dyspnea and undertake an audit of the associated medical records. The specific focus was documenting care for patients, their families, and the management of attending staff in the community setting in relation to dyspnea management. The Malaysian organization has developed a numerical rating scale for assessing the severity of dyspnea intensity. The scale is as follows: no symptom = 0, mild = 1, moderate = 2, severe = 3, and very severe = 4. This paper discusses case studies where dyspnea was the primary symptom for people with both cancer- and non-cancer-related life-limiting conditions. The cases were drawn from a population of adults over 18 years of age.

## Results

The management of 5 patients during the attachment is discussed in detail in this paper. The underlying diagnoses were neurodegenerative disease (n = 1), idiopathic pulmonary fibrosis (n = 1), and cancer-related dyspnea (n = 3). Their medical records showed that every case was regularly visited by palliative care nurses, ranging from once a week to once a month, depending on symptom severity.

### Non-cancer-related dyspnea

#### Case 1

A 55-year-old Chinese Malay woman with motor neuron disease had gradually become weaker and was now unable to carry out any light duties. After bi-level positive airway pressure (BiPAP) therapy was started, her breathlessness markedly improved (dyspnea score declined from 4 to 2). She also attained normal oxygen

saturation. She now slept through the night despite experiencing a dry mouth and eye irritation. Frequently using artificial tear drop and better sealed the rim of facial mask were advised by palliative care nurse. Apart from BiPAP, she used acupuncture and Chinese herbal medicine.

At the first 2 home visits, time was spent on education about the oxygen therapy and the BiPAP machine as well as preparing an advanced care plan. A family conference was conducted at the third visit. However, the patient was not yet ready to discuss ongoing management issues. Discussions regarding prognosis, potential problems, and the future role of trans-tracheostomy ventilation, were conducted with her sons.

#### Case 2

A 31-year-old Indian Christian woman was diagnosed with idiopathic pulmonary fibrosis. The palliative care team had visited regularly once or twice a month for the past 2 years. She was awaiting a lung transplant. Her pulse oxygen saturation without oxygen therapy was 82%, and 90% with oxygen therapy. The dyspnea score ranged from 2 to 3 at rest and escalated to 4 during exertion. She had a home oxygen concentrator and an oxygen cylinder for mobile use. She was dependent on oxygen therapy all the time. Consequently, she had to quit her job and depends on her husband and her mother for almost all her daily activities. Her main issue was financial as she had a problem with paying for the oxygen supplies. This woman was concerned about being a burden on her husband and her mother, although they can afford this increased expenditure. Her husband works as a merchant and has enough income. She coped with stress by spending her time reading the Bible and went to church every weekend.

#### Cancer-related dyspnea

#### Case 3

A 74-year-old man had stage IV lung cancer with underlying chronic obstructive pulmonary disease (severity of COPD was not documented in the medical record). He suffered weight loss, hoarseness, and progressively worsening dyspnea. Two home visits were performed. His oxygen saturation was 90% with room air and 93% with oxygen therapy. He underwent a second cycle of chemotherapy. He still suffered with dyspnea despite no longer being hypoxic at the second visit (99%-98%). The team started oral morphine immediate release 5 mg to be given when dyspnea occurred. Improvement in his dyspnea was reported after the morphine was administered (dyspnea score decline from 3 to 1). His main care takers were his sister and his wife who supported him very well.

#### Case 4

A 75-year-old Indian Malay woman had metastatic breast cancer to her lung, liver, and bones. She was cared for by the palliative care team for 2 months. She also had ischemic heart disease. The dyspnea etiology was controversial. Initially, her geriatrician treated her dyspnea as heart failure. However, she deteriorated and was admitted to hospital. The home care team visited her after discharge from hospital. Her oxygen saturation was 98% on room air. Many doctors had previously explained the cause of her dyspnea in different ways, and her son was so frustrated and angry relating to the uncertainty around the etiology of her symptoms. Her dyspnea was exaggerated by her ongoing anxiety (dyspnea score range from 3 to 4). Dyspnea causes patients to feel uncertainty and meanwhile it provides no time for the caregiver to implement self-care strategies. This case showed how dyspnea with multiple etiologies can cause anxiety to the patient and contribute toward caregiver burden resulting in the expression of anger. The palliative care doctor tried to coordinate care between the specialties, but it was very difficult to do because of system fragmentation.

The treatment plan consisted of nonmedical method, that is, relaxation and breathing training by physiotherapist, oxygen therapy, and medical therapy, including morphine immediate release 5 mg for dyspnea and abdominal pain, and lorazepam 0.5 mg was given orally as need when the anxiety exacerbate. However, the dyspnea did not much improve. During an episode of dyspnea exacerbation and unbearable suffering, her son took her to hospital, where she died 3 days later.

#### Case 5

A 60-year-old married Malay woman was diagnosed with cholangiocarcinoma. Dyspnea was caused by left pleural effusion, hepatomegaly, and ascites. She understood her limited prognosis and decided that if the condition got worse she wanted to be at home. She previously received sustained release oxycodone 20 mg twice a day for pain from the hospital. To treat her dyspnea, palliative care team prescribed additional morphine immediate release 5 mg when necessary. Although the team tried to convince her of its benefits on 3 consecutive home visits, she did not take the morphine. At the first visit, she did explain that she did not take morphine because she was not sure how to take it. The team tried to describe in detail how to use morphine and a 5 mg morphine immediate release dose was tried. At the second visit, the team again discussed the benefits of morphine and described in detail how to use it. The third visit, 2 days later, she still had not used the

morphine. She mentioned that she can tolerate the dyspnea. The palliative team suggested her to have a thoracentesis at the hospital.

## Discussion

From the 5 cases discussed, 3 important issues emerged:

### The cultural contexts which impact on dyspnea management in the home

The majority of people in Malaysia have extended families and these family resources effectively assist palliative home care. <sup>[10]</sup> Malaysian patients prefer to die at home because of the familiar environment and the convenience for final religious rites, especially in the Muslim community. <sup>[10]</sup> Multiple Malay family caregivers share the caring tasks among each other, which results in a decreased caregiver burden. However, they commonly ask the treating doctor not to inform the patient of the diagnosis or worsening prognosis (Case 1). This caregiver reaction is common in Asian countries in order to protect patients from sorrow and clinical deterioration after hearing the bad news. <sup>[11],[12]</sup> The autonomy from an Asian perspective does not only consider patients' rights, but also the need to involve the opinions of family members. <sup>[11]</sup> This approach is seen as the way to empower the family. <sup>[13]</sup>

### The challenge of dyspnea assessment in the Asian community setting

In this Malaysian organization, the key to success in delivering palliative home care was the continuous education of the staff. New palliative nurses are required to take care of patients under supervision by a senior palliative care nurse for 6 months. Nurses take care of the patients under supervision by the doctor. There is case reporting with the multidisciplinary team every morning. In addition, this organization arranged regular conferences and workshops for their own staff. <sup>[9]</sup>

Dyspnea-specific tools are unlikely to be of practical use in routine practice <sup>[14],[15]</sup>; the main reason is that patients are usually experiencing multiple symptoms. Therefore, this organization simplified the assessment process by using a numerical rating scale for every symptom evaluation. The use of such a scale made it very easy to train nurses and patients in symptom evaluation.

### Dyspnea management at home

Dyspnea tends to worsen in severity and reach the peak in the last week of life. <sup>[16]</sup> The competent palliative home care team can assist a patient's life at home with better symptom control, the handling of sophisticated equipment (Case 1), and proper guidance in medical management (via regular visits and a 24-h phone call facility). With palliative home care support, caregivers may benefit from the experience as they can accept the disease and enhance their problem-solving skills. <sup>[17]</sup>

### System fragmentation

Coordination of care is a difficult issue in this setting. Multiple doctors from different centers were consulted by caregivers (Case 4). The unorganized advice from different doctors and unclear multiple etiologies of dyspnea can cause anxiety for the patient and contribute toward caregiver burden, resulting in the expression of anger. Information exchange and task distribution are the hallmarks of effective palliative home care delivery <sup>[18]</sup>

### Strong opioids

Morphine is the main medication for cancer-related dyspnea palliation in the Malaysian organization, whereas it is not prescribed in case of non-cancer-related dyspnea (cases 1 and 2). They obtain opioids from patients' donation and buy opioids direct from authorized licence pharmaceutical companies in Malaysia. They have no problem with morphine availability.

The nurses monitor side effects by telephone consultation, and if any side effects develop, they may arrange a home visit. During the terminal phase, oral doses of opioids are usually converted to subcutaneous morphine. They need to prepare the subcutaneous morphine, visit the patient every day to check the record, assess the patient and change the morphine syringe. In Malaysia, there is still a culture of resistance to the use of morphine <sup>[19]</sup> (Case 5). Many doctors are unaware of the benefits of morphine, especially in dyspnea palliation. <sup>[19]</sup>

### Oxygen therapy

During home visits, oxygen saturation was measured by the palliative care nurse with a portable pulse oximeter. Although the organization in Malaysia lends oxygen concentrators at no charge, these are a limited resource that needs prioritizing as to who will really benefit the most from this intervention. Evidence to date has shown that oxygen therapy failed to improve dyspnea in nonhypoxemic patients. <sup>[20],[21],[22]</sup> All cases in this

study used oxygen as a treatment for refractory dyspnea and for cultural reasons, rather than a treatment of measurable hypoxia. The attitude of the patient and family in the Malaysian context toward oxygen therapy is that it is a vital life-saving equipment. [sup][23] It is difficult to not prescribe oxygen in dyspneic patients. However, continuous oxygen is not without its adverse effects on quality of life. If patients want to leave their home, to shop or visit friends, for example, they have to spend extra money for portable oxygen tanks.

## Benzodiazepines

Anxiety are common feelings in cancer patients. [sup][24],[25],[26] Case 4 had dyspnea with anxiety. This case was prescribed lorazepam 0.5 mg orally for anxiety concomitant with morphine; however, it was not effective. This finding corresponded with the scanty evidence of benzodiazepines in dyspnea management. The evidence of benzodiazepine benefit of dyspnea management is controversial. Lorazepam can use 0.5 mg tablet sublingually to minimize anxiety attacks. [sup][2] Subcutaneous injections or a continuous subcutaneous infusion of midazolam have been found to be helpful. [sup][2] Combining midazolam and morphine improves the baseline dyspnea control. [sup][27] One study showed that midazolam was superior to morphine in controlling baseline and breakthrough dyspnea while waiting for investigation results. [sup][28] However, this study was confounded by the small population. In addition, both morphine and midazolam groups had already taken morphine for pain control. Moreover, the causes of dyspnea were not yet identified. [sup][28] A recent Cochrane review failed to support the benefit of using benzodiazepine for dyspnea treatment because of small effect size. [sup][29]

The authors suggest using benzodiazepine in dyspnea as an additional treatment for individuals who have anxiety and morphine is not well tolerated or effective.

## Nonpharmacologic management

Case 1 used alternative medicine, that is, traditional Chinese medicine. Physiotherapists and nurses in this center often teach breathing exercise and activity pacing in dyspneic patients.

Nonpharmacologic interventions can possibly modify the perception of dyspnea via several mechanisms. A crossover randomized controlled trial (RCT) significantly improves in dyspnea in those people who directed the fan to the facial area rather than leg. [sup][30],[31] Handheld fans are inexpensive, convenient, enhance self-efficacy and are without undesirable side effects. A handheld fan can improve dyspnea via the central drive by stimulating the cold receptors in the V [sub]2 distribution of the trigeminal nerve. [sup][26] One meta-analysis found strong evidence to support the use of neuromuscular electrical stimulations and chest wall vibrations in the improvement of dyspnea. [sup][32] Walking aids and breathing training have a moderate strength of evidence. [sup][32] However, there is only weak evidence to support the use of acupuncture/acupressure. [sup][32],[33],[34] There was no evidence found for the use of music. [sup][32]

Anxiety-reducing techniques are used for breaking the breathlessness-anxiety cycle. Although it has low supporting evidence and needs special training from experienced staff, these interventions appear to be effective in selected patients. [sup][4],[32] Combined nonpharmacologic managements improve breathlessness, performance status, and emotional states. [sup][1],[35] Patients who participate in pulmonary rehabilitation programs can develop their own self-coping skills, self-acquired expertise, and experience an improved quality of life. [sup][36],[37] Home-based pulmonary rehabilitation can improve dyspnea scores and are as effective as hospital-based pulmonary rehabilitation programs in COPD patients. [sup][36]

Nowadays, nonpharmacologic interventions are increased in evidence on benefit of dyspnea management. These interventions make patients and families feel better and have much more of a sense of self-control. Despite these benefits, nonpharmacologic management is often overlooked. To improve dyspnea management outcome, palliative home care team should combine pharmacologic management and nonpharmacologic management.

In summary, management of dyspnea in home care setting need to consider family and social context in order to implement proper comprehensive management. The evidence-based management is crucially important to efficient and effective management. Finally, the authorities in health care system need to improve the care coordination to prepare continuous, comprehensive care along with the hospital and homecare setting.

## Conclusion

Malaysian patients preferred to die at home with their family's support. Multiple family caregivers were the key to success in dyspnea management at home. The uniqueness of the Asian culture and the individual autonomy concept need to be adapted to involve family opinions in advance care planning. A key success in dyspnea assessment and management by the home care team is continuous education for staff, simplified symptom assessment tools using a numerical rating scale, excellent access to morphine and oxygen therapy availability.

Coordination of care is a difficult problem in this setting. This organization fills this gap by collaborating with the hospital via a referral system, training course arrangements, and case conferences. Opioid phobia and the underuse of morphine in dyspnea management were evident in the cases presented. Despite evidence that oxygen is not standard management for nonhypoxic dyspnea, it is still challenging to not prescribe it for nonhypoxic dyspnea due to patient and family expectations of its benefits. To improve dyspnea management outcome, palliative home care team should combine pharmacologic management and nonpharmacologic management.

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