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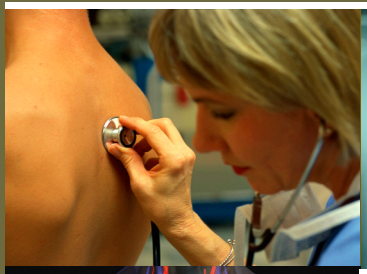
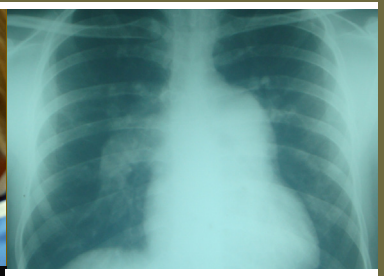
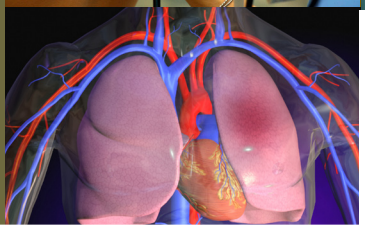

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Case Report Open Access

Barriers to the Provision of Optimal Palliative Care in a Patient Awaiting Lung Transplantation

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Abstract

Idiopathic Pulmonary Fibrosis (IPF) is a chronic, progressive, fatal form of diffuse interstitial lung disease, which is associated with substantial mortality and morbidity. Lung transplantation has become one of the treatments of choice for patients with advanced IPF and has shown a 75% reduction in risk of death compared with patients who remained on the waiting list. Patients undergoing lung transplantation are required to participate in preoperative and postoperative pulmonary rehabilitation. This case report describes palliative and end of life care in a patient with end stage pulmonary fibrosis listed for lung transplantation and discusses the transition from curative restorative care and palliative care to end of life care. The goals of care of patients waiting for lung transplantation should be reviewed regularly and clarified as the clinical condition of the patient changes. End of life care should not only be considered in terminally ill patients or patients who do not fulfil the criteria for lung transplantation, but should also be raised with patients on the lung transplant waiting list. The goal of palliative care is to "enhance quality of life for patient and family, optimize function, and help with decision making" and thus it can be delivered concurrently with life prolonging care.

Introduction

Idiopathic Pulmonary Fibrosis (IPF) is a chronic, progressive, fatal form of diffuse interstitial lung disease, which is associated with substantial mortality and morbidity [1]. The mean survival time for patients diagnosed with IPF is 2.5– 3.5 years. The disease is usually characterized by gradual onset of symptoms, with dyspnea being the most common and disabling symptom.

Risk factors associated with disease development include smoking cigarettes, drug exposure, chronic aspiration pneumonia, infectious agents and genetic predisposition.[1]The management of IPF requires a methodical approach with regular evaluations and the implementation of pharmacological and non-pharmacological treatment strategies [1]. Anti-inflammatory treatments such as corticosteroids and azathioprine have been shown to be useful [2], however, disease progression usually occurs. Lung transplantation has become one of the treatments of choice for patients with advanced IPF [3]. However, patients with IPF are likely to be elderly with multiple medical co-morbidities that may preclude them from lung transplantation. IPF accounts for nearly 30% of lung transplantation procedures performed worldwide [4]. Patients with IPF who received a lung transplant show a 75% reduction in risk of death compared with patients who remain on the waiting list [5]. The chance of death while waiting for lung transplantation is greater for patients with IPF compared with cystic fibrosis and emphysema [6]. Because of the risk of peri operative morbidity and mortality, it is essential to weigh expected survival benefit with gain in quality of life for any candidate waiting for lung transplantation.

Patients undergoing lung transplantation are required to participate in preoperative and postoperative pulmonary rehabilitation. This will help physicians to select appropriate surgical candidates, and also prepare the patients for the physical and psychological stress of surgery [7]. Palliative care originated as end of life care in the 1960s. At that time, it focused on providing control of symptoms and psychosocial and family support during the terminal phase of a serious life limiting disease. Since then its meaning and scope of practice has expanded far beyond its roots. According to the American Academy of Hospice and Palliative Medicine, the goal of palliative care is to "enhance quality of life for patient and family, optimize function, and help with decision making" and thus it can be delivered concurrently with life prolonging care [8]. World Health Organization (WHO) has given a broader definition, which states "Palliative care is an approach that improves quality of life for patients and their families facing problems associated with a life threatening illness. This is provided through the prevention and relief of suffering by means of early identification, accurate assessment and treatment of pain and other problems, physical, psychosocial and spiritual" [9].

The aim of this case report is to describe palliative and end of life care in a patient with end stage pulmonary fibrosis listed for lung transplantation and to discuss the transition from curative restorative care and palliative care to end of life care. It also highlights a need for improved collaboration between palliative care and respiratory team in order to work in a more integrated fashion.

Case Report

The patient, a 54 year old woman, was diagnosed with idiopathic pulmonary fibrosis in 2000. Her past medical history was notable for obesity, gastro oesophageal reflux disease and right knee replacement. She had never smoked and only had a moderate alcohol intake on weekends. She had worked in an aluminium factory as a process worker for fifteen years, and retired in 2009. She had been independent with activities of daily living until a few months before her final hospitalization.

Her disease trajectory was characterized by breathlessness, necessitating long-term ambulatory oxygen therapy and frequent admissions to hospital for exacerbations of lung fibrosis, particularly in the last six months of her life. Her exercise tolerance deteriorated and became limited to 100 metres. For many years she has been treated with

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variable doses of prednisolone and azathioprine. She was assessed for transplantation eight months prior to her death and listed on the active transplant list four months before death.

Her final admission occurred to an acute care tertiary hospital in the thoracic ward for the management of community acquired pneumonia, complicated by type two respiratory failures. Type II respiratory failure is defined as $PaCO_2$ higher than 50 mm Hg. Just prior to this admission her exercise capacity had became limited to 20-30 metres. Due to persistent and significant respiratory failure, she became bed bound and dependent on non-invasive ventilation using bi-level positive airway pressure (BiPAP). She was unable to participate with physiotherapy, which was a necessary component of the preoperative phase of lung transplantation.

She was referred to the palliative care service by the thoracic team two weeks into her final admission for assistance with complex multiple symptom management, and anticipating discharge, for access to community supports. She was commenced on sustained release morphine (*Kapanol)* 10 mg daily, Morphine syrup 2-3 mg prn and clonazepam drops sublingually as required with reasonable improvement in subjective dyspnea.

This admission was further complicated by hospital acquired pneumonia and a further worsening of respiratory failure. She appeared to have fears of impending death and voiced a sense of "giving up." Hope appeared to be a strong persisting theme in her coping strategy – a hope for lung transplantation and resumption of a "normal life." She denied any ongoing depressive and anxiety symptoms and continued to receive psychosocial and emotional support from the ward social worker and the palliative care team. Conversations with her and her family about advance care planning had clarified that she would not receive cardio pulmonary resuscitation or invasive ventilation; although active ward measures and non invasive ventilation were still considered as part of her care plans in the event of a rapid deterioration.

Opioid administration for dyspnea was limited due to concerns of the treating thoracic team about opioid tolerance. Concerns regarding respiratory depression from opioids were also raised by the thoracic team as it was feared this may result in invasive ventilation, a relative contraindication for lung transplantation. The palliative care team attempted to educate the thoracic team about the use of opioids and the evidence that supports use for dyspnea. Her condition continued to deteriorate; the possibility of lung transplantation became increasingly unlikely. There were tensions between the desire of the clinical team to provide good symptom control, particularly relief of breathlessness, and the potential to further limit the opportunity for transplantation. The balance between the restorative curative care and palliative approach was a major challenge for the patient, family and health providers. Although progressive deterioration of her medical condition was well established and acknowledged by the treating team, the focus of care was on lung transplantation. It was extremely difficult for the patient to accept her unpromising situation after many months of "fighting" for lung transplantation. She was hopeful of resuming a normal life and had difficulty accepting that her illness was terminal. She and her family were prepared to accept any treatment that might allow her to receive lung transplantation. These optimistic goals of care appeared to be her major coping mechanism, despite awareness of her continued deterioration and poor prognosis. She remained very hopeful of lung transplantation up until the day prior to her death.

After six weeks of hospitalization and three weeks of continuous deterioration, the focus of her care had clearly changed from curative to completely palliative. She realised that lung transplantation was not a viable option and she continued to experience overwhelming breathlessness and distress. . A continuous subcutaneous infusion of low dose morphine and midazolam was commenced to assist her symptoms. She died peacefully in the hospital in the presence of her family and close friends within 24 hours.

Discussion

This case report highlights barriers to the provision of optimal palliative care, delaying the process of advance care planning, and difficulty balancing the curative restorative care and palliative care to improved quality of life and quality of dying [10].

Over the past two decades, lung transplantation has been recognized to offer significant improvement in survival and quality of life. However, the long term success in achieving these outcomes is limited primarily because of the development of chronic lung rejection and the adverse effects of immunosuppression [11].

In this case one of the barriers to providing optimal palliative care was the patient remaining on the active transplant list even when she had progressive deterioration. This delayed the discussion of end of life care and optimal management of her symptoms, as the patient was frightened that she might be abandoned by the lung transplant team. Despite remaining on an active transplant list, quality of symptom control should not be compromised. Another barrier was the restricted use of opioids, when this had certainly helped dyspnea. There was concern from the respiratory team that excessive opioid administration leading to tolerance and respiratory depression may result in invasive ventilation, a relative contra indication for lung transplantation. An unrealistic patient expectation about her long term prognosis and survival was another barrier for optimal palliative care. Fear of destroying the patient's hope of "new life" also affected the quality of care provided in the terminal phase of illness. All these barriers to optimal palliative care of lung transplant have been described by Colman et al. [12].

Historically, opioids have been used since the 19th century to relieve dyspnea. Opioids were often helpful in relieving breathlessness in advanced respiratory failure. The effectiveness of opioids in treating dyspnea in cancer and COPD patients has been well established [13,14], but they were disappointingly underused. A fear of causing respiratory depression was not found by Bruera et al. [13].

As the patient and her family had a persistent hope for transplantation, the discussion of end of life care and patient preferences had not been initiated in a timely manner. Ideally, an early discussion of treatment preferences of patients with a life limiting disease is a key for the provision of optimal end of life care.This patient was first referred to palliative care four weeks before she died, when her poor respiratory function had severely reduced her quality of life. In this case delayed referral to the palliative care service had hindered the timely discussion of advance care planning. Ironically, the primary goal of care was to maintain patient existence (or well being), so that she could remain listed for lung transplantation. There were ample opportunities for the clinical team to initiate timely advance care planning discussions while pursuing transplantation.

Perhaps despite there being events that might have been anticipated and other unexpected medical changes, there was insufficient dialogue and documentation with her and her family to clarify the goals of care and allow a decision about possibly being removed from the transplantation list and discussion about how this final phase of her life might be managed. Even in the last two weeks of her life a discussion about advance care planning did not occur, as there was a 'hope' for

cure – i.e. transplantation, by the treating medical team, the family and the patient herself.

At times, it is nearly impossible to predict when death will occur or what medical event will lead to a patient's death. Therefore it is important to have ongoing review of the patient's medical condition and advance care planning including review of the patient's treatment preferences. This enables the physician to set realistic goals of care which in turn may minimize inconsistencies in management, at the same time ensuring that the patient and their family's wishes are respected. One should emphasise that the treatment does not stop during the terminal phase of the disease; instead the primary aim will be to alleviate unpleasant symptoms. There is also the opportunity for the patient and family to prepare for death, and time for important decisions to be made such as putting affairs in order and planning a funeral [15].

End of life care should not only be discussed with terminally ill patients or patients who do not fulfil the criteria for lung transplantation, but should also be raised with patients on the lung transplant waiting list.[15]Many health professionals recognize the importance of having discussions about future needs and plans, although uncertainties exist about the timing of, and who in the health team, should have the responsibility for these discussions [16]. In this case choosing the right moment to discontinue curative care and offer only end of life care was a great challenge and therefore, it was reasonable to discuss the patient's preferences for end of life care earlier in the course of her illness, even before her respiratory function was compromised and she became bed bound.

When there is still hope for cure and a better outlook, palliative care planning is often perceived as contradictory to life prolonging treatment. The dual objectives of maintaining hope for transplantation whilst simultaneously preparing for the end of life was a great challenge for this patient, family and her care providers. A decision to forgo life prolonging medical interventions, including BiPAP, would have been made by balancing their potential benefits and burdens.

For patients on the lung transplantation list, the goal is to keep the patient as well as possible until potential donor organs can be found. Given this goal, more aggressive therapeutic options including invasive ventilation, intensive care, enteral feeding, and indwelling catheters are appropriate. However, when there is discussion of potential lung transplantation in the patients whose pulmonary function continues to deteriorate despite maximum medical therapy, issues of prognosis, risk of dying, the potential role and limitations of transplantation, the role of palliative care and the patient's wishes should be raised.

For patients unsuitable for lung transplantation, a planned approach should occur whereby medical therapy for chronic lung diseases continues with an increasing focus on palliation. As palliative care becomes the main focus, the aim should be to maximize symptom relief and quality of life whilst accepting that progressive deterioration is inevitable. In this particular patient's care, communication between the transplant and palliative care team could have been improved. Through improved communication between providers, realistic goals of care are encouraged, whilst the patient and their family's hopes and wishes are maintained.

Conclusion

IPF is a chronic, relentlessly progressive fibrotic disorder associated with substantial mortality and morbidity. Not all patients listed for transplantation will receive a transplant; 50% of patients will die waiting, and for recipients, the life expectancy remains at three to five years. The dual objectives of maintaining hope for transplantation whilst simultaneously preparing for the end of life is a great challenge. In this case despite progressive deterioration, ironically the patient was given hope of lung transplantation until the last day of her life. This resulted insub-optimal end of life care, which was further complicated by the conflicting needs of preparation for possible transplantation and simultaneously optimizing possible end of life care.

Palliative care can be offered concurrently with curative restorative care and the intensity of both cares should be titrated to the needs of the patient and family. In order to achieve the best pre transplant care, it is reasonable to provide the best curative and restorative care, however this approach should not preclude clinicians from early and regular dialogue with the patients and their families to ensure that informed decisions are made on the basis of the benefits and burdens of treatment options as medical conditions change.

In conclusion, the continued aggressive hope for lung transplantation denied this woman the opportunity to receive adequate symptom control and to prepare for the end of her life. Physicians are responsible to timely initiate the discussion of advance care planning and set realistic goals of care earlier in the course of illness. This could potentially improve the overall quality of medical and palliative care.

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