

Palliative care for all Really?

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Introduction

I have a friend, who, alongside her family, struggled with her father's illness for over two years. He travelled a slow and difficult road towards the end of his life. He was diagnosed with a chronic respiratory illness a few years ago, with a life expectancy of six months. The mainstay of their support was the family GP and infrequent visits to the Consultant. When palliative care was suggested by a friend, as a support, their response was 'but he hasn't got cancer'. After a little encouragement and a speedy referral, the local community palliative care team came into their home and he and his family's journey became a more peaceful and managed one. Their journey was transformed, not because palliative care services altered his diagnosis in any way, but because they supported the patient and his family in dealing with the present and immediate future. Palliative care services assisted in managing his symptoms to minimise distress to him, and facilitated his family in keeping him at home, as was his wish, for his final days.

The palliative care needs of people with significant chronic respiratory disease and heart failure have been recognised in international studies for over a decade. However, traditionally, palliative care has been seen as almost synonymous with cancer care, to the detriment of those diagnosed with any other non-malignant (non-cancer) significant chronic illness.

Background

Palliative care is defined was by the World Health Organisation in 2002 as '... an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'. Since the early 1990s, international health policy has acknowledged that palliative care should be available to people with diseases other than cancer, yet palliative care provision in non-malignant illness is still not well developed in an international context.

When examining palliative care provision within Ireland, access of patients with non-malignant diagnosis to palliative care services suggest that only 9 % of all referrals to

the palliative teams were from patients with a non-malignant diagnosis. Traditionally, palliative care has been offered most often to people suffering from cancer, despite the four highest causes of death being chronic illnesses other than cancer. So do we find ourselves in a situation of a 'two-tiered' delivery of care for the palliative patient? Patients with cancer and their families are offered and encouraged to utilise the palliative care services, yet patients with non-malignant chronic illnesses remain self-caring.

Why is it that patients with non-malignant illnesses are not being referred to palliative care services? It could be partly because the disease trajectory of cancer is more predictable including predicting life expectancy, which makes recognising and planning for the needs of patients and their families easier. As well as the uncertainty in identifying the trajectory of the disease process, there is also the difficulty in relation to the reluctance of people to speak about death and dying. It is almost as if death is a more immediate thing when talked about. This would be true of patients with all types of diagnosis. Yet, this reluctance seems more prevalent in relation to significant chronic illnesses, from both a patient and healthcare professional point of view. Again, this may be because of the unpredictable nature and potentially lengthy duration of the non-malignant chronic illness. There is evidence to suggest that there may be a lack of knowledge or understanding of palliative care on the part of many medical teams, as well as a lack of understanding on the part of many patients and the role of palliative care. This lack of understanding is surely an influencing factor in referrals to the palliative care services.

But am I making something of nothing here, is it an issue for patients with significant chronic illness, to have limited access to palliative care? Does it affect their symptom management and quality of life? Would it not be interesting to see how do patients with significant chronic illness manage without a palliative care input?

Method

The aim of this study is to explore the experiences of palliative patients with chronic illness in relation to their own symptom management as this management is the purpose of palliative care services. Symptoms are considered in a broad sense, in relation to physical, psychological and spiritual, as per the definition of what palliative care is. The chronic illnesses considered in this study are Chronic Obstructive Pulmonary Disease (COPD) and Heart Failure. Patients are being asked to share how they are managing the symptoms of their disease. Patients share their story with me, by means of interview. Grounded theory involves analysis of the information, to allow development of theories about the patients experiences based on their interviews, rather than on my prior beliefs about the topic. Ethical approval has been granted for this study. Recruitment is ongoing and patient interviews have commenced.

Conclusion

The information will provide a framework for improvements to clinical practice by helping caregivers understand chronically ill patients' palliative care needs. The findings will be discussed with groups responsible for delivering palliative care and developing policy relating to palliative care in Ireland, with the aim of achieving improvements for chronic illness management.

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