



Blog of the Month

AMPJ Blog of the Month: May 2022 Edition

Dr Sophie Gregg and Dr Elaine Cunningham are Palliative Care registrars based in Northern Ireland. Their interests include palliative medicine and non-malignant disease, the utilisation of the Palliative Care Outcome Collaboration in the hospice setting and medical education. For this month's APMJ blog post, they share with us a piece on the 'labelling' of patients that can take place amongst those with life-limiting illnesses. Thank you both!

Interested in submitting something yourself, have any comments or questions on this piece? Email submissions.apmj@gmail.com or tweet us @APMJuniors

"Oh, they're palliative now"; a discussion around how patients receiving palliative care are often labelled

Sophie Gregg and Elaine Cunningham

Having worked in a specialist palliative care unit over the last year, we have had the privilege of providing care to patients who have life-limiting and terminal conditions. Patients are admitted from the community and acute hospital setting for a period of specialist symptom management, among other reasons. Many of these patients, with improvement in their symptoms, have a renewed *joie de vivre* and improved quality of life, creating a precious space of time for them to make memories and enjoy life.

Perceptions of Palliative Medicine, from the view of those who haven't had the opportunity to work in the speciality, can be vastly different to the reality. We endeavour to treat our patients with compassion, empathy and respect but Palliative Medicine is not mere handholding of the patient as some believe it to be. It is a dynamic and evolving speciality, reflecting the diversity and complexities of our patients. To quote Dr Michael Kearney, a world-leading expert in the field of Palliative Medicine:

*"Patients with incurable illness must no longer be viewed as medical failures for whom nothing more can be done. They need palliative care, which does not mean a hand-holding, second-rate, soft option, but treatment that most people will need at some point in their lives, and many from the time of diagnosis, demanding as much skill and commitment as is normally brought into preventing, investigating and curing illness."*¹

The labelling of patients receiving input from the Palliative Medicine team is a significant problem in our healthcare system. Many patients are deemed “palliative” and this label can have a pervasive toxic effect. For the patient, this can have a number of negative associations. Labelling can lead to patients feeling abandoned by their primary healthcare team and they may feel that a limit has been put on their treatment or care plan. Assumptions can be made by healthcare professionals about a patient’s treatment based on the fact that “they’re palliative”, rather than an assessment of the patient’s need. For medical and healthcare professionals, a patient being branded as ‘palliative’ can impede discussions regarding the provision of care and open communication.

In our experience, this occurs quite frequently when discussing patients’ care with specialities with less experience of palliative care. When discussing interventional drain placement for patients with pleural effusions or ascites to manage symptoms, on a number of occasions we’ve been asked, “but they’re palliative, do they really need the drain?”. It seems to be that patients with terminal conditions receiving input from palliative care teams can have some appropriate treatments, which may help with their quality of life, withheld by mere association with our service. Prognostication remains an extremely difficult, some may say impossible, skill to learn and there is no one size fits all.

Referral to Palliative Medicine is prompted for numerous reasons, such as support in the community, symptom assessment, rehabilitation or indeed for end of life care. The rhetoric “oh they’re palliative” can be an extremely dangerous and damaging statement. The involvement of the Palliative Medicine service does not define our patients, in the same way that their particular diagnosis should not define a patient. Our cohort of patients ranges from people with chronic diseases, to patients living for years with new life prolonging oncological treatments. Each case is individual and no umbrella term is appropriate. The appropriateness of a particular medical intervention needs to be examined on a case-by-case basis in conjunction with the patient themselves. Jennifer Temel’s paper published in the NEJM highlighted the benefit of early integrated palliative and oncological care.² More and more patients are on active treatment with their oncology team whilst receiving input from our service. Interventional radiological procedures and treatment of intercurrent sepsis is often appropriate, when the decision is carefully considered.

It is essential that the primary team referring patients to palliative care are mindful of the implications the referral may have for the patient and their family. A referral to palliative care needs to be tactfully discussed with the patient. Some patients who are referred without an appropriate discussion are so fearful that they refuse to see the palliative care team. For others, referral to palliative care equates to being ‘terminal’. This can be especially problematic for patients who have metastatic, but stable, cancer. These patients may live for some time with their disease but may live in a constant state of fear that they may deteriorate and die at any point.

The Irish healthcare system and its staff are currently under remarkable pressure. Using shortcuts such as using the patient’s room number instead of their name on rounds or descriptors such as “the palliative patient” to colleagues may save seconds of time but is dehumanising for our patients. Language matters and patients pick up on clinicians using language like this and may carry the memory of it and how it made them feel with them throughout the rest of their journey.

It is essential that we continue to be mindful of the unconscious bias that terminology can cause and promote the avoidance of damaging labels in our healthcare system.

References:

1. Kearney M. Palliative Care in Ireland. Irish Coll Phys Surg 1991; 20(3):170
2. Temel J, Greer J, Muzikansky A et al. Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. N Engl J Med 2010; 363:733-742

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