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Patient Issues: Demystifiying Palliative Care

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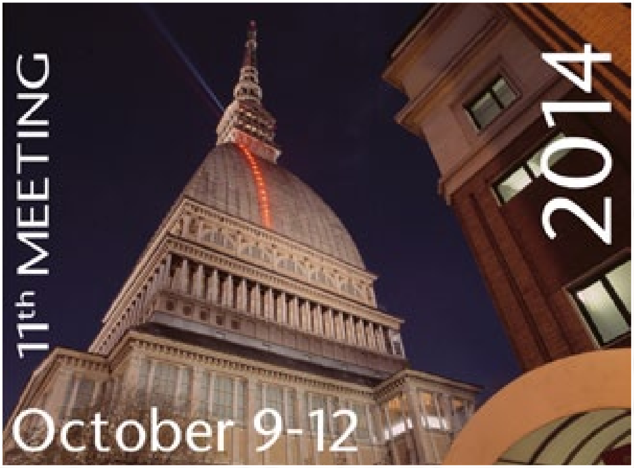

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Demystifying Palliative Care

Kathy Oliver

According to the *New England Journal of Medicine*, palliative care has "an identity problem" [1]. If you ask the man in the street about palliative care, he will most likely say: "It means you're dying." An article in the US National Pain Report (sponsored by the National Pain Foundation) talks about palliative care as part of a "conspiracy of silence" [2]. A 2011 national survey of 800 adults in the United States found that 70% were "not at all knowledgeable" about palliative care [3].

And when palliative care is mentioned to them, the first reaction of many people with a life-threatening illness is often one of fear, because it is associated in their minds with the end of life.

Palliative care: perceptions are confused

Public awareness of palliative care – what it is and where and when it should be optimally provided – is, at best, confused. The WHO definition explains that palliative care "… *is 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.*" [4]

In the survey mentioned above, palliative care is further defined as "… *specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain and stress of a serious illness – whatever the diagnosis … Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.*" [5]

Yet the popular belief is often that palliative care is singularly associated with death and dying. While palliative care certainly plays a critically important role at the end of life, good palliative care is also very relevant to many earlier stages of a disease trajectory, often a considerable time before death is approaching.

The understanding of palliative care amongst healthcare professionals also seems confused. Some physicians asked about the definition of palliative care in connection with the US survey responded: *"[Palliative care is] comfort care during one's last few weeks of life to allow patients to pass in comfort and dignity." "Palliative care is helping families to give them comfort and options for what to do at their loved one's end of life."*

Palliative care for the whole brain tumour journey

In reality, palliative care is not just for people who are dying. Effective anti-epilepsy medication for brain tumour patients with seizures, for example, is palliative care. Help in coping with fatigue is palliative care. Psychological support to combat anxiety and depression is palliative care. Spiritual and existential counseling are facets of palliative care.

For people diagnosed with brain tumours, high-quality early palliative care is essential. High-grade brain tumours, in particular, can cause significant morbidity. Patients can experience severe headache, nausea, vomiting, intense fatigue and seizure activity. Additionally, patients may suffer from aphasia, impaired vision and hearing, hemiparesis, and mood/personality and cognitive deficits. The needs of patients with brain tumours (particularly glioblastomas – GBMs) are complex and require a multi disciplinary approach. Yet, as identified by Lin et al in their paper on "Neuro Oncology and palliative care: a challenging interface", few multidisciplinary teams routinely include in their core group palliative care members [6].

The paper goes on to argue that *"Palliative care teams bring complementary expertise in symptom management, communication skills and practical physical and psychosocial support, both within and outside the hospital environment. With the known consequences of GBM diagnosis, it follows that palliative care should and must become an integrated standard part of best practice neuro-oncologic care…Given the demonstrated benefits of early palliative care integration with anticancer therapies in other cancer diagnoses, the time for robust investigation into palliative care for patients with GBM is now."*

Indeed, several randomized studies very much support the notion that the sooner palliative care is provided to cancer patients, the better this difficult journey becomes for them. Early palliative care intervention can have a very positive impact, resulting in better symptom control and thus significantly improved quality of life.

One study involved 151 metastatic non-small-cell lung cancer patients randomized to receive early palliative care with standard oncological care or standard oncological care alone. The study found that the patients who received early palliative care reported a better quality of life and survived more than two months longer on average than the patients in the standard oncological care only-arm of the study (11.6 months versus 8.9 months), even though the patients in the early palliative care arm received less aggressive end-of-life care [7].

Debunking myths and misperceptions

But what about the need to demystify palliative care, to make it more understandable to patients and their families so that the mention of it doesn't instill confusion and fear? And how can we dispel the popularly-held myth that palliative care only means end-of-life care?

Good, clear communication is paramount. It is important that the professional palliative care community ensures that their messages to patients and caregivers about this crucial aspect of the cancer journey are not disparate but rather that they are consistent across the field.

A good example of promoting clarity and consistency in the way palliative care is described is the online glossary of palliative care terms produced by the Palliative Care Programme Working Group of the Irish Health Service Executive (HSE) [8].

Additionally, palliative care specialists should be given every opportunity to have a much more open and frank dialogue with stakeholders – from patients, families, caregivers and healthcare providers to the media, general public and politicians.

Pragmatic suggestions as to how this can be achieved include easy-to-understand, general purpose leaflets on how palliative care is practiced; specific instructions on how patients can make contact with palliative care specialists and discuss their needs; and media campaigns in the national press. It's also vital that the added value aspects of early intervention palliative care are brought to the attention of key opinion leaders and politicians so that they can support better understanding of the service and promote its importance in terms of prioritizing healthcare expenditure.

Auditing the effects of palliative care is also important. Systems to obtain feedback from patients about the palliative care they are receiving, and its outcomes, as well as seeking the opinions of family, friends and caregivers would be useful.

Of course, pro-active steps like these require both human and financial resources and lack of these is recognized as a barrier which also needs to be addressed.

An important role for brain tumour patient organisations

Brain tumour patient organisations and charities can play a key role in changing attitudes towards palliative care. An important strategy for improving public awareness about palliative care is providing education and publicity – two areas in which many patient organisations have much experience and know-how which they can use to help achieve a better understanding of what palliative care means and the advantages which early intervention can bring.

Brain tumour patient organisations also have extensive networks through which to spread information about the benefits of early palliative care. The palliative care team might even involve representatives from patient organisations who can provide support and information about, for example, social workers and counsellors or religious and spiritual care workers.

Finally, in order to demystify palliative care so it is better understood and better integrated into standard oncological practice, do we need to take radical steps? There seems to be increasing confusion about the use of palliative care terminology. It is important to be consistent and clear.

Should we accept the suggestions from some that the descriptor "palliative care" should be jettisoned and replaced with a term like "supportive care" or "comfort care" or "quality of life care" thus moving away from the widespread belief that palliative care equates only to hospice and end of life care? Whatever you call it, we need to be much more open in our discussions about palliative care.

People need to understand that palliative care is not an approach only associated with dying – nor that the timing of its implementation for individual patients means that all hope has been abandoned.

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