Standards and norms for palliative care in Europe

“The *White Paper on standards and norms for hospice and palliative care in Europe*, which is an official position paper of the European Association for Palliative Care (EAPC), is published in the *European Journal of Palliative Care* in two parts, the first of which appears in this issue (see pages 278–289). It is a welcome piece of research that one could consider to be well overdue. It sets out to establish uniformly accepted definitions of essential elements in palliative care. If you cannot define the terminology, you cannot measure the consistency of quality, or reliability of services, across different organisations in different countries. If you cannot measure services, you cannot compare them. If you cannot compare them, you cannot improve them. Shared understanding of terminology, values, levels of care, patient groups and service settings across Europe is thus essential. It is the first step to ensuring that quality programmes, with reduced variation, are promoted across Europe. Collaborations can then be facilitated between palliative care programmes across various settings.

It is interesting to note the definition of supportive care given in this *White Paper*. It is defined as ‘the prevention and management of the adverse effects of cancer and its treatment’. Further along, the *White Paper* specifies that ‘supportive care should not be used as a synonym of palliative care. Supportive care is part of oncological care, whereas palliative care is a field of its own extending to all patients with life-threatening disease’.

Why should the term supportive care not apply to non-malignant diagnoses such as pulmonary hypertension (PHT)? By definition, all patients with PHT are palliative and they may be receiving treatment not dissimilar to antineoplastic treatments. The differentiation between supportive care and palliative care is thus confusing and may not be helpful. Perhaps this terminology has evolved with the development of the services within a predominantly cancer framework. However, given that 1.6 million patients in the European region will die from cancer and approximately 5.7 million from non-cancer chronic diseases, perhaps, in time, supportive care should become more inclusive.

The *White Paper* acknowledges that 95% of all patients currently treated in specialist palliative care services have cancer. It suggests that providing access to high-quality care for non-cancer patients should be a priority of national and European health policies. If this paper has done one thing and one thing only, by sharing a common understanding, it has highlighted the need for services in the non-cancer population, and it urges national health strategies to address the need for additional resources for this group of patients.

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The *White Paper* challenges the perceived wisdom that 50 palliative care beds are needed for one million inhabitants, suggesting that 80–100 would be more appropriate. The 2008 *End of Life Care Strategy* in England is designed to allow patients to die in their preferred place, which is usually home. It sets out to create strategies for specialist palliative care professionals to empower generic professionals to take the responsibility for the care of patients dying in their own home. Several pilot models of such care have shown this to be possible. The trend is thus away from specialist palliative care beds, even for patients with non-malignant diseases. The jury is thus probably still out as to whether or not additional resources should be focused on inpatient beds or improved community services.

The paper points out the value of good communication skills, which are an essential prerequisite for quality palliative care. Where communication in palliative care is effective, complaints and professional stress decrease and patient care improves. This *White Paper* is to be applauded, as it is indeed an important step to good communications between palliative care units across Europe.”

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