Who’s afraid of palliative care?

“The palliative care movement is still in its infancy. Although the idea is now widely publicised, many people who need such care experience difficulties accessing it, even in countries where it is well developed. Lack of opioids, lack of education and training, and lack of care institutions are among the obvious problems that have been identified by the World Health Organization.

There is also resistance to the development of palliative care arising from people’s perceptions of it. The term itself is not self-explanatory. We need to explain what we mean by it not only to patients and their families but also to our colleagues in the medical world. The word palliative has negative connotations, evocative of termination of care and of death. It is something of a paradox that, in the mind of the public, the word means precisely the opposite of what we want it to say. We want to make it clear that we are delivering proactive care, in which the person is considered to be alive until the end.

Perhaps the word ‘palliative’ is inadequate? But what other word could we use? It is interesting to look at what palliative care institutions choose to call themselves, often dropping the word in their designations. It is tempting to avoid using the word in order to sound politically correct, and to talk, for instance, about ‘supportive’ rather than ‘palliative’ care. However, this trick of language is complicit in the denial of death, which is so typical of our societies. It feeds the silent fear that surrounds palliative care.

Palliative care specialists worldwide complain that patients are not referred to them until far too late in the course of their disease. Yet the WHO and the European Association for Palliative Care recommend early referral, considering it beneficial for patients as well as their families. Early referral enables better assessment of the person’s needs and allows healthcare professionals to anticipate crisis situations.

So why are patients referred to palliative care services so late? Is it the patients who are afraid of palliative care, or is it their doctors? Some GPs, arguing that their patients are not ready, postpone their referral to a palliative care specialist team for as long as possible. However, in an emergency, those same patients might well be admitted to a palliative care service without any preparation whatsoever.

Do patients fall into the palliative care category only when other services lack capacity? Why do some doctors – who never hesitate to seek a specialist’s opinion – avoid calling their colleagues from palliative care when their patient or the patient’s family needs it? Could it be that healthcare professionals are reluctant to recognise palliative care as a specialty in its own right?

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Only a few countries recognise palliative care as a specialty, but the number is growing. Furthermore, people who work in this field develop skills and expertise that can be acquired only through the practice of palliative care.

Maybe one of the reasons why palliative care is still not commonly accepted lies in one of its core principles: the patient must be at the centre of care. This is not a problem in itself, but it is a principle that should apply to all areas of medicine, not just to palliative care. In that sense, perhaps it acts as an unwelcome reminder to a medical profession that sometimes treats the condition rather than the person.

The palliative care model, based on interdisciplinary work, is a challenge for our healthcare institutions, which are highly hierarchic, compartmentalised and resistant to change. Healthcare professionals usually agree on the principles, but when it comes to implementing teamwork, trouble starts.

How can we ensure that palliative care is accepted, both inside and outside the medical world? Alongside our efforts to achieve excellence in the fields of clinical management, research and education, perhaps we ourselves should resort to the help of specialists … in communication?”

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