Translating the World Health Organization definition of palliative care into scientific practice

According to the World Health Organization (WHO), palliative care is concerned with the physical, psychosocial, and spiritual problems of patients with life-threatening illnesses and of their families. This is a tall order for clinical practice, let alone scientific research. Clearly, this task cannot be mastered by one single profession, but requires a cooperation of several disciplines. This has been a hallmark of palliative care teams since the very beginning – Dame Cicely Saunders, who had been trained as a nurse, social worker, and physician, referred to herself jokingly as a “one-woman multi-professional team.” In clinical practice the exact roles and boundaries within the palliative care team often have to be renegotiated periodically. The blurring of professional boundaries can be very beneficial for the overall task to be accomplished, but can also lead to misunderstandings and conflicts between team members. Balfour Mount, the great pioneer of palliative medicine, has been quoted as saying: “So you worked in teams? Show me your scars.”

One way to improve this situation is to look at the specificities of each profession when analyzing palliative care service provision in research projects. Another way is to try to integrate the different professional viewpoints in palliative care research and teaching activities. This is easier said than done, though, because the culture, way of interacting, and research methodologies vary greatly among the different profession involved in palliative care. True interdisciplinary research has to start by acknowledging the unique contribution that each profession and discipline brings to the whole. Even more importantly (and difficult for some, especially doctors) is the acknowledgement of the fact that nowadays no single profession has the ultimate say with regard to the primary outcome in palliative care: the quality of life of patients and their families. Rather, a multiperspective approach is required, taking into account the strengths and weaknesses of each discipline and methodology.

To achieve this goal, it is necessary to allow for each profession to develop its own scientific standpoint within palliative care research, and to then integrate the various perspectives in an interdisciplinary fashion, without pre-conceived hierarchies. In Europe, this has traditionally not been the case so far. Professorships in clinical subjects at medical faculties are usually strictly limited to physicians, and the focus of clinical research is almost uniformly mono-disciplinary. In some instances, this has led to a problematic evolution in the understanding of palliative medicine as a clinical and scientific discipline. Especially in countries such as Germany and Italy, there is a strong push to define palliative medicine as a kind of sub-discipline of pain therapy, and to focus research in the field almost exclusively on pharmacological pain treatment and symptom control. This approach has the strong backing of the pharmaceutical industry, is easier for the medicalized healthcare system to understand, and is therefore more likely to attract funding. Thus, it represents a significant threat to the holistic approach of palliative care.

The only effective counter-measure to such an evolution appears to be a strengthening of palliative care as a self-standing, trans-disciplinary academic subject, with independent chairs and autonomous research programs, in accordance with the WHO definition. In order to achieve this goal, a multi-professional academic network is required. At the Interdisciplinary Center for Palliative Medicine of the Munich University Hospital, such a network has been created thanks to the generosity of several donors, who have allowed for the establishment of four endowed professorships covering the three main domains of palliative care defined by the WHO (Figure 1):

1. A chair in palliative medicine (the incumbent is a neurologist and palliative care physician), responsible for teaching and research at the University of Munich, which has been the first
German medical school to introduce palliative medicine as a mandatory core curriculum subject in 2004.

(2) An associate professorship for pediatric palliative medicine (the incumbent is a pediatrician and palliative care physician), co-based at the Children’s Hospital of the University of Munich. The professorship has established an officially recognized pediatric palliative care network for the whole of Bavaria (12.5 million inhabitants).

(3) An associate professorship for social work in palliative care (the incumbent is a social worker and communication scientist), in cooperation with the Munich Catholic University of Applied Sciences, where the training of social workers takes place.

(4) An associate professorship for spiritual care (with two incumbents one a physician and Catholic theologian; and the other a Protestant theologian and hospital chaplain), in cooperation with the Catholic and Protestant theological faculties of Munich University. To our knowledge, this is the first professorship of its kind in a medical faculty in Europe.

The strength of such a network lies in the opportunities for joint research and teaching projects, which can take advantage of the different viewpoints and methodological strengths of the disciplines involved. Biomedical research is traditionally oriented toward quantitative methods, “hard” outcome measures such as survival time, and randomized controlled studies. The social sciences, on the other hand, contribute their invaluable expertise in qualitative research, allowing for optimal design of cooperative mixed methods trials. Finally, the humanities, such as philosophy, ethics, and theology, favor a hermeneutical, interpretative approach that can be extremely helpful when dealing, for example, with complex end-of-life issues such as the discussion on persistent vegetative state or physician-assisted suicide.

Correspondingly, the research meetings at the Munich center always comprise at least five professions (physicians, nurses, social workers, psychologists, theologians), and additionally have as frequent guests colleagues from the departments of philosophy, ethics, sociology, law, and others. This is reflected in several ongoing research projects within the network, including, for example, meaning in life in pediatric palliative care, sexuality and intimacy in palliative care patients and their relatives, the role of psychosocial and spiritual care in home palliative care service provision for children and adults, the needs of relatives of brain tumor patients, the role of the physician in taking a spiritual history, and a larger project entitled “Palliative Care: a Paradigm for a Change in Professional Attitudes” (in collaboration with the Department of Sociology).

In the teaching curriculum in palliative care at Munich University, the interdisciplinary approach has been present from the beginning, and has led to a three-step approach starting in the third semester with the “breaking bad news” seminar. In the sixth semester, part 1 of the mandatory palliative care seminar covers the topics of psychosocial care, spiritual care, grief, and end-of-life decisions. All tutors in part 1 are non-physicians (social workers, psychologists, chaplains, nurses), a novelty in Germany for a mandatory subject in a medical faculty. In the ninth semester part 2 of the palliative care seminar, taught by physicians, deals with pain therapy, symptom control, and issues such as nutrition and hydration in the terminal phase.

Thus, the multi-professional academic network at the Interdisciplinary Center for Palliative Medicine in Munich aims to provide a workable model for the implementation of the WHO definition of Palliative Care into research and teaching practice, and may, one hopes, contribute to the strengthening of palliative care as an independent academic discipline. The important missing part is a professorship for nursing care research in palliative care, which we hope to establish in the future.

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