

# The implementation of palliative care: opening Pandora's box?

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Due to the rapid influx of palliative care and hospice services over the last two decades, there has been an increase in the number of medical professionals interacting with palliative and terminal patients (1). However, how do we integrate and pay for these services into already busy practices along with providing physicians the education and tools they need to deliver qualified palliative and terminal care? Palliative care programs still have to proceed to be implemented in various health care settings almost everywhere in the world... but many questions remain about the clinical implications of such programs, the scope and services included in palliative programs, and the financing and organization of these palliative programs. The aim of this Editorial is to identify and discuss some of the issues that are associated with the implementation of a comprehensive palliative care program.

The study by Dev *et al.* (2) analyzed the implication of the introduction of a palliative care program at an academic cancer center in the United States between 2000 and 2010 by analyzing the billed palliative care consultations and follow-ups. The researchers found that the number of both in- and outpatient consultations grew considerably in ten years, thereby increasing the clinical burden for physicians, advanced practice for nurses and physician assistants, and ultimately requiring the recruitment of additional staff in an academic center where 12 of the 569 operational beds were dedicated to acute palliative care.

## Clinical implications

Worldwide there is progressively more awareness about the need for palliative care for both oncological and non-oncological patients. All the palliative care programs recruit increasing numbers of patients in the last two decades. It

would be nice if all health care providers become more and more familiar with the basic principles, attitudes and skills of palliative care and that they implement palliative care in their standard clinical practice. This requires that palliative care is part of the basic education of the different health care curriculums and that palliative care issues are part of permanent education programs. In such a clinical environment, only palliative patients with complex or refractory symptoms have to be referred to the dedicated palliative care providers and this referral is preferably as close as possible to the place of care of the patient. The integration of routine palliative care in normal clinical practice makes the clinical workload of professional expert palliative care facilities more feasible with their limited number of experts in palliative care.

But with this ideal scenario of palliative care in echelons is the number of palliative care patients permanently growing everywhere for two reasons: firstly there is the aging of the population and secondly many relatively acute fatal diseases in the past become more chronic diseases with survivals of several more months and even years with a limited quality of life, therefore needing appropriate symptom control. A Belgian study estimated that there are permanently between 10,000 and 20,000 palliative patients out of 11 million inhabitants in Belgium for which less than 400 dedicated palliative beds are available (3). Although these numbers highlight a discrepancy between the potential high demand for palliative care and the limited supply of palliative care beds, it should be stressed that a minority of palliative care patients need a residential palliative bed given that most of them like to be cared for at home. However, in reality many patients do still consult hospital-based physicians as did the US patients in the

outpatient clinic and even die in hospital (2).

Therefore, policymakers and home care providers have to organize palliative care facilities at home and in residential homes for elderly persons for both oncological and non-oncological patients, so that they can get professional palliative advice where they live instead of that these less mobile or immobile patients have to be transferred to hospital-based palliative care providers. Belgium is a nice example where by law patients have the right to get professional palliative advice everywhere they are cared for. There is a geographical spread of palliative home care teams, organized and paid by the government, proportionally to the density of inhabitants. All hospitals and residential homes with more than 60 beds are by law obliged to organize palliative care for their patients. Belgian home care teams care for rapidly growing numbers of patients at home and so the number of home cared palliative patients that need to consult the outpatient hospital palliative care clinic is less rapidly increasing than in the US publication (2).

### **The scope and services included in palliative programs**

A comparison of the clinical burden of palliative care programs between health care settings is fraught with difficulties given that the content of programs may differ between countries and settings and given that patients may select a program for specific reasons (3). The implementation of a palliative care program is not restricted to the physical symptom burden. When using the definition of palliative care by the World Health Organization (4), it is clear that quality of life, effective pain therapy and relief of other physical, psychosocial and spiritual needs are equally important. As a result, palliative care has to be based on an interdisciplinary approach. In the US-academic cancer center, the palliative care team included a social worker, psychiatric nurse counselors, physical and occupational therapists, a case manager and a chaplain in addition to physicians, (advanced practice) nurses and physician assistants (2).

### **Financing and organization**

The growth of the palliative care program at this academic cancer center increased the clinical workload of staff that much that it necessitated the recruitment of additional staff (2). The costs of palliative programs in hospital are

not limited to health care staff, but also include costs of laboratory tests, imaging medicines, medical devices, and interventions, infrastructure and energy, nourishment and other costs... When calculating the costs of palliative care, attention needs to be paid to the following issues (3). First, researchers can choose to compute costs based on actual resource use (as derived from for example accounting data), charges based on reimbursement tariffs, or a combination of both. Second, researchers need to identify, measure and value costs attributable to palliative care, which in practice can turn out to be a challenging and resource-intensive exercise. Third, the costs of a palliative program depend on the services included in the program and requires that researchers can evaluate critically the relevance of some diagnostic tests and therapeutic interventions that are carried out for palliative patients. In other words, the timing of the transition from a curative approach to a palliative care approach and the activities performed within the palliative approach are crucial.

An English study declared that the “Delivering Choice programme in Lincolnshire” significantly increased the proportion of deaths at home and decreased the proportion of deaths in hospital, while keeping the overall combined cost of acute and community care stable for patients with cancer receiving palliative care in the last eight weeks of life (5). A study done by the Belgian Healthcare Knowledge Centre showed that patients labeled as palliative care patients cost less than patients with the same length of life and the same burden of disease but who were treated according to the classic standards of health care (6).

### **Conclusions**

The palliative program at the academic cancer center consisted of an inpatient palliative care unit, a mobile consultation service and an outpatient supportive care clinic (2). This design reflects the continuous changing needs and wishes of palliative patients. Patients can be cared for in hospital for a crisis, but can draw on transmural models that allow patients to go back home or to a nursing home following the crisis. Nevertheless, the majority of clinical activity in the palliative care program at the academic cancer center was in the inpatient hospital setting (2). Similarly, the study by the Belgian Healthcare Knowledge Centre found that hospitalization is the major cost driver for palliative patients in nursing homes in Belgium (7), but that it is much cheaper in the

hospitalization to care for the “palliative” labeled patient than for the “non-palliative” labeled patient (6). This study confirmed that in time palliative care can decrease health care costs compared to classic care in hospitals.

Finally, many questions remain about the implementation of palliative programs. How do palliative programs compare to usual care programs for terminal patients and how does this affect clinical and cost outcomes during a patient’s final months of life? In light of the observed variation in the content of existing programs (3), which services should be delivered by whom to patients and at what time in the care process? How can we organize palliative programs that take into account the patient’s wishes and needs, and that allow for transfer of patients between health care settings? Further research in different settings and countries is essential to answer these questions, so that the implementation of a palliative program does not resemble the opening of Pandora’s box.

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