Inhospital Palliative Care: Should We Need to Reconsider What Role Hospitals Should Have in Patients with End-Stage Disease or Advanced Cancer?

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Abstract: Traditionally, palliative care (PC) systems focused on the needs of advanced cancer patients. But, most patients needing PC have end-stage organ diseases. Similarly, PC models focused on the needs of patients in hospice or at home; however, in most cases PC is provided in acute hospitals. Indeed, the symptom burden that these patients experience in the last year of life frequently forces them to seek care in Emergency Department. The majority of them are admitted to the hospital and many die. This issue poses important concerns. Despite the efforts of attending healthcare professionals, inhospital patients do not receive optimal care near the end-of-life. Also, evidence is emerging that delay in identifying patients needing PC have a detrimental impact on their quality of life (QoL). Therefore, there is an urgent need to early and properly identify these patients among those hospitalized. Several trials reported the efficacy of PC in improving the QoL in these patients. Each hospital should ensure that a multidisciplinary PC team is available to support attending physicians to achieve the best QoL for both PC patients and their families. This
review discusses the role and the impact of inhos pital PC in patients with end-stage disease or advanced cancer.

Keywords: palliative care team, seriously ill patients, end-of-life, quality of life, symptom relief, acute palliative care unit, cost savings

1. Palliative care: for who?

The World Health Organization defines palliative care as: “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” [1].

Aging of the population as well as advances in medicine and public health is currently increasing the prevalence of people affected by progressive, chronic, life-limiting illnesses who would benefit of a palliative care (PC) approach. This phenomenon represents a great challenge for the healthcare systems especially in terms of patients’ assistance and healthcare costs [2].

Traditionally, PC services have been focused on the needs of cancer patients with advanced or metastatic disease. As a matter of fact, inhos pital PC programs have also begun to pay attention on the needs of patients affected by non-oncological diseases, such as end-stage organ failures (heart failure, chronic obstructive pulmonary disease –COPD–, liver cirrhosis, and severe renal dysfunction), as well as neurological illnesses (amyotrophic lateral sclerosis, Parkinson’s disease, multiple sclerosis, Alzheimer’s, and other dementias) [3,4]. Actually, it is important to underline that patients with cancer or heart, chronic obstructive pulmonary, and renal diseases at an advanced stage have been demonstrated to share a similar spectrum of symptoms, and have a common
pathway during the last period of their illness trajectories [5]. Therefore nowadays, the area of
action of PC is the relief of symptoms as well as psychological, social, and spiritual issues of
patients with chronic life-limiting diseases, regardless of the diagnosis [3].

2. Why do patients with chronic serious illness visit the emergency department near the end of
life?

During the last 6-12 months of life, most of the patients with end-stage disease or advanced
cancer experience an increase in symptom burden which forces them to seek care in acute hospital.
These patients are usually admitted to the Emergency Department (ED) in order to administer them
urgent care for the relief of uncontrolled symptoms [6]. Frequently, the visit may be precipitated by
the distress of family members near the end of life (EoL) [7].

A recent study, which has focused on the PC symptom management, has identified pain,
dyspnea, nausea and vomiting, anorexia, anxiety, and constipation as the most frequent symptoms
in seriously ill patients who are admitted to the ED, regardless of the specific disease. In addition,
dehydration and acute urinary retention are other common symptoms of these patients when they
come to an ED [8].

Nearly 50% of patients experience uncontrolled pain at the EoL [5]. Worsening dyspnea is
also frequent in patients in need of PC. Diseases commonly causing severe dyspnea are acute
exacerbations of COPD, lung cancer, and congestive heart failure. Frequent causes of increased
shortness of breath are pneumonia, pulmonary embolism, pleural effusion, pericardial tamponade,
pneumothorax, and superior vena cava syndrome. Nausea and vomiting are common
gastrointestinal symptoms in these patients due to several causes: medications (opioids,
chemotherapy agents), bowel obstruction, impaired gastric emptying, constipation, and increased
intracranial pressure. Frequently, reduced oral food intake or severe weight loss due to anorexia
(appetite loss), dysphagia, early satiety, stomatitis, and taste changes are common reasons for visits
to the ED. Anxiety, confusion or delirium in seriously ill patients represent a quite frequent cause of
access to the ED, as its management in home setting can be very difficult. Constipation is found in up to 90% of PC patients, regardless of the underlying illness. Constipation is typically caused by opioid intake, but also by bowel obstruction in patients bearing peritoneal carcinomatosis or advanced intra-abdominal tumors.

Sometimes, patients with end-stage disease or advanced cancer need in the ED of procedures such as intravenous fluids infusion for dehydration, placement of a urinary catheter for acute urinary retention, paracentesis for symptomatic intractable ascites or thoracentesis for symptomatic severe pleural effusion.

3. How to identify patients in need of palliative care?

Unfortunately, in the medical literature there is no agreement about the definition of the ‘palliative care patient’ [9]. Evidence is emerging that delay or lack in identifying patients in need of PC have a potential harmful impact on their care [10]. In fact, a delayed recognition of those patients is associated with inadequate continuity of care, insufficient support, and increased healthcare costs [11]. Therefore, there is an urgent need to early and properly identify among hospitalized seriously ill patients those in need of PC.

The ED should be considered as a critical point of PC access for patients with end-stage disease or advanced cancer [12,13]. In our study, we found that more than one-third of people affected by these chronic diseases awaiting to be hospitalized after an ED visit should be identified as in need of PC consultation [14]. In order to identify the patients in need of PC, we took into account for cancer patients the indicators elaborated by the National Comprehensive Cancer Network (NCCN) [15] and for patients with end-stage diseases the criteria proposed by the Italian Society of Anesthesia Analgesia Resuscitation and Intensive Care (SIAARTI) [16]. This study demonstrated the feasibility of applying NCCN/SIAARTI screening tools to identify patients in the ED for referral to a PC team.
The identification of PC needs in the ED, at the beginning of the hospital course, might provide a greater benefit to patients, families, and hospitals to anticipate PC consultation, which often occurs later in a patient’s hospital course. Wu et al. showed that PC consultation in the ED was associated with a significantly shorter length of stay for the patients admitted to the hospital [17]. Grudzen et al. demonstrated that an ED-initiated PC consultation improved quality of life (QoL) without shortening survival in advanced cancer patients [18].

4. What role for inpatient palliative care?

Historically, PC models focused on the needs of patients in hospice or at home. However, many patients with end-stage disease or advanced cancer experience repeated unplanned hospital admissions, particularly in the last year of life [19]. In our study, we observed that about 75% of the patients affected by these diseases in need of PC, awaiting hospitalization after admission to the ED, had more than one in-hospital admission during the last year [14]. Moreover, in high-income countries the majority of patients with end-stage disease or advanced cancer die in the hospitals [20] and this issue poses important concerns.

In 1995, the first large controlled trial investigating the EoL decision-making in seriously ill hospitalized patients was published [21]. The aim of this Study was to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT trial) in 9105 adults hospitalized patients with life-threatening diagnoses. The five analyzed outcomes were: 1) pain; 2) days in an intensive care unit (ICU), comatose or receiving mechanical ventilation before death; 3) hospital resource use; 4) incidence and timing of written do-not-resuscitate (DNR) orders; and 5) patient-physician agreement on cardiopulmonary resuscitation preferences. The authors concluded that the care of seriously ill or dying hospitalized patients was not attractive.

Care of patients with chronic life-limiting illnesses has been recognized in the recent years as suboptimal in hospital settings [22-25]. Particularly, patients and their families often complain
inadequate relief of pain and other symptoms as well as futile diagnostic imaging and unwanted life-sustaining treatments at the EoL [26-28].

Another unmet need is the communication between attending physicians and patients/relatives. Frequently this communication is inadequate in explaining complex medical information including prognosis and treatment options, resulting in misunderstandings mainly at the EoL [29,30]. Moreover, referral to hospice are implemented late in the course of illness by physicians, despite was observed that family members of persons referred too late reported lower satisfaction with hospice services [31,32].

Muir and Arnold reported that often dying patients in acute care hospitals were in physical pain, without attention to the emotional and spiritual suffering [33]. The authors emphasized that hospital physicians should become the primary providers of PC for these hospitalized patients with end-stage diseases.

The weak point of this model is that the majority of hospital healthcare professionals do not currently receive proper teaching on communication, especially concerning EoL care in dying patients. In fact, medical and nursing schools worldwide have traditionally had a limited emphasis on EoL care [34]. However, PC and EoL issues are not an easy conversation between attending physician and patient or caregivers. Consequently, many of them relate that they have encountered important ethical dilemmas in managing refractory symptoms, discontinuing life-sustaining therapies in dying patients [35], and, especially, considering palliative sedation [36].

Evidence from clinical studies suggest that patients with end-stage diseases are often treated during hospitalization with aggressive medical intervention, including prolonged ICU stay, rather than with PC [22,28]. Often, the care that these patients receive during ICU stay is more aimed towards prolongation of their lives, rather than to palliation of symptoms [37]. Similarly, aggressive EoL care in the last weeks of life of advanced cancer patients, such as chemotherapy administration or ICU admission are commonly deemed markers of poor quality care [38].
It is of concern that caregivers of patients receiving aggressive care are at higher risk of experiencing a major depressive disorder, and in general a worse QoL, likely because they are unprepared to the death of their relatives [39]. Several studies pointed out that one barrier to providing quality care at the EoL was the lack of communication between the patient/family and the medical team [40]. It has been shown that most of patients would like to have a discussion with their physicians about EoL care, but this often remained an unmet issue [41,42].

In order to better manage patients with end-stage disease or advanced cancer in the recent years hospital-based PC programs have been developed [43,44]. Specifically, the aim of these programs is to improve symptom management, help patients and families in better understand prognosis and treatment options, clarify goals of care, and assist in planning of care as the disease progresses.

Several studies indicated that hospital-based PC services increased satisfaction of patients and families [45], improved QoL [46], reduced ICU length of stay [47], and decreased costs [48,49]. In a very recent review, the authors have underlined the advantages of a PC-oriented approach in improving patient’s outcomes, including symptom burden, QoL, and EoL outcomes, all achieved with lower associated costs [50].

5. How do they work in hospital palliative care services?

Within hospitals, the primary model of PC delivery is the multidisciplinary consultation team, which should be composed of physicians, nurses, and psychologists trained in PC, with the support of specialty physicians (geriatrician, internist, physiatrist, neurologist, psychiatrist) and other healthcare professionals (dietician, physical therapist, respiratory therapist) as well as pharmacists, social workers, case managers, spiritual counselors, and volunteers [51]. The PC team must have a tight bidirectional communication with home PC services, hospices, and primary care physicians.

Indeed, in the United States a PC team is present in almost 90% of hospitals with 300 beds or more and two thirds of hospitals with 50 beds or more [51]. During the last decade, also in Europe,
PC programs in hospitals have significantly increased, although much remains to be done in this area.

The PC team provides consultations to inpatients, working with attending healthcare professionals to ensure patient’s focused and family’s centered care. The most important purpose of the team is to achieve the best possible QoL for both patients and their families/caregivers by assessing and managing refractory symptoms [52]. Also, the team facilities patient’s and family’s understanding of the underlying disease process and promotes decision-making based on informed choices. Actually, the team should be involved for those cases where management of symptoms requires more than the basic knowledge or communication becomes difficult due to arising conflicts.

Both randomized controlled trials and observational studies compared the outcomes in patients with chronic life-limiting diseases who were referred to hospital-based PC teams with those in patients who received usual care and reported reduced symptom burden, improved QoL, and decreased spiritual distress among the patients referred to PC [53-56].

For a few years, a new approach in managing patients with end-stage diseases in the hospital context is represented by the Acute Palliative Care Unit (APCU) [57]. The focus of the APCU is rapid symptom control and intensive psychosocial care, with a shorter length of stay and a lower death rate (20-50%) than those in hospice [58]. Therefore, the APCU differs from hospice which offers more extensive long-term PC or exclusively near-death care.

The APCU provides intensive PC for inhospital patients and families, with the aim of enhancing QoL, facilitating transition to EoL care, and assisting with hospital discharge. The discharge from the APCU represents an important and complex process, as it must provide a location (e.g., home, hospice, or long-term care facility) in which the patient finds appropriate care until death, avoiding unplanned hospital admissions for lack of symptom management skills [10]. The choice of the discharge location depends on availability of caregivers and, mainly, on patient’s
preferences, performance status, and life expectancy as well as other logistic and financial factors [59].

Briefly, the APCU may be the hospital place where to provide patients with end-stage disease or advanced cancer with a personalized medicine tailored to their individual’s needs.

6. Which is the impact of inhospital palliative care services on cost savings?

The increasing development of medical technology gives to inhospital physicians the opportunity to easily opt for life-prolonging therapies or devices in patients with end-stage disease or advanced cancer; e.g., new combination of adjuvant chemotherapy with targeted drugs, left ventricular assisted devices, mechanical ventilation, haemodialysis, and artificial nutrition. Consequently, these patients frequently undergo various imaging techniques, interventional procedures, and therapies, even near the end of their lives. Such behavior of physicians does neither translate in a better management of the PC patient nor in a better patient’s QoL, while often represents a discomfort for the patient and a source of unnecessary costs for the healthcare system.

Several studies suggest that PC consultation is associated with cost saving in hospitalized patients, as it allows to identify those patients who would benefit from a palliative approach rather than an aggressive one. Since 2008, Morrison et al. stated that hospital PC team consultations were associated with significant hospital cost savings [60]. Starks et al. reported that PC team interventions resulted in cost savings for short and medium length of stay, but not for stays more than 30 days; therefore, the authors concluded that cost savings can be achieved by an earlier involvement of the PC team [61].

In a recent review Dalal and Bruera have reported that the magnitude of hospital cost savings with PC involvement ranged from 9 to 32% and these savings were higher when PC team was involved earlier (within two days from patient’s admission) [50]. Two recent studies [62,63] have pointed out that cancer patients’ care was characterized by high-cost and low-value interventions, high hospital readmission rates, prolonged length of stay, hospital deaths, and frequent use of
chemotherapy and other disease-centered interventions near the EoL. These data are indicative of poor care coordination and inadequate EoL planning, and such a management translates into costs escalation, while patients continue to receive nonbeneficial and burdensome health interventions at the EoL. These studies demonstrated that referral to PC team improved various healthcare utilizations and quality measures, including 30-day readmission rates, hospice use, and avoiding of chemotherapy following discharge.

7. Conclusions

The attitudes and knowledge of healthcare professionals towards PC may exert influence on their communication with patients and caregivers and, mainly, on patients’ quality of care near the EoL. Therefore, the best management of PC for hospitalized patients with end-stage disease or advanced cancer should be based on a well-defined cooperation between PC team and treating physicians. Actually, multidisciplinary PC teams aim to address the full spectrum of patients’ health, spiritual, and psychosocial needs, and match treatment choices with patients’ values and will.

In conclusion, we sincerely believe that to improve the care of these inpatients with relevant symptom burden, particularly after an unplanned hospital admission or when the patient is dying, each hospital should ensure that professionals expert in PC are available to support treating physicians.

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