

COVID-19 Pandemic and Cancer: The Importance of Early Palliative Care

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Mrs. E. was a 52-year-old woman with advanced breast cancer with liver and bone metastasis. She had been referred to the early palliative care (EPC) ambulatory because of severe pain and fatigue and was followed for 18 months. She died in November 2019, and 10 days later her husband called on us to give a letter Mrs. E. wrote, to let us know the meaning of the time spent with us:

“I had been suffering from intolerable pain, malaise, and loss of appetite, I was overcome by despair and I felt like I was nobody. When I came into the EPC ambulatory pain was immediately controlled and my smile came back. Day after day after week I started to trust, to feel like living again, to take a perspective of future life and to resume relations with my family. A supportive family environment was created at the EPC ambulatory helping me to live day by day and every day to appreciate little things and think of the present. The will to live, the desire to go out were back and depression passed. When you are very sick you think of death and euthanasia. When you are there, at the EPC ambulatory, you realize that life is easier to live and you don't think about death: if then, death arrives there you can understand and accept. If you live life well, without pain, with dignity and qualities, the idea of death is further away and you have the time to assimilate it. I have been understanding that death exists as life: I can leave life peacefully but the important thing is not to die with pain. When you took away my suffering I realized that death is natural, is part of life and is its rule but life must be without suffering.”

At the end of March, the Emilia-Romagna region of Italy was the second-most-affected by the coronavirus disease 2019 (COVID-19) outbreak, with 14,074 registered cases overall in Modena. From the first Italian government restrictions (February 23), at our Department of Oncology and Hematology, we adopted practical health vigilance recommendations to minimize the risk of exposure to the virus without overlooking cancer management [1]. While being engaged in such efforts, we

had interactions with many colleagues and friends working in intensive care units (ICUs) and deeply understood their distressing and unsatisfied need either to communicate clearly and compassionately about serious illness or to have the proper time to establish and cultivate a relationship with their patients, which was, instead, barred by impending death. Daily working and life experiences have intersected, and some readings from books, newspapers, and scientific journals have been good friends, either inspiring or comforting or helping us to see things as they are. For example, we shared the article “The psychological trauma that awaits our doctors and nurses. Don't underestimate the moral anguish of deciding who gets a ventilator” by Jennifer Senior, published on March 29, 2020, in the *New York Times* [2]. The spiritual testimony of our patient's letter came back to us strongly and forced us to think on the meaning of our professional commitment in the field of oncology and hematology. The emotional stress we were all feeling during the pandemic reminded us of the importance of early and continuous palliative care discussions as standard practice in oncology and in other medical specialties. Recommendations from the Italian College of Anesthesia, Analgesia, Resuscitation, and Intensive Care addressed the overwhelming need for clinical and ethical decision making regarding the COVID-19 epidemic in Italy [3]. As recently noted [4], issues related to “reasonable clinical need” as well as a “soft utilitarian” approach in the face of resource scarcity have been raised in the evaluation of patient management in ICUs. Similar clinical and ethical issues had already been discussed by critical care groups in the U.S. [4, 5]. One of the most important recommendations is the need to separate clinicians providing care from a “triage officer,” supported by a trained expert team responsible for (a) decision-making process in terms of resource allocations (i.e., ventilators, intubation procedures, etc.) by evaluating patients' frailties and making the best possible decisions and (b) communication with patients and families [3–5]. Many European societies have issued recommendations based on

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the ethical principle of utilitarianism—maximizing benefit for the largest number [3, 6]. A multiprinciple allocation framework for rationing care during the COVID-19 pandemic in the U.S. has recently been proposed [7]. A guidance that many U.S. health care facilities are using as a model has been updated by the Department of Critical Care Medicine, School of Medicine at the University of Pittsburgh (https://ccm.pitt.edu/sites/default/files/UnivPittsburgh_ModelHospitalResourcePolicy_2020_04_15.pdf). In addition to decision algorithms for rationing care, current pandemic guidances call for early palliative care interventions, aimed at (a) the effective management of symptoms like breathlessness and agitation; (b) training in facing the challenge of speaking with personal protective equipment alternative and in new delivery methods of palliative care services such as telemedicine; (c) the recognition of patient's wishes and preferences by urgent holistic care plans and the development of a timely and proper way of communication, even several times a day, balancing hopes and fears and showing a combination of honesty and compassion; and finally, (d) death and bereavement support for surviving family members who are likely to be isolated from their loved one at the moment of death [8, 9]. This clinical and ethical framework may represent a valuable and inspiring lesson not only in the case of COVID-19 but also for physicians facing advanced diseases like cancer [8]. However, it should be noted that a key difference exists between routine cancer management and crisis care. In the former, there is a primacy of the doctor-patient relationship in formulating evidence-based and individualized treatment paradigms designed to achieve the best outcome for a specific patient. In contrast, in the latter situations, public health ethics concentrates on the needs and interests of populations, even if that might negatively affect specific individuals [10]. This should always be considered while carefully evaluating the evolving epidemiology of the epidemic in different parts of the world, by consulting the Johns Hopkins University Coronavirus Research Center (<https://coronavirus.jhu.edu/map.html>).

Fojo and Grady commented on what was considered a breakthrough in cancer treatment presented at the annual meeting of the American Society of Clinical Oncology (ASCO) in 2008. This multicenter European trial enrolled patients with non-small cell lung cancer [11]. The addition of the experimental drug to conventional chemotherapy resulted in a 1.2-month overall survival advantage. The authors discussed the escalating price of cancer therapy and made estimations about the need of \$440 billion annually, to extend by 1 year the life of the U.S. people dying of cancer annually at that time [11]. The issues raised were not only "how much life is worth" but also the absence of systematic quality of life (QoL) assessments in this and other cancer trials that might allow a better understanding of the impact of these experimental agents as compared with standard treatments [11].

A few years later, recommendations for incorporating QoL and other type of patient-reported outcomes into clinical comparative effectiveness research were proposed by ASCO [12], and since then, remarkable progress has been made in raising quality standards of QoL assessment [13]. Excellent examples exist on how implementation of QoL endpoints in clinical trials have contributed to a more

comprehensive understanding of the value of new cancer therapies [14]. Notably, systematic monitoring of patient-reported symptoms in daily practice has also been found to improve survival in patients with advanced cancer [15].

In 2010, EPC integrated with standard oncology care was found to reduce aggressiveness of care and prolong survival (11.6 vs. 8.9 months) in patients with advanced non-small cell lung cancer, a population similar to that reported by Fojo and Grady [11] but without the use of new experimental drugs [16]. Both ASCO and the European Society for Medical Oncology have since recognized that patients with advanced cancer should receive dedicated EPC services, concurrent with active treatment, as early as possible in their disease trajectory, because of reported improvements in QoL, lower depression, lower rates of chemotherapy use near death, superior awareness of prognosis, longer enrollments in hospice care, and longer survival [17–19].

More recently, the availability of efficacious and safe targeted therapies and immunotherapies for a variety of malignancies have increased hope among patients, caregivers, and hematologists/oncologists [20, 21]. However, a significant proportion of patients neither respond to nor tolerate precision medicine treatments, despite improving attempts to develop predictive biomarkers. By implementing the value of health care communication along the entire disease trajectory, EPC has been recognized as the optimal way to enable patients and caregivers to get greater prognostic awareness and cope with the psychosocial sequelae and uncertainties still inherent to innovative therapies [20, 21]. By supporting also the implementation of end-of-life supportive measures and even palliative sedation for intractable symptoms for these patients, EPC is associated with less existential suffering for oncologists and other clinicians [22, 23].

However, barriers to EPC integration still exist, especially in hematology wards, because of either variable availability of specialty palliative care programs or misperceptions about prognostic uncertainty of hematologic malignancies and palliative care as just end-of-life care [24]. Therefore, more effort should be made to implement EPC interventions on a routine basis and to recognize the importance and beneficial value of medical/nurse communication with patients with cancer and their caregivers, which has dramatically been recognized as a huge unmet need by physicians and nurses taking care of patients with COVID-19 in ICUs because of necessary isolation constraints.

Moreover, the need for an accurate evaluation of a patient's prognosis and the consequent clinical decision making is shared by physicians caring for patients with COVID-19 in the ICU [3, 6–9] and by those caring for patients with hematologic malignancies or solid tumors [17–19].

Implementation of different EPC service models for advanced cancer has been a matter of discussion for a long time [25]. In the solo practice model, the oncologist attempts to take care of all patient-related issues, namely, of all the primary disease assessment and management as well as the supportive/palliative care needs. Whereas the advantage is that the patient may receive all aspects of care from the same health care professional, the disadvantages include time constraints, limited palliative care training, and increased risk of burnout as a result of the need to assume

all aspects of care [25]. In the integrated care model, which is now the most recommended, the oncologist collaborates closely with the interdisciplinary supportive/palliative care team to provide comprehensive cancer care [25]. Only the integration of highly technical and precision medicine expertise with palliative medicine expertise may improve the cure and the care of patients and families and possibly attenuate burnout among health care professionals facing stressful situations, either during the COVID-19 pandemic or along with the daily, long-term, trench warfare against cancer.

Such an extraordinarily stressful but also emotional and spiritual experience of our present times should represent a memo of the sort of a “privilege” we may have, as oncologists and hematologists, that is, to recognize the importance of and to take advantage of EPC programs integrated with our standard daily practice. However, much more effort should be made for medical and nurse students, in anticipating as early as possible education programs that could be continued and refined in future specialty school courses. Research studies should be designed and funded, hopefully also by health care systems, to compare different models of EPC intervention in different clinical and regional/geographical situations.

In our experience, taking care of both patients with COVID-19 and those with cancer in EPC programs highlights the importance of a “good” communication of bad news and

the “attention” to patients and families, to support them in their acceptance of medical decisions, based on both clinical and ethical judgement, and to prepare them for end-of-life situations, while trying to reinforce, at the same time, patients’ and caregivers’ hopes instead of illusions. The following quotation from Simone Weil sounds modern: “anyone who suffers tries to communicate his suffering to lessen it and in doing so really decreases it. Those who suffer need nothing else, in this world, than people capable of paying attention to them. The ability to pay one’s attention to a suffering person is a very rare and difficult thing, almost a miracle, it is a miracle.”

We hope that information shared by health care professionals, during these different but, somehow, similar clinical and ethical situations may be of help to face future challenges related to this or new pandemics but also to improve the actual management of cancer in our wards and our homes.

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