A Palliative Care Initiative in Dokuz Eylul University Hospital

Kamer Mutafoglu, MD on Behalf of the DEU Palliative Care Strategy Group

Summary: Turkey is among the countries with only "capacity building activity" in terms of palliative care development according to the mapping levels reported by the International Observatory on End of Life Care (http://www.eolc-observatory.net/global/pdf/world_map.pdf). Palliative care units are lacking even in major hospitals. Although some medical oncologists and pain specialists have been providing pain control and symptom relief to some extend, all these interventions remain a fragmented approach to care since there are no palliative care programs. Establishing palliative care services should be a priority in the development of comprehensive cancer care, particularly in a country where more than 60% of the cancer patients present with advanced stage disease. Like all the other university hospitals in the country, palliative care services have not been established so far in Dokuz Eylul University Hospital for several reasons although almost all the modern cancer treatment modalities have been provided to cancer patients. A group of health professionals have recently started a palliative care initiative in the hospital with an aim to raise awareness and to implement basic palliative care interventions to the current cancer care. This paper aims to tell the story of how this initiative get started and which step were taken so far.

Key Words: palliative care, Turkey, initiative

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Dokuz Eylul University (DEU) Hospital is a tertiary center in Izmir with 1001 beds; including a 48-bed Oncology Hospital (Muzaffer Mufit Kayhan Oncology Hospital). The focus of care in the hospital, admitting more than 2000 new cancer cases each year, is on diagnosis, investigation, treatment, and cure. Neither DEU Hospital nor the Oncology Hospital has a palliative care (PC) unit or a PC program. Although some palliative interventions for cancer patients have been provided by the medical staff, these interventions used to remain a fragmented approach to cancer care. Some detail on the situation with regard to PC was earlier presented.[1] A group of health care professionals started an initiative recently with an aim to raise awareness and implement basic PC interventions to the current oncology practice in the Oncology Hospital.

THE TRIGGER FOR A PC INITIATIVE

The lack of a coordinated PC service was leading to a variety of patient and family sufferings,[2,3] and staff exhaustion and burnout syndrome.[4] Although both patients/families and the medical staff was facing serious problems under given circumstances, there was not any collaborative effort until recently. The motivation to set up a PC initiative was kindled after my participation to 2 consecutive Middle East Cancer Consortium (MECC) workshops; the "Workshop on the Stresses and Burnout of Working with Cancer Patients" (June 22 to 24, 2007) and the "Workshop on Psycho-Oncology: The role and involvement of the patient's family" (May 30 to – June 1, 2008). Those meetings elegantly showed the great impact of modern PC on the quality of life (QoL) of patients and their families and health care workers. In contrast, surveys conducted with the parents of pediatric cancer patients for the MECC meeting presentations showed some realities in solid numbers, such as 60% of the parents defining the "child's ability to tolerate pain" as being helpful to deal with cancer experience or only 4% of the parents stating that their child could get professional psychological support throughout the whole cancer trajectory.[3] A self-report questionnaire given to adult cancer patients in our Day Chemotherapy Unit showed that 70% of the adult cancer patients had been experiencing distress to some extend (unpublished data).

After returning home from those meetings, I decided to take an action instead of settling for the ongoing practice. The major need was finding people who used to be sensitive about PC needs and willing to join an initiative on PC. I talked to one of my close friends on June 2008, a nutritionist (R.C.) in our Institution, who had a special interest in medical nutrition therapy in cancer. She had been working on preventing and alleviating painful symptoms through nutritional interventions. Her response was very encouraging in terms of starting an initiative. The first person we invited to join us was a medical oncologist (T.Y). She had a 2-year experience (2004 to 2006) in PC as a research fellow in the Cleveland Clinic. However, she could not find any opportunity to implement the strategy to the oncology practice; instead she kept on working as a busy medical oncologist in our hospital after returning from the United States. She expressed her interest in working with us. Then, a radiation oncologist (E.R.C) joined us who used to be very sensitive about providing "wholistic care." He was also the other participant to the MECC "Workshop on the Stresses and Burnout of Working with Cancer Patients," returning home with important messages. We invited 2 other colleagues; one was a faculty member in the DEU School of Nursing (A.E.), who had 6 months training on PC in the Calvary Hospital, New York. However, she also could not find an opportunity to disseminate her knowledge and experience in the clinics. Another one was an anesthesiologist (L.I) who was the head of the outpatient sedation anesthesia team, working with cancer patients during invasive interventions such as bone marrow aspiration. We came together with an aim to set up a PC initiative.

We started with working on a list of heath professionals in the hospital and defined more than 20 people as

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From the †Institute of Oncology, Dokuz Eylul University, Izmir, Turkey. The names of the professionals taking part in the DEU PC Strategy Group (Names are in alphabetical order). Nurses: A. Elcigil, D. Arslan, G. Esrefgil, H. Maltepe, S. Zeybekci, S. Baysak; Physicians: A. Akay, A. Demiral, C. Cimilli, K. Mutafoglu, L. Iyilikci, O. El, O. Senocak, E.R. Cetingoz; T. Yavuzsen, Y. Erkin; Psychologists: C. Celikoglu, E. Orcin, F.F. Oner; Nutritionist: R. Cehreli; Physiotherapist: D. Karadibak, M. Malkoc.

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candidates to take part in this initiative. The interviews with those candidates ended up with very promising responses. The next step was the interviews with the directors of some departments and some hospital administrators who could be contributing to this effort (Algology, Psychiatry, Child and Adolescent Psychiatry, Medical Oncology, Hematology, Pediatric Oncology and Pediatric Hematology, Physical Medicine and Rehabilitation, School of Physical Therapy and Rehabilitation, and the Medical Director of the DEU Hospital), telling them about the initiative and asking for their contribution. Responses were really encouraging. Except for the hematology teams, they all expressed their interest in contributing to this initiative.

INSTITUTIONAL EFFORTS

Our University has 1 of the 3 Oncology Institutes in the country. Therefore, we wanted to discuss the feasibility of establishing an academic PC Department within the structure of the DEU Oncology Institute to provide clinical services in the DEU hospital and to promote education and research. The Head of the Institution (M.K) and the Head of the Clinical Oncology Department (N.O) expressed their interest in establishing a PC department. The Administrative Board for the DEU Institute of Oncology approved the proposal for establishing a PC department on Dec 14, 2009. After the approval of the DEU Senatorial Committee on Jan 26, 2010, the Institution submitted an application to the The Council of Higher Education on Jan 29, 2010, to establish PC and psycho-oncology departments. The response (June 14, 2010) was negative; however, the institution has been in correspondence for a second evaluation. Although waiting for the final decision, we decided to start with setting up a palliative care working group (PCWG) for cancer patients in DEU Oncology Hospital.

ESTABLISHMENT OF THE DEU PCWG

An invitation from the Oncology Institute was sent out to the directors of some departments and hospital administrators on March 23, 2010, with whom earlier interviews were conducted. The written invitation for this meeting included an attachment, highlighting the sufferings experienced by our cancer patients, briefly describing how PC has been improving the QoL of patients, families, and oncology staff in developed countries, and finally explaining our aim to set up a PC program in the hospital. This meeting took place on March 31, 2010, with participants from 13 different disciplines (School of Nursing, Department of Nursing Administration, Departments of Radiation Oncology, Medical Oncology, Hematology, Pediatric Oncology, Pediatric Hematology, Chest, Algology, Psychiatry, Child and Adolescent Psychiatry, Physical Medicine and Rehabilitation, Nutrition and the School of Physiotherapy). During this meeting, a presentation was made about the current definition and scope of modern PC, emphasizing the need for a PC service for cancer patients in our center. We asked them to empower the professionals from their disciplines, who already had expressed their interest in taking part in this initiative. We encountered no problems in their bosses' approval.

The DEU PCWG had the first meeting on May 26, 2010, with 13 people from 8 disciplines. We started making regular meetings once a week. The number of the participants had increased over a short time, reaching to ≥30 professionals from the different departments of the university hospital, including nurses from the Oncology Hospital and Day Chemotherapy Unit, physicians, psychologists, a child development specialist, dieticians, and physical therapists.

TABLE 1. DEU Palliative Care Strategy Group

Health Care Professional	Affiliation in DEU	No. Participants
Nurses (n = 6)	School of Nursing	1
	Department of Nursing Administration	2
	Oncology Hospital	2
	Day Chemotherapy Unit	1
Physicians (n = 10)	Medical Oncology	1
	Pediatric Oncology	1
	Radiation Oncology	2
	Anesthesiology	2
	Psychiatry	1
	Child and Adolescent Psychiatry	1
	Physical Therapy and Rehabilitation	2
Psychologist (n = 3)	Mental Health Liaison Unit	2
	Child and Adolescent Psychiatry	1
Nutritionist (n = 1)	Institute of Oncology	1
Physiotherapist (n = 2)	School of Physical Therapy and Rehabilitation	2
Total		22

DEU indicates Dokuz Eylul University.

ACTIVITIES OF THE PCWG

The Initial Phase

The group's weekly meetings initially focused on developing a common language on PC in cancer, as modern PC concept was new to most of the members and a number of participants were not working with cancer patients regularly. A multidisciplinary strategy group was formed to develop strategies for implementing PC interventions to the current practice (Table 1). This group worked on a situation analysis. We defined our priority as raising awareness within the oncology professionals and implement some basic palliative interventions at our acute care setting. The PCWG members were in agreement that assessing pain as the fifth and distress as the sixth vital sign, and optimal management based on assessment were the essential basic steps.

THE CONTINUATION PHASE

Inpatient Rounds

Our interdisciplinary team, which consisted of nurses, oncologists, psychologists, psychiatrists, physiotherapists, nutritionists, and a child development specialist, began making regular weekly rounds in both adult and pediatric oncology inpatient clinics.

Outpatient Consultation Service

We started performing interdisciplinary outpatient consultations and follow-up visits for some selected complicated cancer cases.

During the rounds and weekly meetings, we defined some earlier ignored physician or system related barriers. One of these striking barriers was the disconnection of the daily rounds by nurses and physicians in oncology clinics. In pediatric oncology inpatient clinic, we began making daily rounds with the nurses. This connection made a great impact on the motivation of the staff.

The clinical practice by our interdisciplinary team has been focusing mainly on the following aspects of care depending on our available resources:

1. Pain Management: We defined that many patients were suffering cancer pain. Pain had not been assessed and managed on a regular basis. There were some personal attempts but these were not part of a coordinated effort. Some physicians were not aware that there used to be a pain assessment section in the nursing charts (including a faces scale and a numeric scale), and pain assessment had been done in patients who had self-reported their pain. However, the pain assessment scales taking place in a busy nursing chart were not user friendly either for patients or for nurses and doctors. We asked the Nursing Administrators to develop new nursing charts with more user-friendly pain scales. After learning that it would take a considerable time, we provided all oncology nurses and physicians a pocket scale having faces and numerical pain scale at one side, and a distress thermometer at other side. Patients were encouraged to express their pain and other sufferings. Our nurses and physicians are getting more sensitive about symptom management. The nurses expressed some pain barriers related to the doctors, they had been having communication problems with the physicians and there was inconsistent practice around pain treatment. Decision to prescribe any pain medication was up to the assigned resident, varying from one to another. Besides, the treatment outcome was not followed regularly by the doctors. The PC strategy group planned "pain clinical guidelines for cancer pain management" according to our available resources.
   We began using morphine more frequently, particularly for pediatric patients. After my personal experience in the Institute for Palliative Medicine at San Diego Hospice, I started using opioids whenever needed. Before that, our clinic's experience was limited with tramadol and transdermal fentanyl in some selected cases, and occasionally with patient-controlled analgesia provided by the anesthesiologists for terminal patients. After this initiative, we started using oral morphine solution (made of morphine ampoules and juice) in children with cancer to manage severe pain, as we had no oral immediate release morphine available in the market. We have already started giving morphine to relieve dyspnea, which used to be avoided with the fear of respiratory depression.
2. Psychosocial Care: Lack of significant psychosocial care was a significant barrier to holistic care. Before our initiative, psychological support could be given through consultations, only on the demand of the attending physician. With the establishment of our group, 2 psychologists from the Mental Health Liaison Unit and a psychologist from the Department of Child Psychiatry started working with cancer patients. Now, they join our weekly visits, evaluating distress for every inpatient. They also began making consultations for the outpatient clinics. Whenever needed, patients are referred to the psychiatry clinic. An adult psychiatrist and a child psychiatrist are working with us. We have no social workers working with our group; therefore, we cannot provide professional support for social needs. However, PCWG members have been trying to cover these issues as much as they can.
3. Nutritional Care: Cancer patients have been regularly offered either enteral (oral, tube-feeding, gastrostomy) or parenteral nutrition (by central venous catheters/ports) support throughout the whole disease trajectory in our center. In addition, expert nutritional support can be provided to a certain number of patients by a nutrition specialist. The nutritional supportive care has been regularly documented by 2 dietitians, who started working with our PCWG. The goals for medical nutrition therapy in cancer patients are: prevent or reverse nutrient deficiencies, preserve lean body mass, help patients better tolerate treatments, minimize side effects and complications (diarrhea, nausea, vomiting, pain related to mucositis/stomatitis, epigastric pain) with specific nutrients, protect immune function, aid in recovery and healing, and maximize QoL.
4. Physical Therapy Support: Two physiotherapists from the School of Physical Therapy and Rehabilitation and 3 specialists from the Department of Physical Therapy and Rehabilitation started working with PCWG to improve the QoL of cancer patients. They are trying to help to restore normal function for cancer patients. Before our initiative, they were providing occasional consultations on demand of the oncologists. They began joining our weekly visits, evaluating the need for physical therapy support for every inpatient, and making follow-up visits. They also see all patients referred from the outpatient clinics. The aim of the exercises and physical activities is to help condition muscles and restore strength and movement. For example, physical therapy is used to restore arm and shoulder movement and build back strength after breast cancer surgery. They also provide lymphedema treatment to those who have tissue swelling from removal of tumor, lymph nodes, or injury. Physical therapists make recommendations for counteracting fatigue through the use of exercise and strength training.

RELATIONS WITH OTHER STRUCTURES

Relations With DEU Hospital Administrators

We had 2 meetings with the Medical Director of the DEU Hospital (E. H.) to inform him about our initiative and to discuss the feasibility of having a unit with hospital beds and staff exclusively for PC. He was very enthusiastic and supportive about setting a PC unit. He informed us that they were planning to build a new oncology hospital, and a PC unit could be included in the plan. After the second meeting with him, the hospital journal "*Arpa Boyu*" published 4 full pages about PC in cancer and our initiative. This helped us to put this initiative on the map for the interest of all hospital staff.

Relations With the DEU School of Nursing

The DEU School of Nursing had been working on setting up a home care program. We had a preliminary meeting with the Head of the Nursing School and asked to conjoin our efforts. They agreed on collaborating with our group.

Relations With Hospital Staff

The members of the group have been telling their coworkers and colleagues about our initiative during patient rounds, scientific meetings, and during their social contacts. Now, more and more health care professionals know what PC really means beyond supportive care and end of life care. The awareness on cancer PC has been increasing gradually within the hospital.

Relations With Other Centers in the Country

The members of PCWG have been telling their colleagues about our initiative during national scientific meetings. This helps us with raising awareness. Two of us were invited to the 10th National Liaison Psychiatry Congress to give panel talks on PC in cancer recently. During this congress, we made contacts with professionals who were interested in PC, particularly psychosocial oncology. We have already agreed on collaborating to improve our knowledge and experience.

RESEARCH ACTIVITIES OF THE PCWG

There are 3 ongoing surveys on cancer pain management conducted by our PCWG members. These studies aim to define the barriers in cancer pain management among nurses and residents in our hospital and among pediatric oncologists at the region. The members of the PCWG have prepared 2 research projects that have already been granted; one is on cancer cachexia and the other on the management of lymphedema in cancer.

In conclusion, this is a very young initiative. This initiative has taken small, but important steps with the members' consistent valuable contributions. We have been observing an increasing awareness on PC among the oncology staff since we started working as an interdisciplinary team. The staff has started giving more attention to PC needs of the patients. We need more practice with standardized clinical approaches to evaluate the outcome of our collaborative effort in this acute care setting.

All members of the PCWG have primary responsibilities other than PC either in the hospital and/or in the university. Our group activities are voluntary work for all of them. Their work for extra hours without any compensation just to make this initiative successful may show their enthusiasm. The group members need education and training to gain enough knowledge and experience on this new area of interest. We need to raise funds and get some support from the national and international resources for education and training, as we still do not have a budget.

WHAT IS ON THE HORIZON?

- We aim to disseminate the initiative throughout the 1001-bed university hospital, starting with surgical clinics where a significant number of cancer patients have been treated.
- We aim to make connections to the Palliative Medicine experts around the world.
- We have recently started working on a collaboration with the Global Access to Pain Relief Initiative of the Union for International Cancer Control (http://www.uicc.org/programmes/gapri) for a "Pain Free Hospital" Project.
- We are interested in collaborating with the PC Project of the Cancer Control Department of the Ministry of Health Turkey. The Cancer Control Department has been working on a new structure to establish a nationwide PC program for the cancer patients (http://www.kanser.gov.tr/index_en.php). Collaboration between the government and academic institutions is needed to make a better progress in a shorter time period.
- We hope this initiative will eventually lead to providing a better QoL for cancer patients and their families both in our center and in our region.

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