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## Palliative Care in Iran: A long, long way to go

Mamak Tahmasebi<sup>1,\*</sup>

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1. Cancer Research Center, Cancer Institute of Iran, Tehran University of Medical Sciences, Tehran, I. R. Iran

**\*Corresponding Author:**

Mamak Tahmasebi, MD  
Cancer Research Center, Cancer Institute of Iran, Tehran University of Medical Sciences, Tehran, I. R. Iran.

Tel: (+98)09122171438

Email address:

mamaktahma@yahoo.com

“Palliative care is an approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.” According to the World Health Organization (WHO, 2002)<sup>1</sup>.

The origin of palliative care has its roots in history. People have always cared for others, even in prehistoric times before the first written records were ever made.

The first formal documentations of palliative care in western culture were through the work of a physician named Dame Cicely Saunders in 1948 who believed; “suffering is only intolerable when nobody cares”<sup>2</sup>.

The foundation of academic palliative medicine in Iran was established by Professor Norelle Lickiss, a consultant physician and oncologist from Sydney, Australia who had studied and applied important UK research in palliative medicine and had set up a training program for young doctors, including international doctors (and Dr. Tahmasebi from Iran). A surgeon from Tehran (Professor Zahra Eftekhar) noted the value of Dr. Tahmasebi’s help in the Gynecological Oncology Unit directed by Professor Neville Hacker in Sydney. Later on, many doctors involved in the care of patients with cancer participated in the First National Symposium in Palliative Care (Tehran 2004).

Palliative care has had a steady but slow growth in the health system of Iran, and has redefined medical care which had traditionally been referred to as the treatment of diseases and unconditional prolongation of life, with death and dying being considered a medical failure- ignoring the fact that death is inevitable. But the care of those who are dying is very important, and palliative care has become increasingly recognized as an integral part of the health care system.

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Palliative care has its own challenges. Several conventional beliefs and myths prevent the proper management of symptoms for patients suffering from advanced critical illness. Addiction is not the only concern of patients and their relatives in Iran. Opiophobia (unreasonable concerns about the use or prescription of narcotic analgesics) is still a major barrier in pain management despite efforts to provide training for physicians and nurses. Unfortunately, verbal reasoning for using opium for pain management by oncologists has been much more widely accepted by patients than a legal prescription of opioid medications.

In Iran, since families remain the main caregivers for patients with advanced and life-limiting illnesses, many patients receive minimal active end-of-life care, and following the principles of medical ethics and professionalism is a real challenge. From a realistic perspective, it may seem that setting goals for care, wise decision-making and the gist of “holistic care”, may stay in the textbooks. Collusion with relatives and withholding information from the patient may seem like a better approach than dealing with emotional outpour in the setting of a busy oncology clinic.

Imam Khomeini Hospital (IKH)-Cancer Institute is one of the first providers in Iran (Tehran) with a formalized palliative care program, providing a refuge for patients and their families seeking relief from symptoms. Since 2007, the clinic of palliative medicine -by providing care for more than 8000 patients, most of whom suffered from late stage cancer- has been recognized as “the last resort” to support patients and their families through the challenging and unknown experiences of palliative and end-of-life care.

The first specialized palliative care unit (PCU) in Iran with only 6 active beds has admitted more than 2500 advanced cancer patients in a period of 8 years for symptom control, respite and end-of-life care. Most patients

(about 89%) died at home after their relatives were taught how to manage symptoms and provide a comfortable environment for patients during the last days of their lives. IKH’s PCU thrives to meet the needs of patients and their relatives and maximize their satisfaction despite the limited resources available.

Establishing a palliative medicine fellowship program and providing a number of palliative care workshops for nurses and physicians are part of our achievements. Nowadays, palliative care is a subject of interest in almost all national oncology conferences. More out-patient clinics for palliative care and in-patient services are becoming available in different provinces of Iran. Medical universities in Iran are increasingly adopting educational programs addressing palliative medicine especially for the oncology and geriatrics training of residents.

While promising steps have been taken for palliative care in Iran, nationwide we face significant challenges. Some examples are presented here: Oral morphine remains unavailable, posing significant issues in pain management. Palliative care for children has been largely underdeveloped and is a significant area of need. Community oriented palliative care services are rare and not accessible for most of the population without federal and scientific supervision. Since the WHO ladder for cancer pain management has not been properly used, patients are often offered expensive, unnecessary and invasive procedures such as different kinds of nerve blocks or intrathecal morphine pump infusion. Another major concern stems from the fact that Insurance companies do not cover palliative care services. Except for the management of physical symptoms, in Iran little effort has officially been made when it comes to the fundamental elements of palliative care such as family support, interdisciplinary team working, and psychosocial and spiritual suffering. The picture of palliative care in

Iran is barely scraping the tip of the iceberg.

Fortunately, palliative care in Iran is on the verge of a major transformation. The Ministry of Health has recently established a sub-committee branch of the cancer control committee that works specifically on palliative care, with the goal of expanding palliative care services in all areas across Iran.

In order for Iran to no longer be categorized as a Group<sup>3</sup> country with “isolated palliative care provision” based on WPCA categorization<sup>3</sup>, stepwise planning for the future is necessary:

- Policy makers in the Ministry of Health should prioritize palliative care. Palliative medicine needs to be seen as central to medical practice.
- Palliative care should be a part of undergraduate medical and nursing education.
- Short and long term training programs for general physicians, nurses, pharmacists, psychiatrics and social workers should be held regularly.
- Essential pain medications (e.g. oral morphine) should be available and accessible for all patients across the country.
- Inpatient care, outpatient clinics and home care programs should be established.
- To prevent unnecessary hospital admissions and invasive, expensive and futile interventions, palliative care should be integrated into patients’ treatment as soon as cancer is diagnosed.
- Recognizing spiritual suffering is not enough, rather health professionals need to be educated on how to help manage these sufferings.
- Volunteers should be organized and trained for taking part in home care programs.
- With a growing aging population, other age-related life-threatening diseases such as advanced heart failure, advanced pulmonary diseases (e.g. COPD), dementia and Alzheimer’s disease should also be a part of the national program for palliative care.

- Research is necessary in order to find our own models of palliative care based on domestic resources and facilities.

Palliative care is not a luxury, but a basic human right<sup>4</sup>. In order to protect human dignity when it is threatened by pain, fear of dying and suffering, we need a new outlook for patient care. The ultimate goal of medicine is not only to respect life, but as has been said by Mortimer, “to emancipate man’s interior splendor”<sup>5</sup>.

### **AUTHOR’S BIO:**

As the first formally trained palliative care physician in Iran, after completing a fellowship in Sydney (Australia), Dr. Tahmasebi joined the Cancer Institute at Imam Khomeini Hospital in 2007. She is an Associate Professor at Tehran University of Medical Sciences, and is responsible for the out-patient clinic and is head of the Palliative Care Unit.

Below we mentioned author’s most important list of presented posters.

1. **A Rapid Pain Assessment in Cancer Patients in Iran-** 18th International Congress on Palliative Care/ Canada/2010
2. **Palliative Care in Iran-** 9th Asia Pacific Hospice Conference/ Malaysia/2011
3. **Sexuality after Cancer in Women: A Pilot Study from Iran-** 12th World Congress of the European Association for Palliative Care/ Portugal/2011
4. **Palliative Care in the Emergency Department-** 19th International Congress on Palliative Care/ Canada/ 2012
5. **What Do Other Doctors Ask a Palliative Medicine Consultant? A Clinical Audit in Iran-** 10th Asia Pacific Hospice Conference/ Thailand/2013
6. **Palliative Care for Cancer Patients in the Emergency Department in Iran-** 13th World Congress of the European Association for Palliative Care/ Czech

Republic/2013

**7. Indications for Albumin Infusion in Advanced Cancer Patients: A Clinical Audit in Iran-** 20th International Congress on Palliative Care/ Canada/2014

**8. Communication with Cancer Patients**

14th World Congress of the European Association for Palliative Care/ Denmark/2015

**9. After-Hours Telephone Answering Service in Palliative Care: Goals and Challenges-** 21th International Congress on Palliative Care/ Canada/2016

**10. Religion Based End-of-Life Decision-making-** 15th World Congress of the European Association for Palliative Care/ Spain/ 2017

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