

# The need for palliative care services in Iran; an introductory commentary

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Nowadays, there are few people with no experience of a life-threatening condition in their families, friends or in the neighborhood. Of the 58 million people dying each year [1], approximately 60% die with a chronic condition of whom 6 million deaths are from cancer with the majority occurring in developing countries. [2-4] According to the statistics from Ministry of Health and Medical Education, over 30000 deaths occur annually in Iran due to cancer with an incidence of over 70000 new cases. The incidence of cancer in many developing countries is increasing. [5]

These figures do not take into account other chronic illnesses like diabetes, heart failure, gastrointestinal disorders, chronic neurological disorders and lung disease, which also cause symptoms that are distressing such as shortness of breath, constipation, diarrhea, nausea as well as psychological distress, depression and anxiety. Including family members, or close companions, providing care and support to those who are dying raises the number of people benefiting from palliative care to a potential 100 million a year and possibly more. [6] The majority of these potential beneficiaries reside in developing countries. [2]

Around two-thirds of patients with advanced cancer have pain [7] and patients with other chronic conditions suffer similarly if not more [8, 9]. Alleviating other symptoms, either due to cancer itself or as a complication of other harsh treatments, is pivotal in the provision of palliative care. For the majority of people dying in the developing world, cure or disease control in the form of surgery, chemotherapy and radiotherapy for cancer or anti-retroviral drugs is not available. Prevention, although important, does not address the needs of the millions who already have the condition. Improving health-related quality of life of patients and concentrating on reducing the burden of illness on their family caregivers is the only way to help affected patients.

## Palliative care

Patients followed by oncologists are less likely to receive a holistic care for their primary or secondary conditions, i.e. complications of cancer treatments. [10] The range of symptoms varies in different conditions in patients who may benefit from

palliative care. Franks et al [11] reviewed 64 papers, of a total 673, in the time period 1978-1997, that provided evidence for cancer patients' needs, which are summarized in table-1.

The modern hospice movement began with Dame Cicely Saunders, whose philosophy of palliation included holistic care, along with a progressive and modern approach to the medical management of end-of-life symptoms. Dame Saunders opened St. Christopher's Hospice, the first residential hospice, in 1967. As fate would have it, she died in St. Christopher's Hospice at age 87 years, on July 14, 2005.

Palliative care offers specialised treatment to people whose illness is no longer considered curable. Its primary goals are to provide comfort and care for those with life-limiting illnesses and their families, so that patients are able to die peacefully in the setting of their choice often their own home while receiving all necessary nursing, medical, physical, psychological, social, emotional and spiritual care.

## Defining palliative care

According to the World Health Organisation (WHO), palliative care is 'an approach that improves the quality of life of patients and their families facing the problems 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. [12]

Embedded within the WHO definition is a commitment to relieving pain and other distressing symptoms, the affirmation of life while regarding dying as a normal process, an intent to neither hasten

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Table 1: Prevalence of symptoms in terminally ill cancer patients

Symptom	Maximum prevalence reported (%)
Pain	88
Dyspnea	87
Nausea & vomiting	85
Sleep disorders	75
Confusion	75
Appetite	79
Incontinence	64
Constipation	65
Depression	60
Anxiety	69

nor postpone death, an integration of psychological and spiritual aspects of patient care, the provision of support to help patients live as actively as possible until their death, with support being provided to help families cope during their loved ones' illnesses and into their own bereavement. Whenever possible, palliative care endeavors to enhance the quality of life of patients as they move toward death. Palliative care can be applied at all stages of life-threatening disease and should intensify once cure is no longer deemed possible.

### Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. It is only recently that issue of palliative care services for children, young people and their families has been recognised. The needs of these families tend to be multiple and complex. A proportion has learning needs and severe physical disability which present more challenges for service providers. Cancer and rare and complex disorders like genetic diseases are more common cause of death in this group, which in turn require specific services such as genetic counselling.

WHO's definition of palliative care appropriate

#### Box 1: WHO definition for palliative care

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patients illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Will enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

for children and their families is as follows; the principles apply to other paediatric chronic disorders.

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centers and even in children's homes.

### Key themes of palliative care

Palliative care embraces a wide range of healthcare activities such as pain management and controlling other common symptoms in the last days and weeks of a cancer patient life, in one hand, and on the other hand dealing with their family caregivers, spiritual problems and on the very distant way, bereavement. Table 2 demonstrates the tasks included in a typical palliative care service. This very huge task warrants an inter-professional team working encompassing oncologist, palliative care specialist, psychologist or psychiatrist, paediatrician, expert nursing staff, nutritionist, a cleric, and other health professionals as required.

Meanwhile, palliative care services should be cost-effective and affordable and accessible for all people who are in need. Palliative care needs to acknowledge poverty and should not impose more burden to the current out of pocket health expenditures in the country. This is not exclusive to

developing countries, but also has been addressed in the provision of palliative care services in developed countries, where cost of medications is still a serious problem for some patients. [2]

### The level of need

'Need' is usually assessed in one of the following ways: epidemiological approach, comparative, corporate, economic or by examining health service usage. In epidemiological approach, evidence is provided on disease-specific mortality, and related to the duration of symptoms prior to the patient's death. It is suggested that services may need to provide pain control for 2800 patients per million (p/M) population dying from cancer each year and 3400 p/M with non-cancer terminal illness. Using health service usage as an indicator of need, 700–1800 p/M with cancer and 350–1400 p/M with non-cancer terminal illness would require a support team or specialist palliative home care nurse, with 400–700 cancer p/M and 200–700 non-cancer p/M requiring inpatient terminal care. [11] Few beds are available for issues in palliative care such as pain control, which indicates there still remains a high degree of unmet need.

In a study to define whether people with life-limiting illnesses, who do not access specialized palliative care services (SPCS), have unmet needs, a population survey was conducted in Australia. [13] One in three people surveyed indicated that someone 'close to them' had died of a terminal illness in the preceding five years. Of those who identified that a palliative service had not been used (38%), reasons cited included family/friends provided the care (34%) and the service was not wanted (21%). Respondents with income more than AU\$60 000 per year were more likely to report that a SPCS had been used ( $P < 0.01$ ). People who had cancer as their life-limiting illness were more likely to access SPCS ( $P < 0.001$ ). The results generate a model comparing SPCS utilization with client benefit. [13]

One in five Americans die using ICU services. The doubling of persons over the age of 65 yrs by 2030 will require a system-wide expansion in ICU care for

dying patients unless the healthcare system pursues rationing, more effective advanced care planning, and augmented capacity to care for dying patients in other settings. All patients, regardless of diagnosis, should be able to access palliative care appropriate to their individual needs. For this to happen in practice, an integrated approach to palliative care is essential. [14]

### Providing palliative care services in Iran

Unlike primary healthcare in Iran,[15] yet there has been no population-based programme for specialised palliative care services (SPCS). In line with many developing countries,[2] Primary Health Care service in Iran does not offer any kind of palliative and end of life care to patients and their families. In contrary, SPCS had been developed in an ad hoc and informal way, with models of service delivery, funding sources, funding levels, health insurance coverage, disciplines involved (public, private, charities), relationship with primary healthcare (PHC) system, and patient characteristics. In this chaotic service delivery for cancer patients, we can assume that not all patients who need the palliative care services have sufficient access to these facilities. Patients and families are distressed to find a way alleviating suffering pain and in some cases healthcare professionals avoid or unable to provide the right prescription at the right time.

Palliative care is client-centred, which implies that a holistic approach is required to meet patients' and caregivers' needs. This approach allows the understanding of varied physical, psychological, spiritual and cultural needs to be satisfied in relevant and effective care. Palliative care practitioners should tailor the services at the direction of clients, which differs regarding each family resources and liabilities.

### Conclusion

Palliative care is a holistic approach, looking at physical, psychological, social and spiritual dimensions for both patients and their families. If

Table 2: Guidelines for Supportive and Palliative Care; by National Institute for Clinical Excellence (NICE 2004)

User involvement	Information giving
Psychological support services	Symptom control
Social support services	Rehabilitation services
Complementary therapy services	Spiritual support services
Palliative care (specialist and GP)	Face to face communication
Services for families including bereavement care	Workforce planning

palliative care is to be performed perfectly, it is necessary for healthcare professionals to have a good understanding of symptoms the patients present.

The range of symptoms varies from pain, nausea and vomiting, constipation, weakness, anorexia, depression, confusion, dyspnea and breathlessness. There is a considerable pressure to direct patients to receive palliative care services at their own home, yet no evidence available from Iranian cancer sufferers of their desire and preference, which warrants more research. Nonetheless, providing specialist services is highly recommended within the second and third levels of Primary Health Care system in the country.

There is no formal palliative care education included in the medical and other health professionals' curriculum; therefore it is not surprising if more than half of specialist registrars –in a recent study by authors[16]- did not have a relatively good perception of palliative care, 81% stated their weakness to assess cancer patients' pain and 73% were not able to manage cancer pain. It is strongly recommended that palliative care modules included in the current medical training in all levels.

Lack of research is considerable in the field of palliative care in Iran. Cancer research centres, medical schools, educational departments and nursing schools in one hand, and on the other hand funding bodies, pharmaceutical companies and health policy makers are required to conduct, support and encourage the research to provide a better quality of life for end stage patients.

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