

Report on the

# **Palliative care training workshop**

Cairo, Egypt  
17–20 October 2010

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## 1. INTRODUCTION

In order to enhance national capacity in palliative care in the WHO Eastern Mediterranean Region, the WHO Regional Office for the Eastern Mediterranean organized a palliative care training workshop in collaboration with the European Arab School of Oncology (EASO) and the Gulf Federation for Cancer Control (GFCC) in Cairo, Egypt on 17–20 October 2010. The specific objectives of the workshop were to:

- share country experiences;
- discuss challenges and opportunities;
- learn about principles of palliative care;
- discuss and develop recommendations in relation to opioid use and accessibility and palliative care delivery modalities.

The workshop was attended by participants from Bahrain, Egypt, Islamic Republic of Iran, Iraq, Jordan, Lebanon, Libyan Arab Jamahiriya, Morocco, Oman, Pakistan, Palestine, Qatar, Saudi Arabia, Sudan and Yemen. Methods of work included presentations on regional palliative care profiles and country status, panel discussions to develop consensus on key areas (opioid use and palliative care delivery modalities) and group work on country needs and assessment. Expected outcomes were to develop regional and country profiles on palliative care, enhance national capacity in area of palliative care and develop recommendation on opioid use and accessibility on regional level.

The workshop was inaugurated by its organizing representatives: Dr Haifa Madi; Director, Health Protection and Promotion and Dr Ibtihal Fadhil, Regional Adviser Noncommunicable Diseases from the WHO Regional Office; Daniela Mengato from EASO; and Dr Ibrahim F. Al-Sheneber from GFCC. The meeting programme and list of participants are included as Annexes 1 and 2, respectively.

## 2. PALLIATIVE CARE TOPICS

### 2.1 Palliative care (global perspective)

*Professor Stephan Tanneberger, WHO Temporary Adviser*

Figures on cancer prevalence show 17 million people suffering from cancer and a cancer mortality of 7 million cancer deaths yearly. About 30% of the registered patients receive a curative treatment, and 70% of the patients are detected in incurable stages. 4–5 million people are permanently suffering from cancer pain with or without adequate treatment.

Most advanced cancer patients want to have effective control of symptoms, to be near to family/friends, to be at home, live with dignity and improving quality of life. However, the available data show that the percentage of unrelieved cancer pain in developing countries is still very high. Freedom from pain should be seen as a right of every cancer patient and access to pain therapy as a measure of respect. Drug treatment is the mainstay of cancer pain management.

## **2.2 Cancer control and palliative care in the Region**

*Dr Ibtihal Fadhil, WHO/EMRO*

Cancer is ranked as a major cause of death in the Eastern Mediterranean Region, following cardiovascular diseases, infectious diseases and injuries. It is estimated that cancer kills 272 000 people each year in the Region.

The regional strategy on cancer control highlights the needs for capacity-building in area of palliative care and recognizes the variability among countries of the Region in the level of resources for palliative care services. Regional challenges facing palliative care services are:

- Limited palliative care programmes in the Region and of insufficient quality,
- Policies (or attitudes among health care providers) restricting access to opioids mainly because of an over-concern about drug abuse.
- Policy regarding who can prescribe opioids, the duration of prescriptions and the attitudes of health care workers to the administration of opioids needs to be better documented in order to identify obstacles and develop approaches to overcoming them.

Regional priority interventions are:

- Assess cancer patient needs and family needs the most appropriate models of care delivery.
- Raise awareness among health professionals and community.
- Ensure opioid availability and accessibility
- Develop and empower human resources for palliative care
- Enhances the multidisciplinary team collaboration.
- Enhances the home care delivery programmes.

## **2.3 Introduction to palliative care**

*Dr Mohamed Zaffer Al Shahri, Saudi Cancer Foundation*

Palliative care is an approach that improves the quality of life for patients and families facing the problems associated with life-threatening illness. This is through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems. Palliative care provides relief from symptoms, neither hasten nor postpone death, integrates physical; psychosocial and spiritual aspects of care, offers a support system to help patients live as actively as possible until death, as well as a support system to help the family manage and cope with the patient's illness. Forms of palliative care delivery are hospices, inpatient tertiary units, consultation services, outpatient clinics and home care services.

## **2.4 Advocacy in palliative medicine**

*Dr Mohammad Bushnaq, WHO Temporary Adviser*

The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick. Physician failure to understand the nature of suffering can result in medical intervention that – though technically adequate – not only fails to improve suffering but becomes a source of suffering itself. It is important to restore the balance between palliative care and life-prolonging care.

## **2.5 Cancer pain management**

*Dr Samy Alsirafy, WHO Temporary Adviser*

Pain is the most common reported symptom of advanced cancer patients (in 92% of admissions). The experience of pain can induce depression, exacerbate anxiety, interfere with social performance and impair the quality of relationships, prevent work and reduce income. Analgesics (mainly opioids) are a relatively inexpensive yet effective method exists for relieving cancer pain in 70%–90% of patients. Opioids and sedatives, used to palliate severe distress in the terminal stage of cancer, are not associated with patient's survival, addiction or respiratory suppression. Opioids and sedatives are safe when administered with a low initial dosage and adequate titration. However, there are no standard doses for [strong] opioid drugs. The “right” dose is the dose that relieves the patient's pain. The range for oral morphine, for example, is from as little as 5 mg to more than 1000 mg every four hours.

## **2.6 Opioid use and availability**

*Dr Willem Scholten, WHO/HQ*

There are several important medicine classes controlled under the international drug control conventions, including opioid analgesics (pain relievers). Access to many of these medicines is problematic in most countries around the world. Therefore, WHO is working on improving access to all these medicines which are listed on the WHO Model List of Essential Medicines.

The international drug control treaties recognize that controlled substances are indispensable for the relief of pain and suffering. Therefore, there are two objectives in drug control: to ensure access for rational medical use and to prevent harm from substance abuse and dependence.

Countries should establish balanced policies that achieve both these objectives. However, in practice the focus is limited to the second objective, resulting in poor or nonexistent access to controlled medicines and millions of patients suffering from inadequately managed pain and other diseases.

WHO monitors morphine consumption in individual countries as an index of improvement in pain management. In the Region, it is estimated that 76.5 million people live in countries where the adequacy of opioid analgesic consumption is very low (3%–10% of

the average of the top 20 developed countries) and 400 million people live in countries where there is virtually no consumption (< 3% of the average of the top 20 developed countries).

Essentially, there are four types of barrier to adequate access to controlled medicines: inadequate legislation, unbalanced policies, insufficient knowledge on the use of controlled medicines and inappropriate attitudes towards controlled medicines.

WHO foundation measures for implementing cancer pain relief programmes are:

- Drug availability, which requires changes in health care regulations/legislation to improve drug availability (especially of opioids) and improvements in prescribing, distributing, dispensing and administration of drugs;
- Government policy, including national or state policy emphasizing the need to alleviate chronic cancer pain;
- Education of the public, health care professionals (doctors, nurses, pharmacists) and others (health care policy-makers, administrators, drug regulators).

WHO established the Access to Controlled Medications Programme to assist countries in improving access to these medicines at the request of the World Health Assembly and the Economic and Social Council and in consultation with the International Narcotics Control Board (INCB). The programme is developing several practical tools that can be used by the countries for such purposes, including the following.

- A WHO policy guideline on ensuring balance in national controlled substances policies, which will be a comprehensive and practical approach for ensuring access to controlled medicines and prevention of abuse and dependence. It will cover all relevant policy and legislative aspects and it will contain a checklist to identify the most urgent aspects to work on (expected spring 2011).
- A set of three WHO treatment guidelines on pain, together covering all various types of pain. The first of these guidelines is the WHO guidelines on pharmacological treatment of persisting pain in children with medical illnesses (expected spring 2011).
- A joint WHO/INCB manual for establishing the estimates and statistics that countries need to submit annually to the International Narcotics Control Board and which are indispensable for being allowed the importation of controlled substances from other countries, including opioid analgesics.
- Identification of best practices in legislation and development of model legislation.

The programme will also provide practical support to countries that want to improve access to controlled medicines by:

- Assisting countries with situational analysis, including analysis of legislation and policies and the development and introduction of improved legislation and policies
- Updating national essential medicines lists
- Training civil servants for establishing estimates of controlled substances



- Supporting health institutions when establishing adequate curricula on pain management.

Palliative care delivery models are: the ‘free-standing’ inpatient unit or hospice; the hospital-based palliative care unit; and the home-based palliative care model. The ‘free-standing’ inpatient unit/hospice may not be an appropriate model for all cultures.

## **2.7 Hospital-based palliative care**

*Dr Samy Alsirafy, WHO Temporary Adviser*

Hospital-based palliative care includes acute care hospitals, tertiary palliative care units, day hospitals and outpatient centres. Evidence showed that hospital-based palliative teams improve care for patients or their caregivers at the end of life stage. Benefits of hospital-based palliative care include the following.

- Medical staff includes palliative medicine specialists and very experienced nurses.
- The patient does not need to be moved to a hospital or hospice unfamiliar to them.
- The patients can still be visited by doctors and nurses from other units in the hospital.
- The patient can usually return to their home ward when the palliation has been successful.
- All clinical records are available in the hospital. All diagnostic facilities are available in the hospital.
- Ideally physicians and other care-givers can follow patients and their care regimens both in the original unit and through the palliative care unit.

## **2.8 Home-based palliative care**

*Professor Stephan Tanneberger, WHO Temporary Adviser*

Many successful experiences in setting up home-based care exist, including the Italian experience in achieving the Hospital-At-Home Approach, and the Indian experience in achieving ANT/CANSUPPORT Home Care Team. Home care projects in the developing world are realizable and cost-effective (50% cost saving compared to in-bed strategies are possible). Fortunately family solidarity in developing countries still exists. The palliative care survival of patients who died at home was 63 days. Those who died in hospital or ambulance had a shorter survival of 39 days ( $p = 0.04$ ). Those who were visited by a physician at home were more likely to die at home compared to those who were not (92.3% versus 64.2%) and the difference was statistically significant ( $p = 0.008$ ).

## **2.9 Supportive care**

*Professor Stephan Tanneberger, WHO Temporary Adviser*

Supportive care aims to optimize the comfort, function and social support of patients and their families at all stages of the illness. Comfort means control of treatment-associated symptoms, pain and other physical problems. However, comfort also means for a majority of patients to stay at home. A great challenge for supportive care is the growing market of

complementary and alternative medicine. However, not all that is new is good, and not all that is good is needed. Best supportive care in incurable patients starts with a rational assessment of the individual life expectancy, which can be difficult. Depending from the result, one of the two alternatives, chemotherapy +/- supportive care or best supportive care alone has to be chosen. Overuse of cancer chemotherapy is not recommended.

## **2.10 Prognostication in advanced cancer**

*Dr Samy Alsirafy, WHO Temporary Adviser*

Prognostication is defined as a prediction of the probable outcome of a disease based on an individual's condition and the usual course of the disease as seen in similar situations. It provides information about the future to patients and families so that they can set goals; priorities and expectations of care, helps patients develop insight into their dying, assists clinicians in decision-making and provides a common language for health care professionals involved in end-of-life care.

Prognostication is measured by clinical prediction of survival performance status, symptoms, quality of life and biological parameters. The Palliative Prognostic (PaP) Score, the result of measuring survival predictors in patients with advanced cancer, seems to discriminate patients who could benefit by palliative chemotherapy from those who could better benefit by supportive and palliative approach.

## **2.11 Communication skills and breaking bad news**

*Dr Mohamed Zaffer Al Shahri, Saudi Cancer Foundation*

Communication skills with regard to breaking bad news can be considered a code of ethics including what physicians should do and say to comfort their patients. The presenter described in detail the S-P-I-K-E-S strategy (for breaking bad news). Physicians are often poorly trained in breaking bad news. Out of 400 oncologists, less than 5% stated they had received any training in communicating bad news. Evidence continued to demonstrate the need to teach health practitioners communication skills and provide more training in breaking bad news. Patients engaged in “bad news” discussions with their physician experience lower stress, greater satisfaction, lower depression levels and maintain more sense of hope than those who are not.

Fifty years earlier in the Arab world, most doctors did not routinely discuss cancer diagnosis with patients; they barely told their patients if they had cancer. Nowadays, most physicians would tell their patients about a cancer diagnosis, although some would withhold information as per family request. If cancer patients ask for full information, 62% of doctors will tell and 38% will not.

Saudi health professional law states that “In case of incurable or life-threatening diseases, the physician—based on his conscience—may judge the appropriateness (or otherwise) of informing the patient or his relatives with the nature of the disease, provided

that the patient did not prevent the physician from doing so, or appointed a person (or persons) to whom the disclosure is to be limited”.

## **2.12 End-of-life care**

*Dr Mohamed Zaffer Al Shahri, Saudi Cancer Foundation*

End-of-life care is simply acknowledged to be the provision of palliative care in response to the assessed needs of patient and family during the last phase of life. It is clear that the beginning of the end of life phase is variable according to the perspective of individual patients, and the clinical/prognostic judgment of individual professionals.

Based on expert opinion and qualitative research management, priority concerns for patients in the end of life are:

- Supporting families and caregivers
- Ensuring continuity of care
- Communication and making informed decisions
- Surviving longer and spiritual healing
- Sustaining function.

## **2.13 Self care: healing of healers**

*Dr Mohammad Bushnaq, WHO Temporary Adviser*

Palliative care practitioners and caregivers usually suffer from compassion fatigue, which has been described as the “cost of caring” for others; has led helping professionals to abandon their work with traumatized persons due to the severe emotional pain. Therefore, they need time off for relaxation, meditation, vacation and social networking.

## **3. SITUATION IN COUNTRIES OF THE REGION**

**Bahrain:** Palliative care started in January 2009. In March 2010, a palliative care unit was formed, which has a team of oncologists, palliative care specialists, medical officer, residents and nurses. It has two weekly follow-up clinics, one weekly pain clinic and a hotline for home care problems. The key challenges include legalism, public awareness and the need to develop guidelines on palliative care.

**Egypt:** There are pain clinics at most cancer care centres, yet no complete multidisciplinary palliative care team is functioning. Recently, a centre was established At Kasr Al Ainy, Cairo University. Morphine 30mg and fentanyl patches are available, but other formulations are not available. The main barrier is lack of education for patients, families and health care professionals about drug dependency. Policy leaders need to improve drug availability, accompanied by training for health care professionals.

**Iraq:** Palliative care is poorly developed in Iraq. There is a shortage of drugs. No oral morphine is available. Only injectable forms are available, and they are extremely restricted.

There is a shortage in staff, e.g. only two consultants. There is only one pain management centre in Baghdad.

**Islamic Republic of Iran:** Palliative care is in initial stages of development. It started in 2008 in Tehran. There are two pain care centres, one in Tehran and a recent one is founded in Isfahan. With the support of charity, a training programme was recently initiated and a plan to prepare national guidelines for palliative care is under way.

**Lebanon:** There are no definitive palliative care programmes in the country. Palliative care is still not recognized as a specialty by the Ministry of Health. Opioids are generally available but many hurdles prohibit their widespread use. There is general avoidance by many physicians. Although short- and long-acting morphine is available, prescription procedures requires two signatures, one from the prescribing doctor and another from a colleague. Only oncologists are allowed to prescribe outpatient opiates, which reduces the accessibility of morphine.

**Libyan Arab Jamahiriya:** Treatment is covered by the government, all free of cost. There are two oncology centres in two main cities of the country, but no definite palliative care facility. The key challenge is that palliative care is still managed as a part of general oncology.

**Morocco:** Palliative care is included in the national programme with a strategic objective to improve quality of life. The national cancer care plan has been in place for 10 years and includes pain management and home care by family support.

**Oman:** Palliative care is still in its early stages. The medical oncology department at the main hospital is currently providing the essential palliative care services given to terminally ill, but mainly given on day-care basis. The key challenge is lack of training.

**Pakistan:** There are 20 cancer care centres: 17 private and 3 governmental. Treatment is mainly supported by local charity organizations. There are 6 radiotherapy centres, and no separate palliative care centres. Morphine is not available to all, especially to governmental hospitals. A few hospices are present and supported by private nongovernmental organizations.

**Palestine:** There are two oncology centres, including palliative care services. However, there are no specialized trained palliative care doctors or functioning staff. Moreover, there is no palliative care hospice and there are no standardized guidelines for palliative care.

**Qatar:** Only one cancer centre is present in the capital Doha. Palliative care was started in July 2008. A 10-bed inpatient facility is available with an interdisciplinary team. Most essential drugs are available. A budget is approved for establishment of palliative care and end-of-life care.

**Saudi Arabia:** There are more than 15 comprehensive cancer centres and well-established palliative care units with integrated home-based care. 500 patients a year are receiving palliative care services. There are opioids available in county, in more than 23 different forms. Morphine consumption is 0.5 mg/capita. Prescriptions are written by palliative medicine physicians and oncologists, only for one month. There is a need for more awareness and support from high authorities.

**Sudan:** Oncology services are present since 1967 at Radio Isotope Centre Khartoum (RICK) and another two centres. Palliative care services started in February 2010. 259 patients were registered in the first eight months. Chemotherapy drugs are provided free of charge. Morphine tablets in 5mg–15mg–30mg dosages are available free of charge. Main barriers are lack of trained human resources and infrastructure. Opioid products are not available in the necessary dosages. Moreover, there is strong need for advocacy to raise awareness, capacity-building of trained professionals and introduction of home-based care, with availability of opioids and pain killers.

**Yemen:** Oncology started at the National Oncology Centre in 2005. An 80-bed centre with radiotherapy facilities is also present. Khat chewing is a very common in Yemen. Although there is an increasing prevalence of head and neck cancers, most patients present at advanced stages. Pain is managed with non-steroidal anti-inflammatories, morphine and fentanyl patches.

#### 4. CONCLUSIONS

Participants in the palliative care training workshop developed the following key messages for national health care decision-makers and the care-providing medical community in the Region.

- Each year 272 000 people are dying from cancer in the Region. This number will increase in the next decades.
- Dying in dignity is a human right. There are differences among countries of the Region. But in general this human right seems not to be guaranteed for the total population.
- There is urgent need to analyse the situation in detail.
- Based on analysis through the end of 2012, countries should develop national plans on palliative care for incurable cancer patients.
- Cornerstones of this plan must be the palliative care infrastructure and free-of-charge availability of pain killer/radiotherapy for all.
- Hospital-based palliative care (palliative care unit, hospice) is necessary for about 30% of incurable patients. For the remaining 70%, there is a need for hospital-at-home care.
- Hospital-at-home care does not mean outpatient treatment by a hospital. It means assistance to patients at home by mobile care teams (or general practitioners) working closely together with the patient's family. This approach is highly cost-effective.
- Care-giving families are the single and unique resource for palliative care in the Region. Providing care by hospital/hospice-at-home is one of the great challenges for countries.

- To meet this challenge there are three urgent needs:
  - infrastructure for hospital/hospice-at-home care available for all cancer patients who need it
  - broad information for the public about the availability of this infrastructure
  - training for the care-giving staff.
- The “regional organization for palliative care” started in Cairo should work for these aims under leadership of WHO.

## 5. RECOMMENDATIONS

### *To Member States*

1. Comply strictly with the WHO Guidelines for Ensuring Balance in National Controlled Substance Policies. National authorities are expected to complete on an annual basis the checklist designed to ensure full compliance with these guidelines.
2. Identify problems preventing optimal pain management, report such problems to WHO on an annual basis and work with the WHO Access to Controlled Medications Programme to resolve such problems.
3. Develop national plans for improving management of pain and access to controlled medicines, with specific objectives achievable within a clear time-frame. Such plans should include an internal periodic auditing process.
4. Establish a database on drug consumption that is specifically for oncology/palliative care purposes.
5. Facilitate physicians’ ability to prescribe opiates, irrespective of specialty, provided the physician is adequately trained to do so, and ease restrictions on duration and dosage of opiate prescriptions.
6. Develop home-based palliative care programmes with adequate resources and logistic support, including nursing education, outpatient home care teams that visit patients at their home at least once a week and 24-hour availability of phone contact.
7. Conduct a situation analysis and assessment in order to tailor the palliative care programme according to national needs.
8. Integrate palliative care into the educational curricula of health professionals such as physicians, nurses and others, and offer continuous medical education and training of personnel in palliative care.
9. Establish multidisciplinary palliative care teams in major health care facilities.
10. Develop a national database on palliative care services and link with other country databases through WHO.

### *To the Regional Office*

11. Support health care professions educational efforts in palliative and end-of-life care, including tracking such efforts and disseminating related information on the Regional Office website.
12. Establish a palliative care network to facilitate country interactions and exchange of experience and expertise.

**Annex 1****PROGRAMME****Sunday, 17 October 2010**

08:30–09:00	Registration
09:00–09:30	Objectives and Expected Outcomes <i>Dr Haifa Madi, WHO/EMRO</i>
09:30–09:45	Introduction of participants
	Election of officers
	Adoption of agenda
09:45–10:00	Palliative care / global perspective <i>Professor Stephan Tanneberger</i>
10:30–11:00	Cancer control and palliative care / regional status <i>Dr Ibtihal Fadhil, WHO/EMRO</i>
11:00–12:00	Country presentations: Bahrain, Oman, Qatar and Saudi Arabia
12:00–13:00	Country presentations: Egypt, Sudan and Yemen
14:00–15:00	Country presentations: Islamic Republic of Iran, Iraq, Jordan and Lebanon
15:00–16:00	Country presentations: Libyan Arab Jamariya, Morocco, Palestine and Pakistan
16:00–16:30	Country presentations: Pakistan and Qatar

**Monday, 18 October 2010**

09:00–09:30	Summary on previous day
9:30–10:00	Introducing palliative care <i>Dr Mohamed Zaffer Al Shahri</i>
10:00–10:30	Principles of symptom management <i>Professor Stephan Tanneberger</i>
11:00–12:15	Cancer pain management <i>Dr Samy Alsirafy</i>
12:15–13:00	Palliative surgery <i>Dr Ibrahim F. Al-Sheneber</i>
14:00–14:30	Opioid use and availability <i>Willem Scholten, WHO/HQ</i>
14:30–15:30	Plenary session on opioid use and availability on regional level <i>Willem Scholten, WHO HQ and other instructors</i>
15:30–16:00	Recommendations on opioid use

**Tuesday, 19 October 2010**

09:00–09:30	Advocacy for palliative care <i>Dr Mohamed Bushnaq</i>
09:30–10:30	Quality of life in terminally ill cancer patients <i>Dr Ibrahim F. Al-Sheneber</i>
11:00–11:40	Communication skills and breaking bad news <i>Dr Mohamed Zafir Al Shahri</i>
11:40–12:00	Discussion
12:00–13:00	Palliative care delivery models <i>Dr Samy Alsirafy</i>
14:00–14:30	Home based palliative care <i>Professor Stephan Tanneberger</i>
14:30–15:30	Plenary session on home based palliative care <i>Professor Stephan Tanneberger and all instructors</i>
15:30–16:00	Recommendations on home based palliative care

**Wednesday, 20 October 2010**

09:00–09:30	Prognostication in advanced cancer <i>Dr Samy Alsirafy</i>
09:30–09:45	Self care for palliative care providers <i>Dr Samy Alsirafy</i>
10:30–11:00	End of life care issues <i>Dr Mohamed Zaffer Al Shahri</i>
11:00 – 12:00	Getting started <i>Dr Mohamed Bushnaq</i>
12:00 – 13:00	Recommendations, conclusions and closing



**Annex 2**

**LIST OF PARTICIPANTS**

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