Palliative care

Proposal for a national program in Saudi Arabia

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Palliative care can be defined as "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 physical, psychosocial and spiritual problems".[1] Palliative care can generally be provided using effective methods with low cost to relief suffering and improve patients' and families' quality of life.[2-6] The status of palliative care services varies greatly between different countries. Several countries with well-developed health systems have made significant progress in developing palliative care services for their suffering patients and families. However, the majority of countries all over the world have a long way to go, so as to improve palliative care coverage for their people.[7]

Kingdom of Saudi Arabia (KSA) is a large country with an area occupying an approximately four fifths of the Arabian Peninsula and an estimated population of more than 21 million.[8] Cancer is considered one of the major health problems in KSA with a crude incidence rate of 37 per 100,000.[9] Other reports suggest higher incidence rates. In the year 2000, for instance, the estimated number of cancer cases exceeded 15000 and cancer deaths exceeded 10000.[10] King Faisal Specialist Hospital and Research Centre (KFSH&RC), Riyadh, KSA alone receives more than 2500 cancer cases per year.[11] Most of newly diagnosed patients present in relatively late stages of disease that make the option of curative treatment less likely. In these cases and in other non-cancer terminal illnesses, palliative care might be the more realistic and appropriate option for alleviation of suffering and improvement of patients' quality of life. The palliative care ethos is also to support families in coping with the difficult and complex situation of caring for a loved one suffering from cancer or another terminal illness.

The Ministry of Health (MOH) is the main provider of health services in KSA. The health services provided by MOH are based on a 3 level system, namely primary health care centers (PHCCs), secondary general hospitals, and regional referral hospitals. The MOH regional referral hospitals could be one or more in each of the 13 regions, to which KSA is administratively divided. One of the major advantages of the health care system in KSA is the extensive coverage of the whole country by PHCCs with a well-defined catchment population for each center. Military sectors and some major corporations provide health services to their respective personnel. Several university hospitals located in major cities provide free-of-charge health services to patients. Well-developed private health services in KSA are available for the whole population on a fee-for-service basis. King Faisal Specialist Hospital and Research Centre is a super-specialized health care system based mainly in the capital, Riyadh, with a relatively new branch in Jeddah, the second largest city in the country. King Faisal Specialist Hospital and Research Centre is considered as a major tertiary referral center for the whole country, especially for cancer care purposes. The hierarchal health care system of 3 levels with an established referral system makes national health programs

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more feasible and practical. Palliative care services started to develop in KFSHRC in Riyadh in the early 1990s and had slowly evolved into a section in the Department of Oncology. Other programs are currently established on a smaller scale in KFSHRC in Jeddah and in the National Guard health services. Despite the few steps made forward in the road of palliative care development, the consumption of opioid analgesics (as an indicator of palliative care services) is still extremely low in KSA according to international standards. The per capita consumption of morphine for the year 1999 was 0.4 mg, compared to 52 mg for Canada, 30 mg for United States of America, and 20 mg for United Kingdom.[12] Assuming that all cancer patients seen in KFSHRC have access to palliative care, one may estimate that more than two thirds of cancer patients in KSA will have very limited access to specialist palliative care services. Limited availability of palliative care services entails more unnecessary suffering by patients and their families. This emphasizes the ethical obligation of health-policy makers, palliative care specialists, and cancer care professionals to advocate for the promotion of palliative care services in the country.

This proposal for establishing a national palliative care program originates from the fact that palliative care services are needed by patients throughout the country and should be made available to them and their families in the most effective manner. Furthermore, community oriented regional palliative care programs have proven cost-effective elsewhere.[13] The aim of the national palliative care program is to make high quality palliative care services accessible to all patients and families who need these services anywhere in KSA. Emphasis is also placed on the continuous education of health professionals and the promotion of palliative care research.

Organizational structure. The authors suggest that the MOH, being the main provider and the ultimate body for supervision of health services, to review the proposal and assume the overall supervisory role on its implementation. A steering committee, composed of members from MOH, Ministry of Defense Health Services, National Guard Health Services, Security Forces Health Services, Ministry of Interior, KFSHRC, and private health services shall be formed. The committee shall report to the minister of health or his designee. This committee will be responsible for the planning and management of the national program.

Referral system. One or more main MOH referral hospitals in each region shall be designated as the tertiary palliative care center(s) for that region. At the primary health care level, one in every 10 MOH primary health care centers shall be designated as the referral PHCC for palliative care services. In the rest of this document, the referral PHCC will be called main PHCC (MPHCC) and the MOH referral hospital will be called main hospital (MH). Patients diagnosed with palliative care needs in PHCCs and private dispensaries shall be referred to the allocated MPHCC. This MPHCC shall also accept referrals from other health sectors (non-MOH) in which palliative care services are not available. Patients with problems difficult to manage at the MPHCC can be referred to the MH for further management. After stabilization, patients can be referred back to the MPHCC for coordinating and supervising patient care in the community. Patients, whose conditions are judged difficult to manage in any of the MHs, should be referred to KFSHRC in Riyadh for further management. When stabilized, these patients can be referred back to the regional MH or MPHCC. Patients can also be referred from KFSHRC back to other health services (non-MOH) when deemed appropriate. **Figure 1** describes algorithmically the proposed referral system for the program.

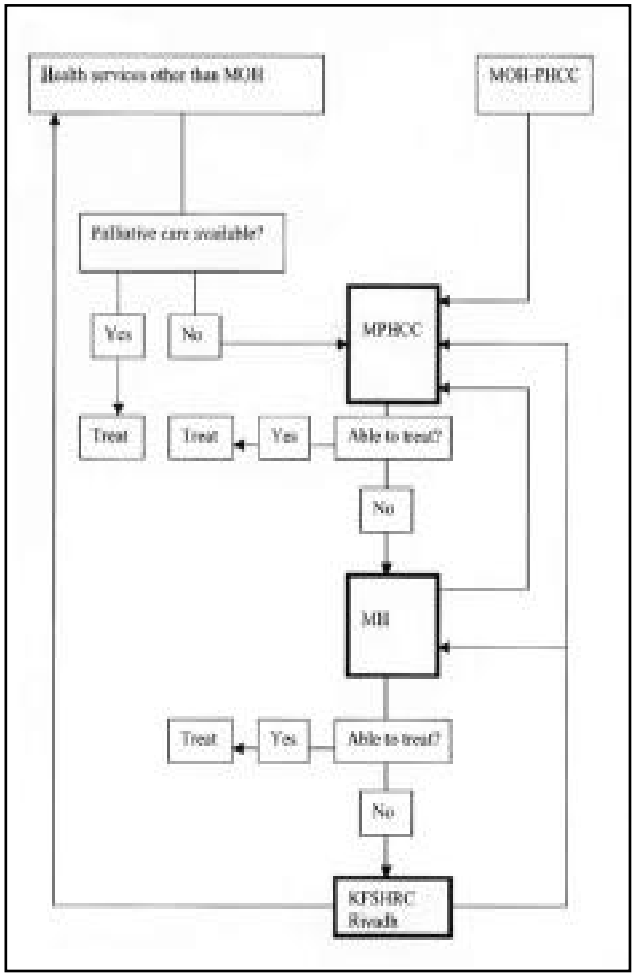

Figure 1 - The referral system for patients with palliative care needs. MOH - Ministry of Health, PHCC - primary health care center, MPHCC - main primary health care center, MH - main hospital, KFSHRC - King Faisal Specialist Hospital and Research Centre.

Delivery of service. The MPHCC will receive patients after having had their diagnoses verified and disease targeted treatment instituted or completed. Patients will be referred to MPHCC from KFSHRC, MH, or other health sectors with no palliative care facilities. These patients will be registered in a palliative care registry book and an initial assessment will take place in the health center or at home based on the needs. Patients will be followed regularly for continuous assessment and adjustment of medications. When home visits are required, the nurse will usually carry out this task. However, a physician may need to visit some patients at home on as needed basis. Every patient admitted to the program shall have a problem list and medication card that enlists the main problems and all the medications the patient is on. This card shall be kept with the patient and shown to health facilities to which the patient may present after working hours of the MPHCC or during weekends. Medications will be prescribed by the physician in the MPHCC and will be dispensed by the MH pharmacy.

The MH will receive referrals from either MPHCC or KFSHRC. The MH shall have a palliative care registry book for all patients admitted to the program from the catchment area. The patients referred from a MPHCC will either need admission to the hospital or an outpatient visit for assessment and adjustment of the management plan. Patients referred from KFSHRC to a MH will need admission, as according to the referral scheme of the program, patients stable enough to be managed at home shall be referred back from KFSHRC to their MPHCC. Discharge of patients from MH shall be carried out in liaison with their MPHCC, with a discharge summary report given to patients to help the team in the MPHCC continue managing the patient in the community. The MH is also responsible for dispensing all prescriptions for palliative care patients in the catchment area.

The palliative care service at KFSHRC will be the ultimate referral center for the national program. Referrals will be received from within the hospital and also from palliative care teams in MHs throughout the country. Referrals will be accepted on the basis of complexity of the case and need for expert management. However, the palliative care team in KFSHRC is expected to respond to phone and facsimile consultations received from all MHs participating in the program.

Training of manpower. Two interested physicians from each MPHCC and MH shall receive palliative care training in KFSHRC. Training of PHC physicians shall include didactic and bedside teaching for one month, during which the trainers will assess the trainees' abilities in managing patients with uncomplicated problems and safely prescribing essential palliative care medications. Hospital-based physicians shall receive 3 months training, as they need to be backing up the PHCC teams for management of moderately complex cases. Trained physicians will receive certificates upon completion of their training. These certified physicians are encouraged to provide in-service training to interested physicians, nurses, pharmacists, social workers and other health workers who can contribute in providing patients and families with the highest possible quality of palliative care services within the frame of resources available. The palliative care specialists from KFSHRC and other sectors may arrange for annual refresher courses for palliative care teams in various regions.

A minimum of 2 nurses from each MPHCC and MH shall receive one month training in KFSHRC. The enrolled nurses will receive hands-on training in caring for terminally ill patients. They will also receive training on the management of infusion pumps in the hospital and community. A minimum of 2 pharmacists from each MH shall receive 2 weeks training in KFSHRC. The training program will cover theoretical and practical aspects of preparing and managing palliative care medications. Establishing and maintaining a record-keeping system for proper documentation shall also be emphasized.

Essential medications. **Table 1** shows the proposed essential drug lists for a MH. The medications shall be made available by MOH to all MHs participating in the program. King Faisal Specialist Hospital and Research Centre and other health sectors shall be responsible for ensuring availability of their own stock of medications, in collaboration with MOH. Despite the negligible likelihood of diverted use of opioids and controlled medications, a strict inventory system shall be agreed upon by the steering committee of the program.[14] The MOH directorate of narcotics shall audit this inventory system regularly.

Budgetary aspects. For the purpose of implementing the program, the MOH will not need to increase the number of staff in any of the participating centers or hospitals. The trained candidates will be providing care for terminally ill patients in addition to their routine duties. Available data suggest that having inpatient palliative care beds as compared to general hospital beds can reduce cost.[15-16] The cost for manpower training shall be covered by collaborative efforts from the MOH, KFSHRC and donations from charity (such as Saudi Cancer Society) and individuals.

Piloting and auditing. The steering committee shall identify one region outside Riyadh for piloting the program. The selected region shall preferably have only one MH and with the smallest number of

PHCCs regardless of the incidence of cancer. This is basically for logistic reasons as it would be more feasible and practical to pilot the program on a smaller rather than a larger scale. Before executing the program, the steering committee shall ensure proper establishment of the infrastructure in the piloted centers. This includes ensuring availability of essential drugs, symptom assessment forms, prescription forms, and the necessary registry books. Two physicians each from the MH and a MPHCC will start training in KFSHRC at the same time. In 3 months time, 8 physicians would have been trained, 2 hospital-based and 6 PHCC-based. Following the first 3 months, 4 PHC physicians will receive training in KFSHRC every month until the required number of trained PHC physicians for the piloted region is met. Cancer patients in the region shall be identified through the National Cancer Registry Program. The first 2 PHC physicians to complete the training shall conduct a survey on the identified patients in their catchment area. The survey must include a formal symptom assessment and may also explore patient satisfaction about the currently available health services. Upon completion of assessment, patients should be provided with the necessary treatment and their questions of the program addressed. The survey data shall be submitted to the steering committee for future analysis. King Faisal Specialist Hospital and Research Centre will remain the referral center for the MPHCC until the hospital-based physicians complete the 3-months training and resume their duties in the MH.

Table 1 - Essential palliative care drug list for a main regional hospital.

Drug class	Drug name
Non-opioid analgesics	Acetaminophen Ibuprofen
Opioid analgesics	Codeine Morphine Fentanyl Hydromorphone Methadone
Opioid antagonists	Naloxone
Corticosteroids	Dexamethasone Prednisone
Laxatives	Bisacodyl Docusate sodium Senna Magnesium citrate
Anti-depressants	Amitriptyline Citalopram
Psychostimulants	Methylphenidate
Anti-epileptics	Gabapentin Phenytoin Diazepam
Sedatives	Midazolam
Neuroleptics	Haloperidol Methotrimeprazine
Anticholinergics	Hyoscine butylbromide Glycopyrrolate
Gastric protection	Omeprazole Ranitidine
Diuretics	Spironolactone Furosemide
Anti-fungal	Nystatin Fluconazole
Anti-emetics	Metoclopramide Prochlorperazine

A comprehensive plan for auditing shall be designed and monitored by the steering committee. Audit topics may include, but not limited to, impact of the program on patients' quality of life; symptom assessment and management; patients' and families' satisfaction; cost benefits; diverted use of medications; knowledge, attitudes and practices of health professionals in the participating centers; and community awareness and support of palliative care services. An audit topic may have one or more quality indicators that are measurable and analyzable to assess performance and outcomes.

In conclusion, although a palliative care service has existed in the KFSHRC for a decade, a nation-wide national program for palliative care is yet to be established. In countries with well-developed health systems, palliative care is recognized an integral and essential component of health care to which the public is entitled. The delay in establishing a national program for palliative care services means that thousands of people may continue to unnecessarily experience tremendous suffering each year. The need for a major expansion in palliative care services for Saudi population cannot be overemphasized. Given the vast nature of the country and the favorable community-oriented health system, a national program of palliative care has a high potential for success in KSA. Key figures and authorities are urged to take the lead in developing a national palliative care program that tailors the best standards of care to the special needs and cultural structure of the Saudi population. Success of the proposed program may encourage other countries in the region to adopt the Saudi example, allowing access to a truly comprehensive cancer care for the people in the whole region.

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