

PALLIATIVE CARE FOR PATIENTS WITH ADVANCED CANCER

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ستصحب الزيادة في متوسط السن (الأعمار) بالمملكة العربية السعودية تغييرات في أشكال الأمراض ، متشابهة في ذلك لما يحدث بالدول الغربية . وأحد هذه الأمراض هو مرض السرطان ، الذي هو ، في الوقت الحاضر ، السبب الثاني في الوفيات في دول الغرب ، حيث يتعرض ما نسبته 1:3 من الناس للإصابة بالسرطان خلال فترة حياتهم ، وتبلغ نسبة الوفيات منهم 1:4 . ونادراً ما يكون الموت بسبب السرطان سهلاً . أما ما يمكن أن يحدثه من الضيق والأسى فهو خرافي ، وبخاصة الألم . إن الرعاية التلطيفية هي رعاية ودراسة حالات المرضى المصابين بأمراض نشطة ومتقدمة ، حيث يصبح العلاج مستحيلاً ، وإمكانية التكهن بالتشخيص قصيرة ، وتتركز الرعاية على نوعية حياة المريض . لقد تم تطوير برنامج الرعاية التلطيفية في مستشفى الملك فيصل التخصصي ومركز الأبحاث منذ العام 1991م . وقد أدى ذلك إلى التوسع في أنواع الخدمة الطبية المتوافرة لمرضى السرطان . إن هناك حاجة للمزيد في مجال الرعاية التلطيفية بالمملكة ، حتى يتسنى التخفيف من أحد مسببات معاناة الجنس البشري .

الكلمات المرجعية: الرعاية التلطيفية، علاج السرطان، ألم السرطان ، الوقاية من السرطان.

The increasing life expectancy in Saudi Arabia will be accompanied by an alteration of the patterns of disease similar to that in Western countries. One of these will be cancer, the second leading cause of death in the west at present, where 1:3 people develop cancer during their lifetime and 1:4 die of it. Cancer deaths are rarely easy. The distress particularly the pain it can cause is legendary. Palliative care is the care and study of patients with active progressive far advanced disease, where cure is impossible, the prognosis predictably short, and the focus of care is the patient's quality of life. A Palliative Care Program has been developed at KFSH&RC, since 1991. This has broadened the spectrum of health services available to cancer patients. Palliative care needs to be more widely available in the kingdom to relieve an important cause of human suffering.

Key Words: Palliative Care Medicine, Cancer Treatment, Cancer Pain, Cancer Prevention.

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INTRODUCTION

The true incidence of cancer in the Kingdom of Saudi Arabia (KSA) is just now being assessed. Hospital statistics reflect patterns of referral, rather than the real incidence of the various types of cancer. In 1993, a National Cancer Registry (NCR) was established, to collect data from all regions, the first report of which was published in 1996. Over the next few years, the NCR will establish a baseline for the incidence of cancer, and provide a means of monitoring the success of its treatment for the whole country.

Much about cancer in KSA can be deduced from the experience of other countries. Cancer is particularly a disease of old age when it is one of the many causes of morbidity and mortality. Although cancer becomes more common as we age, it differs from other diseases of the elderly, in that cancer can occur at any age. With its large population of young people, cancer in children is also a significant problem in KSA. 12.6% of the cancer patients seen at King Faisal Specialist Hospital and Research Centre (KFSH&RC) are children. This is a much higher proportion than is seen in similar referral centers in the West.¹ The average life expectancy for men and women in the Middle East is estimated as 62 years. While it is comparison is 75 years or more, in the West.² With the rapid improvements in nutrition, sanitation, housing, and the highly effective vaccination programs that have been developed, the Saudi populations life expectancy will rapidly increase. The national census conducted in 1992, shows that the average life expectancy here is already 70 years. We can reasonably predict that this increase in life expectancy will be accompanied by an alteration in the patterns of disease similar to that in Western countries; where infectious diseases leading to premature death have

been replaced by more chronic illnesses of old age, such as heart disease, cancer, and cerebro-vascular disease. In the USA, cancer accounts for 22% of all deaths, second only to heart disease.³ Generally, in Western countries, one in every three people will develop cancer during their lifetime, and one in every four will die of it.

PREVENTION OF CANCER

McDonald of Canada has provided a useful description of four phases of cancer "prevention" covering all aspects of the disease: (1) Prevention of the disease (public education and policy) (2) Prevention of advanced disease (early diagnosis programs) (3) Prevention of death (anti-cancer treatment) and (4) Prevention of suffering (palliative care)⁴

Cancer is one of the most treatable of all chronic illnesses. This aspect of cancer is often overlooked, because the disease arouses such fear. It is the most feared of all illnesses, and its diagnosis is usually associated in the patient's mind with premature and unpleasant death. In fact, however, in the West 40-50% of cancer patients will be cured; that is, they will have a normal life expectancy for their age and sex.² In children, the cure rates are even higher, over 60%.⁵ However, these figures rely upon the fact that 70% of cancer patients in the West present "early" at stages 1 and 2. At KFSH&RC, only 30% of patients present with localized stages 1 or 2 disease. Nearly 70% have stage 3 or 4 advanced disease, consequently with a much worse prognosis.¹ As these patients are accepted at this major tertiary referral center on the basis of their likelihood of responding to treatment, other centers are likely to see even more advanced disease. It is likely that 80% or more of cancer patients in this country present with advanced disease, when cure rates will be low. Even so, after surgery, chemotherapy, or radiotherapy, or by the use of one or all three modalities, dramatic remissions can be obtained which may last from months to years before the patient's condition deteriorates

again. At present, however, probably 70% or more of cancer patients in Saudi Arabia will eventually die of their disease.

While there is constant incremental progress in the treatment of cancer, with improvements continually being introduced into the Kingdom, major progress could be made if patients could be encouraged to report early. This involves firstly, improving the public's awareness of their personal health problems and the benefit of presenting early with their symptoms, and secondly, ensuring that there is no delay in diagnosis and treatment of patients with symptoms.

THE PUBLIC'S PERCEPTION OF CANCER

Bedikian and Saleh interviewed one hundred Saudi patients with cancer. They reported that 92% had an adverse reaction to the diagnosis, and the median duration of symptoms was from 3-5 months. None had received professional assistance for these problems, and the authors recommended that psycho-social support be available to patients as part of their total management.⁶ Bedikian in a further study interviewed two hundred and fifty healthy Saudis on their attitudes and knowledge of cancer. This study revealed a considerable degree of fear and anxiety about this disease.⁷ Similarly, Ibrahim et al, interviewed six hundred adults on their attitudes to cancer and confirmed the high level of fear and misconceptions about the disease.⁸ Both groups of authors called for a more comprehensive health education on the awareness of cancer as a treatable disease.

PALLIATIVE CARE

Dying is as natural an event as being born. This is recognized by Islam and its acceptance of death as an expression of God's will. In Western countries where

the population has a long life span and cancer is common, dying of cancer has a special dimension that has made it the most feared of all illnesses. This is because cancer deaths are rarely easy. The distress it causes is legendary. Eighty percent of patients dying of cancer will suffer pain, and in 60% it will be severe enough to require strong analgesics of the morphine type.⁹ Pain is only one of the distressing symptoms caused by advanced cancer. Anorexia, weight loss, tiredness, malaise, shortness of breath, and confusion are some of the other many symptoms that cancer can cause as it spreads to vital organs. Added to the physical distress of advancing cancer, is the emotional distress about impending death.

The explosion of medical technology and the opportunity to finally cure major diseases began at the end of the nineteenth century. This new era may have obscured the need to provide a supportive and caring environment for patients with chronic illnesses. Cancer was once considered by some to be an untreatable disease, and eminent physicians were known to discharge cancer patients once they were diagnosed, on the grounds that nothing further could be done for them. Presently, an enormous amount of knowledge has evolved on the nature and treatment of cancer. Much of this research for newer and better methods of cure has been concentrated on changes at a cellular level. However, in the last twenty years, a body of knowledge known as palliative medicine has evolved for the treatment of the symptoms of advanced cancer, which has failed to respond to anti-cancer treatments. This has now become a specialized area of interest for doctors and nurses.¹⁰ While its practitioners are few, its attitudes are important to medical systems in general, for the following reasons:

1. Providing Continuity of Care

In most Western countries, patient care is dependent upon the primary care physician (family practitioner). This doctor will have a formal or informal "contract" with an indi-

vidual or family to undertake their medical care and act on their behalf at all times. A well organized family practice or polyclinic will have a computerized "template" of routine examinations, screening investigations, and a complete medical record of the patient and their family environment. When a patient has a terminal illness, he has a doctor he knows and can trust, and in turn the doctor knows both the patient and his family. This continuity of care is important, particularly for chronic illnesses and for a terminal disease. It means that "no cure" is not the same as "no care". Unfortunately, at present, in Saudi Arabia, continuing care of patients with either a terminal or chronic illness, even as outpatients is provided mainly by a hospital service.¹¹ This type of care should become an essential part of the primary health care system of the Kingdom.

2. Cure or Palliation?

In Saudi Arabia the emphasis for cancer patients is on curative treatment. There is a strong tendency here to deny the patient information on their illness. This is a problem shared by other countries, but in the last twenty years doctors in Western 3. countries, have treated the individual patient as an independent agent, capable of receiving information and acting upon it. This allows the individual patient to give true informed consent after evaluating the advantages and disadvantages of the proposed treatment. This also allows the patient to participate more fully and cooperate with the treatment, and with such compliance improve the chance of success.¹² In Saudi Arabia, the predominant principle is "beneficence", where the patient is viewed as a member of the larger family that is responsible for the patient. The consent for the patient's treatment is usually a substitute consent by the family, whose purpose is to avoid disturbing the patient emotionally. Thus the family considers it their duty to protect the patient

from harm. Telling patient the truth, would impair his ability to cope with the situation and may consequently lose hope. This attitude seems to apply particularly to female patients. However, Abu Aisha wrote that, it is recognized in Saudi Arabian law that a woman is legally considered a responsible citizen. It follows, therefore, that an adult female patient of sound mind has the right to give her own consent after being adequately informed of the nature of her illness.¹³ There is now ample evidence that patients cope better with a serious illness if they are informed.¹² Without such vital information on their illness Saudi patients will continue to travel overseas at considerable cost, with the unrealistic expectation of a cure. Unfortunately, the development of market medicine elsewhere in the world feeds this expectation, giving treatment which may be neither necessary nor appropriate. If the only purpose of medicine is that of saving people from death, then obviously, medicine cannot win. The art of good medical practice, is to decide when life is no longer sustainable, and therefore, to allow death to occur without further impediment.¹⁴ Physicians should also bear some responsibility for the quality of their patient's death.¹⁵

The Relief of Pain

Chronic pain, particularly as it occurs in cancer, has several distressing features: it gets progressively worse, it has no meaning, creates a feeling of hopelessness, dominates the patient's life, and can destroy their will to live.

One part of pain is its perception, the other the emotional response to it. This is why people experience different degrees of pain. Pain is precisely what the patient says it is, and hurts as much as they say it hurts. Preconceived ideas of how much pain patients will or should have are best avoided. There is a general lack of knowledge of pain relief in the Kingdom, and in many hospitals adequate analgesics of the morphine type are simply not available. There is an unreason-

ble fear of morphine addiction amongst patients and their families, but studies have convincingly shown that addiction is never a problem in a terminal illness.¹⁶

The important point for doctors to know is that no patient needs to suffer pain so severe that their work, sleep, and quality of life are ruined. It should be rare for dying cancer patients to have uncontrolled pain. The World Health Organization recommends a three-step process in pain control moving from simple analgesics such as tylenol at the first stage, to tylenol and codeine based compounds ± NSAID's at the second stage, and morphine or similar compounds for patients with severe or step 3 pain.¹⁹ Each of these regimens require that medications be given regularly around the clock, not PRN. This requires careful monitoring by the physician of the patient's pain level, and their response to medications. Regular analgesics and continuity of care is the secret to good pain control.

CULTURAL ASPECTS

The family unit is the structural foundation of Saudi society. The impression is that patients here cope better with a terminal illness in their home, than happens elsewhere in the West. This is probably because of the close family bonds and their strong Islamic faith with its obligation to provide for parents or children in case of need, to help make their lives as comfortable as possible. The corollary of this is, that a small input of medical and nursing care, results in a magnified response by the extended family to the care for a patient. This can be very gratifying to the doctor and nurse.

There is an impression that palliative care in the Kingdom is confused with euthanasia, which is totally forbidden by Islam.¹⁷ Palliative care is the moral and ethical alternative to euthanasia. Providing

comfort, relieving distress, controlling pain, and offering a service that is available 24 hours a day, sustains the patient's hope. It is not based on the false hope of providing inappropriate and ineffective treatments. This society quite rightly sets great store on hope, and palliative care increases that hope, that each day may be more comfortable than the last.

THE KING FAISAL SPECIALIST HOSPITAL & RESEARCH CENTRE PALLIATIVE CARE PROGRAM

In 1991, a Home Health Care Program was developed at KFSH&RC. This was in response to concerns by staff regarding the distress suffered by patients with terminal cancer, and the loss of the benefits of good quality medical care once the patient returned home.¹⁸ Two years of planning and research went into developing the program. What began as essentially a nursing service for patients with a terminal illness, developed over the years into a nursing and medical service. These efforts resulted in the development of a Section of Palliative Care Medicine in the Department of Oncology in 1996; this appears to be the first such service in the Arab world.

At present, the multi-disciplinary team includes: three palliative care consultants, six nurses, five translator/drivers, a palliative care nurse clinician, and social workers. This team provides total care for the patient and support for the family, as a unit. The program consults with other health disciplines to provide the most appropriate care. The service runs 24 hours a day, seven days a week. To date, over 1500 patients living in Riyadh have been referred to the Home Health Care program. An increasing number of other patients who live outside Riyadh are being followed up in the Palliative Care outpatient clinics. While the Home Health Care Program in Riyadh includes cases of chronic illness, palliative care for a terminal illness makes up 75-80% of the workload. At present, the program has between 40-50 terminally ill patients at any one

time being cared for at home in Riyadh. Ten in-patient beds are provided in the hospital. Many patients require at least one admission for the control of symptoms that cannot be managed at home, and for stabilization of symptoms before being transferred either home or to a hospital in the Kingdom. The average duration of stay has been 6-7 days.

CONCLUSION

What are the aims of a good health service? The American President's Commission for the study of ethical problems in medicine provided the following definition: "to provide treatment that will restore patients to as near normal or usual a quality of life as is possible under the circumstances" or, put more simply, "to maximize the patient's well-being".¹⁹

The patient's perception of this is that the health services will: (1) Restore them to good health, (2) Improve their ability to function (3) Relieve their suffering (particularly if the first two are not possible).

That we fail to cure all our patients, does not mean that we should fail to care for them and relieve their suffering. The purpose of a palliative care service at the KFSH&RC is "the care and study of patients with active, progressive, far advanced disease; for whom cure is impossible, the prognosis predictably short, and the focus of care is the quality of life". Palliative Care has broadened the spectrum of health services available to cancer patients in the Kingdom. It has proven that it is possible to provide palliative care of a standard similar to that in a Western country. Cultural aspects of life in the Middle East, particularly the strong family bonds, the acceptance of matters of life and death, and the emphasis on hospitality, actually enhance and promote this form of care, which inspires Saudi families to care for

dying patients until the end of life.

REFERENCES

1. Annual Report of the Tumor Registry. Oncology Department, MBC 64, King Faisal Specialist Hospital and Research Center, Riyadh, 1995.
2. WHO. Cancer Control in the Eastern Mediterranean Region. EMRO Technical Publications, series 20. 1995; WHO Regional Office, Alexandria, Egypt.
3. Boring CC, Squire TS, Tong T. Cancer Statistics 1992. CA 1992; 42: 19.
4. McDonald N. Palliative Care: The 4th Phase of Cancer Prevention. Cancer Detection and Prevention. 1991; 15:253-5.
5. National Cancer Institute. Ries LA, Hankey BF, Miller BA, et al (editors). Cancer Statistics Review, 1973-88. NIH Publication, No. 91-2789. Bethesda, 1991.
6. Bedikian AY, Saleh V. An Evaluation of the Need for Psychosocial counseling for Saudi Cancer Patients. King Faisal Specialist Hosp Med J 1985; 5: 91-8.
7. Bedikian AY, Thompson SE. Saudi Community Attitudes Towards Cancer. Ann Saudi Med 1985; 5: 161-7.
8. Ibrahim EM, Al Muhanna FA, Saied I. Public Knowledge, Misperceptions and Attitudes about Cancer in Saudi Arabia. Ann Saudi Med 1991; 11: 518-23.
9. Cancer Pain Relief and Palliative Care. Technical Report Series, 1990. WHO, Geneva.
10. Doyle D, Hanks GWC, MacDonald N. Oxford Textbook of Palliative Medicine. Oxford: Oxford University Press; 1993.
11. Al-Swailem AF. Assessing Health care Delivery in Saudi Arabia. Ann. Saudi Med 1990; 10(1): 63-8.
12. Manuel GM, Roth S, Keefe FJ, et al. Coping with Cancer. Journal of Human Stress 1987: 149-58.
13. Abu Aisha H. Woman in Saudi Arabia: Do They Not Have the Right to Give Their Own Consent for Medical Procedures? Saudi Med J 1985; 6: 74-7.
14. Callahan D. Ethics and the Medical Ambivalence Towards Death. Humane Med. 1994; 10: 172-83.
15. F. Porzolt. Goals of Palliative Cancer Therapy. Cancer Treatment Reviews 1993; 19 Suppl A. (Contributions to a workshop sponsored by the German Ministry of Health).
16. Zenz M, Willweber-Strumpf A. Opiophobia and Cancer Pain in Europe. Lancet 1993; 341: 1075-6.
17. Newspaper Report on the 7th Conference of the Islamic Fiqh Academy. Arab News. May 16, 1992.
18. Gray AJ, Ezzat A, Volker S. Developing Palliative Care Services for Terminally Ill Patients in Saudi Arabia. Ann Saudi Med 1995, 15 (4): 370-6.
19. Definition from the American President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research. Washington DC: Government Printing Office; 1983.