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Principles of palliative care

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Introduction

Palliative care arose from the early Hospice Movement founded by Dame Cicely Saunders (1918-2005) in the UK. Dame Cicely was a nurse who re-trained as a medical social worker and eventually as a physician. She researched and championed effective pain management and promoted a more compassionate and holistic approach to patient care. Canadian urological surgical oncologist Dr Balfour Mount readily took up her reforms but because the word “hospice” did not translate well into the French-speaking province of Quebec, the term “palliative care” was adopted.

The World Health Organization has defined palliative care as “an approach that improves the quality of life of patients and their families facing the problem(s) associated with life-limiting 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.”^[1] Currently, more than half of the world’s countries have some form of palliative care services.

The principles of contemporary palliative care challenge a concept of cancer management that involves sometimes debilitating therapies and interventions, proceeding doggedly until the decision is made to “withdraw active treatment” and opt instead for comfort care and quality of life. Clinicians now opt for a more collaborative and cooperative management plan whereby symptom management, supportive care and amelioration of psychosocial, existential and spiritual concerns are acknowledged and managed conjointly between the primary care practitioners, oncologists and an interdisciplinary palliative care team. A patient may both appreciate and benefit from palliative care input early in the course of their cancer journey, and may prefer to negotiate a more gradual transition from active cancer treatments to management with primarily palliative care intent.

A reason for not discussing or offering palliative care in a more timely fashion is the concern that it will cause patients to lose hope. However, empathic and skillful communicators argue that it is possible to be honest without destroying all prospect of hope, and that the intent of treatment ought to be clearly presented to patients and their families.

The general public, and some health care practitioners, often misunderstand the contemporary definition of palliative care. There remains the mistaken belief that palliative care is only about the last few days or weeks of life. This belief is reinforced by the late referral of patients when they are seen to be “actively dying”. To some extent, the limited number of palliative care services in Australia and New Zealand, and the limited resources and staff available to meet palliative care needs, exacerbates this situation.

When is it appropriate to request the involvement of palliative care?

Palliative care is a recognised specialty that is uniquely needs-based. Palliative care is not defined by a diagnosis, organ or system (as in cardiology or urology), but rather by the fact that any patient with a potentially life-limiting illness may experience suffering. That suffering may arise from the pathophysiological effects of a cancer (or non-cancer) diagnosis, the realisation of their own mortality, or the adverse effects of a range of surgical, physical or pharmacological therapies. If a patient is suffering persistent or difficult-to-control symptoms or emotional distress, then consultation with a palliative care practitioner should be considered.

Palliative care practitioners have considerable expertise in managing pain, nausea and vomiting, dyspnoea, delirium and the spectrum of symptoms experienced by cancer patients. They work collaboratively in an interdisciplinary team comprising a range of providers from medical, nursing, allied health, spiritual and supportive disciplines. The focus of this care is to anticipate problems that might arise and to minimise the impact of the progressing illness so that patients can experience the maximum function and comfort that is possible within the limits of their illness.

It is important to guard against the use of “palliative” as a label that defines a patient or that describes the extent of, or limitations to intended treatment. The spectrum of investigations and interventions consistent with a palliative approach is guided by goals and expectations of individual patients and family, and by accepted standards of health care rather than being bound by preconceptions of what is or is not “palliative”.

Palliative care is very often for people with cancer, but is also applicable to, and provided for, patients with a range of non-malignant life-limiting conditions. Increasingly, palliative care is provided to cancer patients in parallel to active treatments such as surgery, chemotherapy or radiation therapy and there is emerging evidence that the “parallel model of palliative care” improves patient and family comfort.

Despite recent advances in the prevention, detection and treatment of malignant disease, cancer remains one of the most dreaded diseases of our age. The role of the healthcare professional is not only to treat, but also to support, guide and empower the patient along their cancer journey. The national code of conduct for all doctors registered to practice medicine in Australia imposes a professional obligation to provide or arrange appropriate palliative care for all patients who need it or request it.

Case study

A 40-year-old married woman with a 5-year-old daughter presented to the emergency department of a peripheral regional hospital with a 2 week history of increasing pelvic and left flank pain, and urinary symptoms. Clinical examination was limited and vaginal speculum examination not possible because of severe pain. CT revealed a mass anterior to the vagina, and she was transferred to the gynaecologic oncology hospital in the capital city. Due to severe pain, the palliative care consultant was asked to advise on and supervise pain management. An examination under anaesthesia confirmed infiltrating tumour in the vagina anteriorly and posteriorly with palpable tumour between the rectum and vagina. Cystoscopy and sigmoidoscopy were normal. Satisfactory analgesia was attained, management of opioid side effects of constipation and sedation were adequately controlled, and the patient was discharged. The formal diagnosis was Stage 3B Grade 3 squamous cell carcinoma of the vagina.

The patient was treated as an outpatient with radiation therapy and concurrent chemotherapy.

She was referred to the local community palliative care team and was visited at home by the visiting palliative care physician who diagnosed a pulmonary embolism.

Further palliative care physician reviews were required 9 months later when a vesico-vaginal fistula was identified and PET scans also revealed new disease activity in the left pelvic side-wall.

Some 1 year and 4 months after her initial diagnosis, the patient was requiring regular analgesic reviews by the community palliative care nurses, and the palliative care physicians negotiated an inpatient admission at a metropolitan specialist hospice for review and possible transition to methadone for control of her complex pain syndrome.

The physicians and nurses at the hospice successfully changed her to methadone and also negotiated with the orthopaedic surgeons at a major hospital to accept her for a left THR because of malignant erosion of the acetabulum.

Monitoring of symptoms, adjustments to analgesia, financial and practical community supports necessitated frequent home visits by palliative care doctors, nurses and a social worker. Although the patient was planning an overseas flight to undergo complementary and alternative medicine (CAM), she was by this time emaciated in the upper body, but grossly lymphoedematous in the lower limbs. The palliative care physician again visited her in her home, and expressed concern about the risks of a prolonged international flight. The palliative care physician and community palliative care nurses negotiated a re-admission into an inpatient hospice bed, and counselors at the hospice were requested to address concerns for the patient and her parents, husband and daughter. She died peacefully in the hospice 2 years and 10 months after her initial diagnosis and referral to palliative care. The inpatient hospice and community palliative care team have jointly provided bereavement counseling and ongoing support to the family after her death.

This case illustrates early palliative medicine involvement, collaboration between a spectrum of disciplines within palliative care, and cooperation with oncologists and orthopaedic surgeons to achieve optimal outcomes. As in this case, a network of palliative care providers from specialist consulting rooms, hospital wards, domiciliary visiting services and inpatient hospice may contribute significantly to a patient and loved ones comfort and support throughout the course of a difficult cancer journey.

References

1. ↑ World Health Organization. *WHO Definition of Palliative Care*. [homepage on the internet] World Health Organization; 2019 May 27 [cited 2014 May 8]. Available from: <http://www.who.int/cancer/palliative/definition/en/>.