

Facts and fallacies in palliative care

Siew Beng KHOO

Department of Primary Care Medicine, Penang Medical College, Penang, Malaysia

Abstract: The concept of palliative care is still quite new in Malaysia. Through the experience of delivering palliative care in both the hospital and community settings, the author has realized that there are many false beliefs among the medical and nursing professionals, as well as patients and their caregivers. By exploring and providing factual explanations to these beliefs, the present article highlights the differences in approach between acute and palliative management and the importance of good communication skills, as well as correcting the myths of patients and their caregivers, with the aim of improving the understanding of palliative care.

© 2003 Blackwell Publishing Asia and Wonca

Key words: communication skills, death, morphine, near death experience, palliative care.

Introduction

Life and death are a mystery. There are many myths, fallacies, misconceptions and superstitions witnessed while caring for patients with advanced and incurable diseases. Through trying to understand them and making efforts to share the correct explanations with patients, the concept of palliative care is developed. The comments and statements in the present report are from medical colleagues, patients and caregivers with whom I have been involved during my personal experience working as a Palliative Medicine Physician in a general hospital and a private oncology hospital. They are not meant to criticize or ridicule any particular party; instead they will be used as a learning tool for better understanding of palliative care.

Concept of palliative care

Myth

'Palliative care means there is no more hope, it is the end of the road, the patient is waiting to die and there is nothing more to be done'.

Correspondence: Siew Beng Khoo, Department of Primary Care Medicine, Penang Medical College, No 4, Sepoy Lines Road, Penang, Malaysia.
Email: sbkhoo@pmc.edu.my

Accepted for publication 11 April 2003.

Fact

Even though there is no more indication for specific therapy, with their physical symptoms relieved and provision of psychosocial support, there is hope of better quality of life during the remaining time in the life of the patients. During this time there is plenty to be done: plans are positively structured and purposeful, with the patients included in decision-making and their wishes respected. It would be ideal for patients to be referred at least 6 months before death to enable the palliative care team to establish a good rapport with the patient.

Pain management

Myths

'Morphine can cause addiction, physical dependence and tolerance'.

'Morphine causes respiratory depression'.

'It is a very strong analgesic, appropriately used only at the terminal stage. There may not be any stronger painkiller later on if it is used too early in the course of the illness'.

'It causes sedation, vomiting and constipation, hence providing no quality of life for patients'.

Fact

Morphine, if used correctly for pain control and other physical symptoms within the context of total patient

care, will not cause psychological dependence or respiratory depression. Pain itself is a respiratory stimulant. Morphine as a strong and useful painkiller has no ceiling dose. The right dose is the one required to control that patient's pain with the fewest side effects. Proper and regular assessment of pain and the use of the right combination of other non opioid drugs and adjuvant analgesics are more important than looking for a stronger painkiller. A certain amount of physical dependence may occur in patients who have taken an opioid regularly for more than 3–4 weeks and this may require gradual tapering off to prevent (the onset of) withdrawal symptoms. Patients develop tolerance to the vomiting and sedation after 2–3 weeks of therapy, but tolerance to constipation does not develop and it is a rule that all patients on opioid drugs should be given a laxative. The benefits of good pain control, euphoria and relief of dyspnea obtained from morphine outweigh these side effects; the net outcome is still better quality of life for the patient.

Myth

'Pain is associated with cancer. You just need to tolerate the pain'.

Fact

Some 20–30% of patients may not experience any pain until the end. Pain is in fact the most easily controlled symptom. Cancer pain can be managed effectively through relatively simple means in 90% of patients. Unfortunately, pain associated with cancer is frequently undertreated¹ and patients are made to suffer through the ignorance of doctors and their unwillingness to refer for another opinion.

Myth

'Fentanyl patch is to be used for all types of pain at anytime; add oral morphine sulfate SR if one patch of fentanyl does not control the pain'.

Fact

Neuropathic pain may not be responsive to opioids, hence a fentanyl patch does not seem to control such pain. It is not suitable for rapid dose titration in patients with unstable opioid requirements and should be used for relatively stable analgesic requirements when rapid increases or decreases in dosage are not likely to be needed. There is a long lag time (at least 2 hours) before an appreciable serum concentration of the drug is achieved, and a steady state is reached only after 12–24 hours. There is also a delay of 16–24 hours after the patch is removed, before the serum concentration of fentanyl falls significantly. Comparison of pain control between fentanyl and

morphine sulfate has shown equal effectiveness. Fentanyl is associated with less constipation and less daytime drowsiness, but greater sleep disturbance.² Fast acting morphine can be given as rescue dose for breakthrough pain while the patient is on fentanyl patch, but it is not appropriate to use both slow release morphine and fentanyl patch at the same time.

Myth

'Use injection pethidine as needed whenever patient complains of cancer pain'.

Fact

Unlike post surgical pain, cancer pain is not self limiting nor is it likely to go off, but instead it is more likely to increase in intensity and severity. World Health Organization recommends analgesics to be given 'by mouth, by the clock, by the ladder and for the individual'.¹ Pethidine is converted into norpethidine, an active metabolite. After several doses, its cumulative effect can cause convulsion, especially in elderly patients.

Management of other physical symptoms

Myth

'Providing patients with hyper-alimentation and good nutrition will control the cachexia and improve their immune system to fight cancer'.

Fact

Cachexia is mainly the result of major metabolic abnormalities, such as cachectin-tumor necrosis factor and interleukins 1 and 6 released by the immune system as a response to the presence of cancer and tumor products such as lipolytic hormones. These factors cause profound lipolysis, negative nitrogen balance and anorexia. Anorexia, being more likely the result of the catabolic process rather than the cause, explains the failure of aggressive nutrition in changing clinical outcomes and the nutritional status of cancer patients.³

Myth

'Intravenous fluid infusion 'builds up' the patients and should be given to all patients who are unable to feed orally'.

Fact

Intravenous fluid infusion is required for treatment of dehydration and hypercalcemia or for correction of

electrolyte imbalance, but definitely not for 'building up' the patient. The disadvantages of intravenous fluid infusion include discomfort, over hydration that causes an increase in the size of the tumor masses, further obstruction and pain, creating a barrier to mobility, fluid overloading that results in pulmonary and ankle edema, predisposition to infection and round the clock nursing care. Careful explanation from the physician regarding the dying process and the potential adverse metabolic effects and fluid overload can assuage the fears of family and caregivers.⁴

Myth

'Emergency surgery is needed for patients with intestinal obstruction caused by the extensive carcinomatosis peritonei'.

Fact

Adverse factors for surgery include advanced age, poor medical or nutritional status, previous surgery documenting extensive intraabdominal involvement with tumor, presence of ascites, palpable masses, distant metastases, previous radiation therapy to the abdomen or the pelvis, previous combination chemotherapy, evidence of small bowel obstruction or multiple sites of obstruction.⁴ Morbidity and mortality rates are high at this stage and there is no need to subject patients to postoperative pain, infection, wound dehiscence and the adverse effects of general anesthesia. Conservative treatment with subcutaneous infusion of morphine, dexamethasone, haloperidol and buscopan may help to control the obstruction and provide better quality of life for the limited period of time left.

Myth

'Ryle's tube feeding is essential at the end-stage to prevent starving the patients to death'.

Fact

Forced feeding through Ryle's tube will make patients more uncomfortable and is of no benefit. More important at this stage is to spend time talking to the patients and providing good nursing care. McCann *et al.* found hunger was less of a problem, despite severe protein-calorie malnutrition, and thirst tended to decrease as death approached, despite probable dehydration.⁵ Dunlop *et al.* comment that most terminally ill cancer patients reach a point during their general decline when they stop eating and subsequently stop drinking. They make the interesting suggestion that the normal homeostatic mechanisms controlling fluid intake and fluid balance may be altered in the dying process.⁶

Myth

'Oxygen relieves dyspnea and prolongs the patient's life'.

Fact

Improvement with oxygen is often considered to be a placebo effect.⁷ The cooling flow of oxygen against the face or through the nose may reduce breathlessness (as does a stream of air) by stimulating the facial and nasal receptors of the trigeminal nerve.⁸ However, oxygen therapy causes discomfort, a sense of claustrophobia, a barrier to communication and imposes a heavy cost and danger when continued at home.

Breaking of bad news

Myth

'Breaking of the bad news of a diagnosis of malignancy during ward rounds. Doctor to the patient, 'You are at the third stage.' Next day, 'You are at the fourth stage and there is nothing more to be done'. Patient's response, 'In that case I might as well discharge myself today before you tell me I am at the fifth stage tomorrow'.

Fact

Breaking of bad news has to be done in the proper setting; a private room with no disturbance, correct documentation of confirmed results, assessing how much the patient already knows and wants to know, use of warning shots, allowing time for ventilation of emotions, assessing the fear and concern of patient and answering any questions.

Conspiracy of silence

Myth

'We do not want my father to know the diagnosis because we are sure he will not be able to take it and will develop depression with suicidal tendency'.

Fact

A conspiracy of silence often occurs out of love for the patient by the family members. Frequently, the patient's ability to know the truth is underestimated. The patient may already suspect the truth, but also tries to spare the family members the pain of knowing that the diagnosis and prognosis are already known to him/her. Sometimes the conspiracy reflects the inability of family members to accept the truth rather than that of the patient. At this stage when the patient is in great need of psychosocial support, false reassurances given by the doctor and family members enforce a

silence around the subject of the diagnosis. At the same time, the family members may suffer from anxiety or depression for it is not easy to try to keep a secret, especially when both the patient and family members are staying close together.

Uncertainty and denial

Myth

'I was told that I would survive for 6 months, but it has been 10 years now since my diagnosis'.

Fact

How often have we been wrong in our estimation of a time frame for patients? It is a common practice in palliative care to find that rather 'well' patients may die suddenly and those who are very ill and expected to pass away anytime, may survive for weeks and months. The time frame that is given to patients is based on statistics that do not take into account each individual's condition. Setting a time frame may cause a lot of anxiety for the patient as the time approaches or may mislead the caregivers in their management plans.

Myth

'Whenever my friends come to pray, I am not allowed to talk about death and dying for it implies that I have lost faith in God. I have to believe that He is going to save me from death'.

Fact

Denial is the most common protective mechanism. Patients may be told the truth, but find it too painful to accept; denial helps them to live from day to day. However, denial on the part of caregivers' may sometimes hinder the patients from expressing their fears and concerns and shut them into silence.

Psychosexuality

Myths

'Cancer is infectious and sexually transmitted. I am afraid of passing the illness to my husband if I have sex with him'.

'Sexual intercourse can cause flare up, recurrence or relapse of cancer or the semen will precipitate other problems'.

Fact

In an ongoing study on psychosexual issues in palliative care (SB Khoo, unpubl. data, 2002), it seems that

the sexual life of these patients ceased once the diagnosis was made, the reason being more because of myths rather than physical problems induced by the treatment be it surgery, radiotherapy or chemotherapy. In the Asian culture, talking about sex is a taboo and female patients do not have the courage to ask their doctors, especially if they are of the opposite sex. Many felt that it would be a great help if the doctor could bring up the subject for discussion and reassure them that it is alright to continue with their sexual life.

Ethical issues

Myths

'Palliative care withholds treatment (limited treatment) helping the patient to die (passive euthanasia)'.

'Doctor, please give me something to sleep it off and never have to wake up again so that I need not have to go to Darwin for it. Life is not worth living. I want a peaceful death, death with dignity'.

Fact

Palliative care neither hastens nor postpones death. The overriding principle is that any treatment can be considered, not for its life-prolonging or curative intent, but rather for its palliative intent to improve the quality of life or allowing death to occur with comfort and dignity.⁹ A limited treatment plan does not mean cessation of professional care or that the patient wants to die, but merely that a decision has been made to forego certain kinds of therapy after considering the benefits versus the adverse effects regarding quality of life.

Fleeting or occasional thoughts of a desire for death are common in people with terminal illness, but few patients express a genuine desire for death.¹⁰ Sometimes patients use a request for euthanasia as a cry for help, implying that life is not worth living now, but if they could manage symptom x, problem y or fear z, then life would still be worth living.¹⁰

Near death experience (NDE)

Myth

'The patient related to his caregiver of his encounter with someone who looked like Jesus calling him to follow Him to a Beautiful Land. He passed away peacefully 2 days later'.

Fact

How often do we hear these experiences from patients at the dying stage, so much so that caregivers are pre-

pared to take patients home from the hospital as soon as possible for they believe that these are warning signs that the patient is going to die soon.

Near death experiences are not hallucinations. A patient who is hallucinating would not be able to hold a logical conversation, but would be completely lost in their hallucinations. However, people who are conversing with deceased relatives will be able to converse in a completely rational fashion.¹¹

In a prospective study conducted on patients who were successfully resuscitated after cardiac arrest, Van Lommel *et al.* proved that the occurrence of a NDE was not associated with the duration of cardiac arrest or brain anoxia, unconsciousness, medication or fear of death prior to a cardiac arrest.¹²

By far the best explanation of NDE is that it is an encounter with a different realm, which is exactly what patients generally believe. No other alternative models of 'brain chemicals', physiological or psychological events better accounts for the evidence in NDE accounts. Does NDE prove that there is life after death?

No one knows. Evidence for life after death includes much more than NDE evidence.^{13,14}

Conclusion

Caregivers have to recognize and accept death as inevitable at a certain stage of a terminal illness; priority has to be given to relieving the patient's symptoms and management of chronic cancer pain calls for a different approach and familiarity with the use of opioid drugs.

Communication skills and good doctor–patient rapport are extremely important for diagnostic and therapeutic purposes. When people die they often reach out to somebody to make the journey easier.

Knowledge becomes a form of security against the unknown. Through beliefs in an afterlife, an attempt is made to understand death. But the beauty (and horror) of death is that it remains unknowable. Death cannot be known because everything we know ends with death.¹⁴

References

- 1 World Health Organization. *Cancer Pain Relief*, 2nd edn. Geneva: WHO, 1996.
- 2 Ahmedzai S, Brooks D. Transdermal fentanyl versus sustained-release oral morphine in cancer pain: preference, efficacy, and quality of life. *J. Pain Symptom Manag.* 1997; **13**: 254–61.
- 3 Bruera E. Chapter 6: Anorexia, cachexia and nutrition. In: Fallon M, O'Neill B (eds). *ABC of Palliative Care*. London: BMJ Books, 1998.
- 4 Joishy Suresh K. *Palliative Medicine Secrets*, 1st edn. Philadelphia: Hanley & Belfus, 1999.
- 5 McCann RM, Hall WJ, Groth-Juncker A. Comfort care for terminally ill patients: The appropriate use of nutrition and hydration. *JAMA* 1994; **272**: 1263–6.
- 6 Dunlop R, Ellershaw JE, Baines MJ, Sykes N, Saunders C. On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far? A reply. *J. Med. Ethics* 1995; **21**: 141–3.
- 7 Faulk C, Carter Y, Woof R. *Handbook of Palliative Care*. Oxford: Blackwell Science, 1998.
- 8 Bruera E, de Stoutz N, Velasco-Leiva A, Schoeller T, Hanson J. Effects of oxygen on dyspnoea in hypoxaemic terminal cancer patients. *Lancet* 1993; **342**: 13–14.
- 9 Jacob Perlow Hospice. *End of Life Care* [Internet]. New York: Continuum Affiliates; [updated 2002; cited 2002]. Available from: <http://www.stoppain.org/palliative.care/index.html>
- 10 Chochinov HM, Tataryn D, Clinch JJ, Dudgeon D. Will to live in the terminally ill. *Lancet* 1999; **354**: 816–19.
- 11 Kircher P. *Love Is the Link: A Hospice Doctor Shares Her Experience of Near Death and Dying*. New York: Larson Publications, 1995.
- 12 Van Lommel P, van Wees R, Meyers V, Elfferich I. Near death experience in survivors of cardiac arrest: a prospective study in the Netherlands. *Lancet* 2001; **358**: 2039–45.
- 13 Long J. Physician and Researcher of Near Death Experience Research Foundation (NDERF). Available at: <http://www.nderf.org/>.
- 14 Smith R. *Lessons from the Dying*, 1st edition. Somerville, MA: Wisdom Publications, 1998.