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Spiritual aspects of palliative care

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There is a growing recognition of the importance of spiritual care in providing quality care to patients with life-threatening illnesses. Subsequently, attention to spiritual issues is increasingly being expected of the health professional.¹ The WHO definition of palliative care includes spiritual care as an aspect of improving the quality of life of patients facing death. Medical doctors are skilled in and comfortable with providing physical care. Psychosocial issues are recognised with appropriate referral to a social worker. However, spiritual care is not easily addressed.²

Spiritual support has been shown to positively affect the quality of life of patients with cancer as they near death.² As patients have to cope with declining health and function, their spiritual focus is increased. As the inevitability of death approaches, the person may express the need for spiritual reflection and review.³ Unmet spiritual needs often escalate into distress which is expressed physically or emotionally, resulting in increased utilisation of health services.³

Concept of total pain

Pain is not just a physical experience. Dame Cecily Saunders introduced the concept of total pain – physical, emotional and spiritual – when describing the complex nature of suffering of patients with advanced illness.⁴ The perception of pain is intensified

by spiritual suffering. While physical pain may be treated with a range of analgesics, these are not effective in treating emotional or spiritual pain. Addressing the non-physical dimensions of pain may reduce the treatment required to control total pain. Patients who express emotional distress related to spiritual issues may be prescribed anxiolytics or antidepressants or may even be sedated, whereas they actually need spiritual care.⁴ Most patients find that their spiritual beliefs are a source of comfort to them; however, for some their beliefs may become a source of distress as they review the meaning of their illness and life.² As doctors who offer palliative care for our patients, we have a responsibility to address the spiritual suffering as much as the physical suffering as the former contributes to the total pain.

Spirituality and spiritual care

There is no single definition that adequately describes spirituality. Robert Twycross describes spirituality as an awareness of the transcendent, something beyond the ordinary human experience, and something of wonder.⁵ Other definitions include attention to meaning, purpose in life, values, and relationships with self, others and God/higher presence as part of the spiritual experience.³ While many may use religion and spirituality interchangeably, religion is only one of many forms of spiritual expression. Spirituality is therefore multidimensional and has a different meaning for each individual, including the patient and the doctor. In offering patient-centred care, the doctor needs to be sensitive to this difference in perception of spirituality and be clear about the meaning and intention of spiritual care.¹

Just as spirituality defies any attempt at a single definition, it is difficult to expediently offer spiritual care in the same way as we diagnose and treat illness. A review of the literature shows that spiritual care is considered as a spectrum of care ranging from the way the patient is treated by health care professionals so that they do not feel depersonalised, staff giving time and being present, to specific assessment and intervention in cases of spiritual distress.³

Spiritual assessment tools such as FICA, HOPE and SPIRIT have been developed to identify patients' beliefs and sources of support in spiritual aspects of their life.⁶ While these tools are very useful, care must be taken that they are not used to 'tick boxes', thereby not identifying or addressing any real spiritual issues. An attentive, experienced doctor may recognise references to spiritual distress from the dialogue or from questions the patient asks. Once a doctor has recognised spiritual suffering, it is necessary to refer the patient to an appropriate specialist, such as a chaplain or pastoral carer. Spiritual care

based on a patient-centred approach is best provided by a multidisciplinary team.⁵

Conclusion

Doctors often feel unqualified to do a spiritual enquiry; however, education is not the only pre-requisite for good spiritual care. A willingness to connect at a human level, to listen attentively, to be reflective and to be spiritually aware enhances the delivery of skilled care. It is important for a doctor to be willing to listen, recognise spiritual distress and refer as necessary. 'Palliative care informed by spiritual attentiveness allows both the patient and provider to give up illusions of therapeutic entitlement to cure and at the same time honour the privilege of intentional and reverent care of the dying.'⁴

References available at www.cmej.org.za

When should one start palliative care?

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The WHO definition of palliative care¹ states that it is applicable early in the diagnosis in conjunction with other therapies that are implemented to prolong life.



The WHO definition of palliative care for children states that it begins when illness is diagnosed, and continues regardless of whether a child receives treatment directed at the disease.

South African palliative care practitioners, the Hospice Palliative Care Association and the Worldwide Palliative Care Alliance¹ endorse the WHO definition of palliative care and provide such care to patients with life-threatening illness from the time of referral to a hospice or a palliative care service. Hospice personnel frequently comment that patients are referred very late and do not experience the full benefit of the service.

There are a number of misconceptions with regard to palliative care that limit access to it. This article considers some of these and then describes how one can improve access to palliative care for those who need this approach.

Is palliative care only care of the dying patient? Palliative care practitioners and hospice personnel do provide quality, compassionate end-of-life care, with support for family members, to a person who is dying. Hospices also provide bereavement care to family members after the death of a loved one. However, palliative care personnel also support people in the active phase of their treatment. The focus of palliative care is on control of distressing symptoms, emotional support, social support and spiritual care with a goal of helping people with life-threatening illness 'to live as actively as possible'.

Is palliative care only compassionate companionship of dying patients? Palliative care is a clinical discipline involving careful assessment and active treatment of distressing symptoms, including identification and treatment of the cause of the symptoms. It aims to relieve suffering, and the response to multidimensional suffering² involves an interdisciplinary team of health carers to respond to a particular person's needs. Palliative care is provided in conjunction with appropriate disease-specific treatment, and hospice staff work in collaboration with the oncologist, GP, HIV clinic and other health care resources.

Is palliative care only for cancer patients? Palliative care developed as a response to cancer patients experiencing severe pain as their disease progressed. The principles and practice of palliative care are effective in the care of patients with any life-threatening illness, and many particular palliative care skills such as empathetic communication skills and control of distressing symptoms are applicable in any health care setting. Patients with heart failure, progressive neurological disorders, renal failure, and advanced HIV also benefit from palliative care. The WHO paediatric definition states that palliative

care 'principles apply to other paediatric chronic disorders'. This is also true of adults with chronic illness, but is a hospice the most appropriate place of referral for patients with chronic illness?

One of the benefits of palliative care is that it can be provided in any setting – the patient does not have to come to a health care facility to access such care. The palliative care practitioner can bring care to the patient – in the GP's rooms, hospital, emergency unit, ICU, frail care centre, hospice, and patient's home. The only requirement is that the health care practitioner – doctor, nurse, oncologist, HIV clinician – is trained in palliative care and applies the appropriate principles to the stage of the person's illness.

Palliative care personnel have identified that, in order to provide appropriate care to patients with progressive illness, it is important to discuss a person's wishes while she/he is still able to have such conversations. It is also important to develop an appropriate care plan – but how can one identify these patients, given the recognised uncertainties of prognostication?

The Gold Standards Framework³ in the UK, which advises on establishing a palliative care service in general practices, recommends three triggers for palliative care:

- the surprise question⁴ – would you be surprised if the patient were to die within the next 6 - 12 months?
- patient choice or need
- clinical indicators – specific indicators of advanced disease for three groups of patients: cancer, organ failure, elderly frail/dementia. In South Africa we would also include patients with advanced HIV and those with XDR TB, with particular challenges for comprehensive care.

The answer to the question posed in the title of this article is that palliative care can be offered from the time of diagnosis of a life-threatening illness; it can be provided by any health care practitioner trained in the discipline; and it can be provided in any setting, including the patient's home.

Summary

Palliative care may be provided from the time of diagnosis of a life-threatening illness. Palliative care is appropriate for patients with any life-threatening illness.

Patients who could benefit from palliative care may be identified by considering the 'surprise' question – would you be surprised if the patient were to die within the next 6 - 12 months?

All health care practitioners should be trained in palliative care.

References available at www.cmej.org.za

'Doctor, my pain is getting worse. Please help me.' Some thoughts on opioid-induced neurotoxicity

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It is usually possible to deal with severe pain in patients with advanced cancer by following basic palliative care principles. Occasionally, however, a patient whose pain had previously been well controlled suddenly starts experiencing pain again.

'Doctor, my pain is getting worse. Please help me.' This is a real challenge for any doctor. Consider the following possible reasons for this change:¹⁻⁷

- The disease has progressed. The appropriate response would be to increase the dose of the analgesics.
- Coping with cancer is challenging. At times the patient's ability to manage is overwhelmed and this distress is expressed in excessive somatic complaints that have no organic basis. Somatisation needs careful exploration rather than more analgesia.⁷
- The patient has developed pharmacological tolerance to the dose of their current analgesics and the dose should be adjusted.^{1-3,7}