

Special Lecture

1449

Hope and quality of life

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The primary objective of cancer care is to improve the quality of patients' lives hopefully by curing them of their cancer and/or ameliorating their worst symptoms. The symptoms of most concern to patients usually have physical, social, emotional and spiritual dimensions. Healthcare professionals often have exaggerated confidence that they can satisfactorily address physical concerns at the expense of dealing with the more emotional and spiritual needs of patients and their families. Most studies show that communication about emotional and psychosocial issues is poor and that formal assessments of quality of life domains are rarely employed outside of a clinical trial setting. Effective communication remains one of the most neglected areas of patient care, and the resultant anxiety and confusion exerts a deleterious impact upon quality of life. Avoidance of truthful disclosure about likely disease outcomes and the therapeutic intent of treatment, together with a failure to encourage patients to discuss their worst fears about what lies ahead, is often justified as *maintenance of hope*. This view will be challenged in my talk and an alternative proposition made that hope comes through knowledge and support, not through ignorance. The quality of patients' lives is sustained through good medical and nursing care together with open expression about the impact that disease and treatment is having. The communication needed can be painful for healthcare professionals and their patients but although truth often hurts, deceit in the long term hurts more.

Plenary Lecture

1450

Transition from cure to palliation

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The transition from cure to palliative care is a process with different dynamics in every patient. The shift from therapy aimed at cure or control of the disease to palliation marks an important transition for cancer patients and their relatives, but also for all those involved in a patient's treatment. Whereas we once talked about helping the patient 'to get better', we talk now about helping the patient 'to feel better'.

Shifts in focus - from control of the disease to improvement or maintenance of quality of life and, ultimately, quality of dying - become apparent.

Quality of life becomes more and more important with the knowledge that time is limited. For the patient and his loved ones, progression of the disease can raise questions that previously remained unasked, and unanswered: how long do I have, who really cares about me, will I suffer, how will I die, how will I be remembered?

Loss of control is one of the most important problems confronting cancer patients with incurable disease. Loss of control refers to an individual's perceived inability to make choices which will affect the outcome of events. It also refers to feelings of powerlessness and helplessness that result from the inability to predict or have an impact on events surrounding their illness. In addition to the physical symptoms and functional deficits, these feelings have a profound impact on quality of life.

As we know from palliative care research patients with advanced cancer are polysymptomatic. Most patients experience 10 to 12 symptoms at the same time. The most important determinants of distress in cancer are pain and other symptoms, treatment related side-effects, impaired role performance, illness related fears and unmet support needs for assistance with daily living and symptom management.

To be able to be pro active we have to gain more insight in specific symptoms (occurrence, experience and distress) and problems. Therefore palliative care asks a comprehensive approach involving options. Palliative care should be a support system integrating medical treatment, nursing, psychological, social and spiritual aspects of symptom management and care.

There is an opportunity for nurses to support the patient and relatives in anticipating and preventing symptoms and complications that could produce unwanted suffering. The challenge of palliative care is to combine compassion and evidence based care.