



# End of Life Care and Issues

## Dr. Preodor's Message

**WHAT IS QUALITY OF LIFE?** The concept of quality of life (QOL) is not new. How many times have we cared for patients who elect to forego aggressive chemotherapy to be with their families, at home, with comfort and palliation as their main medical goal? Most cancer patients have major side-effects which make quality-of-life assessments a valuable tool for our patients and families.

**HOW IS IT MEASURED?** We are now developing ways to measure quality of life. The tools used for this attempt to get at the psychosocial and physical outcomes of treatments as perceived by the patient. Besides the obvious side-effects of therapy, issues such as increased hospitalization time, pain, loss of wages, loss of "quality time" with family, the duration of rehabilitation and recuperation all play an important role in quality of life. In order to be useful, the measurements must be:

1. Reliable (yield consistent values),
2. Valid (measure what they claim to measure),
3. Responsive (detect changes over time), and
4. Sensitive (reflect true changes in individual patients).

There are now 11 of these tools being used in quality-of-life studies for prostate cancer alone.



*Michael E. Preodor, MD, FACP*

**RECENT STUDIES ON PROSTATE CANCER AND QUALITY OF LIFE** Some very interesting things are being discovered. Incontinence and impotence after radiation or surgery for limited prostate cancer have the most dramatic effect on quality of life. The incidence of these side-effects was up to 20% higher than reported in earlier surgical literature when physicians first began to use QOL tools. Potency rates are lower than reported in surgical literature where younger men were sampled. When a man's surgery resulted in incontinence, the patient stated increasing dissatisfaction with the QOL as the time living with their problem increased. In the first year, only 10% "would not have had the surgery if they knew how their quality of life would be compromised." However, this increases to 50% after five years of incontinence. Also learned in these early studies is that spouses report significantly greater psychological distress than do the patients with prostate cancer.

Patients with advanced prostate cancer were found to rank pain, fatigue and urinary dysfunction as side-effects most impacting of their quality of life. Hormone therapy significantly adversely effected the quality of life measurements.

**WHAT CAN BE DONE?** It is no surprise to us that when cancer is advanced, be it prostate cancer, colon cancer or gynecological cancer, the studies show pain control is closely tied to quality of life measurements.

We should also be aware that as more quality-of-life information becomes available, the education of the patient and family about their disease is important. The use of a team of psychosocial and spiritual assistance as well as good symptom control throughout the illness are priorities to the patient and family.

**THE FUTURE** The study of quality of life is still in its infancy. There are problems in accurately measuring the relevant factors and interpreting their meaning. Some illnesses (such as prostate cancer) are slow processes spanning 10 or more years which makes these measures difficult to extrapolate over time. These measures are also affected by one's expectations which may change over time, as well.

This makes for difficult science but so far, many of the findings point to the quality of care Horizon Hospice is committed to providing.

*Michael E. Preodor, MD, FACP is the Medical Director of Horizon Hospice*

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# Physician Newsletter

SUMMER 1998

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Horizon  
Hospice

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## Quality-of-Life Survey

This study's objective was to determine the usefulness of two quality-of-life (QOL) forms in a hospice setting. The compared forms were the McGill Quality-of-Life Questionnaire (MQOL) and the Hospice Quality-of-Life Index-Revised (HQLI). Using a crossover design, hospice nurses first administered one survey to hospice patients and then, in the study's second phase, administered the other survey to newly enrolled hospice patients. Nurses were interviewed regarding each form and possible changes in patient care that were made following the assessment. Hospice care plans were reviewed to look for specific changes as a result of the surveys. The results showed that the QOL assessments were useful for the nurses when determining the care plan of the hospice patients. The MQOL was preferred by the nurses over the HQLI.

*Abstract from Article entitled, "Two Hospice Quality-of-Life Surveys: A Comparison"*  
*The American Journal of Hospice and Palliative Care - May/June 1998*  
*Volume 15, No. 3*

*Mary J. Eischens, BS*  
*Barbara A. Elliott, PhD*  
*Thomas E. Elliott, MD*

### HOSPICE CARE BENEFIT PERIODS

The Balanced Budget Amendment (BBA) of 1997 restructured the hospice benefit periods available to Medicare beneficiaries as provided for under subsection 1812 of the Social Security Act (the Act). Effective upon the date of enactment, August 5, 1997, the hospice benefit has two initial 90-day periods followed by an unlimited number of subsequent 60-day periods. At the beginning of each period, two physicians must certify that the individual has a terminal illness with a prognosis that the individual's life expectancy is 6 months or less. 42 CFR 418.22(b) clarifies that a physician's certification specifies that the prognosis is for a life expectancy of 6 months or less, but qualifies it with the words "if the terminal illness runs its normal course," recognizing that such a prognosis is not entirely predictable. This provision of the regulation remains unchanged.

*Program Memorandum Intermediaries*  
*Department of Health and Human Services*  
*Health Care Financing Administration*  
*September 1997*

## Medicare Update

## Save The Date

**HORIZON HOSPICE CONFERENCE- OCTOBER 15, 1998** The 5th Annual Horizon Hospice conference, jointly sponsored with the Northwestern University Medical School, will be held Thursday, October 15, 1998, at The Westin Hotel in downtown Chicago. Titled *Challenges In Patient Communication: Building Skills for Hospice and Palliative Care*, the conference will address such topics as DNR discussions, talking to patients about making treatment decisions, evaluating the Benefit/Burden ratio and understanding the emerging paradigm for end-of-life care. Physician Category 1 Credit CMEs will be offered by Northwestern University Medical School.

For more information, call Sarah Rutledge at 312-733-2233.

- A referral to Horizon Hospice can be made by calling Liz Carney, Admissions Coordinator, at 312-733-8900
- If you have further questions, please call Michael Preodor, MD, FACP, at 773-725-7557 ext. 220