55

IMPLEMENTATION OF QUALITY OF LIFE ASSESSMENT IN HEALTH CARE SETTINGS

Cull A. ICRF Medical Oncology Unit, Western General Hospital, Edinburgh, Scotland.

Enthusiasm for the concept of quality of life (QL) assessment has grown as increasing emphasis is being given around the world to measuring health care benefits. If the potential value of QL Assessment is to be realised in oncology settings, closer collaboration needs to be established between clinicians and social scientists to address problems in the implementation of QL assessment which have bedevilled early efforts. Progress and problems will be reviewed in the following areas:

1. Specifying the purpose of the assessment.
2. Developing and selecting appropriate methods.
3. Study Design.
4. Resource and infrastructure necessary for success.
5. Current issues in data analysis.
6. Deriving clinically useful conclusions.

On the basis of past experience some simple recommendations can be made to promote successful implementation of QL assessment in oncology settings.

56

HOW QUALITY OF LIFE CAN HELP DECISION MAKING IN ONCOLOGY

Fernando Calais da Silva, Hospital do Desterro, Dpt.of Urology
Lisbon - Portugal

The traditional evaluation endpoints employed in cancer clinical research include such biomedical outcomes and frequency of local recurrence, development of metastatic disease, lenght of disease-free and overall survival, and the control of major physical symptoms. In recent years, however, there has been a growing recognition of the need to include evaluation parameters that are more subjective innature. Thus, the inclusion of such subjective criteria as performance status and clinical toxicity has become the rule rather than the exception in Cancer clinical trials. Most recently consideration has been given to the possibility of employing "Quality of Life" assessment in clinical investigation.

Working within a multi-dimensional framework, those aspects of quality of life that may be relevant evaluation endpoints in cancer research include: (1) disease symptoms; (2) side-effects of treatment; (3) functional status; (4) psychological distress; (5) social interaction; (6) sexuality and body image; and (7) satisfaction with medical treatment. No claim is made as to comprehensive of this taxonomy. Rather, it is intended to reflect the range of issues, both physical and non-physical, that have been found to be relevance to patients undergoing cancer treatment (Coates et al, 1983).

The literature contains relatively few reports dealing specifically with symptom paliiation in patients with urological cancer. Performance status and pain are occasionally considered in patients with advanced cancer. Improvement or worsening of pretreatment micturition problems is less often dealt with. Changes in symptoms during treatment have usually been rated by an external observer. Even less information is available about Quality of Life alterations as a consequence of cancer treatment and malignancy development. Rather, most of the literature deals with treatment-related toxicity and morbidity and the role of subjective symptoms as prognostic parameters, (e.g. performance status and pain) Fossa et al. 1984; Marcial et al. 1985; Smith et al. 1986).

The lack of reports of prospectively evaluated subjective response rates and of specifically designed Quality of Life studies in patients with urological cancer necessitates increased activity in these areas in the future. Quality of Life studies offer the opportunity for truly interdisciplinary, cooperative research between physicians, researchers from the behavioural sciences and members of the nursing staff.

57

QUALITY OF LIFE AND DECISION MAKING AT MICRO, MESO AND MACRO LEVELS

Sutherland, HJ. Ontario Cancer Institute, Toronto, Canada.

It is particularly important to differentiate the objectives of quality of life assessments (QoL) at different levels of decision making within the health care system when one is establishing QoL research priorities.

The purposes of this presentation are to briefly describe three levels of decision making (micro, meso and macro); examine the uses of QoL information in decision making at these different levels; and comment on the state-of-the-art concerning the relationship between QoL and decision making. To accomplish this, individualized, group and population-based QoL and preference assessments will be used as illustrative examples.

It will be shown that different priorities arise at different levels. If a major emphasis is placed on applications of QoL information to clinical (micro-level) decision making, perhaps research on uses of QoL information will be based on a perspective that is much too limited.

Keywords: Decision Making, Quality of Life, Research

58

QUALITY OF LIFE AND DECISION MAKING, THE TREATMENT POLICY IN ADVANCED BREAST CANCER

JCJM de Haes, MA Nooy, LVAM Beex
(Dept of Medical Decision Making, University Hospital Leiden; Department of Endocrinology, University Hospital Nijmegen; Department of Medical Psychology, AMC, Meibergdreef 15, 1105 AZ Amsterdam, The Netherlands)

Over the last decades different endpoints are increasingly being considered relevant for establishing the effectiveness of cancer treatment. Today, survival as well as quality of life are often assessed in clinical trials. The consequent issue to be resolved is, how data with regard to these parameters can be used to reach a decision on treatment policy. To do so, it is necessary to integrate the outcomes with regard to both endpoints implictly or explicitly. Explicit ways are preference and utility assessment. Preferences refer in a direct way to the the treatment option respondents (patients, clinicians, the general population or policy makers) favour under different conditions. In utility measurement values are assigned to quality of life and survival concomitantly. These values may be introduced in decision trees or models.

In the EORTC randomized trial comparing long versus short term CMF in advanced breast cancer (EORTC 10852) results indicate that survival is alike in both treatment arms but long term (continuous) CMF seems to prolong time to progression. This implies that the side effects of chemotherapy, a factor likely to impair quality of life, have to be weighed against gain in time to progression. To get insight in how these results have to be weighed in the decision about the treatment to be chosen, clinicians involved in the trial (N=15-20) are being asked about their preferences regarding the outcomes and the values they assign to the different disease/treatment states involved. With the latter data it is possible to fill in an adjusted Q-TWIST model. Provisional results indicate 1) that a three month gain in time to progression is considered worth the undergoing of side effects of treatment, and 2) that the adjusted Q-TWIST model results in a one month gain in quality adjusted survival after continuous treatment.

59

CURATIVE VS. PALLIATIVE TREATMENT IN ONCOLOGY

R. Zittoun, Service d'Hématologie - Hôtel Dieu - 75181 Paris 04 - France

One of the most frequent and difficult decisions in oncology is the choice between curative and palliative treatment. In classical decision analysis, the utility of the outcome of each treatment option is based on value judgements, where the individual preferences of the patient and his/her surrounding family must be weighted. Usually, the utilities of cure and death are respectively quoted 1 and 0, whereas the utility of treatment failure with persistent disease is quoted at an intermediate value, mainly based on the assessed quality of life (QOL).

The application of this model to the choice between curative and palliative treatments raises a number of questions. The first are conceptual and deserve refinement of definitions : curative treatments include actually all treatments that either have a curative intent, or are aimed at reducing the tumor burden and prolonging the survival duration. These "curative" treatments include in fact the phase II-III trials, even when applied to an incurable disease. Palliative treatments have as main objective the preservation or improvement of QOL, even during the terminal phase of the disease.

In addition some basic concepts of the decision analysis should be revised in the following way : 1. The utility of a fatal outcome can be weighted positively in case of appropriate and successful palliative care or negatively in case of "horrible death". 2. The utility of cure - or persistent disability - should be weighted negatively after integrating intercurrent somatic and psychosocial morbidity, and positively when taking into consideration coping resources and adaptation. 3. The psychological and ethical basis of patients participation to the medical decision-making should be elicited.

Some examples will be presented which illustrate the problems raised by the choice between curative and palliative treatment.

60

LONG-TERM EFFECT OF PROGRESSIVE MUSCLE RELAXATION WITH GUIDED IMAGERY IN HIGHLY DISTRESSED CANCER POPULATION.

Baider, L, Uziely, B, Kaplan De-Nour, A. Hadassah Univ. Hospital, Dept. of Oncology, Jerusalem, Israel.

The aim of the present study was to gather information on the immediate and long term effects of a specific type of behavioral intervention on the psychological distress of a mixed group of cancer patients. Fifty-eight cancer patients underwent six sessions of group Progressive Muscle Relaxation with Guided Imagery. Patients were followed up every two months for a six month period after termination of the psychological treatment. Patients' psychological distress and coping with cancer was assessed by three self reports, the Multiple Health Locus of Control, the Impact of Events and the Brief Symptom Inventory. The study showed that even though patients were very distressed at the beginning of treatment, the specific psychological group intervention was indeed effective and that the effectiveness was maintained for at least six months.