Quality of Care in the Management of Lymphomas

Advances in treatment have increased the survival rates of patients with lymphomas, both Hodgkin’s disease and the non-Hodgkin lymphoma. Hodgkin’s disease now has a standardized 5-year relative survival rate of 71.7% in Europe and 74.9% in America, and non-Hodgkin’s lymphoma of 46.7% and 50.3%, respectively (1). However, the road to survival is long and difficult, both for the patient and the physician.

Patients with lymphomas have to cope, usually at the active period of their lives, with a relatively sudden onset of life-threatening illness; long and intensive treatment; fear of recurrence; and physical, psychological, and social consequences of treatment. The diagnosis and treatment are associated with physical side effects (hair loss, spontaneous nausea, vomiting, manifestations of conditional responses to chemotherapy, and loss of libido), psychological morbidity (anxiety, depression, and memory impairment) and social problems, such as reduction of leisure activities and the need for early retirement (2,3). Often, the effects of therapy may consist of symptoms similar to those generated by the disease itself, and patients may be unable to detect any benefit from therapy for long periods. Due to these difficulties and suffering, patients are frequently unable to cope with their illness and wish to discontinue the treatment. The clinician has to steer a fine course between wishing to cure the patient and causing meaningless suffering. It is therefore important for the clinician to have accurate information on the quality of delivered care.

As in other conditions, the quality of care of patients with lymphoma can be assessed by the outcome of care and by its process. The most important aspect of the process of care in these cases is patient’s satisfaction, since it contributes to his or her resolve to actively cope with the illness and persist in the treatment. The outcome of care is primarily assessed by the response rate, response duration, disease-free survival, and survival. Furthermore, since both the disease and its treatment significantly influence the quality of life, the latter is also considered to be a critical outcome of the quality of care (4).

In patients with malignant disease, the most important factor contributing to patient satisfaction is the contentment with the information provided to them and their family. A recent survey of over 2,000 people currently receiving treatment for malignant disease in one of 34 outpatient departments in the UK, found that 87% of patients preferred to be given as much information about their illness as possible, both good and bad (5), whereas the most common complaints of such patients are concern because of inadequate communication and insufficient information (6). Information is vital for the understanding the illness, learning about available treatments and their side effects, and sharing decisions about treatment options (7). The shared decision-making model is a departure from the informed choice model with its emphasis on the patient to making the decision, as well as from the traditional, paternalistic model where the physician alone makes the decision. It is important to tailor information to suit patients’ educational background, cultural orientation, and general level of comprehension (8). In order to communicate adequately with their patients and provide sufficient information, clinicians need good communication skills and reliable sources of information. In a survey of all consultant non-surgical oncologists working in the UK (83% response rate out of 470 consultants) almost half felt that they had not received sufficient training in communication skills (9). In the UK, current sources of evidence-based information include the Cancer Library (accessible via the Cochrane Library) cancer database (being developed by Mac Millan Relief and the Centre for Health Information Quality), as well as the National Electronic Library for Health (7).

Quality of life refers to the patients’ satisfaction with their current level of functioning (physical, psychological, and social) compared with what they perceive to be possible or ideal (11). Aspects of quality of care are now increasingly included in studies addressing treatment of malignant disease and ethical committees require some form of its assessment in randomized trials. The health index frequently used is the Karnofsky Performance Scale (KPS), formulated in 1949 (12). Vitagram is another index; it was used in one of the first studies on the quality of life of patients with malignant disease (13). With the growing interest in the assessment of quality of life in patients with malignancies, it became obvious that the two previously mentioned indices did not meet all requirements since the assessment need also include the psychological implications of a specific treatment and the efficacy of different treatment alternatives for which response rate and survival do not show significant differences. The Life Ingredient Profile (LIP) was
developed to fill the gap between simple function indices (Karnofsky Performance Scale and Vitagram) and more detailed questionnaires like Sickness Impact Profile (SIP), Nottingham Health Profile (NHP), or Cancer Rehabilitation Evaluation System (CARES). The Life Ingredient Profile may be used in randomized trials of chemotherapy and is intended mainly for patients with leukemia, lymphoma and myeloma, but can be augmented with disease-specific questions, if and as required. It is a robust and rapid tool for assessing the quality of life and side effects of treatment, reflecting the patient’s evaluation of the symptoms of the disease as well as the side effects of treatment, and is designed for comparison of different regimens of chemotherapy. It has good validity, reliability, and sensitivity to change (14). Another tool is the Rotterdam Symptoms Checklist (RSC), which serves for self-reporting specific aspects in patients with malignant disease, such as fatigue, pain, nausea, and vomiting (15).

To improve the quality of care in the management of patients with lymphoma, treating physicians should place a high priority on informing the patients, understand the patients’ need for information and provide it as much as possible. This implies the necessity to improve physicians’ communication skills and their awareness of information sources. Patients’ involvement in their own care will result in increased satisfaction with care, reduced anxiety, and greater compliance with and adherence to the management plans for their illness. Since the treatment of lymphoma produces substantial morbidity, the assessment of the quality of life and understanding the factors contributing to it will provide a more comprehensive picture of the risks and benefits of therapy, and contribute to the improvement in its quality.

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