

Educational and emotional support of patients with non-Hodgkin's lymphoma

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Patients diagnosed with an illness such as high-grade non-Hodgkin's lymphoma experience a roller-coaster ride of care. Nurses can guide these patients through difficult decisions about treatment options for various stages of the disease. They can also help patients become knowledgeable partners in their own care so patients can better cope with the changing emotions they may experience. Honest and open communication with healthcare professionals is an extremely valuable aspect of care for patients with advanced lymphoma, and nurses can play a key role in fostering such supportive relationships.

According to 2005 Leukemia and Lymphoma Society statistics,¹ more than 300,000 people in the United States are living with various stages of non-Hodgkin's lymphoma (NHL). Approximately 40% of patients with B-cell NHL have low-grade or follicular disease, characterized by a slow progression and long survival.

Although low-grade NHL usually responds to treatment, patients experience a roller-coaster ride of care, with periods on and off treatment as their disease responds and relapses, each remission becoming shorter and shorter. This type of NHL is not curable, and treatment often is delayed, as studies have not shown a survival advantage for treatment of early asymptomatic disease. High-grade disease, for which cure rates can be as high as 60%, is nonetheless characterized by an aggressive progression; survival is measured in months.

Guiding patients through such treatment certainly requires offering information about their illness and the expected side effects of surgery and treatments, but more is needed. Beyond clinical information, patients need nurses to deliver emotional support as well, a vital component of care. What follows is an outline of both the clinical and emotional sides of the equation.

Educational support

In 1976, the National League for Nursing defined patient education as the process of giving patients knowledge to improve skills and enhance

competency. In 1999, Engelke established that patient education is a necessary component of patient care and contributes to outcomes.²

Staging

Many patients do not understand the importance of accurate staging. This information can help them understand why they are treated differently throughout the course of their illness. Staging also allows for accurate treatment planning,

KEY POINTS

Patients need nurses to deliver more than clinical treatments.

Nurses can educate patients about treatment options, their expected side effects, and prognosis, as well as offer emotional support.

Assessing quality-of-life issues should be a nursing standard when helping patients with treatment decisions.

Honest, open communication is valued by most cancer patients.

Manuscript received December 28, 2005; accepted June 12, 2006.

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Commun Oncol 2006;3:449-451 © 2006 Elsevier Inc. All rights reserved.

evaluation of treatment results, formulation of a more accurate prognosis, and standardization of information exchanged between healthcare professionals and institutions.^{3,4}

Symptoms of advancing disease

The presence or absence of symptoms is another consideration that affects the timing and type of treatment utilized. Symptoms of NHL often include one or more of the following:

- unexplained weight loss of more than 10% of body weight,
- unexplained fever with temperatures above 38°C,
- drenching night sweats, and
- enlarged lymph nodes.

Because these symptoms are often ignored by patients, the information should be included in the overall education plan. Awareness that these symptoms may develop could alert patients to possible early disease progression. Nurses should stress the importance of seeking medical intervention when symptoms arise.

Treatment options

Many patients with NHL do not understand why they are not treated as soon as they are first diagnosed. They should be informed that current treatment options include:

- “watchful waiting” (generally used for certain types of asymptomatic indolent NHL³),
- chemotherapy,
- monoclonal antibody therapy,
- radiation therapy,
- radioimmunotherapy, and
- bone marrow or stem-cell transplantation.

These treatments may be used alone or in combination. Patient education should include the fact that there is variability in treatment regimens, responses, and also tolerance to treatment. Although clinical trials have demonstrated efficacy, expected side effects, and responses for a given medication, patients should know that everyone has a slightly different

experience. As with all clinical trials, the median patient is simply an ideal.

In the absence of a cure for NHL, new treatments that produce and prolong remission in patients with the indolent form of the disease are important considerations. Studies of monoclonal antibodies may suggest a survival advantage in these patients. Treatment modalities that include targeted treatments, such as radioimmunotherapy (RIT), may offer higher tumor cell death with much less toxicity. With the median life expectancy for a patient with low-grade NHL of only 10 years,⁵ the majority of which includes time on some form of treatment, management options for relapsed NHL should therefore take toxicity into consideration. RIT is administered in a single treatment cycle with 2 days of treatment. The dose-limiting side effect is hematologic toxicity, which is delayed and occurs between weeks 4 and 7. Grade 3/4 thrombocytopenia and neutropenia can be easily managed. When comparing RIT with other treatment options, such as chemotherapy, which can last for months and is associated with side effects such as hair

loss, nausea, vomiting, and neutropenia, it is easy to see why quality-of-life (QOL) issues are less of a problem with RIT.

Furthermore, the choice of initial or refractory treatment should include its impact on a patient's QOL. When patients resist current treatment options, they need to be supported in their decision. They may wish to enter a clinical trial or initiate palliative or end-of-life care. These are options the clinical team should discuss with patients. Such communication is fundamental to improving patients' QOL.

Emotional support

Nurses should be attentive to the emotional symptoms exhibited by patients with NHL, such as depression and denial. Patients and their family members need time to ask questions in a supportive environment.

In the early 1950s, a landmark study in this field was established by Bard and Sutherland. They stated that psychosocial support should be an integral part of caring for cancer patients. Further research was performed by Weisman, Kubler-Ross, and Holland, who also stressed the importance of addressing psychosocial and emotional factors in cancer patients as part of their care.⁶

The pendulum has swung far from the days when many doctors actually withheld information from their patients about a cancer diagnosis in a misguided attempt to “protect” them from distress. It now seems that patients are *more* likely to become distressed when they *do not* know the truth about their prognosis. Complete disclosure and obtaining informed consent are the order of the day, which ultimately may help them “worry less and find greater resourcefulness,” according to Weismann.⁷ “Uncertainty paralyzes the individual's coping mechanism,” he points out. But inevitably, patients will need to grapple with their fears and worries.

Caring for patients with NHL: the psychosocial challenges

- Help patients make difficult treatment decisions based on complete disclosure and informed consent.
- Create workable relationships between patients and their caregivers (physicians, nurses, family).
- Help patients develop coping mechanisms, such as joining an exercise class or performing art therapy, yoga, or other relaxing activities.
- Establish emotional support systems, perhaps by joining support groups at local hospitals, churches, and through the Leukemia & Lymphoma Society (www.leukemia-lymphoma.org).

Often overlooked by healthcare professionals, depression is considered to be a natural response to undergoing cancer care. Establishing a good rapport with one's physician as well as one's nurse may help prevent or identify depression. One study of the value of good communication in the mood of patients was performed in lung cancer patients. One group of patients suspected their diagnosis but did not want to discuss the subject with their physician, and the second group had knowledge of their diagnosis through communication with their physician. The group that had discussed their diagnosis with their physician exhibited fewer depressive symptoms than the group that chose not to talk to their physician about their prognosis.⁸

As a way of coping with their diagnosis, some patients engage in some form of denial: "It can't happen to me" is a common response. Some patients may only accept parts of their disease, such as having cancer, but not others, such as the fact that it is incurable. Patients who do not ask questions pertaining to their diagnosis and prognosis may act as though the disease is not serious. They may be aware of the truth but choose not to disclose the extent of their illness to their loved ones. As healthcare professionals, we are also at risk of exhibiting denial when we develop a close bond with a patient, causing us to downplay the evidence of disease progression. In certain situations, however, denial can be seen as a positive response, such as when it enables patients to hold on to hope and maintain a "fighting spirit."⁹

Patient-to-patient support groups are helpful to many people with cancer. Contact between a newly diagnosed patient and a "veteran" with the same illness can be invaluable because it allows patients to share their per-

One patient's perspective: honesty is the best policy

Q: What do you feel was negative about your cancer care experience?

A: *The oncology nurse could have spent more time with my wife and me, discussing the upside of the therapy we had elected.... Her information was quite "cookie cutter" in nature, and she only communicated the worst-case scenarios about this treatment.*

Q: What did you find was positive about your cancer care experience?

A: *The oncologist was quite candid and direct about the diagnosis and prognosis.*

spective. The newly diagnosed patient may then feel less alone, which can help alleviate anxiety. As caregivers, we can steer patients and their families to support groups as one way of helping them to strengthen their coping mechanisms. It is important for us to identify and support their strengths without imposing our beliefs.

Conclusion

When people are diagnosed with a serious illness such as NHL, they may undergo many emotions as they pass from diagnosis through treatment and then perhaps to palliative care. These emotions will range from denial to anger and finally acceptance. The change and uncertainty of this disease process give nurses many opportunities to provide emotional support to patients with NHL; it can be highly beneficial to patients, as well as nurses, when remissions are achieved and patients are encouraged to return to a normal life without treatment. It will also be critical for nurses to continue to be accessible to listen and offer encouragement when the disease returns repeatedly.

In most cases, nurses will be the primary caregivers in establishing an open, intimate relationship with patients. The development of this close relationship will ultimately provide a unique environment, where nurses can become both an advocate and a supporter in helping patients gain control of their illness. Regardless of how knowledgeable patients are prior to a cancer diagnosis and its treatment, they deserve a sympathetic ear and a caring heart from nurses who can offer what may be needed most: knowledge, compassion, and understanding.

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Conflicts of interest: Ms. Hendrix is on the speakers' bureau for GlaxoSmithKline and Genentech.