

# Understanding the Concept of Uncertainty in Patients With Indolent Lymphoma

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**Purpose/Objectives:** To review the literature on uncertainty in cancer populations, apply this concept to patients diagnosed with indolent lymphoma, identify sources of uncertainty, and present interventions aimed at assessing and addressing the management of uncertainty.

**Data Sources:** English-language literature related to uncertainty in adult patients with cancer, psychological distress, and non-Hodgkin lymphoma, located through electronic databases PubMed® and CINAHL®, hand searches, and personal contacts.

**Data Synthesis:** Review of the literature revealed that uncertainty is being managed in breast cancer survivors and patients with prostate cancer with watchful waiting or active surveillance. The chronic and incurable nature of indolent lymphoma, coupled with symptoms that are vague and transient, are possible sources of uncertainty in patients diagnosed with lymphoma. Nursing interventions should be aimed at assessing, educating, and supporting patients as they work toward a new view of life that incorporates uncertainty.

**Conclusions:** Literature about the experience of patients diagnosed with lymphoma is lacking. The concept of uncertainty should be recognized by clinicians as an important aspect of living with indolent lymphoma because it is present throughout the disease trajectory and, if left untreated, can have a negative effect on patients' overall quality of life.

**Implications for Nursing:** Uncertainty should become an ongoing component of nursing assessment in patients diagnosed with lymphoma. Further research is needed to support the application of uncertainty theory to this patient population.

## Key Points . . .

- ▶ Indolent lymphoma is a chronic and incurable form of non-Hodgkin lymphoma that can be characterized by vague and transient early symptoms, often mimicking less benign illness such as the flu.
- ▶ The concept of uncertainty in illness examines patients' inability to determine the meaning of illness-related events because of insufficient cues and has been applied and researched in other populations of patients with cancer.
- ▶ Nursing assessments and interventions aimed at reducing uncertainty can improve patient quality of life and psychological adjustment to living with a chronic and incurable malignancy.

with cancer, but the causes of uncertainty have been studied in populations of patients with rheumatoid arthritis, asthma, and AIDS. In those studies, the erratic nature of symptom onset and disease progression and the inability to distinguish symptoms from normal bodily changes were sources of anxiety for patients (Braden, 1990; Janson-Bjerklie, Ferketich, & Benner, 1993; Weitz, 1989). Studies aimed at identifying and managing uncertainty through nursing-specific interventions in noncancer populations have been conducted in pregnant women with multiple sclerosis (Smeltzer, 1994), adolescents with diabetes (Hoff, Mullins, Chaney, Hartman, & Domek, 2002), and patients with heart failure (Winters, 1999). To date, the concept of uncertainty has not been explored in patients diagnosed with lymphoma. The purpose of this article is to provide an overview of the concept of uncertainty, review the related literature in other cancer populations, and put forth recommendations for nursing interventions that focus on assessing and addressing uncertainty in patients with indolent lymphoma, with the goal of optimizing the quality of life in this population.

## Background

NHLs are a broad classification of malignancies arising from the lymphatic system, marked by the presence of abnormal lymphocytes. Lymphomas have approximately 30 classifications, ranging from slow-growing, indolent lymphomas, such

Non-Hodgkin lymphoma (NHL) is the fifth most commonly diagnosed cancer in Canada; for reasons that are unknown, incidence and mortality rates continue to rise (Canadian Cancer Society, 2007). Indolent or slow-growing lymphomas are an incurable form of NHL and affect one-third of all patients. Because early symptoms can be vague, at times mimicking the flu, some patients ignore the symptoms, resulting in delayed diagnosis. The journey into uncertainty begins at diagnosis. Patients diagnosed with cancer experience emotional turmoil, including anxiety and uncertainty. This sense of uncertainty often continues throughout the disease trajectory (Butow et al., 1996; Schofield et al., 2003).

Recent medical advances provide patients living with NHL, indolent lymphoma in particular, a certain amount of hope for their future. The introduction of new treatment modalities, such as monoclonal antibodies (rituximab) and radioimmunotherapies (ibritumomab and tositumomab), is improving overall survival and disease-free survival rates; however, little is known about the experience and psychological effect of a lymphoma diagnosis on patients' lives (Bertero, Eriksson, & Ek, 1997a).

Since the 1980s, the concept of uncertainty has been applied to populations of patients living with chronic illness. Mishel's (1999) early work in uncertainty began in patients with gynecologic malignancy. Her major focus has remained on patients

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