Lymphoma is one of the malignant diseases in which more effective treatments are leading to steady progress in improving survival rates, therefore increasing the number of patients living with active disease or in remission. Lymphomas are a heterogeneous group of malignancies that originate from the lymphoid system with frequent bone marrow involvement (Diehl & Fuchs, 2007; Evans & Hancock, 2003), making the disease trajectory more uncertain than is usual in patients with solid tumors (Elphee, 2008). The most common forms of lymphoma include two types of non-Hodgkin lymphoma (NHL), large B-cell and follicular lymphomas and Hodgkin disease. To date, no effective methods are available for lymphoma screening. Instead, patients are identified only after they develop lymphadenopathy or other disease-related symptoms. Depending on the specific histology and morphology, disease progression can vary from being relatively slow to quite aggressive. In addition, survival time and cure rates vary among lymphomas (Diehl & Fuchs, 2007; Evans & Hancock, 2003). Because of this heterogeneity, a variety of active treatment alternatives as well as “wait and watch” strategies are used. However, when patients require treatment, therapy often is intensive, generally with major systemic effects. Although signs and symptoms of lymphoma, such as lymphadenopathy and systemic B-symptoms (i.e., fever, night sweats, and weight loss) are well recognized in the diagnostic process, surprisingly little empirical research is available on the symptom experience of patients with lymphoma undergoing treatment. Since 2000, numerous researchers have begun to elucidate theories of symptom experience (Armstrong, 2003), although a lack of consensus in definitions still exists. For example, in their now classic definition, Rhodes and Watson (1987) described symptoms as “subjective phenomena regarded by individuals as an indication of a condition departing from normal functions, sensation, or appearance” (p. 242). The broad concept of symptom experience often is described as multidimensional, with Rhodes and

Symptoms Before, During, and 14 Months After the Beginning of Treatment as Perceived by Patients With Lymphoma

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Lymphoma is one of the malignant diseases in which more effective treatments are leading to steady progress in improving survival rates, therefore increasing the number of patients living with active disease or in remission. Lymphomas are a heterogeneous group of malignancies that originate from the lymphoid system with frequent bone marrow involvement (Diehl & Fuchs, 2007; Evans & Hancock, 2003), making the disease trajectory more uncertain than is usual in patients with solid tumors (Elphee, 2008). The most common forms of lymphoma include two types of non-Hodgkin lymphoma (NHL), large B-cell and follicular lymphomas and Hodgkin disease. To date, no effective methods are available for lymphoma screening. Instead, patients are identified only after they develop lymphadenopathy or other disease-related symptoms. Depending on the specific histology and morphology, disease progression can vary from being relatively slow to quite aggressive. In addition, survival time and cure rates vary among lymphomas (Diehl & Fuchs, 2007; Evans & Hancock, 2003). Because of this heterogeneity, a variety of active treatment alternatives as well as “wait and watch” strategies are used. However, when patients require treatment, therapy often is intensive, generally with major systemic effects. Although signs and symptoms of lymphoma, such as lymphadenopathy and systemic B-symptoms (i.e., fever, night sweats, and weight loss) are well recognized in the diagnostic process, surprisingly little empirical research is available on the symptom experience of patients with lymphoma undergoing treatment. Since 2000, numerous researchers have begun to elucidate theories of symptom experience (Armstrong, 2003), although a lack of consensus in definitions still exists. For example, in their now classic definition, Rhodes and Watson (1987) described symptoms as “subjective phenomena regarded by individuals as an indication of a condition departing from normal functions, sensation, or appearance” (p. 242). The broad concept of symptom experience often is described as multidimensional, with Rhodes and

Purpose/Objectives: To explore occurrence of symptoms and relationships between them as perceived by patients with lymphoma before, during, and 14 months after the beginning of treatment.

Research Approach: Qualitative and longitudinal.

Setting: A major oncology center in the United Kingdom.

Participants: 10 adult patients with lymphoma (3 women and 7 men) were recruited at treatment initiation.

Methodologic Approach: Semistructured audiotaped interviews were conducted with participants in median 15 days, 4 months, and 14 months after diagnosis. Analysis of the verbatim transcripts was inspired by interpretive description, which is a grounded approach articulating patterns emerging in relation to clinical phenomena.

Main Research Variables: Symptoms.

Findings: Symptoms commonly reported by patients in this sample were lack of energy, lymphadenopathy, weight loss, itching, pain, sadness, night sweats, sleeping difficulties, and hair loss. Co-occurring prediagnosis symptoms seem to have led patients to seek medical attention; co-occurring symptoms during treatment seem to have a cumulatively distressing effect. Several of the symptoms were described as interrelated, with one symptom leading to one or more other symptoms.

Conclusions: The data confirm a complex symptomatology in patients with lymphoma. In addition, the findings support that co-occurring symptoms may have a synergistic effect on patients’ health outcomes and add new knowledge about relationships between symptoms from patients’ perspectives.

Interpretation: Illustrating symptoms and interrelationships between symptoms using diagrams may be useful to support communication as well as in identifying targets for symptom management.