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.

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 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

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as follicular lymphoma, to more aggressive forms, such as diffuse large cell lymphoma (Rogers, 2006). Indolent lymphoma includes follicular lymphomas, small lymphocytic lymphoma, and chronic lymphocytic leukemias, all chronic and incurable diseases with a median survival of years rather than months. New treatments are providing patients with longer disease-free survival periods (Marcus et al., 2005).

Indolent lymphoma is considered a disease of older adults, because the incidence and prevalence rates increase with age and the disease trajectory is complicated by the presence of other comorbidities. This is consistent with the overall incidence of NHL, which increases from 2.4 cases per 100,000 in individuals aged 20–24 years to more than 100 cases per 100,000 in individuals older than age 75 (Reis, Eisner, & Kosary, 2005).

Indolent lymphomas can progress very slowly, with some patients living with their disease for years before seeking medical attention or being diagnosed during routine medical examinations (Hamblin, 2001). Patients present with painless, enlarged peripheral lymph nodes; constitutional signs and symptoms that include fevers of 38 ºC or greater; weight loss of at least 10% body mass; and night sweats. Other symptoms of indolent lymphoma include a persistent, chronic cough; generalized pruritus; splenomegaly; and bone marrow infiltration. These symptoms may be dismissed by patients and healthcare providers and attributed to a more benign illness that would resolve without intervention.

Indolent lymphomas are characterized by periods of relapse and remission; therefore, the timing and type of treatment chosen vary depending on the extent and severity of the disease. A watch-and-wait approach is the most conservative management strategy, involving active monitoring through blood tests and physical examination until symptoms progress or begin to interfere with patients' quality of life. More aggressive forms of treatment include localized radiation therapy and systemic oral or IV chemotherapy.

The Concept of Uncertainty

Mishel (1988) defined uncertainty as the inability to determine the meaning of illness-related events because of a lack of sufficient cues that allow patients to assign value to objects or events and accurately predict outcomes. Uncertainty in illness has been referred to as "Damocles Syndrome," which is based on the Greek myth about the courier who was invited by the ruler Dionysius to a lavish banquet and sat beneath a very large, sharp sword suspended overhead by a single strand of horse hair. The sword represented the omnipresent danger accompanying the wealth and material possessions of being ruler. In today's context, Damocles' sword has come to represent cancer survivors' lingering feeling that their disease may recur at some unknown point in time.

In her concept analysis of uncertainty, McCormick (2002) made the assertion that the concept of uncertainty is embedded in the complex situations experienced by patients with all chronic illnesses. Uncertainty exists because of the very persistent, inconsistent, and incurable nature of those disease trajectories. Situations that elicit uncertainty tend to occur when symptoms or events are characterized by the following attributes: ambiguity, vagueness, unpredictability, inconsistency, lack of familiarity, and lack of information. Specific to cancer, this sense of uncertainty is not unique to survivors; it also is a real concern for those who are diagnosed with cancer and do not require any form of treatment as well as those who are undergoing active treatment, such as chemotherapy or radiation. Although the degree of uncertainty changes over time, it can be present at all stages of the cancer trajectory.

Mishel's (1990) Uncertainty in Illness Model identifies structure providers and stimuli frame as antecedents of uncertainty. These are important concepts for healthcare professionals because they provide the framework for a comprehensive assessment. **Structure providers** include patients' social supports, the degree of trust and confidence they have in their healthcare team or their "credible authority," and their knowledge level. **Stimuli frame** includes (a) the symptom pattern or the degree to which symptoms present with consistency to form a pattern or configuration, (b) event familiarity or the habitual or repetitive nature of the healthcare environment, and (c) event congruence or the consistency between what patients expect and what actually is experienced as it relates to their illness (Mishel, 1988).

The presence of uncertainty can affect psychosocial adaptation and become a significant source of stress for patients (Neville, 2003). Left unacknowledged, uncertainty can lead to disruptions within broader life issues, such as the inability to achieve valued goals, because of disturbances in routine, structure, and order (Bailey, Mishel, Belyea, Stewart, & Mohler, 2004). However, uncertainty should not only be considered as a negative response to illness. Prolonged uncertainty appraised as an opportunity can lead to a positive transition to a new, more evolved orientation. This orientation incorporates uncertainty as a natural rhythm of life, where the need for continual certainty and predictability is abandoned. To preserve this view of life, social supports and healthcare providers must believe in and promote this probabilistic thinking with patients (Mishel, 1990).

Literature Review

Mishel's work on uncertainty initially was in patients with gynecologic malignancy (Mishel & Braden, 1988); since that early application, the concept has been explored in other populations of patients with chronic illnesses (Mishel, 1999). Uncertainty has been researched extensively in two patient populations: breast and prostate cancer. For example, breast cancer survivors reportedly face uncertainty as a result of living daily with a preexisting disease and the possibility of recurrence, which affects their ability to plan for the future (Nelson, 1996; Wonghongkul, Moore, Musil, Schneider, & Deimling, 2000). Although this uncertainty does diminish over time, women reportedly continue to see reminders of their cancer diagnosis in everyday life (Gill et al., 2004; Wonghongkul, Dechaprom, Phumivichuvate, & Losawatkul, 2006). The inability to distinguish symptoms of their illness or recurrence from normal bodily changes also has been reported as a source of uncertainty in this cancer population (Hilton, 1988).

Men diagnosed with prostate cancer have treatment options that are similar to patients with lymphoma because the option of active surveillance may be appropriate in early-stage disease. In a 2003 study of 19 men diagnosed with prostate cancer, Wallace reported a significant relationship among uncertainty, anxiety, and perception of danger, which altered overall quality of life. According to Bailey et al. (2004), interventions that reduce uncertainty allow men to see their lives in a new light, reducing

depressive symptoms, improving overall quality of life, and increasing anticipation for the future. Although Mishel's (1990) stimuli frame and structure providers antecedents of uncertainty have been tested and supported in men undergoing a watchful-waiting management approach (Wallace, 2005), this hypothesis has not yet been explored in the lymphoma population.

Substantive evidence exists related to uncertainty in the breast and prostate cancer populations; however, little is known about the psychological adaptation of patients diagnosed with indolent lymphoma. Outcome variables such as quality of life, anxiety, and depression have been the focus of more recent research, but the studies have included only patients with the more aggressive and potentially curable types of lymphoma and acute forms of leukemia or small sample sizes of patients with indolent lymphoma. The experiences associated with high-dose chemotherapy, bone marrow transplantation, prolonged hospitalizations, and periods of isolation are unique to these patient populations; therefore, results cannot be generalized to patients with more indolent, chronic hematologic malignancies (Montgomery, Pocock, Titley, & Lloyd, 2002, 2003; Persson & Hallberg, 2004).

Psychological distress significantly decreases the quality of life of patients with cancer. Patients with acute leukemia and aggressive forms of lymphoma who are unable to make sense of their illness experience or integrate this event into their life story in a sensible manner report feelings of being out of control and of losing belief in life (Persson & Hallberg, 2004). Anxiety in cancer populations varies, with prevalence estimates ranging from 10%–30% (Stark & House, 2000). High levels of undetected anxiety and depression have been reported in patients undergoing treatment for hematologic malignancies (Zittoun, Achard, & Ruszniewski, 1999). In addition, more than 50% of patients with Hodgkin lymphoma or NHL experience borderline or excessive levels of anxiety, depression, or both at some point in their disease trajectory (Devlen, Maguire, Phillips, Crowther, & Chambers, 1987; Montgomery et al., 2003). Psychological morbidity is greatest in the three months prior to treatment, but new episodes of anxiety or depression can occur anytime within the year following treatment and frequent reminders of the treatment experience in daily life can lead to persistently high levels of anxiety and impaired quality of life (Cella, Pratt, & Holland, 1986; Devlen et al.).

Although patients with indolent lymphoma have a less aggressive form of cancer, the diagnosis still is associated with negative sequelae. These patients suffer from similar states of anxiety and uncertainty that any patient diagnosed with cancer endures. Disbelief, denial, anxiety, depression, confusion, and uncertainty are commonly cited emotions that may be short lived or have lasting repercussions for patients with lymphoma or leukemia (Bertero et al., 1997a; Jacobs, Ross, Walker, & Stockdale, 1983; Lloyd, Parker, Ludlam, & McGuire, 1984). Body image, social and family functioning, and overall health can be affected by ineffective coping for patients diagnosed with leukemia or lymphoma (McGrath, 1999; Bertero, Eriksson, & Ek, 1997b; Saifollahi, Rouhani, Roth, & Holland, 2001). Patients with chronic leukemia fear the course of their illness, treatment-related toxicities, pain, disability, and death (Saifollahi et al., 2001).

The application of uncertainty in different clinical cancer populations is relatively new but has been shown to be a significant source of negative outcomes in patients with breast or prostate cancer. Healthcare professionals should not assume that uncertainty is confined only to these patient populations, and clinical assessments should be performed to explore its significance in other patients.

Sources of Uncertainty

The incurable nature of indolent lymphoma means that the disease trajectory may be long and variable. The antecedents of uncertainty can assist clinicians to assess uncertainty in this patient population. The stimuli frame (symptom pattern, event familiarity, and event congruence) in Mishel's Uncertainty in Illness Model (1990) has been applied successfully and supported in patients with breast and prostate cancer (Gill et al., 2004; Wallace, 2005). This model could be adapted to serve as a framework for clinicians to identify possible sources of uncertainty for patients diagnosed with lymphoma (see Figure 1).

For patients with lymphoma, sources of uncertainty may include inconsistent and vague symptoms such as enlarged lymph nodes, night sweats, and fatigue; numerous diagnostic tests in different departments with new staff at each location; and unclear expectations as patients navigate through the healthcare system for the first time. Throughout this experience, the healthcare team and nursing staff as well as patients' social networks can help to ease uncertainties through the provision of information, reassurance, and emotional support. As uncertainties are addressed and minimized, patients will begin to adapt and cope in a positive way.

Symptom Pattern

When symptoms of illness present with sufficient consistency to form a pattern, patients are less uncertain (Mishel & Braden, 1988). Conversely, an inconsistent symptom pattern has been identified as the greatest predictor of uncertainty (Mishel & Braden, 1987). Many patients are diagnosed with indolent lymphoma during routine examinations with their family doctors and do not have pronounced symptoms of disease. Fatigue, weight loss, fever, and enlarged lymph nodes rarely all occur at the same time, and the symptoms can be vague and difficult to distinguish from the common cold or flu. Enlarged lymph nodes and fatigue are normal physiologic reactions to fighting infection. In addition, symptoms may wax and wane; therefore, patients initially may appraise them as non-life-threatening and not seek medical attention.

The perception of symptoms and subsequent appraisal also are affected by patients' mental states. Patients who perceive themselves as active and healthy may assign less meaning to a slight decline in their performance status than those who have fewer physical reserves. Once patients are diagnosed with lymphoma, the threats become real and patients may interpret their symptoms to be more severe than they actually are, thus creating a sense of more uncertainty about their future (Mishel, 1988). As patients live with their illness and acquire more knowledge, their ability to distinguish symptoms of lymphoma recurrence improves and uncertainty is believed to decrease.

Event Familiarity

Event familiarity refers specifically to the habitual and repetitive nature of the healthcare environment and not the physical symptoms of the disease. The level of uncertainty present is associated with the novelty and complexity of the

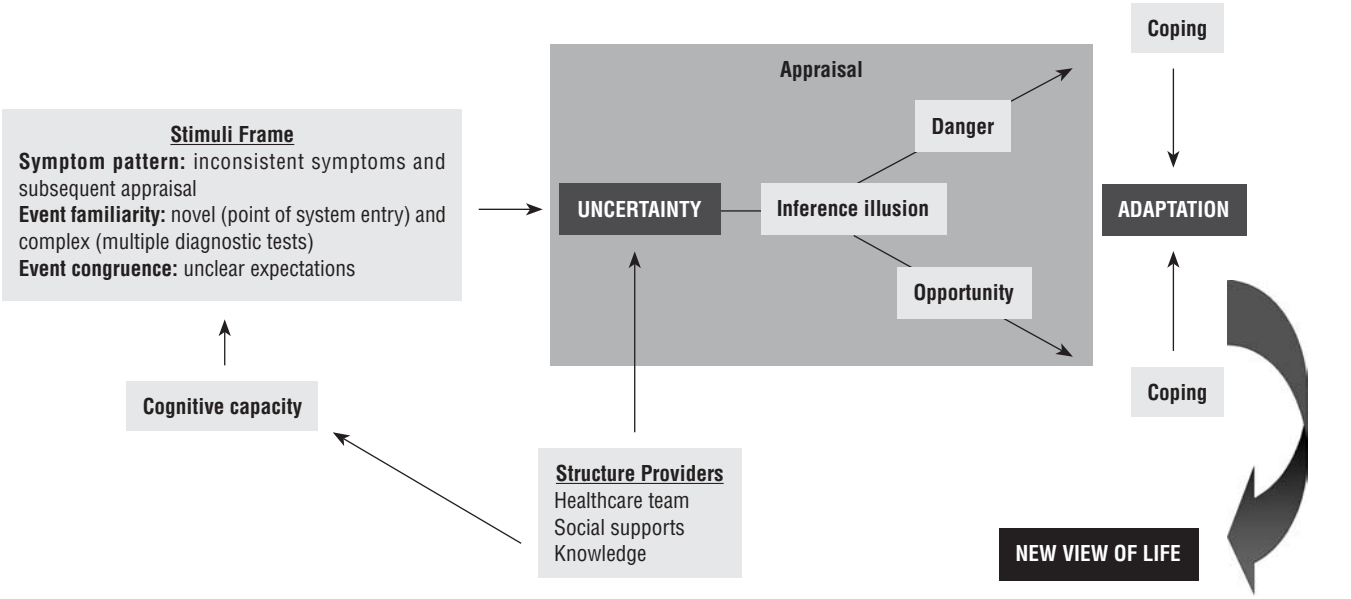

Figure 1. The Uncertainty Framework for Patients Diagnosed With Lymphoma

Note. From "Reconceptualization of the Uncertainty in Illness Theory," by M.H. Mishel, 1990, *Image: Journal of Nursing Scholarship, 22*(4), p. 258. Copyright 1990 by Blackwell Publishing. Adapted with permission.

given situation (Mishel, 1988). New situations, such as a patient's first visit to a cancer center, the first bone marrow or lymph node biopsy, or the first chemotherapy regimen, all are unfamiliar. Although novel and complex situations can promote uncertainty, novel events in particular can generate it (Mishel, 1988).

Complex situations have multiple cues that make appraisal difficult. During the initial period of diagnosis and staging, patients are subjected to various tests, including repeated blood tests and bone marrow and lymph node biopsies, lymph node biopsies guided by computed tomography, and scans. Patients are shuffled among hospital departments with unfamiliar staff, machines, and routines, where the lack of consistency exacerbates their feelings of uncertainty. As patients live longer with their illness, the tests that once provoked by anxiety become part of their routine and their levels of uncertainty purportedly diminish.

Event Congruence

Event congruence is the correlation between what is expected and what actually is experienced. Oncology nurses play a critical role in helping to establish clear expectations for patients with cancer. Lack of congruence can result in less predictability and event consistency for patients, thus producing higher levels of uncertainty (Mishel, 1988). Initial diagnostic tests and results often are ordered and reviewed by busy general practitioners before patients are referred to an oncology center; therefore, patients may not receive accurate or sufficient information about what is happening to them and what lies ahead. Patients who are newly diagnosed with lymphoma are unsure about what to expect, often relying on anecdotal information from friends and family members. This type of information has been shown to create uncertainty in breast cancer survivors (Gill et al., 2004). Social and familial pressure to start cancer treatment immediately makes the conservative, watchful-waiting approach seem more like watchful worrying to patients and their loved ones.

Preparing for chemotherapy or radiation therapy also may be a time of uncertainty for patients. Lack of information related to expected side effects and response time to treatment may cause anxiety. Drenching night sweats, lymphadenopathy, and fevers often resolve quickly once systemic treatment is initiated and the response to treatment becomes evident. Once remission is achieved, daily life begins to return to normal and patients are in a better frame of mind to assess situations and differentiate noncancer from cancer-related illness symptoms. Mishel (1988) asserted that education and event familiarity promote personal understanding as well as an understanding of the meaning of the event. As time passes, experience is gained and familiarity with events, symptoms, and their surroundings improves.

Structure Providers

As patient resources, oncology nurses are in a unique position to reduce uncertainty for patients with lymphoma. They are present throughout the disease trajectory to educate and provide emotional support. At the time of diagnosis, nurses can provide general education about lymphoma and tailor patient teaching to validate or normalize symptoms and experiences to date. When treatment becomes necessary, nurses can discuss treatment side effects and toxicities and management strategies. Anticipating questions and concerns and addressing them early can help to minimize uncertainty.

Implications for Nursing

Uncertainty perceived as aversive is associated with negative psychosocial outcomes, including emotional and psychological distress, anxiety, and depression (Neville,

2003). Nurses play a critical role as structure providers in assisting patients to adapt to their diagnosis of lymphoma. Interventions should be aimed at assessing, educating, supporting, and helping patients integrate this incurable, chronic illness into their lives, thereby allowing them to have a positive view of their lives and thus improving the quality of their lives.

The presence of uncertainty in patients' cancer experience can affect their quality of life in multiple domains. Lack of expectation and understanding of symptoms and treatment side effects can hinder management and leave patients in a poor functional state caused by unnecessary pain, nausea, vomiting, or infection. Uncertainty affects psychological well-being when patients fear recurrence or progression of their disease and lack control because they cannot identify and recognize illness-related cues. Role function and interpersonal relationships suffer because patients do not adjust to their new life after cancer diagnosis. With assistance in the positive appraisal of uncertainty, patients are able to reprioritize and make adjustments that integrate the uncertainty and cancer diagnosis into their lives.

The nurse-patient relationship begins prior to the initial visit to the cancer center. Providing patients with details of their appointments, including an estimated time frame, parking information, scheduled procedures, and members of the multidisciplinary team who will be present, will familiarize patients to this new experience. Assessing patients' understanding of their current condition at the first visit allows nurses to clarify any inaccurate information, determine the extent of patients' and families' knowledge base, and normalize the symptom experience (Bailey et al., 2004). Based on previous research in other patient populations, determining patient and family needs for information, information preferences, and patient perceptions of uncertainty as either negative or positive is very important (Neville, 2003). This assessment should occur early in the therapeutic relationship to minimize confusion and have patients see their nursing staff as a present and credible authority. Assessment of uncertainty should be ongoing because of its variable nature.

Patient appraisal is a continual process because patients change over time; therefore, measurement tools such as **Mishel's (1981) Uncertainty in Illness Scale (MUIS)** should be implemented repeatedly and results trended to gain a greater understanding of the experience over time (Penrod, 2001). MUIS is a 28-item questionnaire that uses five-point Likert scales and can be used in the outpatient setting to accurately assess uncertainty in patients with lymphoma. It has been tested and is a reliable and valid measurement tool that has been applied in numerous research settings involving other cancer populations.

Patients who have established a relationship with their healthcare providers should be encouraged to engage in open and honest discussions about the status of their health. Items from the MUIS (see Figure 2) can be used as building blocks during nurse-patient discussions and should be directed specifically toward assessing that (a) patients understand their diagnosis; (b) explanations provided have been understood and patients are able to explain in their own words their present condition, treatment options, and prognosis; (c) patients understand the roles and responsibilities of each member of the healthcare team; and (d) a general time frame and plan of upcoming events have been discussed (Mishel, 1981). Assessing and addressing uncertainty early can prevent escalation to a more severe state of psychological distress.

- I don't know what is wrong with me.
- I have a lot of questions without answers.
- I am unsure if my illness is getting better or worse.
- The explanations they give me about my condition seem hazy to me.
- Because of the unpredictability of my illness, I cannot plan for the future.

Note. Items are scored using a five-point Likert scale: strongly agree (5), agree (4), undecided (3), disagree (2), and strongly disagree (1). Higher overall scores indicate the presence of more uncertainty.

Figure 2. Sample Items From Mishel's Uncertainty in Illness Scale

Open communication and the implementation of interventions that address uncertainty specifically will promote and encourage the integration of uncertainty into daily living. The act of exploring and validating for patients what may seem dark and hazy will help to shed new light on the subject of uncertainty and the possibilities and opportunities available to them in their lives.

Summary

The clinical course of lymphoma can be unpredictable and the symptoms atypical, vague, and variable over periods of time. Novel and complex situations occur frequently for patients newly diagnosed with cancer because they lack sufficient knowledge to accurately assess and appraise stimuli and cues presented to them as they enter into and navigate through the healthcare system. Feelings of uncertainty may be overlooked by clinicians unfamiliar with the concept and its application. Nurses in outpatient ambulatory care oncology clinics are in an ideal position to develop long-standing patient relationships that span the illness trajectory. Situations and symptoms that have come to be routine for healthcare professionals are still new and frightening sources of uncertainty for individuals with lymphoma. By taking a proactive approach to assessing and managing uncertainty, nurses can help to prevent maladaptive coping and minimize psychological distress. Through assessment and implementation of interventions aimed at reducing uncertainty, nurses and patients will begin to place less importance on the notion of certainty and adopt uncertainty into the natural rhythm of their lives.

Further research is needed to explore the lived experience of patients with lymphoma, including quality of life and uncertainty at all points in the disease trajectory. Nurses walk alongside patients as they navigate their way through their cancer experience. At times nurses may take the lead, but patients will not always want or need a traveling companion. By assessing and addressing sources of uncertainty, nurses empower patients to travel alone along a well-lit and safe path in search of their new view of life.

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