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Authentic Caring Occasions for Patients in Hairy Cell Leukemia Clinical Trials

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Background: Rare diseases present challenges for patients, healthcare providers, and researchers. Rare disease communities exist for collaboration, dissemination of information, and to promote support for all community members. Patients with a rare disease desire to be supported through a rare disease community. Hairy cell leukemia (HCL) is a rare adult B-cell lymphocytic cancer that currently has no cure.

Objectives: Patients with relapsed or refractory HCL may need to consider participation in a clinical trial. The research nurse can initiate a planned caring occasion based on Watson's Theory of Human Caring. The purpose of the planned caring occasion for patients with HCL in clinical trials is to establish authentic intentional caring encounters between the research nurse and patients and meaningful caring encounters between patients.

Observations: Relapsed or refractory patients enrolled in an HCL clinical trial identify the trial as a microcommunity and the research nurse as an advocate and liaison. Patients seek support, empowerment, and the opportunity to connect with other patients with HCL. The planned caring occasion has the potential to provide a healing environment and facilitate shared experiences of living with HCL. The potential outcome for patients is strengthened holistic wellness.

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A rare disease diagnosis is a significant life event for patients and has the potential to alter patients' sense of security and elicits feelings of vulnerability and isolation (Haylock, 2010). Rare disease communities have formed around the world to support patients, healthcare providers, and researchers (Colledge & Solly, 2012). Patients seek participation in a rare disease community for many reasons, including increased knowledge, quality of life, holistic wellness, connection, and collaboration with other patients, as well as expert healthcare providers. Researchers and healthcare providers seek participation in rare disease communities because of the limited number of researchers dedicated to working with rare diseases (Aymé, Kole, & Graft, 2008; Budych, Helms, & Schultz, 2012; Colledge & Solly, 2012; Grever & Lozanski, 2011; Holzman, 2009; Huyard, 2009; Patsos, 2001; Schieppati, Henter, Daina, & Aperia, 2008; Walker, 2013). Key members of the rare disease community include the National Organization of Rare Disorders (NORD), established in the United States, and the European Union Committee of Experts on Rare Diseases. The primary mission of NORD includes promoting translational research and advocacy, and funding the search for cures for rare disease. NORD (2013) defines rare disease in the United States as affecting less than 200,000 individuals within the total population. The European Union Committee of Experts on Rare Diseases is committed to identifying rare disease centers of expertise, as well as establishing a collaborative network for information sharing (Aymé & Rodwell, 2014; Humphreys, 2012).

Patients with a rare disease face challenges in terms of treatment. Hairy cell leukemia (HCL) is a rare adult B-cell lymphocytic