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.