Decay, Transformation, and Growth: Meaning-Making Processes of Patients With Acute Leukemia Within the First Year After Diagnosis or Relapse

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Finding meaning in life events is embedded in human nature (Frankl, 2011; Richer & Ezer, 2000; Skaggs & Barron, 2006). Particularly when facing negative events that challenge the existing construction of the world, individuals attempt to integrate their experiences (the ones of order and the ones of stress) in a new, meaningful reality through a search for meaning (Bonanno & Kaltman, 1999; Davis, Wortman, Lehman, & Silver, 2000; Janoff-Bulman, 1992; Josef & Linley, 2005; Lepore & Helgeson, 1998; Neimeyer, 2001; Park, 2010; Taylor & Gollwitzer, 1995). Finding meaning in or making sense of adverse events has been shown to increase subjective well-being (Lyubomirsky, King, & Diener, 2005) and subsequently enhance resilience, creativity, and distress tolerance (Fredrickson, Cohn, Coffey, Pek, & Finkel, 2008).

The integrated meaning-making model by Park and Folkman (1997) frequently is used in the context of illness (Lee, Cohen, Edgar, Laizner, & Gagnon, 2004; Park, 2010) because it provides operational definitions for the model’s different components. However, available evidence still is limited in amount and quality. Therefore, whether meaning-making during illness differs according to the stage, type of illness, and treatment trajectory remains unclear. In the context of acute leukemia, which is a malignant disease characterized by the rapid multiplication and spread of abnormal white blood cells, the disease progresses quickly, and the patient’s life is affected profoundly. Patients are faced with a great number of unknowns, such as how to cope with the disease, the treatment, and the uncertainty of their prognosis.

Purpose/Objectives: To explore the processes through which patients construct their meanings of acute leukemia (AL).

Research Approach: An exploratory design was employed using serial, in-depth interviews, guided by Smith’s Interpretative Phenomenological Analysis approach.

Setting: Two inpatient hematology clinics in the United Kingdom.

Participants: 10 adult patients with AL.

Methodologic Approach: Two serial interviews were conducted with each participant, two to four weeks apart, within the first year of diagnosis or post-relapse.

Findings: AL creates a state of imbalance, which may initiate a search for new equilibrium. Patients’ journeys toward making sense of their illness may involve three interchangeable processes: decay, transformation, and growth. As patients learned of their diagnosis and their treatment commenced, a sense of decay dominated their lives. Running in parallel, signs of transformation started to become more evident as time elapsed. Within growth, reprioritizing values was prominent.

Conclusions: Findings of this contextually and methodologically novel study highlight the complex nature of sense-making for patients experiencing AL.

Interpretation: Nurses can take valuable lessons on how to manage the invisibility of AL, enhance trust in healthcare professionals, address the impact of isolation, and facilitate the making-sense processes of patients in ways that favor their short- and long-term psychosocial adjustment.