Hematopoietic Stem Cell Transplantation

Stress, psychoneurologic symptoms, and coping strategies in adolescents and young adults

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Strategies to assist emerging adults (aged 18–28 years) and the adolescent and young adult (AYA) population overall in coping with cancer-related stressors and psychoneurologic symptoms have been insufficient to improve the quality of cancer care (Peckham, Block, Buchanan, & Pommier, 2017; Robb et al., 2014). Psychoneurologic symptoms commonly reported by AYAs following hematopoietic stem cell transplantation (HSCT) include anxiety, depression, fatigue, and pain. The prevalence of these symptoms has spurred researchers to recommend that patients be screened for these symptoms prior to HSCT to inform personalized coping strategies (Kreitler & Kreitler, 2012; Tecchio et al., 2013).

Complementary and alternative medicine (CAM) appeals to AYAs as a means of coping with these symptoms. One example of CAM is a publicly available illness blog authored by a young adult woman undergoing HSCT.

**AT A GLANCE**
- Internet ethnography was used to study the online illness blog; this relatively new method allows the researcher to understand the lived experience of an individual in an online world.
- Psychoneurologic symptoms experienced by a blogger aligned with symptoms outlined in previous qualitative studies of AYAs undergoing transplantation.
- Blogging is a CAM method that may be useful to the upcoming, technologically savvy population during times of intense stress and isolation, such as during HSCT.

**KEYWORDS**
hematopoietic stem cell transplantation; coping strategies; adolescents; young adults

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Psychoneurologic symptoms commonly reported by adolescents and young adults (AYAs) following hematopoietic stem cell transplantation (HSCT) include anxiety, depression, fatigue, and pain. Complementary and alternative medicine (CAM) appeals to AYAs as a means of coping with these symptoms. One example of CAM is a publicly available illness blog authored by a young adult woman undergoing HSCT.

The purpose of this article is to analyze how the blogger described stressors, psychoneurologic symptoms, and coping strategies during reverse isolation following HSCT and to discuss how illness blogging may inform future research and practice.

**Methods**
This project used a longitudinal design and Internet ethnography methods (Keim-Malpass, Steeves, & Kennedy, 2014) and was informed by McCain, Gray, Walter, and Robins’ (2005) psychoneuroimmunoology-based framework. This framework describes how illness-related stressors affect the nervous and immune systems and contribute to the development of psychoneurologic symptoms. The local institutional review board reviewed the project and determined that it was not research; therefore, approval was not required. As a courtesy, the public blogger was informed of the project by email. Twelve blog posts, published from March 29, 2012, to October 15, 2015, that mentioned HSCT were examined (Jaouad, 2015). Directed content analysis was used to sort phrases by McCain et al.’s (2005) framework components (stress, psychoneurologic response to stress, coping strategy).
Findings
At the time of diagnosis, the blogger was aged 22 years, had recently graduated college, and had started a job. The posts were divided into three phases (phase one: days –13 to 0, phase two: days 0 to 15, and phase three: days 29 to 50), defined by the major stressor and coping strategy used.

Phase One: Managing Uncertainty With Distraction and Cognitive Reframing
The day –13 post communicated anxiety caused by uncertainty about the future, including whether she would survive, how much pain she would have, and whether she could function through the pain.

Daunting questions that most of my peers won’t have to consider for many more years have become my urgent, everyday concerns: How will I hold onto health insurance if I’m unable to work? Will I be able to have children? How long will I live? (Jaouad, 2012a, para. 7)

Another stressor was the disruption of a newly independent lifestyle. For example,

Cancer magnifies the in-betweenness of young adulthood. . . . I increasingly rely on my parents to take care of me. . . . Today my friends are busy starting their lives, but at 23, I am worried that mine might end before it has really begun. (Jaouad, 2012a, para. 7)

One coping strategy attempted was distraction, which, for the blogger, was writing, an activity used during school and work. Uncertainty was addressed by “writing about it, talking about it, bringing my fears and thoughts to the fore, out into the open.” Another strategy was cognitive reframing, in which negative written statements were balanced with positive statements. For example, “I’m lucky that my brother is a perfect bone marrow match. . . . The alternative is something that shadows my thoughts these days.”

Phase Two: Managing Symptoms by Problem Solving
From days 0–15, expressions of fear and anxiety diminished, and the posts focused more on bodily changes and physical symptoms, such as alopecia, pain, and isolation.

The hours and days busy themselves with pain management. The chemotherapy is eating away at the mucous membranes. . . . My mouth is covered in sores, which makes it impossible to eat, drink, or even swallow. . . . I’ve been sick to my stomach all week. . . . I find myself pretending to be a statue, trying to sit still in hopes that it might calm my bubbling stomach. . . . By Sunday, my head was bald. (Jaouad & McKiernan, 2012, para. 6)

Evidence of cognitive reframing lessened; some posts contained none. This shift seemed to represent being overwhelmed by the need to address these more immediate and salient stressors. Problem-solving strategies, including lying at an angle to control pain, were used. The blogger also used writing as a way to relate to her essence as a person: “It [writing] helped me reconnect to myself when the person staring back at me in the mirror had become unrecognizable.”

Phase Three: Managing Social Isolation by Rejoining Social Media
The day 29 post reflected a turning point in recovery from HSCT. The blogger described being fearful of using Facebook when her body looked so different, yet depressed when isolated from Facebook friends. Cons of rejoining Facebook were not looking the same and not feeling like the same person as prior to transplantation. Pros included connecting with members of an established social network and even expanding that network during a lonely time. Deciding to join Facebook made the blogger happy and hopeful about the future.

For the first time since I’ve been sick, I feel connected to a responsive community I hadn’t previously known existed. I like hearing from other cancer patients, and their caregivers, who share with me their own stories and wisdom. . . . When I go to my Facebook profile, I see myself again. (Jaouad, 2012b, para. 15)

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Discussion and Implications
The blogger experienced similar psychoneurologic symptoms to those previously reported by other patients with cancer (Kreitler & Kreitler, 2012; Tecchio et al., 2013). Analyzing posts during several weeks showed shifts in feelings related to the stress experienced by an emerging adult in reverse isolation and strategies used to cope with that stress. Although the psychoneuroimmunology framework does
not include this concept, uncertainty was a major stressor for the blogger. Given this finding, nurses should be sensitive to extreme uncertainty among AYAs undergoing HSCT and incorporate this concept in future research with AYAs who have been diagnosed with cancer.

Nurses can introduce blogging to AYAs undergoing HSCT as a strategy for documenting experiences and mitigating anticipatory uncertainty and psychoneurologic symptoms. Nurses can advise AYAs about sharing private health information online. AYAs who are not natural writers or lack experience with social media deserve particular attention.

Conclusion

Studying illness blogs is a way to observe the course an illness takes and how patients respond to their individual treatment. At the same time, offering blogging or expressive writing as a coping strategy to those preparing to undergo HSCT is a potentially beneficial intervention to improve patients’ health-related quality of life while in the hospital and after leaving.

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