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The Unique Supportive Care Needs of a Mother With Acute Myeloid Leukemia During Treatment

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Abstract

Acute myeloid leukemia (AML) is an aggressive cancer of the blood that is linked with poor survival. The disease requires immediate intensive chemotherapy treatment that leaves patients hospitalized for at least one month and often longer, depending on their supportive care needs. Mothers undergoing treatment for AML may benefit from having attention paid to their supportive care needs during that time.

Keywords

acute myeloid leukemia; supportive care; parental cancer

Acute myeloid leukemia (AML) is a disease of the blood and bone marrow that is fatal if not treated emergently (Pulte, Gondos, & Brenner, 2010). Patients with AML typically receive inpatient induction chemotherapy during the course of one week, then remain hospitalized for at least one month because of treatment-associated complications, such as neutropenic fever, anemia, and thrombocytopenia. Patients commonly experience fluctuating levels of health, and they may have the potential to become ill quickly (Button & Chan, 2014). Patients' labile health may exacerbate what is already a stressful experience (Danhauer et al., 2013). Therefore, the hospitalization period for the patient diagnosed with AML must include vigilant nursing and supportive care.

Case Study

J.C., a 43-year-old mother of four children, was diagnosed with AML seven months ago. Her initial induction chemo-therapy treatment was complicated by infectious colitis and fungal pneumonia, which left her hospitalized for more than 45 days. She was discharged and returned to the hospital two weeks later to begin consolidation chemotherapy; she learned that her disease had relapsed. In addition, she was exhibiting new and concerning

symptoms, including visual changes and a constant dull headache. A lumbar puncture confirmed the presence of blast cells in her cerebrospinal fluid. She then began another induction treatment that was administered in conjunction with intrathecal chemotherapy for the AML that now also involved her central nervous system.

J.C. confided to her nurse that she felt nervous about everything. The goal of her treatment was to get her into remission long enough to receive a transplantation, but J.C. was wary. She shared that she had a cousin with AML who received a transplantation and then died soon afterward. She did not know what was best for her; the induction treatments were awful, she said, and she was not sure that the transplantation would be any better. J.C. told the nurse that she was tired of being so sick and that she missed being at home with her children. Her twins just started kindergarten, but she did not have the opportunity to put them on the bus. Her middle daughter also just started high school, which J.C. referred to as a tough time; she said she does not feel able to be there for her daughter like she wants to be.

J.C.'s second induction was complicated by pneumonia. She was again hospitalized for 44 days for supportive care as her counts recovered and the infection was managed with IV antibiotics. This hospitalization took an immense toll on her hope.

Patient Assessment

Nurses caring for J.C. noted that she was continually down and even distraught at times. They remarked that J.C. was upset because she did not have an updated family photograph, and was afraid she was not going to live to marry her fiancé or to see her children off to college. Throughout her hospitalization, J.C. complained of severe pain (rated 3 out of 4), numbness and tingling (rated 3 out of 4), sweats (rated 3 out of 4), depression (rated 5 out of 10), and overall distress (rated 7 out of 10). J.C. also told the nurses that she frequently worried, was anxious, and had trouble sleeping. She was neutropenic with an absolute neutrophil count of less than 500, and on a few occasions had developed a temperature of 38.3°C (101°F). In addition, she required transfusions to keep her platelets above 10,000 mcl and her hemoglobin above 8 g/dl.

Nursing Management

J.C.'s nursing care included systemic and psychologic support. Febrile neutropenia is a common complication for patients with hematologic cancers, and is defined as a single oral temperature of 38.3°C or greater or a temperature of 38°C (100.4°F) or greater that is sustained during a one-hour period in combination with neutropenia (Freifeld et al., 2011). In several instances, J.C.'s fever exceeded 38.3°C, and she underwent testing that included peripheral and central line blood cultures, a urine culture, and a two-view chest x-ray (Bryant, Walton, & Albrecht, 2014).

J.C.'s treatment was complicated by the neutropenic fevers and fungal pneumonia. To treat known and potential infections, J.C. received broad-spectrum antibiotics and antifungals during her hospitalization. Nursing care included timely administration of these drugs, monitoring for allergic reactions, strict neutropenic precautions, and supportive care, which involved supplying cool washcloths and encouraging hydration, for example.

The constant headache that J.C. experienced was a critical nursing concern, given her severe thrombocytopenia. However, her neurologic status and vital signs were stable, and a computed tomography scan ruled out an intracranial hemorrhage. Therefore, her pain was managed with analgesics. At this time, supportive care also included the clustering of care by nurses, which allowed J.C. to have periods of rest in a quiet, dimly lit room.

Emotional distress is common in patients with cancer and has been of interest to healthcare providers for decades (Holland, 1977; Weisman & Worden, 1976). Emotional distress is an established factor in patients' decisions to reduce or stop treatment (Nerenz, Leventhal, & Love, 1982). The psychosocial support that J.C. requires is extensive and not uncommon, particularly because she is a parent (Compas et al., 1994). Further assessment is necessary to determine the source of J.C.'s distress. If her symptoms and distress are related to a lack of information or challenges pertaining to decision making, she may benefit from a psychoeducational intervention. Psycho-educational interventions can include education and supportive attention, which are recommended for the reduction of anxiety (Galway et al., 2012). For J.C., a psychosocial intervention could consist of equipping her with specific information about her treatment options or side effects, or making her aware of resources that would help her to cope with cancer after discharge.

However, if J.C.'s distress is found to be related to her family life, her concerns for her children, and her desire to be there for them during treatment, that distress is a challenge that also must be approached by nurses (Helseth & Ulfsaet, 2005). The resources that are available for families dealing with a parent's diagnosis of cancer have grown considerably and now include an array of materials geared at parents and children of all ages: literature, live and online support groups, camps and retreats, and information clearinghouses (see Figure 1). Various technologic advances, including video conferencing tools like FaceTime and Skype, allow families to stay connected even when they cannot physically be together. In addition, continued work is being done regarding "legacy making" (Allen, 2009). Legacy making involves the creation of a scrap-book, cookbook, audiotape, or other item that celebrates the relationships of the person with the life-threatening illness. J.C.'s distress may be eased if she and her family are provided with an opportunity to have a family portrait taken, which would help to construct and celebrate their legacy.

Meeting J.C.'s needs for deciding a course of treatment and being able to better communicate with and find strategies to support her children may alleviate some of her feelings of generalized distress, depression, anxiety, and worry, as well as help to address her trouble sleeping. Compassionate validation by her treatment team of all that she is experiencing, along with team members' presence and sensitivity to her situation, may also aid in improving J.C.'s emotional state. J.C. and her family members each met with a psychologist to receive psychoeducational support and discuss the complex feelings they were experiencing.

Other interventions to ameliorate depression, anxiety, and sleeping problems include exercise (Brown et al., 2012; Galvão & Newton, 2005; Mishra et al., 2012). If J.C. is able, she should be encouraged to conserve her energy and walk around the inpatient unit a couple of times a day, potentially after school with her high school-aged daughter; doing so would

create time for them to be together. In addition, mindfulness-based stress reduction is another strategy that has been recommended to mitigate depression, anxiety, and sleep disturbance (Piet, Würtzen, & Zachariae, 2012; Win-bush, Gross, & Kreitzer, 2007).

Conclusion

This case illuminates some of the physical and psychologic complexities that are involved in the care of adults with cancer who are caring for young children. Oncology nurses must provide medical management, as well as psychosocial care, to these patients. This care should often include other members of the interdisciplinary healthcare team in the supportive care plan. Oncology nurses must work in collaboration with other healthcare professionals to promote the best outcomes for patients and their families.

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At a Glance

- The fluctuating health of many patients with cancer, particularly those who care for young children, may further intensify their stress levels during hospitalizations.
- These periods of hospitalization should include vigilant nursing and supportive care.
- Many resources are available for families dealing with a parent's diagnosis of cancer.

Books

Because Someone I Love Has Cancer: Kids' Activity Book
Hope the Bear
How Do We Tell the Children?: A Step-By-Step Guide for Helping Children Two to Teen Cope When Someone Dies
How to Help Children Through a Parent's Serious Illness: Supportive, Practical Advice from a Leading Child Life Specialist
It Helps to Have Friends: When Mom or Dad Has Cancer
Mom and the Polka-Dot Boo-Boo
Our Mom Has Cancer
Our Dad Is Getting Better; Our Mom Is Getting Better
Psycho-Oncology, 2nd ed.
 Chapter 74: "Addressing the Needs of Children When a Parent Has Cancer"
 Chapter 75: "Psychosocial Research and Practice with Adult Children of Cancer Patients"
Raising an Emotionally Healthy Child When a Parent is Sick
When a Parent Has Cancer: A Guide to Caring for Your Children

Camps

Angel Foundation Kids Kamp
<http://bit.ly/1qZFdgE>
Camp Carefree
www.campcarefree.org
Camp Kesem
www.campkesem.org

Online Resources

American Cancer Society
 "Helping Children When a Family Member Has Cancer"
<http://bit.ly/1gchx0l>
American Psychosocial Oncology Society
www.apos-society.org
Cancer.Net
www.cancer.net
CancerCare
www.cancercares.org
Cancer Really Sucks
www.cancerrealsucks.org

Cancer Support Community

www.cancersupportcommunity.org

Children's Treehouse Foundation

"Support Groups"
<http://bit.ly/1AbCAtV>

Council of Dads

www.councilofdads.com

Dana-Farber Cancer Institute

"Family Connections"
<http://bit.ly/1AEYKtS>

Group Loop

www.grouploop.org

Kids Connected

www.kidsconnected.org

KidsCope

www.kidscope.org

Leukemia and Lymphoma Society

"Do I Tell Anyone I Have Cancer?"
<http://bit.ly/1qZGowC>

Life Institute

www.thelifeinstitute.net

Livestrong Foundation

www.livestrong.org

Marjorie E. Korff PACT Program

www.mghpact.org

National Cancer Institute

When Your Parent Has Cancer: A Guide for Teens
<http://1.usa.gov/1wDcY88>
Young People with Cancer: A Handbook for Parents
<http://1.usa.gov/1sxoAUR>

Parenting With Cancer

"Resources"
<http://bit.ly/1vWzUu2>

PBS Parents

"When Families Grieve"
<http://to.pbs.org/1AijMmt>

Stand Up To Cancer

"And We Laughed . . ."
<http://bit.ly/1wYTJl2>
 "Learning to Live After Loss: An Open Letter to Bereaved Spouses"
<http://bit.ly/13xKzp7>

University of North Carolina Cancer Care

"A Child's Grief: Resources"
<http://bit.ly/1GMFEgi>

FIGURE 1.
 Resources for Families Dealing With a Parent's Diagnosis of Cancer