Creating a Palliative Educational Session for Hematopoietic Stem Cell Transplantation Recipients at Relapse

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Relapse after hematopoietic stem cell transplantation (HSCT) is a stressful event for patients and families, but provides an opportunity for education and psychosocial support. Little available research satisfies the needs of transplantation recipients at this critical time in the cancer trajectory. This article will apply the End-of-Life Nursing Education Consortium content principles to tailor an education session in an advanced practice nursing research intervention after a relapse from HSCT. The components were a specific session devoted to relapse, family-focused education and assessment, and bereavement follow-up. The details of the three steps are discussed with application to four case studies, which describe the variety of scenarios that can occur and illustrate how a standard approach should be tailored for each situation. In addition, the actual teaching tools and forms used for the intervention are included.

At a Glance

- Education and psychosocial support for hematopoietic stem cell transplantation recipients and their families at the time of relapse are vital.
- Relapse is a time of crisis for patients and families. Teaching needs are unique and must be tailored for the situation.
- Education must encompass physical and psychosocial issues for both the patient and family.

Although survival after hematopoietic stem cell transplantation (HSCT) has improved from 20%–30% in the 1970s to 60%–70% to date, the mortality rate remains substantial (Horowitz, 2009). Unfortunately, relapse after transplantation with progression to end-of-life care is a reality for 30%–50% of recipients (Negrin & Blume, 2006; van den Brink et al., 2010). Only one article (Yoon, Conway, & McMillan, 2006) was found that addressed the educational needs of transplantation recipients at end-of-life care after relapse. However, a few relevant articles have addressed educational and palliative care concerns at the end of life in intensive care unit and hematology populations, as well as in patients with advanced cancer.

Relapse is a stressful event for patients and their families. Vital education and communication provided by healthcare professionals to patients and families may decrease psychological distress. Effective educational strategies to assist HSCT recipients and their families through the relapse phase have been identified (Yoon et al., 2006). Strategies included one-on-one teaching from a healthcare professional, psychological approaches, encouraging physician involvement, maximizing the use of the Internet, and facilitating professionals’ one-on-one partnerships with the patient and family (Yoon et al., 2006). Lautrette et al. (2007) discussed the need for close communication with the relatives of patients dying in the intensive care unit. The study concluded that proactive communication with the family and supportive literature may lessen the burden of bereavement (Lautrette et al., 2007). Bowman, Rose, Radziewicz, O’Toole,
and Berila (2009) promoted the use of a tailored communication intervention for families of patients with advanced cancer in hopes of affecting quality-of-life outcomes for their caregivers. In addition, Rolland (2005) discussed the terminal phase of illness and listed tasks such as completing the process of anticipatory grief and unresolved family issues, supporting terminally ill family members, helping survivors and dying family members live as fully as possible with the time remaining, and beginning the family reorganization process.

Manitta, Philip, and Cole-Sinclair (2010) discussed the challenges of why hematologic patients access palliative care team services less frequently. Although Manitta et al. (2010) focused on hematologic patients in general rather than transplantation recipients, the barriers for access to palliative care are worthy of consideration and applicable to the HSCT population. Barriers included the variability of the illness trajectory, with acute exacerbations needing highly technical therapies, unpredictability of prognostication, unclear goals of care, the focus on cure precluding palliative care, lack of knowledge of palliative care, and the complex structure of the healthcare system (Manitta et al., 2010).

The lack of literature discussing educational and palliative care needs for transplantation recipients at relapse may be related to the goal of transplantation being cure, not control. Nonetheless, relapse can be devastating and unexpected. An organized evidence-based approach to assist this population can be beneficial for healthcare staff, patients, and families. This article will present an evidence-based palliative care educational intervention for relapsed allogeneic HSCT recipients and will discuss its application by the use of case studies based on compilation of actual patients.

The author aimed to apply End-of-Life Nursing Education Consortium (ELNEC) content principles to tailor a session in an advanced practice nursing (APN) research intervention after a relapse from HSCT occurred. The overall APN research intervention was a National Cancer Institute–funded research study using a mixed-methods longitudinal clinical trial to test the effects of a standardized teaching intervention on quality-of-life outcomes for allogeneic HSCT recipients at discharge, 100 days, 6 months, and 12 months after hospitalization (see Figure 1). After the research project began, a gap was identified. Although six sessions covered materials for post-HSCT recipients (see Figure 2), no specific tailored intervention content was available for patients and families when a relapse occurred and the patients’ condition progressed to end-of-life care.

**Session Creation**

Two APNs attended an ELNEC course and designed a three-pronged approach to address the lack of palliative and end-of-life content in the research intervention. The Institute of Medicine’s (1998) report “Approaching Death: Improving Care at the End of Life” identified large gaps in medical professionals’ knowledge of end-of-life care, indicating that education is lacking in this area. Part of the report outlined a series of changes needed in the United States to enhance professional education. For nurses, ELNEC spearheaded the national initiative focused on education to improve palliative care (American Association of Colleges of Nursing, 2010, 2011). The ELNEC project provides training in palliative care to undergraduate and graduate nursing facilities; continuing education providers; staff development educators; specialty nurses in pediatrics, oncology, critical care, and geriatrics; and other nurses to assist in the dissemination of end-of-life education (Malloy et al., 2006). More than 10,000 nurses and other healthcare professionals, representing the United States and 63 international countries, have received ELNEC training that comprises eight modules, a 1,000-page syllabus, a palliative care textbook, and a wealth of resources and strategies to teach the content to others (American Association of Colleges of Nursing, 2011). The content of this module is a tailored resource addressing the needs of transplantation recipients who have relapsed and are approaching the end of life. Specific content was tailored to enhance the research intervention and enrich the end-of-life experience for transplantation recipients.

![Figure 1. Clinical Trial Testing the Effects of the Standardized Teaching Intervention](image-url)
and their families. The components included a specific session devoted to relapse, family-focused education and assessment, and bereavement follow-up.

**Part 1: Relapse Session**

The specific relapse session consisted of education and open-ended questions that ascertained the patient’s knowledge and led him or her to face hope and the need to mobilize resources (Ersk & Cotter, 2010). The first section of the relapse session aimed to normalize common feelings of anger, disappointment, and uncertainty. Three National Cancer Institute booklets were discussed with patients and given to them, and the session continued with eight questions (see Figure 3).

Information gained from patient and family responses was used to create a plan to address concerns. Integrated with the content was discussion about advanced directives as appropriate to the situation. The session ended with an offer to write a letter. The letter was an opportunity for patients to do a life review, teach their children principles that they wanted to pass on to future generations, ask and apply forgiveness, formally thank their friends and family, and express love to their spouses, children, and friends. The life letters were powerful tools to communicate sacred issues to children, spouses, and friends; parts of them were even read at patients’ funerals.

**Part 2: Family Focus**

In the second part of the intervention, APNs clarified the meaning of hope, encouraged family involvement, and offered information to improve understanding and maintain open communication for teaching and support (Davies & Steele, 2010). The family focus consisted of three segments: a teaching sheet about death and dying, assessment for complicated grief, and literature to discuss with families. The APN reviewed the teaching sheet about the signs of death and dying with the families (see Figure 4).

A tool was created to assess for complicated grief. Complicated grief is prolonged or inappropriate grief that may include substance abuse, self-destructive behaviors, post-traumatic stress behaviors, absent grief, depression, and behaviors that are not within the norm of grief expression (Brown-Salzman, 2006). The tool was created based on risk factors identified in the literature (Brown-Salzman, 2006; Ellifritt, Nelson, & Walsh, 2003; Marwit, Chibnall, Dougherty, Jenkins, & Shawgo, 2008; Prigerson et al., 1997; Sanders, Marwit, Meuser, & Harrington, 2007) (see Figure 5). The tool was used as a vehicle to identify and chart risk factors, refer the family to a therapist in their area for grief follow-up, and use as communication with other healthcare professionals.

Finally, the intervention APN reviewed two pieces of literature with the family. The first was a book from the California State Cemetery and Funeral Bureau (2005) entitled *Consumer Guide to Funeral and Cemetery Purchases*. The second was an online reference titled *Preparing to Say Good-Bye: Care for the Dying* (Center on Aging, 2002).

**Part 3: Bereavement**

The last component, bereavement follow-up, focused on offering informal support and ongoing grief assessment (Corless, 2002).
Introduction
We are meeting today because you have been given the news that your cancer has returned. This is something you have probably considered and hoped would not happen. You might be thinking how unfair it is. You might also be angry, saying, “I’ve done everything,” and, “The treatment didn’t work.” This session will focus on looking to the future, planning, and setting goals of care.

Relevant Literature
• When Cancer Returns (National Cancer Institute [NCI], 2010b)
• When Someone You Love Has Advanced Cancer (NCI, 2010c)
• Coping With Advanced Cancer (NCI, 2008)

Case Studies
The following case studies were based on the compilation of actual patients and families and demonstrate how the relapse session was implemented.

Case Study 1
A.R., a 40-year-old woman from Syria, immigrated with her family to the United States about 10 years ago. She had three children, aged 7, 9, and 11. Following a difficult allogeneic sibling-matched post-transplantation course with multiple re-admissions and infections, A.R. relapsed in the eighth month following transplantation. She did not want to talk with the intervention APN about relapse and end of life, and she continued her denial or avoidance of the subject up to the moment of death. However, the intervention APN had established a good relationship with A.R. and her family by conducting the teaching sessions in the home, and she was able to easily conduct a grief assessment of the family. The family was resilient; they had good social support, and the parents were close to the children. The father was open to interventions by the medical team to assist his children with closure. The family had the following risk factors for complicated grief (Ellifritt et al., 2003): the patient was in denial, and children younger than age 18 lived in the home. A child advocate was asked to see the children with the father present and process some of the information. While A.R. was dying in the hospital, the child advocate assisted each child in making a pillow with a handprint of their mother as a memorial. The family decided not to have the children present at the time of death, but the intervention APN stayed with the husband and relatives before and during A.R.’s death to discuss the signs and symptoms of dying. A bereavement card was sent to the husband and family, and the husband contacted the APN later to thank her and the medical team for the care given to his wife and children. Unfortunately, A.R. never left the denial stage. However, the social support of the family coupled with the intervention for the children did assist with bereavement follow-up and coping with grief.

Case Study 2
L.S., a 55-year-old divorced mother of four adult children, relapsed six months after an unrelated allogeneic transplantation for non-Hodgkin lymphoma. She lived alone and had few social supports. L.S. had shared with the intervention APN that her previous marriage was abusive, and the children had resented her for not setting more limits on their father. The intervention APN was able to proceed with the relapse session, and L.S. was very open to discussing her feelings, regrets, and unfinished business in her life with her children. The intervention APN and the physician contacted the eldest daughter and asked for a family conference with the children. The physician explained that their mother had no other options left for cure and the focus would now shift to comfort care. All children were present at the meeting, asked a few questions, and seemed united in their

As you look to the future, sometimes thinking about the goals you have for yourself and for your family and loved ones can help you discover inner strengths and a sense of purpose at this point in time. The following is a list of questions to ask yourself as you reflect on your desires and needs.

What is your understanding of the probable course of your illness?

How hopeful are you right now, and how does your illness affect this sense of hope?

Who are you most likely to confide in when you have a problem or a concern?

What gives you hope?

What helps you make sense of your situation right now?

What goals do you have going forward?

What resources do you have for meeting these goals?

How can we help you meet these goals?

Figure 3. Special Session on Disease Relapse: Setting Goals and Maintaining Hope

2010). Each family member was sent a handwritten note by the nurse within one week of the patient’s death. With the note was a small paperback book provided to the caregiver and family called Healing Your Grieving Heart: 100 Practical Ideas (Wolffert, 2001). The book has a helpful idea of providing 100 ways of grieving that can be used to assist caregivers and families during their grief experience. Each idea is presented on one page, which the family members appreciated because the text was simple and not overwhelming to read. In addition, some family members chose to meet with the APNs for closure to process the death experience.
Having changes in breathing pattern such as long periods without
breathing followed by several quick, deep breaths
Not hearing as well as usual
Eating or drinking less
Confused
Not being able to concentrate
Turning blue around the nose, mouth, fingers, and toes
Becoming more confused
Hearing or reading less
Sleeping more
Difficulty swallowing
Trouble breathing
Worsening of any of your loved one's medical problems
Losing control of urination and bowel movements
Eating or drinking less
Talking about leaving or taking a trip or journey
Becoming more confused
Sleeping more
Keeping things calm around the patient
Allow the patient to sleep as much as he or she wishes.
Eating or drinking less
Sleeping more
Make the patient comfortable as much as possible.
Open a window or use a fan in the room if the patient is having
difficulty breathing.
Keep a light on in the room; the patient cannot see well and may be
disturbed by darkness and shadows.
Keep the patient at a comfortable temperature.
Avoid strong odors or sudden movements.
Keep things calm around the patient.
Make the patient comfortable as much as possible.
Write down what the patient says; such messages may comfort you.
Encourage visitors to talk directly to the patient and tell the patient
how much they care.
Signs and Symptoms That Your Loved One Is Close to Death
- Sleeping more
- Speaking to people not present
- Talking about leaving or taking a trip or journey
- Withdrawing from people or having little to say
- Eating or drinking less
- Having trouble swallowing
- Becoming more confused
- Making moaning sounds
- Losing control of urination and bowel movements
- Having moist breathing or sounding congested
- Having changes in breathing pattern such as long periods without
breathing followed by several quick, deep breaths
- Having blurred vision
- Not hearing as well as usual
- Having less pain
- Having cool-feeling hands and arms or feet and legs
- Turning blue around the nose, mouth, fingers, and toes
Things You Can Do to Make Your Loved One Comfortable
- Allow the patient to sleep as much as he or she wishes.
- Include the children in your family in the experience of the patient’s
death.
- Turn the patient if it makes him or her more comfortable.
- Moisten the patient’s mouth with a washcloth or cotton ball.
- If the patient has a fever or is hot, apply a cool rag to the forehead.
- Give medications ordered by the doctor to decrease anxiety, restless-
ness, agitation, or moist breathing.
- Write down what the patient says; such messages may comfort you
later.
- Continue to talk clearly to the patient and say the things you need
or want to say. Remember that the patient may be able to hear even
when he or she is not able to respond.
- Keep a light on in the room; the patient cannot see well and may be
scared by darkness and shadows.
- Play the patient’s music softly.
- Encourage visitors to talk directly to the patient and tell the patient
who they are.
- Keep things calm around the patient.
- Open a window or use a fan in the room if the patient is having
trouble breathing.
- Continue to touch and stay close to your loved one.
- Continue medications rectally if oral route is no longer an option.

Figure 4. Family Resources at End-of-Life
Note: From Patient/Family Teaching Sheet: Final Days, by the Hospice
hpna.org/pdf/teachingsheet_finaldays.pdf. Copyright 2010 by the Hos-
pice and Palliative Nurses Association. Used with permission.

Case Study 3

B.M., a 55-year-old executive, was diagnosed with myelodys-
plastic syndrome with refractory anemia with excess blasts.
Prior to transplantation, B.M. and his wife were looking for-
ward to celebrating 50 years of marriage and attending their
daughter’s graduation from college in the coming months.
B.M. and his wife also were involved with their church, and
he was the director of the adolescent music program. Follow-
ing transplantation, B.M. was welcomed home with a life-size
cardboard replica of himself, along with banners in his front
yard created by the adolescents he had mentored. B.M.’s work
colleagues arranged for meals to be delivered daily and had
regular uplifting messages sent to his home. At four months,
B.M. developed leg pain and struggled with immobility. Tests
revealed multiple chloromas, which were localized masses of
malignant immature myeloblasts, unfortunately signifying a
relapse. B.M. and his wife opted for salvage chemotherapy in
hopes of inducing another remission.

During the relapse session, the APN reviewed with B.M. and
his wife their understanding of the situation and goals for the
future. B.M. wanted to make sure his wife and daughter were
secure financially. The APN worked with his wife to make sure
all financial arrangements were in order. During this time,
B.M. and his wife celebrated their 30th anniversary. The APN
arranged with the unit staff for an anniversary cake to com-
memorate the occasion. During the celebration, B.M.’s daughter
and her long-time boyfriend announced their engagement. Both
B.M. and his wife remained hopeful while undergoing salvage
chemotherapy. Unfortunately, B.M. developed a lung infection
and required a ventilator in the intensive care unit. The APN
stayed with B.M. and his wife periodically over the course of sev-
eral days. When the fact that B.M.’s condition was not going to
improve became evident, the APN reminded his wife that even
though B.M. was no longer responsive, he could hear her. The
wife was able to say everything she wanted to say to B.M. His
daughter needed time to travel to the hospital to say goodbye to
her father; therefore, B.M.’s wife placed the telephone receiver
next to his car so he could hear his daughter say she was on her
way to the hospital. B.M.’s daughter and her fiancé were able to
be at his bedside several minutes before he died. On the one-
year anniversary of B.M.’s death, his wife called the APN to say
she and her daughter were doing well. She was grateful for the
APN’s support and caring.

Case Study 4

T.J., a 19-year-old man, had refractory Hodgkin disease. He
had been diagnosed with Hodgkin disease as a young child
and had experienced multiple relapses. The transplantation
was T.J.’s only hope for cure in the face of resistant disease.
He received an unrelated transplantation, after which he de-
veloped graft failure, coupled with persistent and progressive
disease at six months. T.J. was an independent young adult
and strongly requested that the medical team involve him in
all decision making. He struggled with the dependence that gradually increased over the course of his physical decline. His parents both were physicians and worked hard to respect his independence, although not being involved in the decision making of his treatment was challenging for them. The medical staff respected T.J.’s choice to direct all treatment decisions, but at times felt awkward about excluding both parents (who were physicians themselves) from medical decisions.

T.J. did not want to discuss his relapse with the intervention APN, although he did discuss his long history of medical treatment, frustration with his lack of control, and many existential questions. The intervention APN suggested a referral to the psychologist and chaplain, who were able to work with T.J. and address his anxiety and existential issues. Over a few months, T.J. was able to accept his death, although he never spoke of it with his parents or the medical team. His acceptance was communicated by the chaplain and psychologist to the team. Although no risk factors for complicated grief were present, the intervention APN referred T.J.’s parents for grief counseling. T.J. eventually developed fungal pneumonia and died in the intensive care unit on his last admission. T.J.’s parents, the attending physician, and the intervention APN were at the bedside at the time of death. A bereavement letter was sent to the parents one week after T.J.’s death, and the attending physician went to the funeral. T.J.’s mother met with the attending physician and the intervention APN three months after his death to express her thanks for the support given to her family. This case reminded the team of the existential and dependence issues common to young adults.

## References


## Figure 5. Complicated Grief Risk Assessment for Patients’ Caregivers and Families

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Description</th>
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<tr>
<td>Prior death within one year</td>
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<td>Suicide ideation of the caregiver</td>
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<td>Prior loss (e.g., job, divorce) within the past three months</td>
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<td>History of psychiatric issues or illnesses such as depression and anxiety</td>
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<tr>
<td>Survivor is experiencing a concurrent life crisis.</td>
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<tr>
<td>Denial of illness or end-of-life situation at the time of death</td>
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<td>Conflict with the healthcare team over death</td>
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<td>Lack of social support for the family or caregivers</td>
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<td>Poor caregiver coping skills</td>
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<td>History of drug or alcohol use or abuse</td>
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<td>Male gender, particularly in older adults, and no children or perceived social support</td>
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<tr>
<td>Presence of children younger than 18 years in the household</td>
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<td>High degree of enmeshment within the family: few boundaries or autonomous behavior, coalitions in the family, and little personal decision making and freedom</td>
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