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Creating a Palliative/Educational Session for HCT Patients at Relapse

Liz Cooke, RN, MN, ANP, AOCN,
City of Hope, Duarte, CA

Robin Gemmill, RN, MSN, CNS, CWOCN, and
Private Practice, Burbank, CA

Marcia Grant, RN, DNSc, FAAN
City of Hope, Duarte, CA

Introduction

Although the mortality rate after HCT has improved substantially within the last 20 years, mortality is still substantial. The one year survival rate after transplantation remains approximately 60-70%, up from 20-30% in the 1970's (Horowitz, 2004). Relapse after transplant with progression to end-of-life care is unfortunately a reality for 30-50% of the patients (Negrin, 2006; van den Brink, et al., 2010). Only one article was found that addressed educational needs of transplant patients at end-of-life care post relapse (Yoon, Conway & McMillan, 2006). There are however a few articles which address educational and palliative care concerns at end-of-life from the ICU, hematology and advanced cancer populations.

Relapse is a stressful event for patients and families. Vital education and communication by health care professionals to the patients and family may decrease psychological distress. Effective educational strategies to assist HCT patients and families through the relapse phase have been identified (Yoon, Conway, & McMillan, 2006). These included using one and one teaching from a health care professional, using psychological approaches, encouraging MD involvement, maximizing the use of the internet, and facilitating professional's 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. (Lautrette, et al., 2007). This study concluded that proactive communication with the family and literature support may lessen the burden of bereavement (Lautrette, et al., 2007). Bowman et al, (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 caregivers of advanced cancer patients (Bowman, 2009). Rolland (2005) in his article on cancer and the family discussed the terminal phase of illness and listed tasks as 1) completing the process of anticipatory grief and unresolved family issues, 2) supporting the terminally-ill member, 3) helping survivors and dying member live as fully as possible with time remaining, and 4) beginning the family reorganization process (Rolland, 2005).

Manitta et al (2010) in an eloquent article titled "Palliative care and the hemato-oncological patient: Can we live together? A Review of the Literature" discusses the challenges of why hematology patients less frequently access the palliative care team services (Manitta, Philip, & Cole-Sinclair, 2010). Although the article does not focus specifically on the transplant population but rather the hematology patient in general the barriers for access to palliative are worthy of consideration, and applicable to the transplant patient. Barriers included: 1)

the variability of the illness trajectory with acute exacerbations needing highly technical therapies, 2) unpredictability of prognostication, 3) unclear goals of care; 4) the focus on cure precludes palliative care, 5) lack of knowledge of palliative care, and 6) the complex structure of the healthcare system. This lack of literature discussing educational and palliative care needs for transplant patients at relapse may be related to the goal for transplant being cure not control. Nonetheless, a relapse can be devastating and unexpected. An organized evidence-based approach to assist these patients can be very beneficial for staff, patients and families. This paper will present an evidence-based palliative care/ educational intervention for relapsed allogeneic transplant patients and will discuss its application by the use of case studies based on compilation of actual cases.

Purpose

The purpose of this article is apply the ELNEC (End-of-life Nursing Education Consortium) education and content principles to tailor an education session in an ANP (Advanced Practice Nursing) research intervention after a relapse from a HCT (Hematopoietic Cell Transplantation). The overall ANP research intervention was an 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 HCT patients at discharge, 3, 6, and 12 months post hospitalization (see Figure 1). After the research project began, a gap was identified. Although there were 6 sessions that covered materials for post-transplant patients, (See Figure 2) there was no specific tailored intervention content for patients and families when patients relapsed and then progressed to end-of-life care.

Relapse/End-of-Life Session Creation

Two research intervention nurses, both APNs, attended an ELNEC course and designed a three-pronged approach to address the lack of palliative/end-of-life content in the research intervention. The 1998 IOM report “Approaching Death” identified large gaps in the medical knowledge of care at end-of-life indicating that education of health care professionals is lacking in this area (IOM, 1998). Part of this report outlined a series of changes needed in the United States to change professional education. For nurses, the national initiative that focuses on nursing education to improve palliative care was spearheaded by the End-of-Life Nursing Consortium(ELNEC) (AACN & 2010). The ELNEC project provides undergraduate and graduate nursing faculty, CEU providers, staff development educators, specialty nurses in pediatrics, oncology, critical care and geriatrics and other nurses with training in palliative care to assist nurses in the dissemination of end-of-life education (Malloy, et al., 2006). Over 10,000 nurses and other healthcare professionals, representing all 50 US States and 63 international countries have received ELNEC training which comprises 8 modules, 1,000 page syllabus, palliative care textbook, and a wealth of resources and strategies to teach the content to others (ELNEC, 2010). The content of this article is a tailored resource addressing the needs of transplant patients who have relapsed and are approaching end-of-life. Specific content was tailored to enhance the research intervention and enrich the experience of end-of-life for transplant patients and families. The components were the following: 1) a specific session devoted to relapse 2) family focused education and assessment, and 3) bereavement follow-up.

Part 1: Relapse Session

The specific relapse session consisted of both education and open-ended questions which ascertained the patient’s knowledge, and lead the patient to face hope and the need to mobilize resources (Ersek, 2010)(See Appendix A). The first section of the relapse session was to normalize common feelings of anger, disappointment, and uncertainty. Three NCI booklets were discussed with the patients and given to them: “When Cancer Returns”,

“When Someone You Love Has Advanced Cancer”, and “Coping with Advanced Cancer” by National Cancer Institute. The session continued with eight questions: 1) what is your understanding of the probable course of your illness? 2) How hopeful are you right now, and how does your illness affect this sense of hope? 3) Who are you most likely to confide in when you have a problem or a concern? 4) What gives you hope? 5) What helps you make sense of your situation right now? 6) What goals do you have going forward? 7) What resources do you have for meeting these goals? 8) How can we help you meet these goals? 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 and as appropriate to the situation. The session ended with an offer to write a life letter. The life letter was an opportunity for the patient to do a life review, teach their children principles that they wanted to pass on to further generations, ask and apply forgiveness, formally thank their friends and family, and to speak love to their spouses, children and friends in words that would endure. These life letters were powerful tools to communicate “sacred” issues to children, spouses and friends and parts of them were even read at funerals.

Part 2: Family Focus

“The second part of this intervention focused on the family. In this section of the intervention the APNs would clarify the meaning of “hope” (for example, hope may change from “hope for cure” to “hope for a peaceful loving death experience”), encourage family involvement, offer information for better understanding and maintaining open communication for teaching and support (Davies, 2010). It consisted of three parts: 1) teaching sheets about death and dying, 2) assessment for complicated grief, and 3) literature to discuss with families. The first part was a teaching sheet that was reviewed with the families by the APN about the signs of death and dying (See Appendix B). This sheet was adapted from the “Patient and Family Teaching Sheet: Final Days” from the Hospice and Palliative Nurse’s Association website (HPNA, 2010). The second part was a created tool to assess for complicated grief. Complicated grief simply stated is prolonged or inappropriate grief which may include behaviors such as 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 (See Appendix C) (Brown-Salzman, 2006; Ellifritt, Nelson, & Walsh, 2003; Marwit, Chibnall, Dougherty, Jenkins, & Shawgo, 2008; Prigerson, et al., 1997; Sanders, Marwit, Meuser, & Harrington, 2007). It 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 health care professionals. The third part of the family intervention consisted of two pieces of literature. The first was a book from the State of California titled “Consumer Guide to Funeral and Cemetery Purchases (California, 2005). The second was an online reference titled “Preparing to Say Goodbye”(Aging, 2002). Both were reviewed with the family by the intervention nurse.

Part 3: Bereavement

The last component of the intervention was bereavement follow-up, and the focus of the intervention was to offer informal support and ongoing grief assessment (Corless, 2010). Each family member was sent a hand written note by the nurse within one week of the death. Along with the note was a small paperback book provided to the caregiver and/or family called “Healing Your Grieving Heart: 100 Practical Ideas”. The book has a helpful idea of providing 100 ways of grieving which can be used to assist caregivers and families during their grief experience. Each idea is presented on one page and was appreciated by the family members because it was simple and not overwhelming to read (Wolfelt, 2001). In addition, some family members chose to meet with the nurses for closure, to process the death experience.

Case Studies

The next section will give four case study examples based on the compilation of actual patients and families and will demonstrate how this extra session was implemented.

Case Study 1

Anna was a 40 year old middle-eastern woman from Syria who immigrated with her family to the United States about 10 years ago. She had 3 children, ages 7, 9 and 11. Following a stormy allogeneic sibling matched post-transplant course with multiple readmissions and infections, she relapsed in the 8th month following transplant. She did not want to talk with the APN intervention nurse about relapse and end-of-life, and continued her “denial” or “avoidance” of the subject right up to the moment of death. However, the APN-intervention nurse had established a good relationship with this patient and family by conducting the teaching sessions in the home, and was able to easily conduct a grief assessment of the family. The family was very resilient, had good social support and the parents were very close to the children. The father was open to interventions by the medical team to assist his children with closure. The risk factors for complicated grief (Ellifritt, Nelson, & Walsh, 2003). in this family were the following: the patient in denial, and children less than 18 years of age in the home. A child advocate was asked to see the children with the father present and process some of the information. While the patient was dying in the hospital, the child advocate assisted each child in making a pillow with the handprint of the mother as a memorial. At the time of death, the family decided not to have the children present, although the intervention nurse stayed with the husband and relatives before and during the time of 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 nurse later to thank her and the medical team for the care given to his wife and children. Unfortunately the patient 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 2

Laura was a 55 year old divorced woman, mother of 4 adult children, who relapsed 6 months after an unrelated allogeneic transplant for Non-Hodgkin's lymphoma. She lived alone, and had few social supports. She had shared with the intervention nurse that her previous marriage was an abusive one, and the children had resented her for not setting more limits on their father. The intervention nurse was able to proceed with the relapse session and Laura was very open to discussing her feelings, her regrets, and the unfinished business in her life with her children. The intervention nurse and the MD contacted the eldest daughter and asked for a family conference with the children. The MD did explain that their mother had no other options left for cure, and that the focus would now shift to comfort care. All children were present at the meeting, asked a few questions, and did seem to be united about their desire to “be there for their mom as best as they could”. In the meantime, the intervention nurse and the patient together wrote her “life letter”. The composition of the life letter assisted Laura with how to organize her thoughts, feelings and regrets about estrangement especially from one child. At the time of death, she was able to call all four children into the room separately, and express her regrets and ask for forgiveness, and the reconciliation with the estranged child was very powerful. The intervention nurse did assess the family for complicated grief, but no risk factors seemed present. The intervention nurse was not able to be with Laura at the time of death, but according to one of her children “her mom passed peacefully at home on hospice surrounded by her 4 children”. The life letter was read at the funeral, and the children were very grateful to have that memorial of their mother. The life letter written by the patient and the healing extended from the patient to the estranged child and visa versa was a significant intervention for this family. The children

were able to keep the letter as a legacy and feel closure with some of the unresolved issues of their childhood.

Case 3

Bill was a 55 year old executive diagnosed with Myelodysplastic Syndrome (MDS) with refractory anemia with excess blasts (RAEB). Prior to transplant Bill and his wife were looking forward to celebrating 30 years of marriage and attending their daughter's graduation from college in the coming months. Both Bill and his wife were very involved with their church. Bill was the director of the teen music program. Upon returning home following transplant, Bill was welcomed home with a life-size cardboard replica of himself along with Welcome Home banners in his front yard created by the teens he mentored. Bill's work colleagues arranged for meals to be delivered daily and had regular uplifting messages sent to his home. At 4 months Bill developed leg pain and struggled with pain and immobility. Tests revealed multiple chloromas which were localized masses of malignant immature myeloblasts, unfortunately signifying a relapse. Bill and his wife opted for salvage chemotherapy in hopes of inducing another remission. During the relapse session the APN reviewed with Bill and his wife their understanding of their situation and goals for the future. Bill wanted to make sure his wife and daughter were financially secure. The APN worked with Bill's wife to make sure all financial arrangements were in order. During this time Bill and his wife did celebrate their 30th anniversary. The APN arranged with the unit staff for an anniversary cake to celebrate the occasion. During this celebration, his daughter and her long-time boyfriend announced their engagement. Both Bill and his wife remained hopeful while undergoing salvage chemotherapy. Unfortunately, Bill developed a lung infection and required a ventilator in the ICU. The APN stayed with Bill and his wife periodically over the course of several days. When it became evident that Bill's condition was not going to improve the APN reminded Bill's wife that even though Bill was no longer responsive he could hear her. Bill's wife was able to say everything she wanted to say to Bill. Bill's daughter needed time to travel to the hospital to say good-bye to her father. So, Bill's wife placed the phone receiver next to Bill's ear so he could hear his daughter say she was on her way to the hospital. Bill's daughter and fiancé were able to be at his bedside several minutes before Bill died. On the one year anniversary of Bill's death, his wife called the APN to tell her she and her daughter was doing well. Their daughter had been married and was looking forward to attending graduate school in Chemistry. Bill's wife had become a Stephens's Minister at their church. She was very grateful for the APN support and caring.

Case 4

Tony was a 19 year old man with a diagnosis of refractory Hodgkin's disease. He had had Hodgkin's disease since he was a young child and had experienced multiple relapses. The transplant was his only hope for cure in the face of resistant disease. He had an unrelated transplant after which he developed graft failure, coupled with persistent and progressive disease at 6 months. He was an independent young adult and strongly requested that the medical team involve him in all the decision-making. He struggled with the dependence that gradually increased over the course of his physical decline. His parents were both physicians and worked hard to respect his independence although it was challenging for them not to be involved in the decision-making of his treatment. The medical staff respected Tony's decision to drive all treatment decisions, but at times felt awkward excluding both of parents (who were physicians themselves) from medical decisions. Tony did not want to discuss his relapse with the intervention nurse although he did discuss his long history of medical treatment, frustration with his lack of control, and many existential questions. The intervention nurse suggested a referral to the psychologist and chaplain, both who were able to work with him and address his anxiety and existential issues. Over a few months, he 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. Even though there were no risk factors for complicated grief, the intervention nurse did refer his parents for grief counseling. Tony eventually developed fungal pneumonia and died in the ICU on his last admission. Both parents, the attending MD, and the intervention nurse were at the bedside at the time of death. A bereavement letter was sent to the parents one week after Tony's death and the attending MD went to the funeral. Tony's mother met with the attending MD and the intervention nurse 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 so common to young adults.

Discussion

Since some transplant patients do experience relapse, end-of-life care is vital for this population. Previous studies do show that educational and tailored approaches for families of patients facing relapse do have an impact. This article presented content for a relapse session in an APN intervention. The content highlighted included a discussion with the patient, a complicated grief family assessment and referral, and family teaching and bereavement follow-up, and its application to patient care. Case studies describe the variety of scenarios that can occur and illustrate how a standard approach needs to be tailored for each situation. Since few articles discuss a tailored intervention content applicable to various situation with HCT patients in this phase of patient teaching, it seeks to contribute to the literature. The effectiveness of the relapse content is currently being studied in patients with lung cancer and their caregivers and should provide additional evidence for the value of the specific content. Testing the content in other vulnerable populations is recommended. Meanwhile, the clinical success of the approach in the transplant population warrants it being applied to the current care of other relapsed cancer patients and their caregivers.

Acknowledgments

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Appendix A: Special Session: Disease Relapse-Setting Goals Maintaining Hope

We are meeting today because you have been given the news your cancer has returned. Something you have probably thought of and hoped would not happen. You might be thinking how “unfair” it is. You might also be angry, “I’ve done everything and “it didn’t work”. This session will focus on looking to the future, planning and setting goals of care.

Special Session: Disease Relapse-Setting Goals Maintaining Hope

Relevant Literature

1. “When Cancer Returns” by National Cancer Institute
2. “When Someone You Love Has Advanced Cancer” by National Cancer Institute
3. “Coping with Advanced Cancer” by National Cancer Institute

Literature for Disease Relapse Session: (Review each with the patient thumbing through pages and discussing content)

1. “When Cancer Returns” by National Cancer Institute
2. “When Someone You Love Has Advanced Cancer” by National Cancer Institute
3. “Coping with Advanced Cancer” by National Cancer Institute

As you begin to think about the future sometimes thinking about the goals you have for yourself, for your family and loved ones can help you discover inner strengths and a sense of purpose at this point in time.

The following are a list of questions to ask yourself as you reflect 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?

Appendix B: Standardized Nursing Intervention Protocol Family Resources at End-of Life

Signs and Symptoms that your loved one is close to death:

As death nears your loved one may:

- Sleep more
- Speak to people not present
- Talk about leaving or taking a trip or journey
- Withdraw from people or have little to say
- Eat or drink less
- Have trouble swallowing
- Become more confused
- Make moaning sounds
- Loss control of urination and bowel movements
- Have moist breathing or sound congested
- Have changes in the pattern of breathing such as long periods without breathing followed by several quick, deep breaths
- Have blurred vision
- Not hear as well as usual
- Have less pain
- Have cool feeling hands and arms or feet and legs
- Turn 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 they wish
- 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 moist 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, restlessness, 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 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 is oral route is no longer an option.

Adapted from HPNA.org “Patient and Family Teaching sheet: Final Days”

Appendix C: Standardized Nursing Intervention Protocol Caregiver/Family Complicated Grief Risk Assessment

Please check each applicable risk factor and initial referral if any risk factors are present:

☐	Prior death within one year
☐	Suicide ideation of the caregiver
☐	Prior loss within 3 month such as job, divorce
☐	History of psychiatric issues/illness such as depression, anxiety
☐	Survivor is experiencing a concurrent life crisis
☐	Denial of illness or end-of-life situation at the time of death
☐	Conflict with the health care team over death
☐	Lack of social support for the family or caregivers
☐	Poor caregiver coping skills
☐	History of drug/alcohol use/abuse
☐	Male sex, especially if elderly, and no children or perceived social support
☐	Presence of children younger than 18 in the household
☐	High degree of enmeshment within the family: few boundaries or autonomous behavior, coalitions in the family, little personal decision-making and freedom
☐	Comments: _____ _____
☐	Referral: _____
☐	Signature: _____

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At a glance (3 points)

1. Relapse is a time of crisis for patients and families. Teaching needs are unique, and must be tailored for this situation.
2. Education must encompass physical and psychosocial issues for both the patient and family.
3. Case studies illustrate practical intervention at relapse.

Participants in each group: Intervention n = 141; Control n = 141; total n = 282

Figure 1.
Design and Study Variables

Session 1: Immediate Post Discharge Care	
Relevant Literature	
<ol style="list-style-type: none"> 1. The City of Hope “Bone Marrow Transplantation” binder [City of Hope Medical Center (2002). “A Patient’s Guide to Blood and Marrow Stem Cell Transplantation”. Third Edition. 2. “Bone Marrow Transplantation” by Leukemia and Lymphoma Society. The Leukemia & Lymphoma Society. <i>Blood and Marrow Stem Cell Transplantation</i>. 1-153. 	
Outpatient and Inpatient Routines	
Reportable Signs and Symptoms	
Medication Review	
Session 2: Infection Precautions and Diet	
Relevant Literature	
<ol style="list-style-type: none"> 1. “Eating Hints for Cancer Patients” from NIH. National Cancer Institute. <i>In Eating Hints for Cancer Patients: Before, During, and After Treatment</i>. Retrieved June 9, 2005, from www.nci.nih.gov/cancertopics/eatinghints/allpages/print. 2. City of Hope information on Low-Bacteria Diet. City of Hope National Medical Center. Clinical Nutrition Services. <i>Low Bacteria Diet</i>. 31-35. 	
Signs and Symptoms of Infection	
Infection Precautions	
Hickman teaching reinforcement. City of Hope National Medical Center. (2004) <i>Patient Guide: How to Take Care of Your External Center Vascular Access Device</i> . 1-23.	
Diet/Nutrition and Fluid Support	
Session 3: GVHD and Other Symptoms	
Relevant Literature	
<ol style="list-style-type: none"> 1. “Fatigue Questions and Answers” from the Oncology Nursing Society. National Cancer Institute. April 20, 2005. <i>Fatigue: Health Professional Version</i>. Retrieved June 9, 2005, from www.cancer.gov/cancertopics/pdq/supportivecare/fatigue/healthprofessional/allpages/ 2. “Touching Lives” from Leukemia and Lymphoma Society. The Leukemia & Lymphoma Society. <i>Touching lives: Guide to patient services</i>. 	
Community and Hospital Resources	
Fatigue Management	
Hygiene, mouth care and skin management	

Session 1: Immediate Post Discharge Care
Relevant Literature
<ol style="list-style-type: none"> 1. The City of Hope “Bone Marrow Transplantation” binder [City of Hope Medical Center (2002). “A Patient’s Guide to Blood and Marrow Stem Cell Transplantation”. Third Edition. 2. “Bone Marrow Transplantation” by Leukemia and Lymphoma Society. The Leukemia & Lymphoma Society. <i>Blood and Marrow Stem Cell Transplantation</i>. 1-153.
Outpatient and Inpatient Routines
Reportable Signs and Symptoms
Medication Review
Session 2: Infection Precautions and Diet
Relevant Literature
<ol style="list-style-type: none"> 1. “Eating Hints for Cancer Patients” from NIH. National Cancer Institute. <i>In Eating Hints for Cancer Patients: Before, During, and After Treatment</i>. Retrieved June 9, 2005, from www.nci.nih.gov/cancertopics/eatinghints/allpages/print. 2. City of Hope information on Low-Bacteria Diet. City of Hope National Medical Center. Clinical Nutrition Services. <i>Low Bacteria Diet</i>. 31-35.
Signs and Symptoms of Infection
Infection Precautions
Hickman teaching reinforcement. City of Hope National Medical Center. (2004) <i>Patient Guide: How to Take Care of Your External Center Vascular Access Device</i> . 1-23.
Diet/Nutrition and Fluid Support
Session 3: GVHD and Other Symptoms
Relevant Literature
<ol style="list-style-type: none"> 1. “Fatigue Questions and Answers” from the Oncology Nursing Society. National Cancer Institute. April 20, 2005. <i>Fatigue: Health Professional Version</i>. Retrieved June 9, 2005, from www.cancer.gov/cancertopics/pdq/supportivecare/fatigue/healthprofessional/allpages/ 2. “Touching Lives” from Leukemia and Lymphoma Society. The Leukemia & Lymphoma Society. <i>Touching lives: Guide to patient services</i>.
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Fatigue Management
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Figure 2.
Teaching and Rehabilitation Program Outline