BMTCN Review Course
Professional Practice

How the Experts Treat Hematologic Malignancies

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Disclosures

No disclosures
Objectives

• Describe professional issues related to the field of transplant nursing
  – Ethical and legal issues
  – Clinical trials
  – Scope and standards of practice
  – Accreditation standards
  – Continuous quality improvement
  – Professional boundaries
  – Compassion fatigue and moral distress
  – Chemotherapy and biotherapy competence
  – Sources of data for evidence-based practice

Note: the primary reference source for this course is
Oncology Nursing Society, Pittsburgh, PA
Ethical and legal issues – Nursing considerations

• Nurses “being in the middle.” (Hamric, 2001)
  – Resource allocation
  – Religious beliefs
  – Societal mores
  – Clinical trials

• RN self awareness, cultural competency
  – Life and death decision making
  – Patient (and donor) confidentiality and privacy
  – Pediatric HCT – parent perceptions of child’s well-being
Ethical and legal issues

• Minors as donors
  – Psychological and developmental assessments of minor donors
  – Minor donors with comorbidities (may increase risk of donation)
• Parents conceiving a child, as a potential donor for sibling
• UBCT – for-profit companies versus UCB registries
  – Informed consent (when child reaches maturity)
• Healthy donors – informed of risk of donation
• Patient preferences – consistent with plan of care?
• Treatment / after care
  – Advanced directives
  – DNR orders
  – Medical futility – discontinuation of care
  – Sanctity of life
Ethical and legal issues – Concerns with patient eligibility during work up for HCT

- Issues / concerns
  - Addictive / abusive behavior
    - Tobacco, drug, alcohol abuse
    - Violence
  - Special needs
    - Aging / co-morbidities, disability, blindness
  - No identified caregiver
    - Concerns related to caregiver ability / caregiver with special needs
  - Unrealistic expectations
  - History of non-adherence, missed or rescheduled appointments
  - Psychiatric diagnosis without active treatment
  - Financial concerns

Adapted from Ezzone (2013) Figure 14.4 pp 273
Ethical and legal issues – Nursing self care

• Unresolved issues – may lead nurse to experience moral distress
• Improved communication
  – Compassionate, clear messages will lead to less conflict
• Patient advocacy
• Ethics rounds (Neumann, Pentz & Flamm, 2001); Schwartz Center Rounds (http://www.theschwartzcenter.org/supporting-caregivers/schwartz-center-rounds/)
  – Know the goals of care, challenge inconsistencies if they arise between the patient’s understanding of the goals and the medical plan of care (Neumann, 2013)
Ethical and legal issues – Survivorship Issues

- Late term complications, secondary cancers, myelodysplasia
- Insurance – cost of care
  - Fragmented care delivery for patients with chronic conditions
- Knowledge deficit – health care providers and patients
- Lack of awareness, funding for survivorship care and research
- “Failure of society to value outcomes other than cure.”
  - Tables in report
    - Acute, Chronic, and Late Effects of Cancer Treatments
    - Recommended Laboratory and Imaging Tests for Surveillance for Selected Cancers

Oncology Nursing Society report Red Flags for Cancer Survivors (2014)

https://www.ons.org/sites/default/files/media/Red%20Flags%20for%20Cancer%20Survivors.pdf
Clinical trials -

Clinical trials – only 3% enrollment in US in general.
Comprehensive Cancer Centers = ~ 12 – 20%

- Organizational barriers
  - Time, effort, cost
    - Regulatory requirements
    - Insurance authorizations

- Patient barriers
  - Appropriateness of trials
  - Eligibility (i.e. ruled out for co-morbid conditions)
  - Cost (transportation, insurance coverage)

- Barriers in HCT
  - Type and stage of diagnosis
  - Age of patient and donor
  - Stem cell source
Clinical trials -

- Primary immunodeficiency states
  - Severe Combined Immunodeficiency Disease (SCID)
  - Wiscott-Aldrich syndrome
  - Beta-Thalassemia Major
  - Sickle Cell disease

- Autoimmune Diseases
  - Systemic lupus erythematosus
  - Multiple sclerosis
  - Systemic Sclerosis
  - Rheumatoid arthritis
  - Autoimmune Type 1 Diabetes
    - High dose immunosuppression and autologous HCT
Clinical trials -

- AIDS
  - Allogeneic HCT for HIV+ patients with hematologic malignancies
  - Autologous HCT for HIV+ patients with relapsed or refractory Non-Hodgkin lymphoma or Hodgkin lymphoma
    - Meets all other eligibility criteria for AuHCT
    - Well controlled viral load on HAART therapy

- Nursing research
  - Symptom expression and management
  - Quality of life
  - Long term outcomes / survivorship
  - Pain / oral pain from mucositis
  - Family caregiver needs

- Interdisciplinary research
  - Evidence-based practice / HCT practice variation
  - Survivorship and Health-related QOL
  - Problem solving and reintegration after HCT
Clinical trials - BMTCTN – Blood and Marrow Transplant Clinical Trials Network – 2001

- Large scale, multi-center clinical trials (often international)
- Two National Institutes of Health centers:
  - National Heart, Lung, and Blood Institute (NHLBI)
  - National Cancer Institute (NCI)
The BMT CTN Data Coordinating Center (DCC) maintains continuity of operations and facilitates effective communications. The DCC effort is a collaboration between:

- Center for International Blood and Marrow Transplant Research (CIBMTR)
- National Marrow Donor Program (NMDP)
- The EMMES Corporation (EMMES) [contract clinical research collaborator]
Clinical trials - ASBMT Research Priorities (2011)

Eight priority areas of research focus

- Stem Cell Biology
  - Cell manipulation
  - Sources of stem cells
  - Inducible pluripotent stem cells
  - Cancer stem cells

- Tumor Relapse
  - Prevention and therapy for post-transplant relapse
  - Immunotherapy with T cells and dendritic cells
Clinical trials -

ASBMT Research Priorities (2011)

- Graft-versus-Host Disease
  - Separation of GVHD and graft-versus-tumor effects
  - Immune reconstitution and GVHD
  - Markers predicting GVHD
  - Role of regulatory T cells
- Expanded Indications for HCT
  - Solid tumors
  - Regenerative medicine
  - Autoimmune diseases
  - Response to bioterrorism
  - Radiation Accidents (RITN)
Clinical trials -

ASBMT Research Priorities (2011)

- Improving Current Use of HCT
  - Graft sources
  - Conditioning intensity
  - Cost-effectiveness

- Transplants in Older Patients
  - Biology of aging
  - Indications
  - Outcomes and quality of life
Clinical trials -

ASBMT Research Priorities (2011)

- Survivorship
  - Long-term complications
  - Longevity
  - Quality of life

- Applying New Technology to HCT
  - Genomics
  - Proteomics
  - Imaging
  - Markers of immunologic recovery
  - Pharmacogenomics
A Patient’s Words……

I believe everything was explained thoroughly and explicitly. But I don’t think that when you face a last option to be able to live that you process it. You hear, understand and acknowledge it but only when you are on the other side of transplant you allow your mind and heart to process that it basically cost everything you own. When hope reappears, you process it because then you have a value to balance it against.
STANDARDS OF PRACTICE FOR TRANSPLANT NURSING

STANDARD 1. ASSESSMENT
The transplant nurse collects comprehensive data pertinent to the patient’s health or the situation.

STANDARD 2. DIAGNOSIS
The transplant nurse analyzes the assessment data to determine the nursing diagnoses or health-related problems or needs.

STANDARD 3. OUTCOMES IDENTIFICATION
The transplant nurse identifies expected outcomes for a plan individualized to the patient or the situation.

STANDARD 4. PLANNING
The transplant nurse develops a plan that prescribes strategies and alternatives to attain expected outcomes.

STANDARD 5. IMPLEMENTATION
The transplant nurse implements the identified plan.
STANDARDS OF PRACTICE FOR TRANSPLANT NURSING

STANDARD 5A. COORDINATION OF CARE
The transplant nurse coordinates care delivery.

STANDARD 5B. HEALTH TEACHING AND HEALTH PROMOTION
The transplant nurse employs strategies to promote health and a safe environment.

STANDARD 5C. CONSULTATION
The transplant nurse coordinator or advanced practice registered nurse provides consultation to influence the plan of care, enhance the abilities of others, and effect changes.

STANDARD 5D. PRESCRIPTIVE AUTHORITY AND TREATMENT
The advanced practice registered nurse uses prescriptive authority, procedures, referrals, treatments, and therapies in accordance with state and national laws and regulations.

STANDARD 6. EVALUATION
The transplant nurse evaluates progress towards attainment of outcomes.
STANDARDS OF PROFESSIONAL PERFORMANCE FOR TRANSPLANT NURSING

STANDARD 7. QUALITY OF PRACTICE
The transplant nurse systematically enhances the quality and effectiveness of nursing practice.

STANDARD 8. EDUCATION
The transplant nurse attains knowledge and competency that reflects current nursing practice.

STANDARD 9. PROFESSIONAL PRACTICE EVALUATION
The transplant nurse evaluates one’s own nursing practice in relation to professional practice standards and guidelines, relevant statutes, rules, and regulations.

STANDARD 10. COLLEGIALITY
The transplant nurse interacts with, and contributes to the professional development of, peers, colleagues, and others.
STANDARDS OF PROFESSIONAL PERFORMANCE FOR TRANSPLANT NURSING

STANDARD 11. COLLABORATION
The transplant nurse collaborates with patients, the family, and others in the conduct of nursing practice.

STANDARD 12. ETHICS
The transplant nurse integrates ethical provisions into all areas of practice.

STANDARD 13. RESEARCH
The transplant nurse integrates research findings into practice.

STANDARD 14. RESOURCE UTILIZATION
The transplant nurse considers factors related to safety, effectiveness, cost, and impact on practice in the planning and delivery of nursing services.

STANDARD 15. LEADERSHIP
The transplant nurse provides leadership in the professional practice setting and the profession.

Transplant Recipients in the US, by Transplant and Donor Type

- Autologous
- HLA-identical Sib
- Other relative
- URD+UCB

* 2013 Data incomplete
Accreditation standards

• FACT – Foundation for the Accreditation of Cellular Therapy
  – Founded in 1996
  – **FACT Common Standards for Cellular Therapies**
    • Clinical program
    • Collection standards
    • Processing facility standards
• C.W. Bill Young Cell Transplantation Program (US Department of Health and Human Services)
  – Stem Cell Transplant Outcomes Database
    • TED – Transplant Essential Data
• Nursing / program requirements
Continuous quality improvement

• Designated program director
• Accredited organizations
  – BMT Quality Plan / Quality Management
  – BMT Quality Committee
    • Ongoing continuous quality improvement projects
  – HCT Standard operating procedures (SOPs)
• Care continuum / care coordination
  – Inpatient / Outpatient
  – ICU
  – Multidisciplinary team / consultants (clinical pharmacy, infectious disease, pulmonary, cardiology, renal, radiology, laboratory, nutrition, social services, psychiatry, rehabilitation, spiritual care, others)
Continuous quality improvement

- Patient and Caregiver education
- Caregiver burden and needs
- Cost of delivering quality HCT care
Top Patient Barriers to Transplant

- Language: 5% (Third), 2% (Second), 3% (First)
- Comorbidity: 77% (Third), 22% (Second), 3% (First)
- Housing: 17% (Third), 9% (Second), 7% (First)
- Psychosocial: 36% (Third), 20% (Second), 23% (First)
- Geography: 18% (Third), 9% (Second), 8% (First)
- Caregivers: 52% (Third), 26% (Second), 12% (First)
- Insurance: 89% (Third), 29% (Second), 57% (First)
Top barriers to program growth

- Lack of patients: 17% (Third), 7% (Second), 3% (First)
- Lack of providers: 57% (Third), 25% (Second), 23% (First)
- Lack of space: 76% (Third), 28% (Second), 20% (First)
- Reimbursement issues: 9% (Third), 21% (Second), 28% (First)
- Internal competition: 29% (Third), 10% (Second), 9% (First)
- External competition: 47% (Third), 11% (Second), 11% (First)
- Lack of capital for expansion: 33% (Third), 23% (Second), 12% (First)
Top staffing needs

- Physicians: 29% (First), 25% (Second)
- Advanced Practice Professionals: 25% (First), 21% (Second)
- Nurses: 19% (First), 22% (Second)
- Other (pharmacy, lab personnel, data managers, BMT administrators): 26% (First), 31% (Second)
Professional boundaries

HCT is long, multi-episodic process
  – Of course, RN is going to bond with patients and families
  – Follow-ups – HCT reunion
Appropriate to maintain friendship with patients / families?
  – Think carefully, decide carefully

• Pictures / social media
• Face book, Instagram
Crossing Professional Boundaries

… and becoming deeply and personally involved with the child and family … was particularly salient for nurses. Crossing the boundary was described as “becoming over involved,” “not being objective,” and “wearing their hearts on their sleeves.”

Participants indicated this phenomenon made it difficult for nurses to give palliative care to children and families and took a personal toll on them. It also caused professional strife and affected the quality of care. One person summed it up as follows:

… nurses are chastised when they take it all too personal. And it makes it difficult and professional boundaries get crossed time and time again. And it's not good practice in terms of patient care and it also takes a very high toll on the staff. And if they are going to survive in this work, they need some better skills to know how to transition into palliative care.
Compassion fatigue and moral distress

- HCT care complex, demanding, intensive, extensive training, high emotional intensity
  - Long episodes of care
  - Quality of life and suffering implications for patients / families
- Period of high vulnerability and sensitivity for patients, families, nurses
- Sabo (2011) “Compassionate Presence” - Sabo suggests potential buffering effect against adverse consequences of HCT nursing work, underscored the value of the relationship as an integral component of nursing work
Compassion fatigue and moral distress
Compassion fatigue and moral distress

Moral Distress: Definition (ANA, 2008)

“Moral distress is the pain or anguish affecting the mind, body or relationships in response to a situation in which the person is:

– aware of a moral problem,
– acknowledges moral responsibility, and
– makes a moral judgment about the correct action yet, as a result of real or perceived constraints, participates in perceived moral wrongdoing.”
Compassion fatigue and moral distress

Moral Distress can be caused by internal or external barriers. When we act in a manner contrary to personal & professional values undermines the individual’s integrity & authenticity. Moral Distress can affect the whole person physically, emotionally, behaviorally and spiritually. Feelings labeled as stress, burnout, emotional exhaustion, and job dissatisfaction may actually be symptomatic of moral distress. These symptoms may be the reason given by nurses for leaving a specific work environment or even for departure from the nursing profession (Elpern et al., 2005).
Compassion fatigue and moral distress

Moral Residue: Definition

• “is that which each of us carries with us from those times in our lives when in the face of moral distress we have seriously compromised ourselves or allowed ourselves to be compromised” (Webster and Baylis, 2000)
Compassion fatigue and moral distress

Moral distress can develop:

- **Dueling expectations.** Role conflict has been characterized as a type of stress that occurs when management has conflicting expectations of an organizational position (Corley et al., 2001),

- **Differences between physicians and nurses.** Conflicting expectations and perceived powerlessness are concepts further illustrated by a study comparing the ethical thinking of physicians and nurses; surprising underlying similarities were found (Oberle & Hughes, 2001).

- **Critical care vs. futile care** "the frequency with which critical care nurses encountered moral distress situations involving futile care was directly and significantly related to the experience of emotional exhaustion" (Meltzer & Huckabay, 2004, p. 205). The experience of moral distress may be the result of nurses' own expert clinical judgment, permitting them early recognition of the futility of providing further care in some situations (Hanna, 2004).
Chemotherapy and biotherapy competence

ONS Core Competencies for the generalist RN

- Demonstrates safe administration and management of chemotherapy and biotherapy agents.
- Demonstrates knowledge and utilization of protective measures for the immunocompromised patient.
- Demonstrates appropriate care and maintenance of venous access devices used in the oncology patient population.
- Provides education appropriate to the needs of the patient and caregivers.

2013 Updated American Society of Clinical Oncology/Oncology Nursing Society Chemotherapy Administration Safety Standards Including Standards for the Safe Administration and Management of Oral Chemotherapy

https://www.ons.org/sites/default/files/2013chemostandards.pdf
Evidence based reflects/includes all sources of evidence from expert opinion to meta-analyses. It means integrating individual clinical expertise with the best available external clinical evidence from systematic research.” (Sackett D, 1996) EBP is the integration of clinical expertise, patient values, and the best research evidence into the decision making process for patient care.
Sources of data for evidence-based practice

- Oncology Nursing Society (ONF, CJON, PEP [Putting Evidence Into Practice] resources, BMT Special Interest Group)
- American Society of Clinical Oncology (JCO)
- American Society of Hematology (BBMT)
- American Society for Blood and Marrow Transplantation
- Blood and Marrow Transplant Information Network (BMTInfoNet)
- BMT Clinical Trials Network
- Center for International Blood and Marrow Transplant Registry (CIBMTR)
- C.W. Bill Young Cell Transplantation Program bloodcell.transplant.hrsa.gov
- European Group for Blood and Marrow Transplantation
- Foundation for the Accreditation of Cellular Therapy
- International NetCord Foundation
- International Society for Cellular Therapy
- National Marrow Donor Program / Be the Match
- National Comprehensive Cancer Network Clinical Practice Guidelines (www.nccn.org)
- National Guidelines Clearinghouse (www.guideline.gov)