



## Moral/Ethical Issues Inherent in Transplant Nursing

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*Joyce Neumann RN, MS, AOCN  
Program Director, BMT  
Adjuvant Ethicist*

THE UNIVERSITY OF TEXAS  
MD ANDERSON  
CANCER CENTER

## Learning Objectives

- At the conclusion of this session, attendees will be able to:
  - Describe the process for handling an ethical dilemma from one of the case studies presented.
  - List interventions that can be used in your own institution to deal with a moral issue in patient care.

## Ethical Consideration

- Deontological Ethics: an act is right if it is in accord with some law or principle
  - Beneficence:** to help or benefit
  - Non-maleficence:** do no harm
  - Justice:** fairness giving every individual their due
- Other ethical considerations
  - Autonomy:** 1990 Patient Self-Determination Act; US Supreme Court- liberty to refuse unwanted treatment
  - Benefit vs. Burden:** action present greater benefit than burden
  - Feminist ethics of care:** relationship, vulnerability, experience (Jonsen, Siegler, & Winslade, 2002)

## Ethical Considerations (continued)

Relationship between Clinician and Patient: clinician has a fiduciary responsibility to care for sick

Professional integrity of clinicians: no responsibility to provide treatment not indicated

Issues of Community, Cultural and/or Religious Variation

## When to offer HSCT as Treatment Option (Ethical consideration)

- Disease status/Eligibility criteria – non-myeloablative transplantation (Do no harm-Non-maleficence)
- Limits – 5%? 10%? 20%? cure or control of disease? (Justice vs good stewards of limited resources)
- Psychiatric disorder/coping style (Benefit vs Burden, autonomous decision) Depression has been studied (Prieto, Atala, Blanch, et al. 2005, JCO)

## Who should be offered transplantation? (Foster, McLellan, Rybicki, Tyler, & Bolwell (2009) Ethical reasoning about pt. eligibility in allogeneic BMT based on psychosocial criteria. BMT 44, 607-612).

| Case- responses= do NOT proceed        | Ethicist (n=22) | Nurse (n=260) | MD (n=250) | SW (n=60) | P value |
|--|-----------------|---------------|------------|-----------|---------|
| Current suicidal ideations             | 82%             | 85%           | 89%        | 85%       | 0.45    |
| Current use of addictive/illicit drugs | 86%             | 80%           | 82%        | 84%       | 0.80    |
| History of non-compliance              | 68%             | 83%           | 79%        | 75%       | 0.20    |
| Living far away, no caregiver          | 64%             | 67%           | 71%        | 68%       | 0.71    |
| Patient told he is alcoholic           | 64%             | 66%           | 65%        | 60%       | 0.87    |
| Mild dementia (early Alzheimer's)      | 27.3%           | 68%           | 63.5%      | 52%       | <0.001  |



## Self-Care as a Patient in the Stem Cell Transplantation and Cellular Therapy Program

This information describes how you and your health care team will contribute to your care while you are in the Stem Cell Transplantation and Cellular Therapy program. Please read this information carefully and ask a member of your health care team if there is anything you do not understand. You will be asked to sign a patient acknowledgement form, once you understand your role in your care. The signed form will be kept with your medical record and you will receive a copy.

The Stem Cell Transplantation and Cellular Therapy Center approaches your care as a team. You and your caregiver are important members of this team, just like your doctors, nurses, pharmacists and other health care professionals. You will do better physically and emotionally when you take an active role in your treatment and recovery. It is very important that you be involved in your care at the hospital and when you are discharged.

It is important that you remain as active as possible, even if you feel very tired. The more independent you are the better you may feel. If you are unable to do certain self-care activities, your doctors and nurses will make sure that you have someone to help you.

### Self-Care Activities

Your nurse or doctor will explain your self-care activities in detail. It is important for you to participate in these activities as much as possible.

If you are an **inpatient**, your self-care activities will include:

## Role of the Caregiver in the Stem Cell Transplantation and Cellular Therapy Program

A Stem Cell Transplant (SCT) caregiver provides essential physical and emotional support to the patient. Caregivers assist patients in their recovery, ensure that they come to the hospital for appointments or emergencies, make sure they eat, drink, sleep, and take their medications as instructed, and help them remain safe during recovery.

This information describes how you will contribute to the care of your patient while they are in the Stem Cell Transplant and Cellular Therapy program. Please read this information carefully and ask a member of the patient's health care team if there is anything you do not understand. You will be asked to sign a caregiver acknowledgement form, once you understand your role as a caregiver. The signed form will be kept with the patient's medical record and you will receive a copy.

Various members of the health care team will work with you and educate you about your role during inpatient and outpatient care. If you are employed, you will need to take time off from work. Some caregivers use vacation time from work, while others take leave under the FMLA.

## Patient Education



### Patient and Caregiver Acknowledgement Form

The form contains sections for Patient Acknowledgement and Caregiver Acknowledgement, each with a signature line and a date field. It includes detailed instructions for patients and caregivers regarding their roles in the Stem Cell Transplantation and Cellular Therapy program.

## Advanced Care Planning

- Have the “what if” talk before treatment starts.....
- How to have the talk and stay hopeful?
- Encourage completion of Advance directive (Living will/loving will, medical power of attorney, out of hospital DNR) then we need to read what they say

## Patient Education



### Advanced Care Planning before Your Stem Cell Transplantation

Preparing for cancer treatment can be a difficult and confusing time. Our main goal with stem cell transplant treatment is to cure or control your disease as much as possible. As a transplant patient, it is especially important that you plan for your time here at MD Anderson Cancer Center as well as after your treatment. Doing advanced care planning ahead of time will help you and your caregiver(s) as you go through your treatment experience.

#### Advance Directives

Advance directives (living wills, medical power of attorney) should be completed by all of us, whether we have cancer or not. These forms are important legal documents that will help your family know and communicate your wishes or make health care decisions in case something unexpected happens to you. Although it is difficult and sometimes scary to think about situations or problems that could happen, it is important to become knowledgeable about your medical treatment before you need such care. Remember, **talking or thinking about it does not mean it is going to happen**. Advance directives are available through the Department of Social Work.

## Advanced Directives: SCT Inpatients

|   | 7/03 (100 pt) | 7/09(50 pt) | 8/11 (64 pt) |
|---|---------------|-------------|--------------|
| Have AD   | 39%           | 42%         | 50%          |
| Copy at time of admission   | 30%           | 32%         | 35%          |
| Copy in chart (hard copy or scanned)                              | 15%           | 32%         | 35%          |
| Both LW and MPA   | 19%           | 34%         | 21%          |
| Requesting continued treatment-terminal or irreversible condition | 1%            | 1%          | 1%           |

## When is enough, enough? What does our experience tell us?

- When should we start the conversation?
- CPR/ICU for SCT pt with refractory (no response after 28 days of treatment) grade IV GVHD?
- SCT patient to ICU for invasive monitoring and mechanical ventilation with progressive fungal pneumonia after 2 weeks of max. antifungal therapy?
- Maintain patients in ICU on mechanical ventilation and hemodialysis? (strongest predictor of death at 1 year but not 100%)

Price, Thall, Kish, et al. *American Journal Respir Critical Care Med*, (1998); Huaranga, Leyva, Giralt, et al. *Critical Care Med* (2000); Scales, Thiruchelvam, Kiss, et al., (2008) *Critical Care*; Levine, Logan, Wu, et al. CTN (2010) *BBMT*

## End of life - Burden outweighs Benefit for patient/family

- Palliative care from beginning of transplant process
- DNR ....medical order (some states pt/surrogate signs) AND\*
- Not “what do you want us to do?” .....”what can you tell us about values, beliefs, wishes that will help us make the best (not right) decision?”.....

\*Venneman, Narnor-Harris, Perish, Hamilton (2008). Allow natural death vs. do not resuscitate three words that can change a life. *Journal of Medical Ethics*, 34:2-6.

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## Moral Distress HCP

- Painful feelings or state of psychological disequilibrium that results from **recognizing the ethically appropriate action, yet not taking it**, because of such obstacles as lack of time, supervisory reluctance, an inhibiting medical power structure, institutional policies or legal considerations (Corley, *Nursing Ethics*, 1995; Erlan & Sereika, 1997; Livingston & Livingston, 1984; Sorlie, et al. 2005)

## End of life - HCP/Medically appropriate care

- Moral distress and compassion fatigue experienced by 60% nurses on our (NMDP) surveys. Also found to be experienced by oncology nurses (Corley, 1995)
- Rated very high importance (2.54, 0-3 scale) content included for ONS/ONCC HSCT certification
- Major potential for impacting recruitment and retention not just nurses but all disciplines

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## Additional Potential Solutions

- Institutional policy anyone can call ethics consult, available by page 24 hours/day
- Ethicist available for informal consult/advice or formal consult (ethicist at care conference, team or committee)
- Consider interdisciplinary (Swartz) rounds/Monthly Nursing Ethics rounds on the HSCT unit

## Ethics consult: recommendation

Formulate advisory recommendations

- Help the patient or surrogate decision-makers in cooperation with the experienced recommendations of the healthcare team and assessment of the medically appropriate options is best for that patient given the current prognosis and in light of that person's/family's values.