Moral/Ethical Issues Inherent in Transplant Nursing

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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

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? (Source: McLellan, Hybrook, 
Jen, & Brown [2006] Ethical reasoning about, eligibility in allogeneic BMT based on psychosocial criteria. BMT 44, 617-622.)

<table>
<thead>
<tr>
<th>Case responses</th>
<th>do NOT proceed</th>
<th>Ethicist (n=22)</th>
<th>Nurse (n=260)</th>
<th>MD (n=250)</th>
<th>SW (n=60)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current suicidal ideations</td>
<td>82%</td>
<td>85%</td>
<td>89%</td>
<td>85%</td>
<td>0.45</td>
<td></td>
</tr>
<tr>
<td>Current use of addictive/licit drugs</td>
<td>80%</td>
<td>80%</td>
<td>82%</td>
<td>84%</td>
<td>0.80</td>
<td></td>
</tr>
<tr>
<td>History of non-compliance</td>
<td>68%</td>
<td>83%</td>
<td>79%</td>
<td>75%</td>
<td>0.20</td>
<td></td>
</tr>
<tr>
<td>Living far away, no caregiver</td>
<td>64%</td>
<td>67%</td>
<td>71%</td>
<td>68%</td>
<td>0.71</td>
<td></td>
</tr>
<tr>
<td>Patient told he is alcoholic</td>
<td>64%</td>
<td>66%</td>
<td>65%</td>
<td>60%</td>
<td>0.87</td>
<td></td>
</tr>
<tr>
<td>Mild dementia (early Alzheimer’s)</td>
<td>27.3%</td>
<td>68%</td>
<td>65.5%</td>
<td>52%</td>
<td>&lt;0.001</td>
<td></td>
</tr>
</tbody>
</table>
Other considerations - Justice

- Religious/spiritual - Jehovah’s Witness – (Kerridge, 1997; Mazzi, 2000)
- Age/comorbidity
- Time from diagnosis to transplant – delay in ethnic minority groups
- Cultural
- Informed consent – does patient really understand?

Donor Issues

- Donor risks
- When donor is child – policy to protect donor
- Confidentiality – for donor and recipient
- Cord blood – saving cord for own use later

Interdisciplinary Goal Differences

- Research/cutting edge-nature of treatment
- Privileged information from patient-what is the patient’s understanding of the study?
  - Therapeutic misconception – phase 1
- Futility of care – research yes but at what expense? Benefit vs. burden
- Communication with medical team - authority gradient
- Patient outcomes and impact on morale/moral distress/compassion fatigue

Disparities Between Patient and Physician Estimates of Success of BMT

- Prospective cohort study 313 BMT patients and physicians
  - Examined pt/MD estimates of
    - Treatment-related mortality (TRM)
    - cure with/without BMT
    - disease free survival
  - Results: both groups accurate when TRM <30%, but with higher TRM (i.e. allo) patients remained optimistic
  - Patients with advanced disease fail to recognize higher risks associated with their situations.


Methods to address issues before treatment begins

- Promote environment that allows for team members to question/share concern
- Organize care conference – outpt/inpt care team, patient/caregiver, ethicist, AYA, pt. advocate
- Care agreement/caregiver agreement, individualized agreement/contract as needed
- Ethics consult – provide documented recommendations
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
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%)


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?“

* Vemmeman, Narnor-Harris, Perish, Hamilton (2008). Allow natural death vs. do not resuscitate three words that can change a life.

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

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.