HSCT in 2020
System Capacity Initiative

Ethical Issues Inherent in HSCT

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Learning Objectives

- At the conclusion of this session, attendees will be able to:
  - Describe the ethical dilemmas associated with HSCT therapy.
  - Identify initiatives that will contribute to future concepts, methods, technology, treatment, and services that drive the field of HSCT.

Case 1

- Peter, a 23 y/o from city 150 miles away was seen by SCT center for treatment of his leukemia.
- After meeting the eligible criteria an admission date was set, he returned home until admission date.
- He was admitted and started chemo.

Case 1

- Four days later after his preparative chemo was given, he was irritable during rounds and said he wanted to be discharged.
- As the day progressed he became increasingly agitated and repeatedly requested to leave.
- Nurses were having difficulty time keeping from going off unit, started biting through his IV tubing when the nurses would not disconnect the IV.
- Medical team was called……and the medical team called psych, BMT Director.

Case 2

- Mary comes by herself to clinic to see HSCT physician for discussion about an aggressive new protocol.
- She has missed many appointments in the past or not had transportation to come to the hospital.
- Mary's leukemia has been refractory to treatment.
- She asks you what you think…

Ethical Considerations

- 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 thinking
  - Autonomy: 1990 Patient Self-Determination Act; US Supreme Court-liberty to refuse unwanted treatment
  - Benefit vs. Burden: action presents 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-DNH)
- 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

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

Discrepancies Between Patient and Physician Estimates of Success of BMT

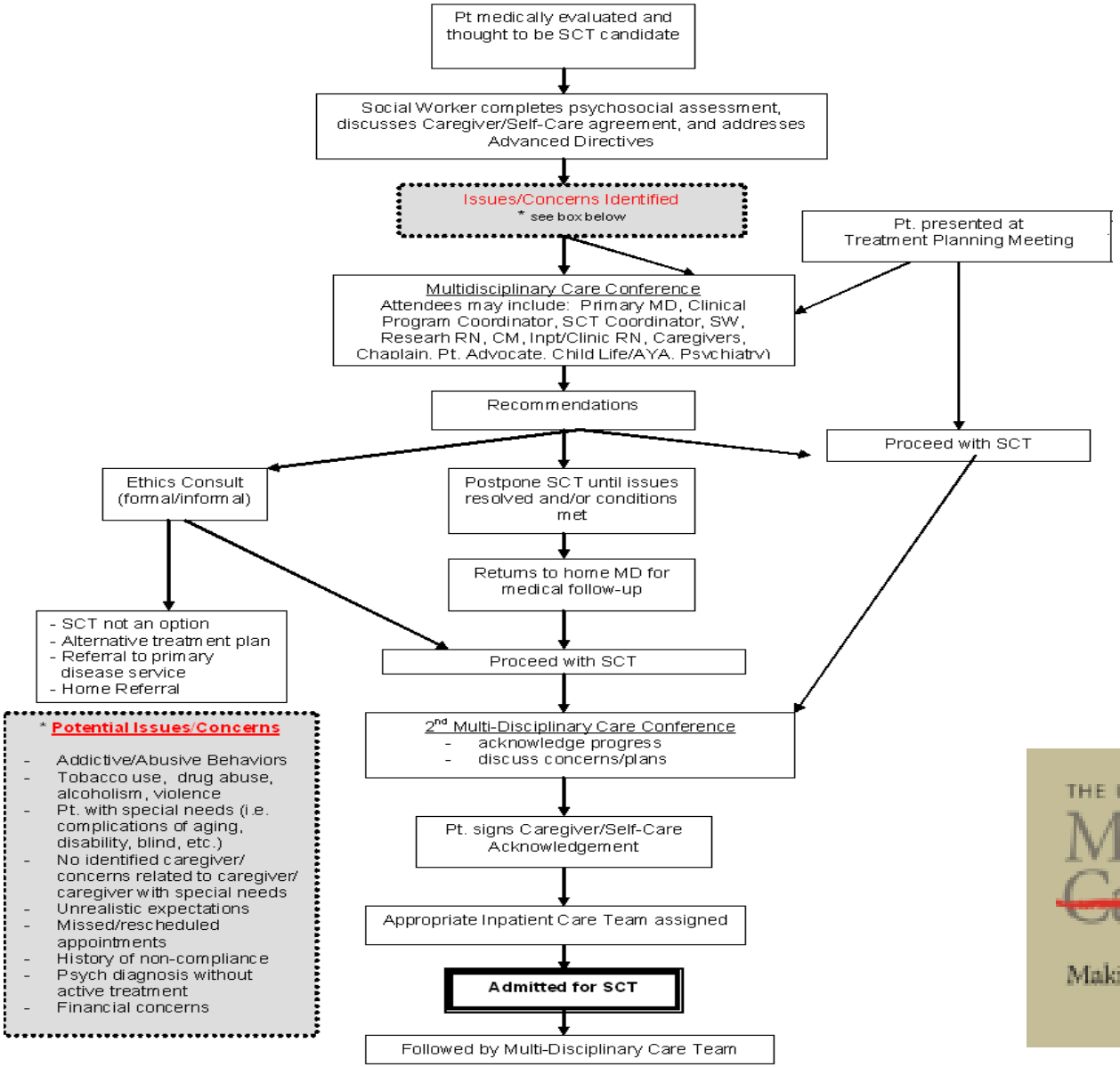
- Prospective cohort study 313 BMT patients and physicians
- Examined pt/MD estimates of
  - Treatment-related mortality (TRM)
  - cure with/without BMT
  - disease free survival
- Results: both groups accurate when TRM <30%, but with higher TRM (i.e. allo) patients remained optimistic
- Patients with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

Lee, S., Fairclough, D., Antin, J. & Weeks, J. (2001). *JAMA,* 285(8),1034-1038.

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 – recommendation

Special Needs Algorithm for SCT Patients



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Advance 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), read them
- "Advance Care Planning prior to your transplant" - MDACC, 2010

Advance Directives: HSCT 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%

Case 3a: The Patient and the do not resuscitate (DNR) order

- This 55 year old very thin patient 2 months after SCT with GVHD who has not responded to third line GVHD treatment started last week. He receives 4 units of PRBC on admission and platelets.
- You think it is time for the medical team to talk to him about DNR and hospice, but the family has told you that they want everything done, even sending him to the ICU unit.

Case 3b: The Patient and the DNR order

- In a quiet moment when you are hanging a IV medication and the family is not in the room, the patient asks you to give him something that will end his life because he cannot take any more suffering.
- The team has written for narcotic pain medication with titration orders as needed.

Case 4a: Patient intubated on the venilator

- This 32 year old patient post chemo for CML, who had pulmonary bleeding and fungal pneumonia. He has been on the ventilator for 3 weeks and now in renal failure on dialysis.
- The chest x-ray shows no improvement and the patient is getting platelets 1-2 times/day depending on the blood supply (there has been a shortage of blood products).

Case 4b: Patient intubated on the venilator

- The team wants to stop treatment and turn off the ventilator, but the wife says that would be would be like her putting a gun to his head and she could never do that. What are you going to do?

Case 4c: Intubated patient

- The copy of the advance directive in the chart indicates that the brother has durable power of attorney for medical decisions and that the patient wanted everything, even if he was in an irreversible condition.
- Now what?

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?
- HSCT patient to ICU for invasive monitoring and mechanical ventilation with progressive fungal pneumonia after 2 weeks of maximal 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); Huaringa, 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?"…

*Vemmeman, 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.

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 SCI surveys – also experienced by oncology nurses (Corley)
- 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

Questions or Comments

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