

# Methods to Address Moral Distress Experienced by Stem Cell Transplantation Nurses and Build Resiliency

MDAnderson Cancer Center

Making Cancer History®

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## Background

- **Strong relationship** between a patient with life threatening illness and health professionals (Kovács, Kovács, Hegedus, 2010).
- Demand for health professionals to be competent in both the rendering of care, the provision of emotional comfort and moral obligation to advocacy for their well being.
   These demands may lead physical and mental exhaustion, with negative work-related results (Demirci, Yildirim, Ozsaran, Uslu, Yalman, Aras, 2010).
- Life and work events may erode work engagement, professionalism and ultimately influence quality of care (Shanafelt, Boone, Tan, et al. 2014).

### Moral Distress(1)

Painful feeling or state of psychological disequilibrium that results from recognizing the ethically appropriate action, yet not taking it because of constraints: lack of time, supervisory reluctance, an inhibiting medical power structure, institutional policies or legal consideration (Corley 1995, Erlen & Sereika, 1997; Livingston & Livingston, 1984; Sorlie et al. 2005; Epstein, 2014). First described by Jameson in 1984.

### Moral distress (2)

- Exposure to patient suffering and deaths, despite improved outcomes and faced with challenges of recognizing the ethically appropriate action undertaking.
- Ethical issues may be present across the transplantation continuum

Who do we offer treatment to (do no harm)?

How do we prepare (veracity)?

What do we do when bad things happen (autonomy)?

Transitioning to end of life care (do no harm)?

### Moral distress (3)

Unresolved ethical conflicts and moral distress lessen job satisfaction and cause burnout.

Varies among professional, may result in the following:

- Numbing of moral sensitivity and withdrawal from involvement in challenging patient situations;
- Conscientious objection by voicing opinions, refusing to care for a patient on artificial life-support when perceived as having no chance for meaningful recovery
- Demonstration of the effects of burnout and leave the job or even the profession;

Houston, Casanova, Leveille, et al., 2013; Allen, Judkins-Cohn, deVelasco, et al. 2013; Lazzarin, Biondi, Di Mauro, 2012.

### Factors contributing to MD (4)

- Unrealistic expectations (patient/ family/provider) what we CAN do vs. what we SHOULD do.
- Not telling the patient/family likely outcome denying them opportunity to decide how they will spent the rest of their life, however long.
- Not having a voice to share observation and concern.
- Not understanding and accepting each others perspective



## Impact on Healthcare Providers / Patients

- Need for HCT provider increase becoming more complex
- Projected shortage of health professionals will greatly impact capacity to meet the need for patients
- Needs assessments conducted identified challenges in recruitment/retention including:
  - Burnout = medical errors, loss of professionalism, reduced hours/turnover
  - Moral distress =  $\downarrow$  moral sensitivity and withdrawal from ethically challenging situations; leaving the job/profession

#### ARTICLE IN PRESS

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#### Biology of Blood and Marrow Transplantation



journal homepage: www.bbmt.org

Burnout, Moral Distress, Work–Life Balance, and Career Satisfaction among Hematopoietic Cell Transplantation Professionals

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#### ABSTRACT

A projected shortage of hematopoietic cell transplantation (HCT) health professionals was identified as a major issue during the National Matrow Donor Program/Be The Match System Capacity Initiative. Worle-related distress and world-life balance were noted to be potential battiets to recruitment/retention. This study examined these barriers and their association with career satisfaction across HCT disciplines. A cross-sectional, 90item, web-based survey was administered to advanced practice providers, nurses, physicians, pharmacists, and social workers in 2015. Participants were recruited from membership lists of 6 professional groups. Burnout (measured with the Maslach Burnout Inventory subscales of emotional exhaustion and depersonalization) and moral discress (measured by Moral Discress Scale-Revised) were examined to identify work-related distress. Additional questions addressed demographics, world-life balance, and career satisfaction. Of 5759 HCT providers who received an individualized invitation to participate, 914 (16%) responded; 627 additional partici pants responded to an open link survey. Significant differences in demographic and practice characteristics existed across disciplines (P < .05). The prevalence of burnout differed across disciplines (P < .05) with an overall prevalence of 40%. Over one-half of pharmacists had burnout, whereas social workers had the lowest prevalence at less than one-third. Moral distress scores ranged from 0 to 336 and varied by discipline (P < DS); pharmacists had the highest mean score (62.9  $\pm$  34.8) and social workers the lowest (42.7  $\pm$  24.4). In multivariate and univariate analyses, variables contributing to burnout varied by discipline; however, moral dist tess was a significant contributing factor for all providers. Those with butmout were more likely to report inadequate world-life balance and a low level of career satisfaction; however, overall there was a high level

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#### **Predictors of EE, DP and BURNOUT for Nursing Participants**

All factors were statistical significant (P≤ 0.05) ↑indicates positive correlation, ↓indicates negative correlation

EE	
Work environment	Work setting: inpt ↓ Pt pop: both pedi/adult ↓ Program size: w > 150 allo ↑ Hrs work/wk: 51-60 ↑ Hours/week on research > 10 hrs: ↑ Hrs spend CE/certification > 10hrs.: ↓ No personal factors
DP	
Working environment	Hrs/wk on research: > 10 个
	Program size: w >150 auto HCT ↓ Program size: w >51 allo ↑; >150 ↑
Personal factor	Age: > age 40 years ↓ - progressively < as age increases/decade
Burnout – 38%	Multivariate logistic regression
Working environment	Nights on call: 1-5 nights on call ↑  Work setting: inpt. ↓  HCT vol.: 51-150; >150 ↑
Moral distress - 37% high 2 <sup>nd</sup> highest mean score ;	Hrs. work/wk: 51-60 hrs 个
widest range of scores	↑ by 2% for every 1 point increase on MDS-R

## Most frequently occurring MDS-R items by discipline

Questions from MDS-R – bolded items greater than 75% respondents		Frequency – rank order				
experienced situation (question number)		RN	MD/ DO	APP	Pharm	SW
Witness healthcare providers giving "false hope" to a patient or family (2)	85	3	3	4	4	2
Follow the family's wishes to continue life support even though I believe it is not in the best interest of the patient (3)	87	2	1	1	4	3
Initiate extensive life-saving actions when I think they only prolong death (4)	80	4	5	4	4	7
Carry out the physician's orders for what I consider to be unnecessary tests and treatments (6)	76	5		3	1	
Work with nurses or other healthcare providers who are not as competent as the patient care requires1 (17)	72	7	7	7	7	
Witness diminished patient care quality due to poor team communication (18)	88	1	2	2	2	1
Watch patient care suffer because of a lack of provider continuity (20)	80	6	4	6	3	4

## Nursing Ethics at MDACC

#### Background:

Ethical dilemmas are inherent in oncology nursing practice due to the complexity of care, patient/family expectations, and the treatment direction provided by the healthcare team

Created standing Ethics PACT (September 2012) in Nursing Practice Congress

Plan: Survey

Computer Based Training (CBT)

Train the Trainer

Implement Unit Based Nursing Ethics Rounds

Re-survey

## Survey

- Completed summer 2015
- 8.5% response rate (n=316)
- 75% of respondents aware of resources
- 68% able to identify and manage difficult ethical situations
- 40 commented feeling uncomfortable initiating ethics consult

## Confident in ability to identify and discuss (32% responded no)

- Uncomfortable MD pushing for chemo or refusing to talk end of life discussion
- Don't feel equipped/training/inexperienced
- Don't know who to call
- Conversation with medical team difficult, negative response from MD, retaliations (X3), MD ignore requests
- Don't agree with MD decision to make the patient happy
- I don't have all facts, on the fringe

## Confident in ability to identify and discuss (32% responded no)

- Lack of support from management/clinic team
- Too much emotion involved
- Does not occur
- Swept aside by the providers/got shot down when brought up
- Hard to know right thing to do
- Cultural difference make it difficult

## Reasons Identified For Discomfort With Ethics Consult (40 comments)

- Overstep boundaries, MD makes decision, policy here who calls consult
- Retribution, new fear of getting in trouble/losing job, may cause issues in my office
- Ethics committee not effective
- Not sure I know the whole story
- Don't know how to call one, never had done one, not familiar with ethics consult

## Ethical dilemma most frequently identified

#### **Goals of care:**

 aggressive treatment in elderly, futility, transfer to ICU end of life establish DNR, code status MD gives false reassurance more treatment available,

patient may not want further trx/medical team (or family) wants to continue,

idea is to give the patient treatment and get the patient out (unmet needs)

Need for better explanation of protocols, treating MD pushing research nurse to put on protocol, treating patients with a lot of co-morbid condition, what is best for research NOT what is best for patient

International patients
Conflict of interests

## Next Steps

- Most nurses where aware of resources and felt comfortable using those resources, younger nurses used discussion with colleague
- Opportunities for increasing education and establishing forums for discussion
  - Computer based training (CBT) in education center now will be required post EPIC
  - Ethics rounds on other units: train the trainer X1, first unit to go live next month
  - Resurvey in 2 year planned

## **Computer Based Training**

- Mandatory content
- Interactive
- Released summer 2016
- 93% compliance (total 2700 RNs)
- Added to nursing orientation
- Promoted to other groups APPs, Research Nurses

#### **Ethical Principles**

### for Nursing practice



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NEXT

#### **Nursing Professional Practice Model**



#### **Ethics of Nursing Practice**

Ethical issues and dilemmas are inherent in care provided to patients and their families across the life span and especially at the end of life.



Professional codes and standards serve to assist in the resolution of ethical dilemmas.

Nurses, individually and collectively, are responsible to serve as advocates for the resolution of ethical issues.









## Quarterly Nursing Ethics Rounds

- Multiple Train the Trainer sessions offered
- Monthly PACT meetings started 2016
- Tool kit distributed
- Collaborated with Nursing Education
  - Plan
  - Advertise
  - Offer CEU

## **Topics for Discussion**

- Professional nursing code of ethics Ethical terms and theories (ANA handout)
- Advanced Directives patient's self-determination act (PSDA) nursing role
- Shared decision making end of life
- Do not resuscitate orders (DNR)/Allow natural death (AND)
- Communication with patients/families breaking bad news/communication sensitive information.
- Informed consent patient autonomy, therapeutic misconception
- Moral distress / Resiliency
- Professional Caregiver Fatigue (also known as compassion fatigue)
- Withholding and withdrawal of life sustaining treatment
- Social media and ethical issues
- Use of palliative care cultural perspective
- Care for high risk vulnerable people children, prisoner, international patients.
- Balancing truth-telling (veracity) and preservation of hope

#### Goal

Provide nurses with a forum for discussion of difficult/challenging patient situations (23 practice areas – inpatient / outpatient; over 65 offerings)

Increase knowledge base/use of supportive institutional resources

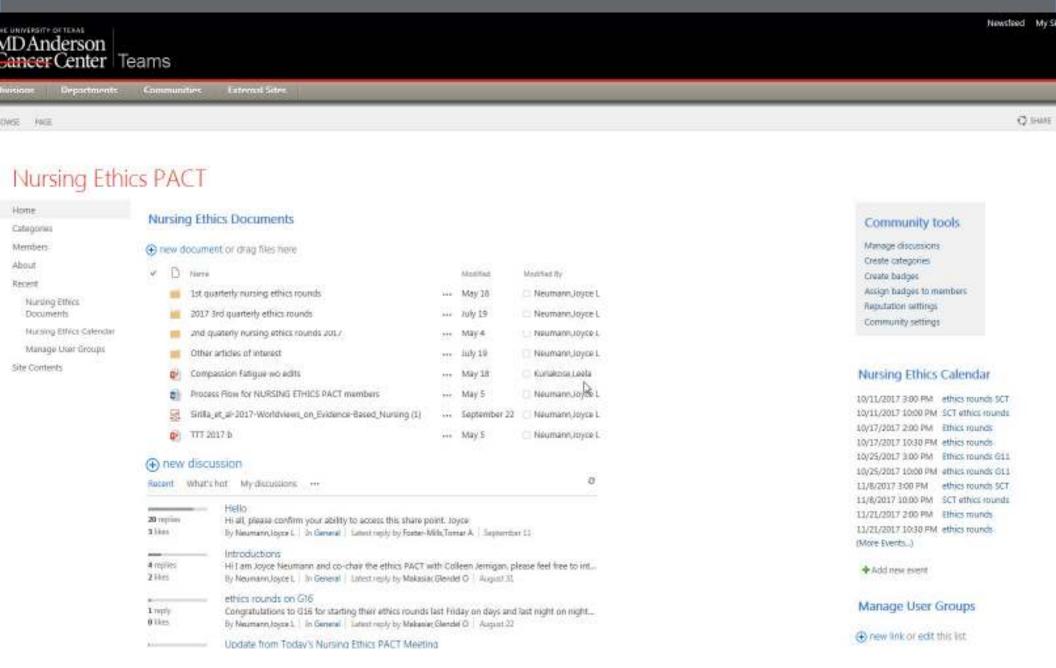
Enhance unit based skill regarding management of ethical dilemmas

Decrease compassion fatigue/moral distress

Advance professional nursing competency

#### NURSING ETHICS PACT SHAREPOINT WEBSITE

https://myteams.mdanderson.org/cop/nursingethicspact/SitePages/Community%20Home.aspx





By Cynda Hylton Rushton, PhD, RN, FAAN

#### **Cultivating Moral Resilience**

Shifting the narrative from powerlessness to possibility.

ABSTRACT: Decades of research have documented the frequency, sources, and consequences of moral distress. However, few studies have focused on interventions designed to diminish its negative effects. The cultivation of moral resilience—the ability to respond politively to the distress and adversity caused by an ethically complex situation—is proposed as a method to transform moral distress.

Keywords: moral distress, moral resilience, nursing

oral distress occurs when "one recognizes one's moral responsibility in a situation; evaluates the various courses of action; and identifies, in accordance with one's beliefs, the morally correct decision—but is then prevented from following through." Proadly understood, moral distress is a particular form of moral suffering that reflects the anguish experienced in response to moral harms wrongs, or failures and is often accompanied by the feeling that one's integrity has been compromised.

The concept has been studied since 1984, when philosopher Andrew Jameton first proposed it to describe the distress nurses experience when institutional and systemic barriers prevent them from acting according to their own moral judgment<sup>2</sup> In 2001 Corley and colleagues developed the Moral Distress Scale (MDS)—an instrument for measuring the degree of moral distress among nurses.3 The tool has since been refined and revised, most notably in 2012 by Hamric and colleagues who reintroduced it as the MDS-R in order to measure moral distress in other health care workers (in addition to nurses) and in various settings.35 The concept continues to be studied and refined, and evidence of the prevalence of moral distress among nurses, physicians, pharmacists, and other health care workers is increasing?

Sources of moral distress in nurses include internal factors such as real or perceived power-lessness'; external factors such as inadequate resources or staffing, and insufficient administrative or organizational support, and specific clinical contexts, such as end-of-life care, \*10 critical care, "I and neonatal or pediatric care, \*10.

Despite the burgeoning interest in moral distress, controversies have persisted. \*\* \*\*Decause it has increasingly become an umbrella term used to describe a variety of moral stresses. \*\*\*P\*\* some believe the concept

should be overhauled, 14.16 whereas others have sought to further refine its definition. 17.18 Still others have suggested new conceptualizations, involving a more nuanced understanding of clinicians as moral agents acting within complex organizational contexts.

#### CONSEQUENCES OF UNIRESOLVED MORAL DISTRESS

Moral distress has been associated with negative consequences such as a motional distress—often manifested as frustration and anger—and nurse attrition. <sup>12</sup> It has also been correlated with burn out and long-term consequences such as emotional exhaustion, depers onalization, feelings of disengagement, numbness, and diminished moral sensitivity, <sup>3,9,50</sup>

Negative effects aren't limited to dinicians; patient care is also affected. As specified in the 2015 update of the Code of Ethics for Nurses with Interpretive Statements from the American Nurses Association (ANA), nurses' primary obligation is to their patients, whom they must treat with "compassion and respect for [their] inherent dignity, worth, and unique attributes."21 Unresolved moral distress can compromise nurses' ability to uphold these ethical standards if feelings of depletion or powerlessness diminish the physical and emotional energy they need to fully address patients' needs. The inability to care for patients with integrity raises the risk of burnout, which further affects the quality of patient care and the stability of the workforce; it can also lead to higher mortality rates.22 In response to clinicians' increasing feelings of exhaustion, depletion, and frustration in the workplace, the Critical Care Societies Collaborative recently released a statement calling on professional and academic health care organizations to join together to stem the rising prevalence of burnout22

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#### **Nursing Ethics Rounds**

#### 3<sup>nd</sup> Quarterly Nursing Ethics Rounds

#### August / September, 2017

#### Unit/Area Based

Article: Rushton, C.H.(2017) Cultivating Moral Resilience: Shifting the narrative from powerlessness to possibility. AIN, 117, 2, S11-S15.

#### Objectives for Discussion

- 1. Define moral resilience and factors which contribute to its occurrence.
- 2. Identify moral resilience as a method to cope with moral distress.
- 3. Identify strategies for incorporating moral resiliency into the practice of oncology nurses in different work settings.

At a Glance: Decades of research have documented the frequency, sources, and consequences of moral distress. However, few studies have focused on interventions designed to diminish its negative effects. The cultivation of moral resilience—the ability to respond positively to the distress and adversity caused by an ethically complex situation—is proposed as a method to transform moral distress.

#### Introduction

**Moral distress definition:** Moral distress occurs when "one recognizes one's moral responsibility in a situation; evaluates the various courses of action; and identifies, in accordance with one's beliefs, the morally correct decision—but is then prevented from following through." (Rushton C. Building moral resilience to neutralize moral distress. *Am Nurs Today* 2016;11(10).

**Moral distress sources:** "internal factors such as real or perceived powerlessness; external factors such as inadequate resources or staffing and insufficient administrative or organizational support; and specific clinical contexts, such as end-of-life care, critical care, and pediatric care"

**Moral resilience:** "person's capacity to sustain, restore, or *deepen* her or his "integrity in response to moral complexity, confusion, distress, or setbacks." (page S13).

#### Consequences of unresolved moral distress

Emotional distress – frustration, anger and leaving profession. Burnout with emotional exhaustion, depersonalization, feeling of disengagement, numbness, and dimished moral sensitivity.

Compromised patient safety - nurse feeling powerlessness to uphold the code of ethics for pursing practice. Upresolved moral distress can also lead to burnout which may affect quality of patient

### Key Characteristics of Moral Resilience

- Cultivating mindfulness to support focus and clarity of mind
- Learning to self-regulate to disrupt negative patterns of thinking and behaving
- Developing self-awareness and insight
- Deepening moral sensitivity
- Wisely discerning ethical challenges and principled actions
- Nurturing the willingness to take courageous action
- Discovering meaning in the midst of adversity
- Preserving one's integrity, as well as the integrity of the team, and others.

Rushton CH. Moral resilience: a capacity for navigating moral distress in critical care. *AACN Adv Crit Care* 2016; 27(1):111-9.

## Resiliency training

- Personal resilience plans
  - External activities developing problem-solving skills or engaging in work, prayer, physical exercise, play or art
  - Internal ways of thinking that lessens impact of experiences – sense of hope – sense of meaning or purpose in life- sense of value of life even if lived strenuously in adverse circumstances.
     Coping, hoping, meaning

Rushton, Bacheller, Schroeder, & Donohue, 2015. Burnout and Resilience Among Practicing in High-Intensity Setting. American Journal of Critical Care.

## Mindfulness Training

- Strategies for renewal
  - Mindfulness practices communication and self-awareness enhance spiritual well-being and improve attitude associated with patientcentered care
  - Meditation





#### A CALL TO ACTION REPORT



## PROMISING PRACTICES

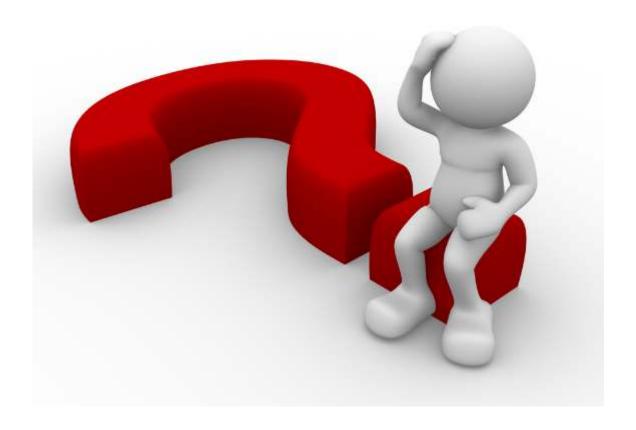
Promising Practices to Optimize Individual Moral Resilience and Organizational Responsibilities to Create a Culture of Ethical Practice

The American Nurses Association Center for Ethics and Human Rights convened a Professional Issues Panel with an Advisory Board to explore promising solutions to build individual and organizational capacities for addressing the detrimental impact of moral distress and other forms of moral suffering. 'Promising practices' does not imply endorsement, but rather acknowledges various current mediums of interventions that have not yet been studied or published in the literature. Individuals and organizations are encouraged to do their own evaluation to determine appropriateness.

#### Resource Toolkit

Media Type	Year	Title & Author(s)	Web Address	Description
Program Website	2012	University of Virginia School of Nursing Compassionate Care Initiative (CCI)	h <del>rtps://cci.nursing.virginia.edu</del>	The purpose of the CCI is to cultivate a compassionate workforce through educational programs. The vision is to have safe and high-functioning health care environments with happy and healthy professionals caring for others with heart and humanity. The program bosters resilience in the process of teaching compassion, including a public radio documentary called Resilient Nurses. University of Viriginia, 2017, School of Nursing compassionate care initiative. Retrieved from www.cci.nursing.virginia.edu
Program	2016	Johns Hopkins University School of Nursing & Johns Hopkins Hospital Mindful Ethical Practice and Resilience Academy		This six-session program focuses on building moral resilience in nurses. The goals are to 1) apply mindful practices to ethical issues in clinical practice, 2 demonstrate ethical competence by applying tools and skills to ethical issues in clinical practice, and 3) cultivate resilience in response to ethical challenges and moral suffering including moral distress. Skills in mindfulness, moral discemment and analysis, self-regulation, communication, and principled action are fostered through experiential, didactic, and high-fidelity simulation methods.
Article	2014	Clinical Residency Program for Nuises (CERN)	<b>∖</b>	The CERN was developed to strengthen moral agency and provide clinical ethics competence through didactic learning, simulation and role-play, and clinical mentorship over a nine morth period.  Robinson, E. M., Lee, S. M., Zollfrank, A., Jurchak, M., Frost, D., & Grace, P. (2014), Brhancing moral agency: clinical ethics residency formurses. Hastings Center Report, 44(5), 12-20.
Program Website	2017	George Washington University School of Nursing Professional Well-Being Initiative	https://nuising.gwu.edu/ wellness	This program of nine seminars is designed to develop knowledge and skills to help nursing students cope with stress and adversity in a healthy and proactive manner.
Program Website	2013	Lee Memorial Health Journey to Empowerment	http://www.nuisinglibrary. org/vhl	Professional development seminar designed to focus on a health care provider's individual journey to emproverment, self-efficacy, emotional intelligence, spiritual intelligence, and moral courage.  McNutty, D. M. (2015). Using the journey to empowerment professional development seminar to enhance nurses' sense of empowerment. Retrieved from http://www.nursinglibrary.org/hl/bitstream/10755/602909/1/3 McNutty_D_p69934_1.pdf
Program	2014	Mercy Health Saint Mary's/Trinity Health Tea for the Spirit		With the support of our oncology social worker and chaplain, A safe environment established for nurses to process difficult and traumatic evens though debriefing and verbalizing of feelings with others who understand the workplace environment. Tea for the Spirit is led by social work and chaplaincy as an open forum where use of reflection and self-care are discussed for maintenance of nurses' emotional health and resiliency. Nurse's report improved sleep ability, less fatigue, and greater capacity for compassion.  Antol, M. N. (1996). Healing teas: Boost your health. New York: Avery, American Association of Oftical-Care Nurses (2004). The 4As to Rise Above Moral Distress Handbook, Retrieved http://www.accn.org/Nancy.ol. Bush, D. A. (2012, Self-healing through relection: A workbook for nurses, Pittsburg: Oncology Nursing Society.

## Questions



#### Other interventions in HCT

- Proactively discuss issues before treatment begins, psychosocial as well as medical
- Appropriate co-morbidity evaluation before treatment and record baseline
- Pre-hab (enhanced recovery) program for vulnerable
- Multidisciplinary care conferences with specific care agreements as indicated
- Disseminate what we have learned
- Encourage administrative support for employees
- Develop interventions:
  - Schwartz Rounds
  - Multidisciplinary Rounds
  - Professional Networks
  - Need for personal time and relief from emotional exhaustion
- Consider interventions study

#### Methods to address HCT

- Team decision and promotion of transparency:
  - Provide opportunities for input from team members in a patient-review forum
  - Provide opportunity for team to witness discussions and consent sessions of patient/donor's preparation
- Presence of inpatient/outpatient team at care conference discussed risks
- Compliance 'trial' to determine improvement pre-SCT
- Donor evaluation by MD not caring for recipient to review risks/benefits