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The Integration of Palliative Care in Stem Cell Transplantation:

A New Language for Palliative Care

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DISCLOSURE

Speaker (Dr. J.J.Strand)

Relevant Financial Relationship(s)

None related to this talk

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Objectives

- Define key concepts of the palliative care philosophy
- Employ expanded definitions of palliative care in conversations with your patients & colleagues
- How palliative care can improve the quality of care to patients with stem cell transplantations.

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CASE: SW

- 48yoF w/AML, continued relapse despite induction, 2 rounds of consolidation, salvage chemotherapy.
- Facing decision about intensive chemotherapy with goal of transplant vs. “chemo-lite” vs. “doing nothing”

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SW Had Heard of Palliative Care on NPR

- Significant rectal pain & mucositis with last round of salvage therapy.
- Significant anxiety, insomnia, anticipatory nausea.
- Four children from a blended marriage. “I am really not sure how to talk to my kids”

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My Initial Consultation with SW

- Symptom Assessment:
  - Severe fatigue
  - Anxiety & associated insomnia
- Coping, Illness Understanding, Goals:
  - “I am not sure I am ready to give up yet”
  - Goals focused living her life & being with her family.

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What Did I Need to Know Before This Visit with S.W.?

What Patients Want When Facing a Serious/Life Threatening Illness

- Pain and symptom control
- Control
- Strengthening of relationships
- Relief of family burden
- Not to linger

Singer et al. JAMA 1999; 281 (2) 163-168

Quality of Life at the End of Life for Patients with Hematologic Malignancies

- When compared with solid tumors in the last 30 days of life:
  - More likely to:
    - Visit the emergency room
    - Be admitted to the hospital
    - Experience prolonged hospital stay
    - Chemotherapy in last 14d of life
    - Die in the ICU

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Hui et al., Cancer. 2014 Feb 18. [Epub ahead of print]

Family & Caregivers Suffer a Cost as Well

- When a patient dies in the ICU, bereaved caregivers suffer:
  - 11 times higher rates of PTSD
  - 9 times higher rates of GAD
- When a patient dies in the hospital, bereaved caregivers suffer:
  - 10 times higher rates of prolonged grief disorder
- When a patient dies at home with hospice, caregivers report:
  - Higher satisfaction with care

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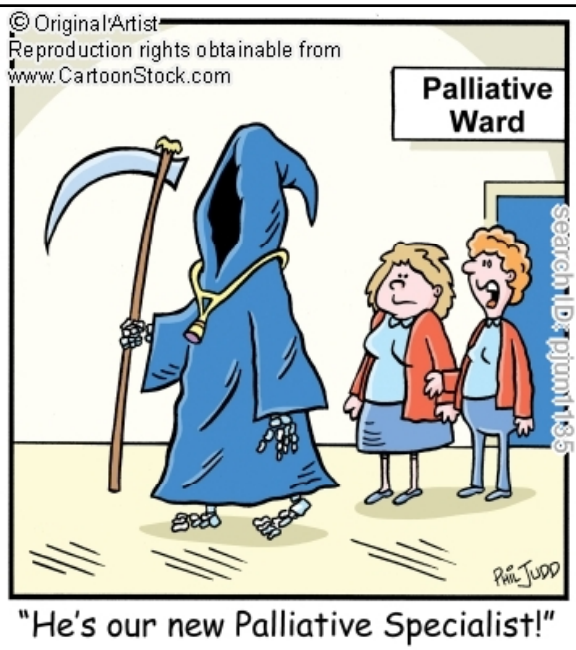
Turn to your neighbor

(please)



"He's our new Palliative Specialist!"

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Official Definition: Part 1

Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis. The **goal is to improve quality of life for both the patient and the family**.

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Center to Advance Palliative Care, 2011

Official Definition: Part 2

Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

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Center to Advance Palliative Care, 2011

Why Language Matters

- Goal is to improve care for all patients with a serious illness.
- Many patients who benefit from palliative care not dying, *and may be cured.*
- No one wants to die & few (especially us) are able to be at peace with this label until the very end.

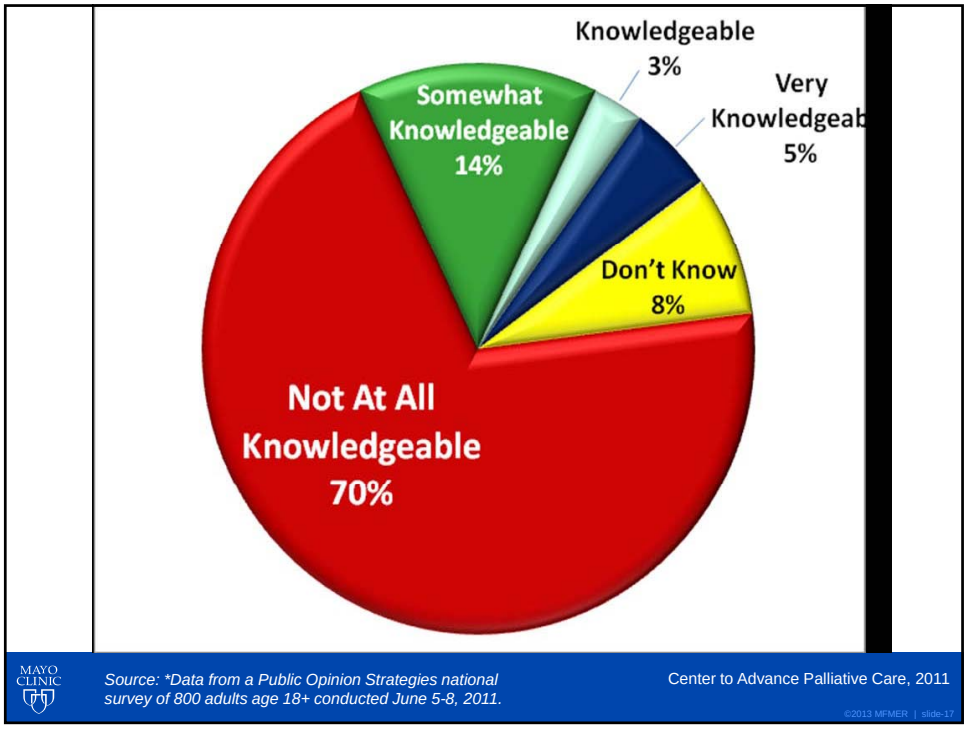
Why Language Matters

"Aggressive Treatment"

"Do Everything"

"You have failed multiple rounds of chemo"

"Nothing More We Can Do"


Knowledgeable
3%
Somewhat
Knowledgeable
14%
Very
Knowledgeab
5%
Don't Know
8%
Not At All
Knowledgeable
70%
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Source: *Data from a Public Opinion Strategies national survey of 800 adults age 18+ conducted June 5-8, 2011.
Center to Advance Palliative Care, 2011
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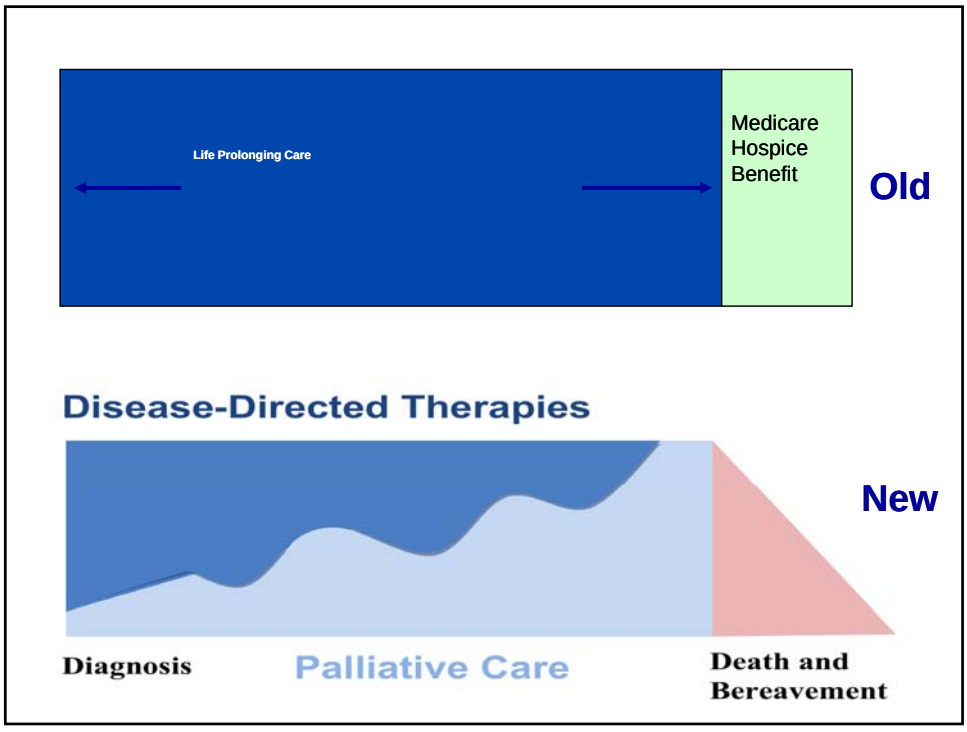
Life Prolonging Care
Medicare
Hospice
Benefit
Old
Disease-Directed Therapies
New
Diagnosis
Palliative Care
Death and
Bereavement

Early Integration of Palliative Care Is Becoming the New Standard of Care for Patients with Advanced Cancer

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A., Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H., Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H., J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.

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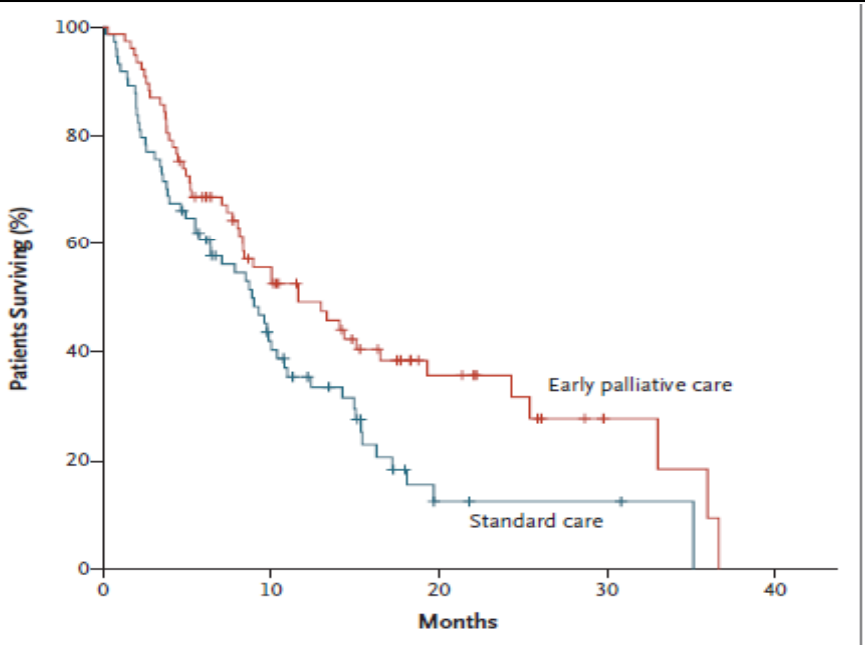
Temel et al., N Engl J Med 2010 Aug 19;363(8):733-42



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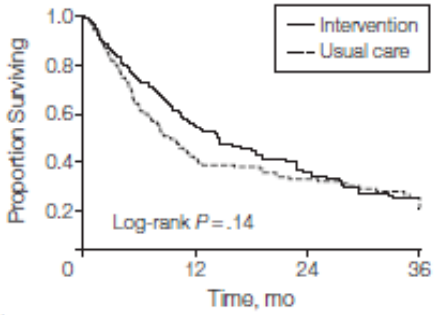
Temel et al., N Engl J Med 2010 Aug 19;363(8):733-42

Figure 4. Kaplan-Meier Estimates of Survival According to Treatment Group



No. at risk

Intervention	161	83	35	16
Usual care	161	62	33	16

Survival was calculated as the time of enrollment (within 8 weeks of diagnosis with new or recurrent advanced stage disease) to the time of death or study completion (May 1, 2008). Median survival for the intervention group was 14 months (95% CI, 10.6-18.4 months) and 8.5 months (95% CI, 7.0-11.1 months) for the usual care group ($P = .14$).

- **Didn't Die Earlier**
- Improvement in QOL measures
- Decreased depressive symptoms

Bakitas et al., JAMA. 2009 Aug19;302(7):741-9

Improved symptom management and quality of life					
Rabow, et al.[31,32]	2003, 2004	Palliative care consultation in a primary care clinic	Late-stage COPD, CHF, and cancer	Prospective, cluster randomized controlled trial	• Improved dyspnea ($p=0.01$) and anxiety ($p=0.05$), improved spiritual well-being ($p=.007$), and sleep quality ($p=0.05$) • No difference in pain, depression, or quality of life
Bakitas, et al.[33]	2009	Telephonic, advance practice nurse-led psychoeducational intervention	Advanced cancer	Prospective, randomized controlled trial	• Improved quality of life ($p=0.02$) and depression ($p=0.02$)
Temel, et al.[34–36]	2010, 2012	Early palliative care co-management	Metastatic non-small cell lung cancer	Prospective, randomized controlled trial	• Improved quality of life and well-being ($p=0.04$) • Less depressive symptoms ($p=0.03$)
Mortality					
Brumley, et al.[29,30]	2003, 2007	In-home palliative care	Late-stage COPD, CHF, and cancer	Prospective, randomized controlled trial	• No significant differences in survival time (log rank test = 2.98; $p=0.08$)
Temel, et al.[34–36]	2010, 2012	Early palliative care co-management	Metastatic non-small cell lung cancer	Prospective, randomized controlled trial	• Longer survival (median survival 11.6 versus 8.9 months; $p=0.02$).
Impact on health care utilization and readmissions					
Brumley, et al.[29,30]	2003, 2007	In-home palliative care	Late-stage COPD, CHF, and cancer	Prospective, randomized controlled trial	• Fewer visits to the emergency department ($p=0.01$) • Fewer hospitalizations ($p=0.001$)

Rabow et al., J Palliat Med. 2013 Nov 13

It Is Not Giving Up To Plan For All Scenarios

- Palliative Care:
  - Clarify goals of care with patients & families
  - Identify those treatments and settings that help patients meet their goals at each stage of illness.
  - Talking/planning does not compromise hope
  - Patients with poorer prognoses make different choices about their care.

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Mack et al., J Clin Oncol. 2007 Dec 10;25(35):5636-42
Weeks et al., JAMA. 1998 Jun 3;279(21):1709-14.
Pfeiffer et al., J Gen Intern Med 1994;9:82-8

"There's no easy way I can tell you this, so I'm sending you to someone who can."

Early Palliative Care Is Different

- Focus is on developing longer-term relationships with patients and families
- More time to address difficult topics & promote adaptive coping strategies
- Focus on quality of life throughout the course of the illness
- Care is highly collaborative with referring team

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Jackson et al., J Palliat Med. 2013 Aug;16(8):894-900.

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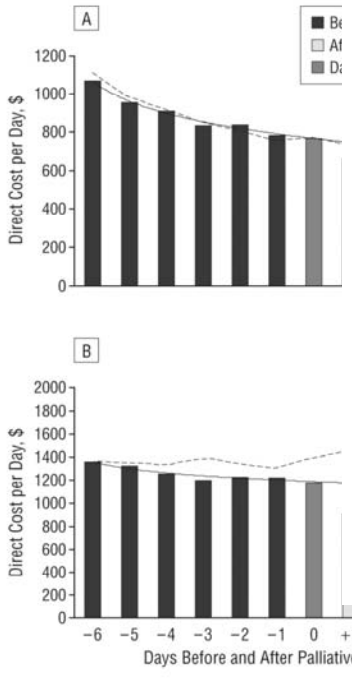
Value = Quality / Cost

Palliative Care Enhances Health Care Value



Care, Not Cure

Average cost for terminally ill patients in palliative and nonpalliative programs during their final five days at one hospital.

	Non-PCU	PCU
Drugs and chemotherapy	$2,267	$511
Lab	1,134	56
Diagnostic imaging	615	29
Medical supplies	1,821	731
Room & nursing	4,330	3,708
Other	2,152	278
Total	**$12,319**	**$5,313**

Note: PCU stands for palliative care unit. Each figure represents average cost of last five days for a cancer patient aged 65-plus, prior to in-hospital death. Figures are for 2001 and 2002.

Source: Virginia Commonwealth University medical center

Morrison et al., Arch Intern Med. 2008 Sep 8;168(16):1783-90

Palliative Care Is Quality Care

1. Beneficial
2. Patient centered
3. Efficient
4. Timely
5. Safe
6. Equitable

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National Quality Forum (www.qualityforum.org)

Palliative care and BMT together? Really?

- Improvements in high-dose therapies, and increasing success rate
- Better supportive care → Better Outcomes
- Though mortality improved, risk still exists
  - Impacted by age, comorbidities, disease genetics
- QOL remains a consideration regardless of outcomes

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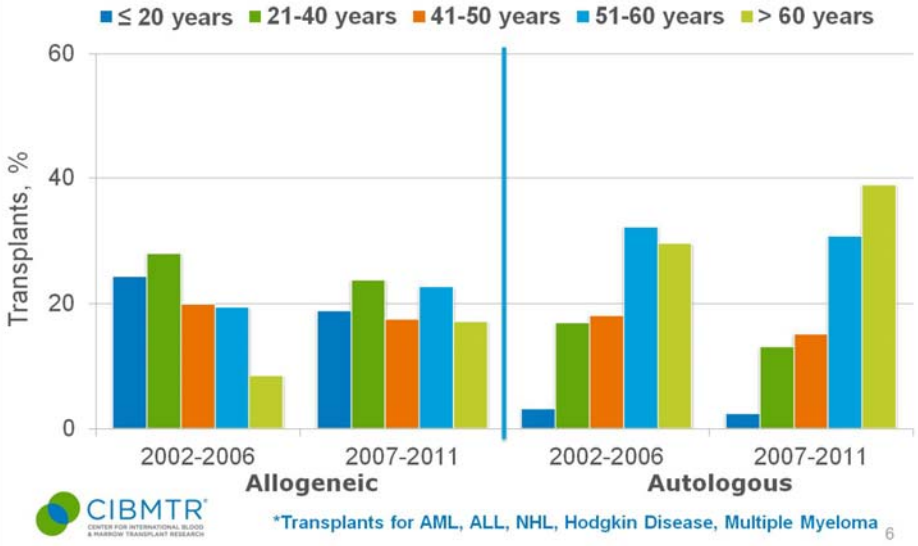
Chung et al. Bone Marrow Transplant. 2009;43(4):265-63.

Trends in Transplants by Type and Recipient Age*



CIBMTR

*Transplants for AML, ALL, NHL, Hodgkin Disease, Multiple Myeloma

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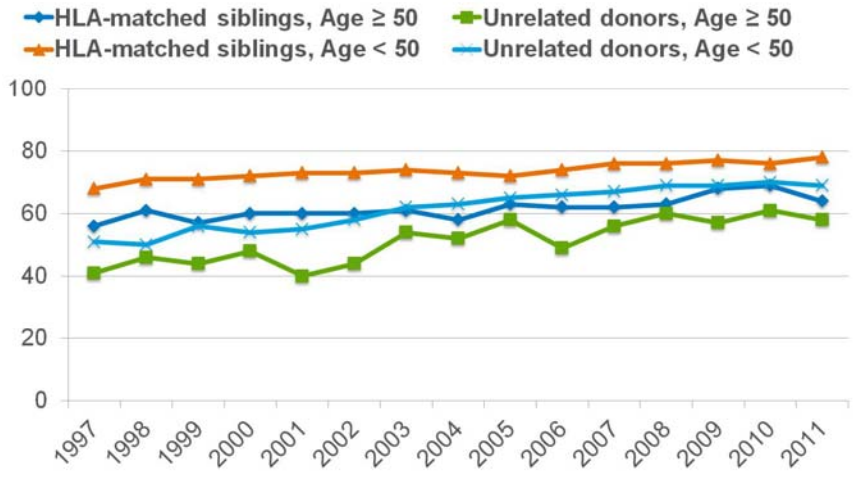
One-year Survival by Year of Transplant, Donor and Age, Worldwide



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Acute Leukemia, CML or MDS early disease status.

14

Commonly encountered PC issues in BMT

- Symptom assessment and management
  - Pain control (40-50% of patients)
    - Mucositis
  - Fatigue, nausea, and diarrhea
- Need for honest communication about medical prognosis
- Goals of care delineation

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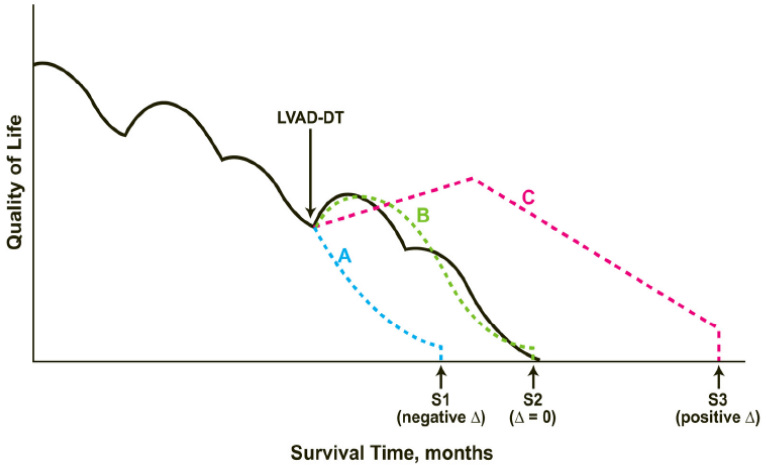
Chung et al. Bone Marrow Transplant. 2009;43(4):265-63.
Manitta et al., J Pain Symptom Manage. 2011 Sep;42(3):432-42

QOL trajectory in LVAD-DT patients—a useful paradigm comparing post-transplant outcomes?



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Philos Ethics Humanit Med 2008;3:20

Why engage palliative care earlier?

- Patients may opt to decline more aggressive stem cell transplant path.
- Patients who choose transplant may benefit from a **"preparedness plan"**
  - Aggressive trial of therapy now, with emphasis on palliation later
- Treat symptoms including those associated with adverse events; pain

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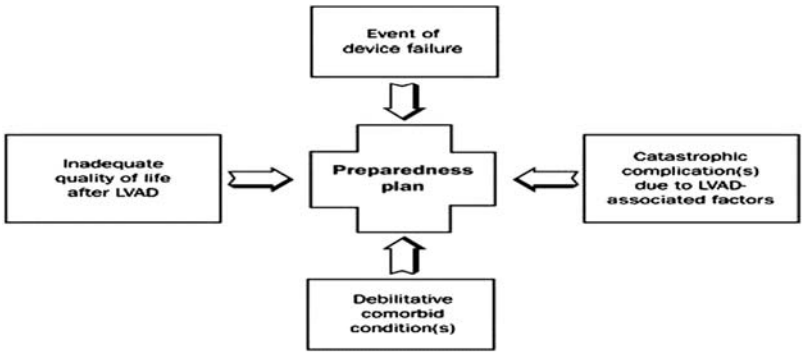

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Swetz et al., J Pain Symptom Manage. 2013 Oct 2. S0885-3924(13)00391-6.

SW & Her Preparedness Plan

- Trial of S-HAM, goal to get to transplant
- Plans for new treatment strategies for mucositis
- Discussed her prognosis with her hematologist and her family on several occasions.
  - *"I am not going to die in the hospital."*
- Changed code status to DNR/DNI

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TABLE 2 Consult characteristics of patients referred for palliative care consultations

Characteristic	No. of consultations (%)[a,b]
Disease	
Leukemia	196 (50)
Lymphoma	101 (26)
Multiple myeloma	51 (13)
Myelodysplastic syndrome	20 (5.1)
Treatment status	
Poststem cell transplant	161 (41)
Reason for consult	
Pain	278 (71)
Goals of care	172 (44)

[a]N = 392. [b]Patients could be referred to the palliative care team for multiple reasons, leading to summative percentages greater than 100%.

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Selvaggi et al., J Support Oncol. 2014;Feb;12(2):50-55.

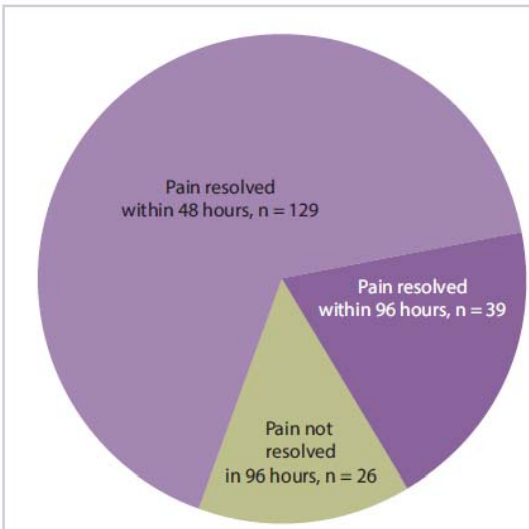

FIGURE 1 Pain management consults with unacceptable pain (n = 194)

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Selvaggi et al., J Support Oncol. 2014;Feb;12(2):50-55.

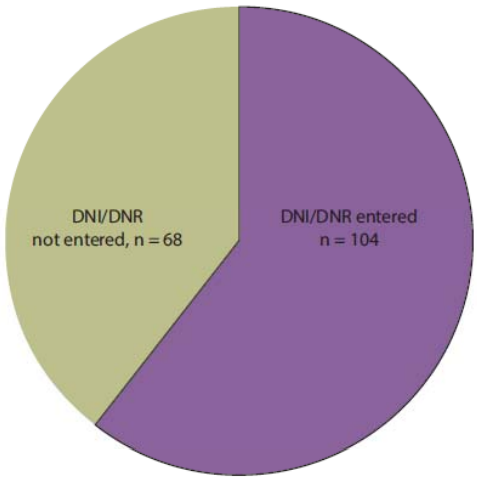

FIGURE 2 DNI/DNR status of consults referred for goals of care conversations (n = 172)

DNI, do not intubate; DNR, do not resuscitate.

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Selvaggi et al., J Support Oncol. 2014;Feb;12(2):50-55.

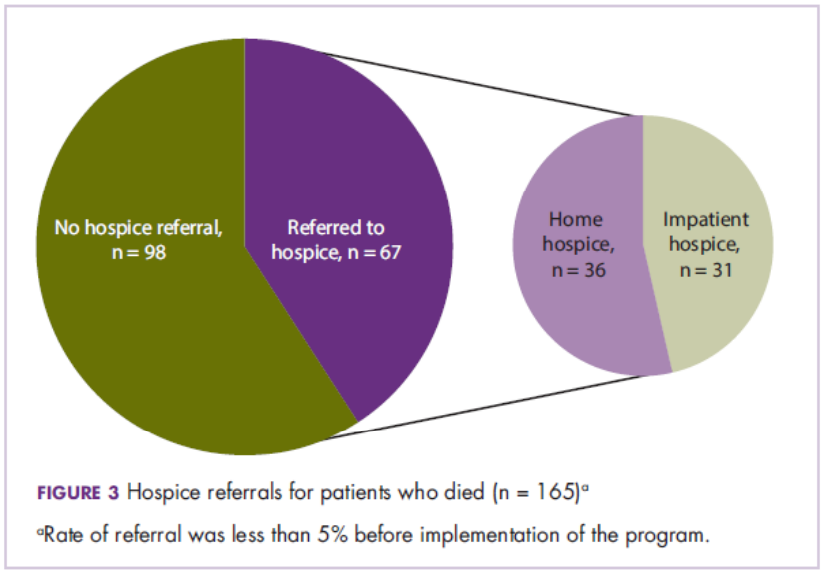


FIGURE 3 Hospice referrals for patients who died (n = 165)[a]

[a]Rate of referral was less than 5% before implementation of the program.

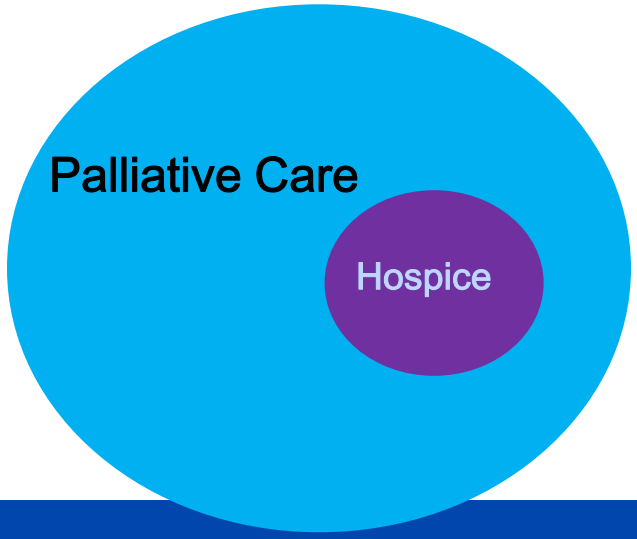
Selvaggi et al., J Support Oncol. 2014;Feb;12(2):50-55.

Hospice Has Significant Benefits for Patients and Families.

- Does Not Specifically Exclude Therapies That Can Help With Quality of Life:
  - Can provide antibiotics
  - Can provide transfusions
- Higher rating of quality of life and quality of death
- Improved caregiver quality of life at follow-up

Teno et al., J Am Geriatr Soc. 2011 Aug;59(8):1531-6
Connor et al., J Pain Symptom Manage. 2007 Mar;33(3):238-46
Wright, A. A. et al. JAMA 2008;300:1665-1673.

Palliative Care & Hospice



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Palliative Care Is:

- ✓Excellent, evidence-based treatment
- ✓Care of pain and symptoms throughout illness:
  - ✓*"Any age, any stage"*
- ✓Care that patients want *at the same time* as efforts to cure/prolong life

Palliative Care Is NOT:

- ✕ Not "giving up" on a patient
- ✕ Not in place of curative or life-prolonging care
- ✕ Not the same as hospice or "comfort care"

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Generalist plus Specialist Palliative Care — Creating a More Sustainable Model

Timothy E. Quill, M.D., and Amy P. Abernethy, M.D.

Representative Skill Sets for Primary and Specialty Palliative Care.

Primary Palliative Care

- Basic management of pain and symptoms
- Basic management of depression and anxiety
- Basic discussions about
  - Prognosis
  - Goals of treatment
  - Suffering
  - Code status

Specialty Palliative Care

- Management of refractory pain or other symptoms
- Management of more complex depression, anxiety, grief, and existential distress
- Assistance with conflict resolution regarding goals or methods of treatment
  - Within families
  - Between staff and families
  - Among treatment teams
- Assistance in addressing cases of near futility

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N Engl J Med. 2013 Mar 28;368(13):1173-5

Palliative Care Benefits Clinicians

- **Can help offload** by assisting with repeated, intensive patient-family communications & coordination of care in multiple settings
- **Supports the primary team** with hands-on management of complex pain and symptom distress 24/7
- **Highly collaborative** nature can improve patient and family satisfaction with the primary clinician care plan.

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Take Home

- Be an active participant in removing barriers to palliative care:
  - *"Added layer of support"*
  - *"Alongside curative/life prolonging treatment"*
  - *"Relieve the pain, symptoms and stress of a serious illness"*
- Get involved in the unique opportunities offered by collaboration with palliative care

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Questions & Discussion

strand.jacob@mayo.edu

"To cure sometimes, relieve often, comfort always."
Dr. Edward Trudeau