Palliative Medicine and Hospice: Exploring Myths, Realities, and the Science that it just might help you live LONGER

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Objectives

- Review and discuss the differences between palliative medicine and hospice
- Provide examples of the kind of support we provide
- Brief overview of Advanced Care Planning [Living will/HCPOA and the MOST form]
- Review briefly the impact of Palliative Care on mortality

Myth or Reality:

This talk is only appropriate for people who are going to die, and that’s not me

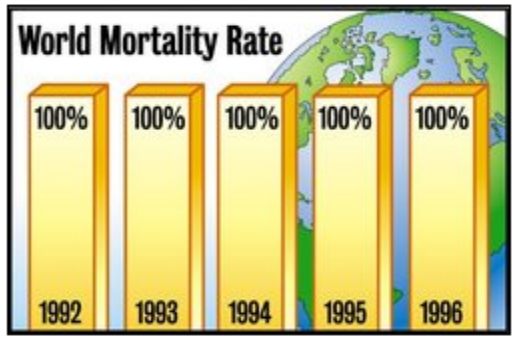
NEWS

World Death Rate Holding Steady At 100 Percent

JANUARY 22, 1997 | ISSUE 31•02

GENEVA, SWITZERLAND—World Health Organization officials expressed disappointment Monday at the group's finding that, despite the enormous efforts of doctors, rescue workers and other medical professionals worldwide, the global death rate remains constant at 100 percent.

Enlarge Image



Death rates since 1992

Death, a metabolic affliction causing total shutdown of all life functions, has long been considered humanity's number one health concern. Responsible for 100 percent of all recorded fatalities worldwide, the condition has no cure.

"I was really hoping, what with all those new radiology treatments, rescue helicopters, aerobics TV shows and what have you, that we might at least make a dent in it this year," WHO Director General Dr. Gernst Bladt said. "Unfortunately, it would appear that the death rate remains constant and total, as it has inviolably since the dawn of time."

Many are suggesting that the high mortality rate represents a massive failure on the part of the planet's health care workers.

"The inability of doctors and scientists to adequately address this issue of death is nothing less than a scandal," concerned parent Marcia Gretto said. "Do you have any idea what a full-blown case of death looks like? Well, I do,

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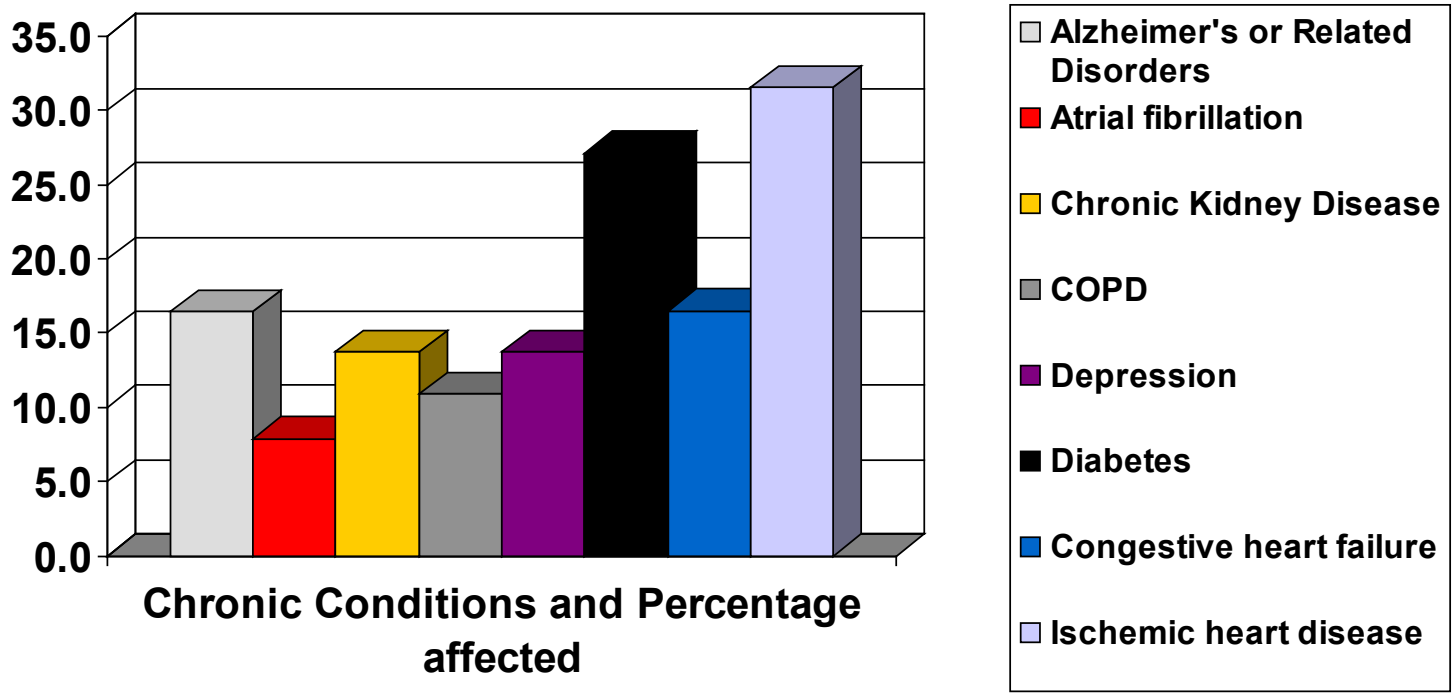
AMERICAN VOICES »
Android Phones May Be Harvesting Data

"What a relief! Now I can stop writing down detailed accounts of my day to send to my phone company."

Many people suffer from chronic conditions that will limit life length in some fashion



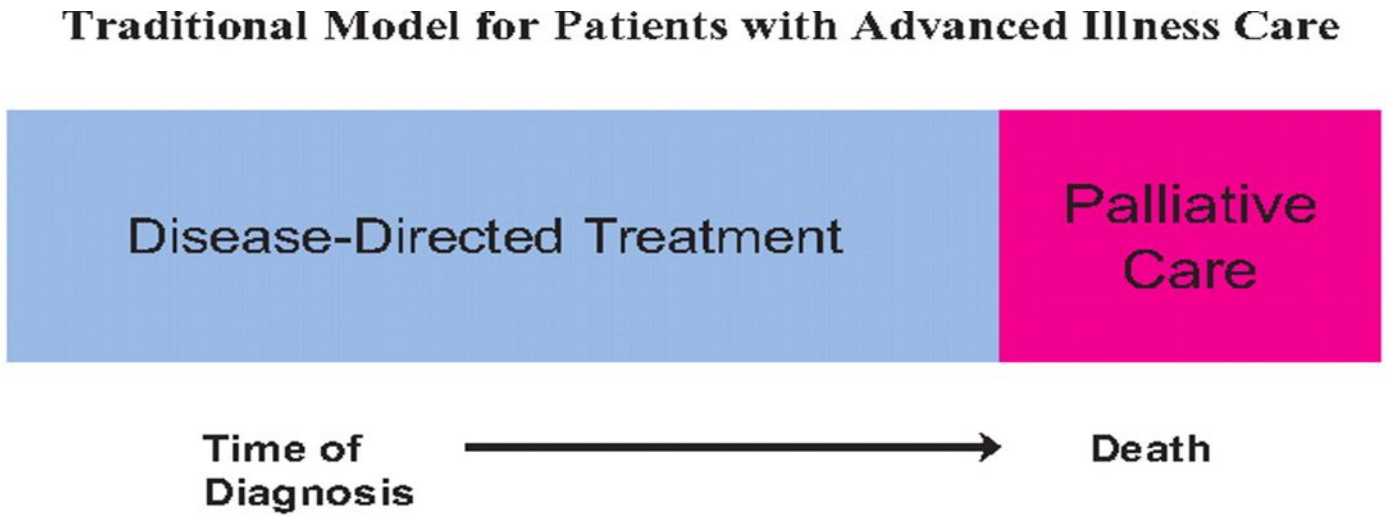
Source: http://www.ccwdata.org/summary-statistics/chronic-condition-statistics/index.htm

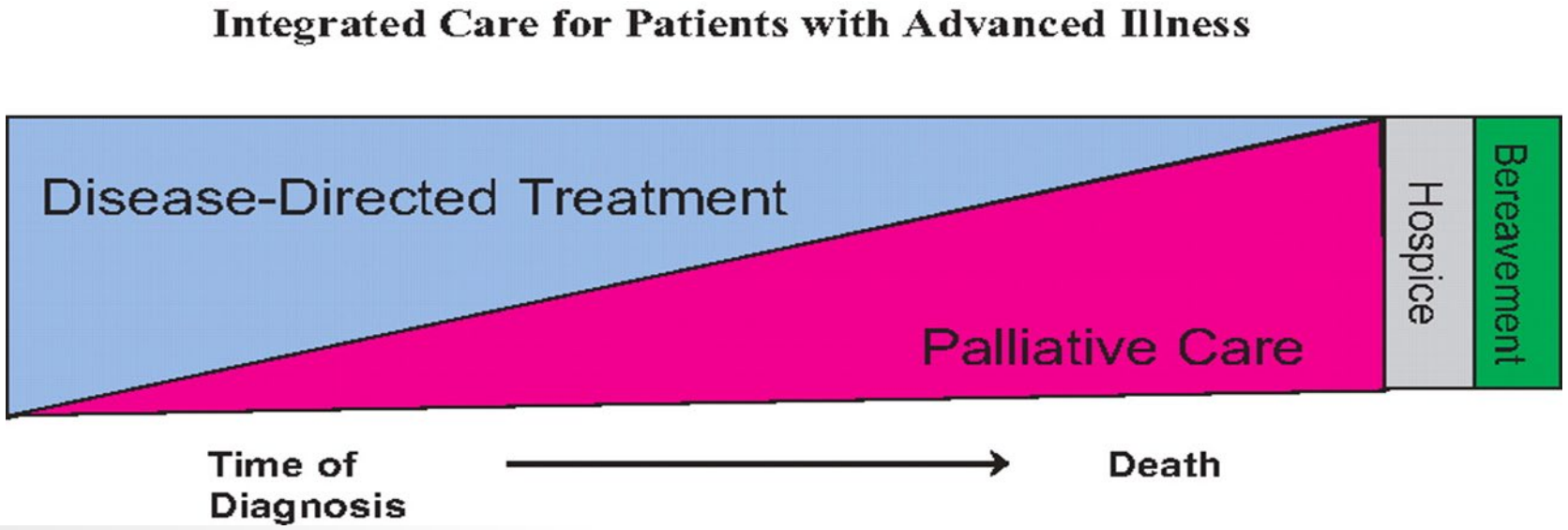
So, what is Palliative Care anyway?

And…..
How is it different than Hospice?
Aren’t they the same?

Education in Palliative and End-of-life Care

www.epec.net





Why would I want to meet a Palliative Care physician?

- Symptom Management
  - Symptoms related to the illness ; Pain, Nausea/Vomiting, Dyspnea, Anxiety, Depression.
  - Symptoms related to treatment – Neuropathy, pain, constipation or diarrhea, poor appetite
- Communication
  - Diagnosis, Prognosis
  - Treatment Goals and Options
  - Advance Care Planning
  - Family discussions
  - Support!!!!!!

Who may not be as appropriate for referral to a Palliative Medicine clinic?

- Patients that only need help completing advance directives
- Patients with a cancer diagnosis who have not yet met with their Oncologist

** = "It's complicated"	Palliative Medicine	Hospice
Chemotherapy	Yes	Rarely
Radiation Therapy	Yes	If palliative, yes
Can have "Full Code" status	Yes	Yes Except for Hospice House
Can receive artificial nutrition, blood products, antibiotics	Yes	Yes **
Receive care at home	** Used to be no, now yes	Yes
Receive care in hospital	Yes	Yes
Receive outpatient care	Yes **	Yes **
Receive care at NH	Usually but facility dependent	Rarely **
Manage symptoms	Yes	Yes

Hospice is always palliative

Palliative Care does NOT always mean hospice

Words are powerful !

NEST questionnaire

www.epec.net

None										A great deal
0	1	2	3	4	5	6	7	8	9	10

1. How much of a financial hardship is your illness for you or your family?
2. How much trouble do you have accessing the medical care you need?
3. How much help do you need with things like getting meals or getting to the doctor?
4. How often do you confide in someone?
5. How much do you suffer from physical symptoms such as pain, shortness of breath, fatigue, bowel or urination problems?
6. How often do you feel confused, anxious or depressed?
7. How much does this illness make life seem senseless and meaningless?

8. How much spiritual support do you feel that you need? [6]

9. How much have you maintained good relationships with the people close to you? [7]

10. How much do you live life with a special sense of purpose? [7]

11. How much do you feel your doctors and nurses respect you as an individual?

12. How clear is the information from the medical team about what to expect regarding your illness?

13. How much do you feel that the medical care you are getting fits with your goals?

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The reality is…

- We want to be a source of light and positive energy
- And I don’t bite ;)

What other tough things can you help me with??

MYTH:

I don’t need to think about advanced care planning.

That’s not thinking positively!

Living wills	Medical Order forms [like MOST or Goldenrod /Out of Facility DNR]
Often vague	Extremely specific
May be limited to desires related to resuscitation	Address Resuscitation MOST also addresses IV hydration, Artificial feeding and Antibiotics
Rarely travel with a patient or are not accessible	MUST travel with a patient
Express preferences but are not medical orders	Medical Orders that MD's, EMT's, RN's can follow
Can be revoked	Can be revoked
Can be copied for the medical record	Copies are NOT used

ADVANCE DIRECTIVE FOR A NATURAL DEATH ("LIVING WILL")

NOTE: YOU SHOULD USE THIS DOCUMENT TO GIVE YOUR HEALTH CARE PROVIDERS INSTRUCTIONS TO WITHHOLD OR WITHDRAW LIFE-PROLONGING MEASURES IN CERTAIN SITUATIONS. THERE IS NO LEGAL REQUIREMENT THAT ANYONE EXECUTE A LIVING WILL.

GENERAL INSTRUCTIONS: *You can use this Advance Directive ("Living Will") form to give instructions for the future if you want your health care providers to withhold or withdraw life-prolonging measures in certain situations. You should talk to your doctor about what these terms mean. The Living Will states what choices you would have made for yourself if you were able to communicate. Talk to your family members, friends, and others you trust about your choices. Also, it is a good idea to talk with professionals such as your doctors, clergypersons, and lawyers before you complete and sign this Living Will.*

You do not have to use this form to give those instructions, but if you create your own Advance Directive you need to be very careful to ensure that it is consistent with North Carolina law.

This Living Will form is intended to be valid in any jurisdiction in which it is presented, but places outside North Carolina may impose requirements that this form does not meet.

If you want to use this form, you must complete it, sign it, and have your signature witnessed by two qualified witnesses and proved by a notary public. Follow the instructions about which choices you can initial very carefully. ***Do not sign this form until*** *two witnesses and a notary public are present to watch you sign it. You then should consider giving a copy to your primary physician and/or a trusted relative, and should consider filing it with the Advanced Health Care Directive Registry maintained by the North Carolina Secretary of State:* http://www.nclifelinks.org/ahcdr/

My Desire for a Natural Death

I, _____, being of sound mind, desire that, as specified below, my life not be prolonged by life-prolonging measures:

1. When My Directives Apply

My directions about prolonging my life shall apply ***IF*** my attending physician determines that I lack capacity to make or communicate health care decisions and:

NOTE: YOU MAY INITIAL ANY OR ALL OF THESE CHOICES.

_____ *(Initial)*	I have an incurable or irreversible condition that will result in my death within a relatively short period of time.
_____ *(Initial)*	I become unconscious and my health care providers determine that, to a high degree of medical certainty, I will never regain my consciousness.
_____ *(Initial)*	I suffer from advanced dementia or any other condition which results in the substantial loss of my cognitive ability and my health care providers determine that, to a high degree of medical certainty, this loss is not reversible.

2. These are My Directives about Prolonging My Life:

In those situations I have initialed in Section 1, I direct that my health care providers:

NOTE: INITIAL ONLY IN ONE PLACE.

_____ *(Initial)*	may withhold or withdraw life-prolonging measures.
_____ *(Initial)*	shall withhold or withdraw life-prolonging measures.

3. Exceptions — "Artificial Nutrition or Hydration"

NOTE: INITIAL ONLY IF YOU WANT TO MAKE EXCEPTIONS TO YOUR INSTRUCTIONS IN PARAGRAPH 2.

EVEN THOUGH I do not want my life prolonged in those situations I have initialed in Section 1:

_____ *(Initial)*	I DO want to receive BOTH artificial hydration AND artificial nutrition (for example, through tubes) in those situations. ***NOTE: DO NOT INITIAL THIS BLOCK IF ONE OF THE BLOCKS BELOW IS INITIALED.***
_____ *(Initial)*	I DO want to receive ONLY artificial hydration (for example, through tubes) in those situations. ***NOTE: DO NOT INITIAL THE BLOCK ABOVE OR BELOW IF THIS BLOCK IS INITIALED.***
_____ *(Initial)*	I DO want to receive ONLY artificial nutrition (for example, through tubes) in those situations. ***NOTE: DO NOT INITIAL EITHER OF THE TWO BLOCKS ABOVE IF THIS BLOCK IS INITIALED.***

4. I Wish to be Made as Comfortable as Possible

I direct that my health care providers take reasonable steps to keep me as clean, comfortable, and free of pain as possible so that my dignity is maintained, even though this care may hasten my death.

5. I Understand my Advance Directive

I am aware and understand that this document directs certain life-prolonging measures to be withheld or discontinued in accordance with my advance instructions.

HIPAA PERMITS DISCLOSURE OF MOST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY

Medical Orders for Scope of Treatment (MOST)

This is a Physician Order Sheet based on the person's medical condition and wishes. Any section not completed indicates full treatment for that section. **When the need occurs, first follow these orders, then contact physician.**

Patient's Last Name:	Effective Date of Form: _____ *Form must be reviewed at least annually.*
Patient's First Name, Middle Initial:	Patient's Date of Birth:

Section A *Check One Box Only*

CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing.

☐ **Attempt Resuscitation (CPR)** ☐ **Do Not Attempt Resuscitation (DNR/no CPR)**

When not in cardiopulmonary arrest, follow orders in **B, C**, and **D**.

Section B *Check One Box Only*

MEDICAL INTERVENTIONS: Person has pulse and/or is breathing.

☐ **Full Scope of Treatment:** Use intubation, advanced airway interventions, mechanical ventilation, cardioversion as indicated, medical treatment, IV fluids, etc.; also provide comfort measures. **Transfer to hospital if indicated.**

☐ **Limited Additional Interventions:** Use medical treatment, IV fluids and cardiac monitoring as indicated. Do not use intubation or mechanical ventilation; also provide comfort measures. **Transfer to hospital if indicated. Avoid intensive care.**

☐ **Comfort Measures:** Keep clean, warm and dry. Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. **Do not transfer to hospital unless comfort needs cannot be met in current location.**

Other Instructions _____

Section C *Check One Box Only*

ANTIBIOTICS

☐ **Antibiotics if life can be prolonged.**
☐ **Determine use or limitation of antibiotics when infection occurs.**
☐ **No Antibiotics** (use other measures to relieve symptoms).

Other Instructions _____

Section D *Check One Box Only in Each Column*

MEDICALLY ADMINISTERED FLUIDS AND NUTRITION: Offer oral fluids and nutrition if physically feasible.

☐ **IV fluids long-term if indicated**	☐ **Feeding tube long-term if indicated**
☐ **IV fluids for a defined trial period**	☐ **Feeding tube for a defined trial period**
☐ **No IV fluids** (provide other measures to ensure comfort)	☐ **No feeding tube**

Other Instructions _____

Section E *Check The Appropriate Box*

DISCUSSED WITH AND AGREED TO BY:

Basis for order must be documented in medical record.

☐ Patient
☐ Parent or guardian if patient is a minor
☐ Health care agent
☐ Legal guardian of the person
☐ Attorney-in-fact with power to make health care decisions
☐ Spouse
☐ Majority of patient's reasonably available parents and adult children
☐ Majority of patient's reasonably available adult siblings
☐ An individual with an established relationship with the patient who is acting in good faith and can reliably convey the wishes of the patient

MD/DO, PA, or NP Name (Print):	MD/DO, PA, or NP Signature (Required):	Phone #:

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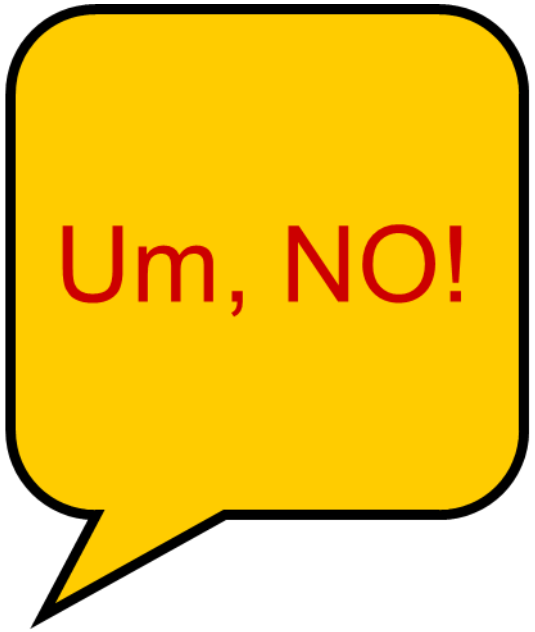
How should I choose a Surrogate Decision Maker?

- Knows you and your values/what's important to you
- Not afraid of difficult conversations or decisions
- You are comfortable having them speak for you
- Can cope with family conflicts
- Lives close or can travel
- Physically and emotionally able to assume the role and what comes with it

So what about this “make me live longer” thing…was that just a teaser?

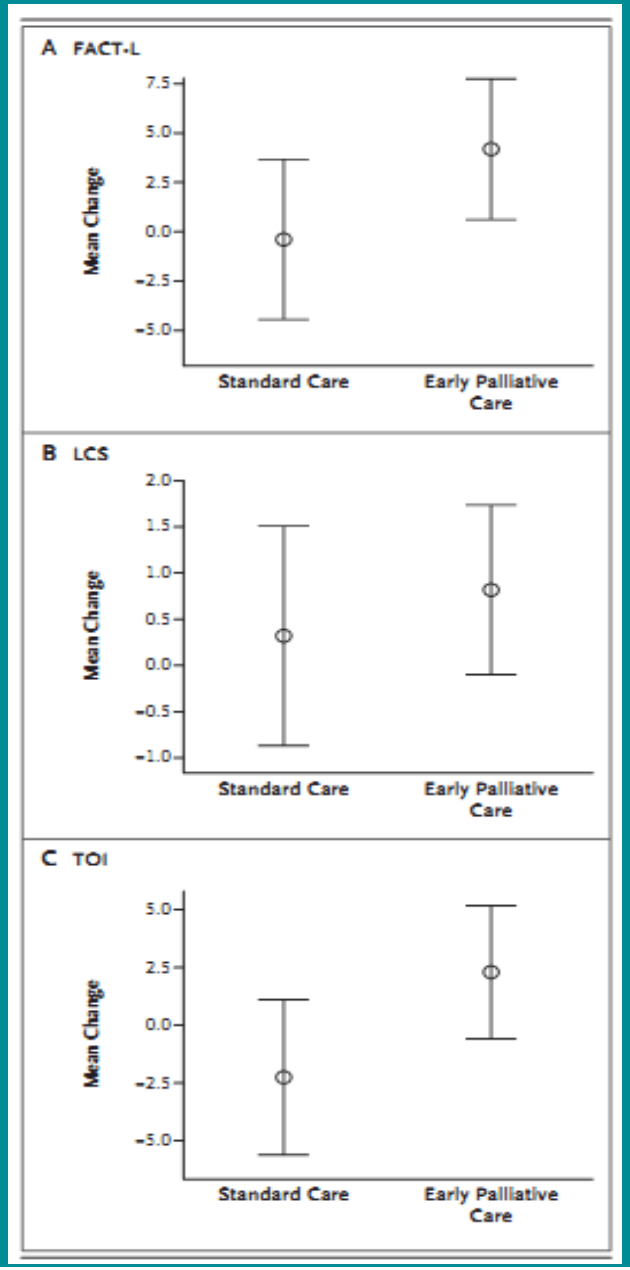


The OG study, published in Aug 2010

- 151 patients
- All patients had Stage IV, metastatic, non-small cell lung cancer
- Eligible patients were enrolled within 8 weeks after diagnosis and were randomly assigned to either early palliative care or standard care
- Patients who were assigned to early palliative care met with a member of the palliative care team, which consisted of board-certified palliative care physicians and advanced-practice nurses, within 3 weeks after enrollment and at least monthly thereafter in the outpatient setting until death
- Additional visits with the palliative care service were scheduled at the discretion of the patient, oncologist, or palliative care provider

Figure 1. Mean Change in Quality-of-Life Scores from Baseline to 12 Weeks in the Two Study Groups.

Quality of life was assessed with the use of the Functional Assessment of Cancer Therapy–Lung (FACT-L) scale, on which scores range from 0 to 136, with higher scores indicating a better quality of life; the lung-cancer subscale (LCS) of the FACT-L scale, on which scores range from 0 to 28, with higher scores indicating fewer symptoms; and the Trial Outcome Index (TOI), which is the sum of the scores on the LCS and the physical well-being and functional well-being subscales of the FACT-L scale (scores range from 0 to 84, with higher scores indicating a better quality of life). With study group as the independent variable, two-sided independent-samples Student's t-tests showed a trend toward a significant between-group difference in the mean (±SD) change in scores from baseline to week 12 on the FACT-L scale (−0.4±13.8 in the standard care group vs. 4.2±13.8 in the palliative care group; difference between groups, 4.6; 95% confidence interval [CI], −0.8 to 9.9; P=0.09) (Panel A), no significant between-group difference in the mean change in scores on the LCS (0.3±4.0 and 0.8±3.6 in the two groups, respectively; difference between groups, 0.5; 95% CI, −1.0 to 2.0; P=0.50) (Panel B), and a significant between-group difference in the mean change in scores on the TOI (−2.3±11.4 vs. 2.3±11.2; difference between groups, 4.6; 95% CI, 0.2 to 8.9; P=0.04) (Panel C). Data are from the 47 patients in the standard care group and the 60 patients in the palliative care group who completed the



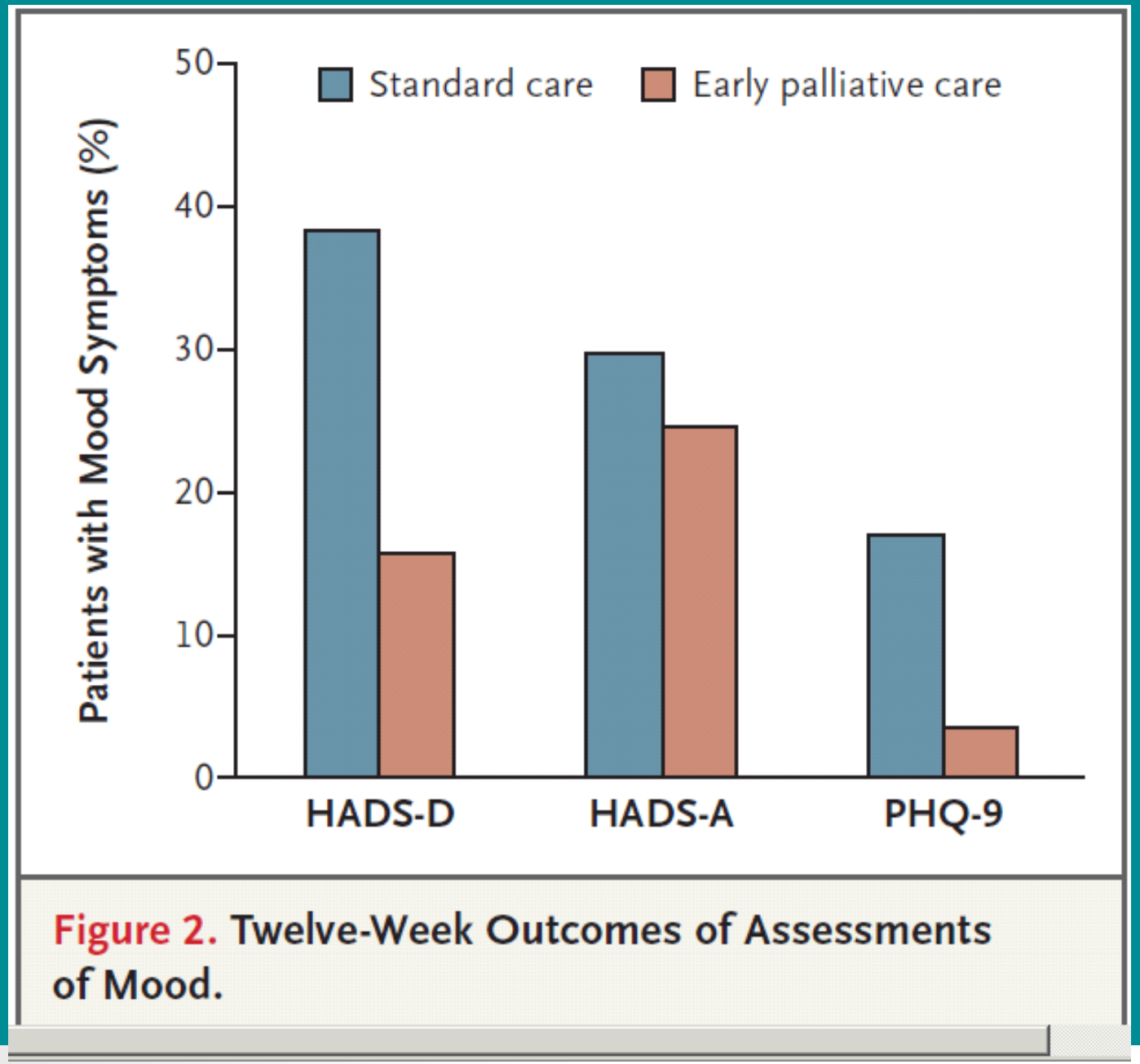


Figure 2. Twelve-Week Outcomes of Assessments of Mood.

The results

- Patients were classified as having received aggressive care if they met any of the following three criteria: chemotherapy within 14 days before death, no hospice care, or admission to hospice 3 days or less before death
- A greater percentage of patients in the group assigned to standard care than in the group assigned to early palliative care received aggressive end-of-life care (54% [30 of 56 patients] vs. 33% [16 of 49 patients], P = 0.05)
- Despite receiving less aggressive end-of-life care, patients in the palliative care group had significantly longer survival than those in the standard care group (median survival, 11.6 vs. 8.9 months; P = 0.02)

What about other cancers?

ASCO Special Articles

Check for updates

Palliative Care for Patients With Cancer: ASCO Guideline Update

Justin J. Sanders, MD, MSc[1]; Sarah Temin, MSPH[2]; Arun Ghoshal, MBBS, MD, MRes[3]; Erin R. Alesi, MD[4]; Zipporah Vunoro Ali, MD[5]; Cynthia Chauhan, MSW[6]; James F. Cleary, MD[7]; Andrew S. Epstein, MD[8]; Janice I. Fim, PhD, MSW, HEC-C[9]; Joshua A. Jones, MD, MA[10]; Mark R. Litzow, MD[11]; Debra Lundquist, PhD, RN[12]; Mabel Alejandra Mardones, MD[13]; Ryan David Nipp, MD, MPH[14]; Michael W. Rabow, MD[15]; William E. Rosa, PhD, MBE, APRN[8]; Camilla Zimmermann, MD, PhD, FRCPC[3]; and Betty R. Ferrell, PhD[16]

DOI https://doi.org/10.1200/JCO.24.00542

ABSTRACT

ASCO Guidelines provide recommendations with comprehensive review and analyses of the relevant literature for each recommendation, following the guideline development process as outlined in the ASCO Guidelines Methodology Manual. ASCO Guidelines follow the ASCO Conflict of Interest Policy for Clinical Practice Guidelines.

Clinical Practice Guidelines and other guidance ("Guidance") provided by ASCO is not a comprehensive or definitive guide to treatment options. It is intended for voluntary use by providers and should be used in conjunction with independent professional judgment. Guidance may not be applicable to all patients, interventions, diseases, or stages of diseases. Guidance is based on review and analysis of relevant literature, and is not intended as a statement of the standard of care. ASCO does not endorse third-party drugs, devices, services, or therapies and assumes no responsibility for any harm arising from or related to the use of this information. See complete disclaimer in Appendix 1 and 2 (online only) for more.

PURPOSE To provide evidence-based guidance to oncology clinicians, patients, nonprofessional caregivers, and palliative care clinicians to update the 2016 ASCO guideline on the integration of palliative care into standard oncology for all patients diagnosed with cancer.

METHODS ASCO convened an Expert Panel of medical, radiation, hematology-oncology, oncology nursing, palliative care, social work, ethics, advocacy, and psycho-oncology experts. The Panel conducted a literature search, including systematic reviews, meta-analyses, and randomized controlled trials published from 2015-2023. Outcomes of interest included quality of life (QOL), patient satisfaction, physical and psychological symptoms, survival, and caregiver burden. Expert Panel members used available evidence and informal consensus to develop evidence-based guideline recommendations.

RESULTS The literature search identified 52 relevant studies to inform the evidence base for this guideline.

ACCOMPANYING CONTENT

Appendix

Data Supplement

Accepted March 28, 2024
Published May 15, 2024

Evidence Based Medicine Committee approval: March 13, 2024

J Clin Oncol 42:2336-2357

View Online Article

RECOMMENDATIONS Evidence-based recommendations address the integration of palliative care in oncology. Oncology clinicians should refer patients with advanced solid tumors and hematologic malignancies to specialized interdisciplinary palliative care teams that provide outpatient and inpatient care beginning early in the course of the disease, alongside active treatment of their cancer. For patients with cancer with unaddressed physical, psychosocial, or spiritual distress, cancer care programs should provide dedicated specialist palliative care services complementing existing or emerging supportive care interventions. Oncology clinicians from across the interdisciplinary cancer care team may refer the caregivers (eg, family, chosen family, and friends) of patients with cancer to palliative care teams for additional support. The Expert Panel suggests early palliative care involvement, especially for patients with uncontrolled symptoms and QOL concerns. Clinicians caring for patients with solid tumors on phase I cancer trials may also refer them to specialist palliative care.

Additional information is available at www.asco.org/supportive-care-guidelines.

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Palliative Medicine and COPD [chronic obstructive pulmonary disease/emphysema]

Palliative care has been shown to:

- Improve quality of life
- Reduce symptom burden
- Increases prognostic awareness
- Proven to be cost-effective for people with COPD

Early palliative medicine integration is essential for people with COPD, but is often delayed due to misconceptions which equate palliative medicine exclusively with end-of-life care

Effectiveness of palliative care interventions on patient-reported outcomes and all-cause mortality in community-dwelling adults with heart failure: A systematic review and meta-analysis

- Eleven studies; total of 1535 patients
- Compared to usual care, palliative care interventions demonstrated statistically significant effects on:
  - ✓ Improving generic health-related quality of life
  - ✓ Improving heart failure-specific quality of life
  - ✓ Reduced anxiety
  - ✓ Reduced depression
  - ✓ Enhanced spiritual well-being
  - ✓ NO adverse effect on all-cause mortality

Yuan Li, et al. Effectiveness of palliative care interventions on patient-reported outcomes and all-cause mortality in community-dwelling adults with heart failure: A systematic review and meta-analysis. International Journal of Nursing Studies, Volume 160, 2024, https://doi.org/10.1016/j.ijnurstu.2024.104887.

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Questions?????

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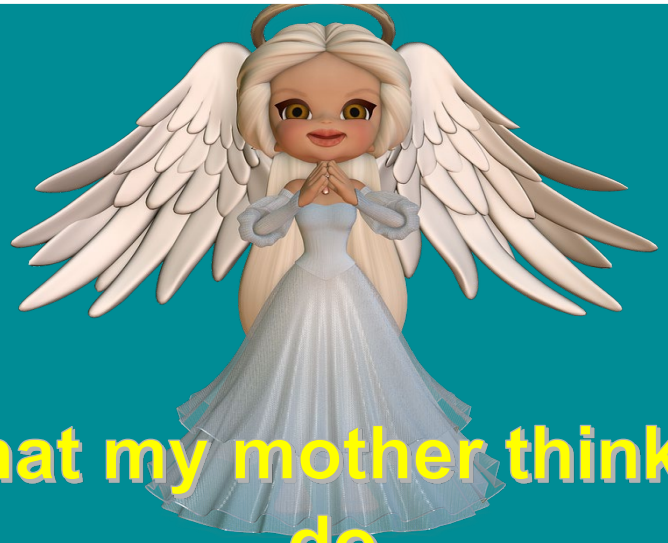
What laypeople think I do

What other medical professionals think I do



What my mother thinks I do

What I actually do