

Palliative Care and End of Life  
Decision Making:  
The Impact of Population-based Cancer Data

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6/16/16

# Case

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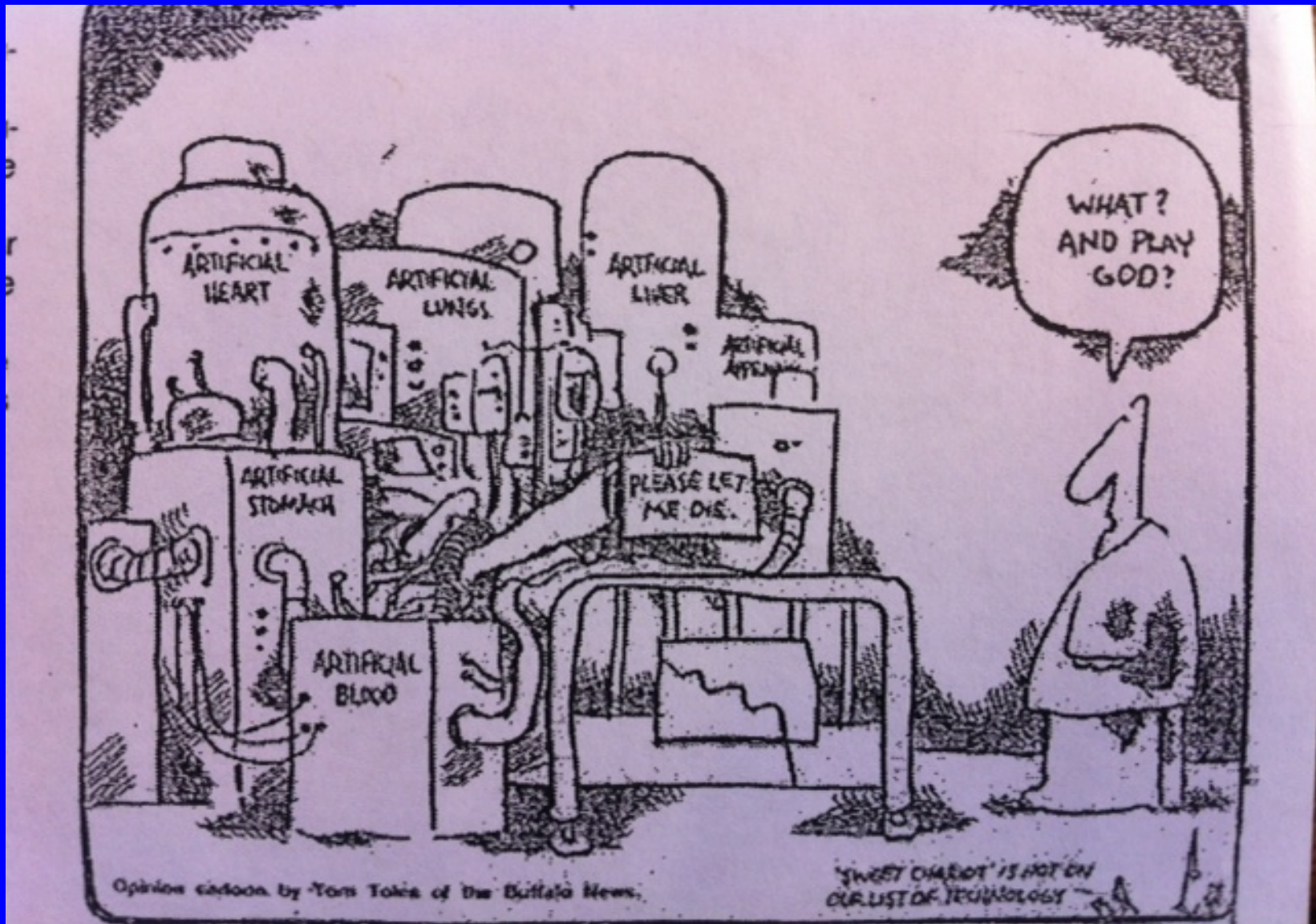
- Rose, 67yo Caucasian lady from rural Missouri with stage IV non-small cell lung cancer, admitted to hospital with lung collapse, massive pleural effusion, dyspnea, hypoxia, and respiratory failure
- Diagnosis made 9 months before, minimal response to chemotherapy, then progression and decline over 4 months
- Husband is an unemployed laborer. Daughter is a nurse's aide at local nursing home. Pastor has driven to hospital for pastoral visit. They all feel "everything should be done"
- No advance directives or limitation of treatment orders
- The clinical team feels she is dying. Not recommending further chemotherapy or radiation due to performance status and risk of harm and minimal chance of benefit. Comfort care recommended
- A palliative care consult and ethics consult are requested

# Hospice and Palliative Medicine: This is what most Americans say they want





This is what we usually get



# Objectives

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- To highlight what population-based cancer data tell us about the prognosis and natural history of common cancers
- To review how palliative care and hospice services are optimally applied for qualified and interested patients and families to improve quality of life and symptom management in advanced cancer cases
- To discuss together ways in which professional and public dialogue and education can use population-based cancer data to improve end of life care for cancer patients in the U.S. and beyond

# Introduction



- Hospice and Palliative Care (HPC) as a part of health care is integral to cancer care and cancer control
- Population-based cancer data (PBCD) will enhance HPC impact
- Improved HPC impact will improve quality and quantity of life for cancer patients and survivors
- Thus, HPC is a critical element of cancer control, albeit usually on the “back end” of care provision
- Integration of PBCD and HPC is pivotal for optimal cancer care and cancer control

# Background



- Rapid changes in the last 20 years in cancer care and treatment, HPC, and healthcare landscape, but
- These advances are not particularly synchronized or supportive of each other, and yet
- The integration of HPC with cancer care is ahead of most areas of healthcare (Cardiology, Nephrology, etc.)
- Integration will be facilitated by better data management in cancer care and cancer epidemiology
- The role of PBCD in this integration is paramount

# PBCD for Dummies (me)



- Cancer registries
- Catchment area (denominator)
- Cooperation with all other cancer registries and U.S. and international agencies
- Demographics and epidemiology
- Role in improved cancer care in “real time”
- Role in Cancer Control and Cancer Research
- Hospital-based vs. population-based



# HPC Primer (for you)

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- Advanced cancer – on or off cancer treatment
- Limited life expectancy – days to 3 years (surprise question)
- Burdensome symptoms
- Other burdens – emotional, social, spiritual, financial
- Need for person- and symptom- and goal-directed care
- Need for advance care planning

# Disease Dialogue

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- Compassionate truth telling throughout the disease continuum makes the “bad news” part much easier on everyone
- Starts at the time of diagnosis, continues throughout illness
- Includes a discussion of patient/family understanding, values, goals, wishes, preferences, fears
- Includes diagnosis, prognosis, natural history of disease, potential outcomes, current options, future options, and what will be done if the disease cannot be cured or can no longer be treated effectively
- Is repeated at critical junctures of disease trajectory, or any time at patient/family request, with a focus on prior discussions and new realities
- Includes both good news and bad news

# What are the challenges?

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- Communication
- Symptom management
- Psychosociospiritual care
- Caregiver support and empowerment
- Limited knowledge and resources and expertise in different settings
- Clash of values/culture/conflict

# Who is dying?

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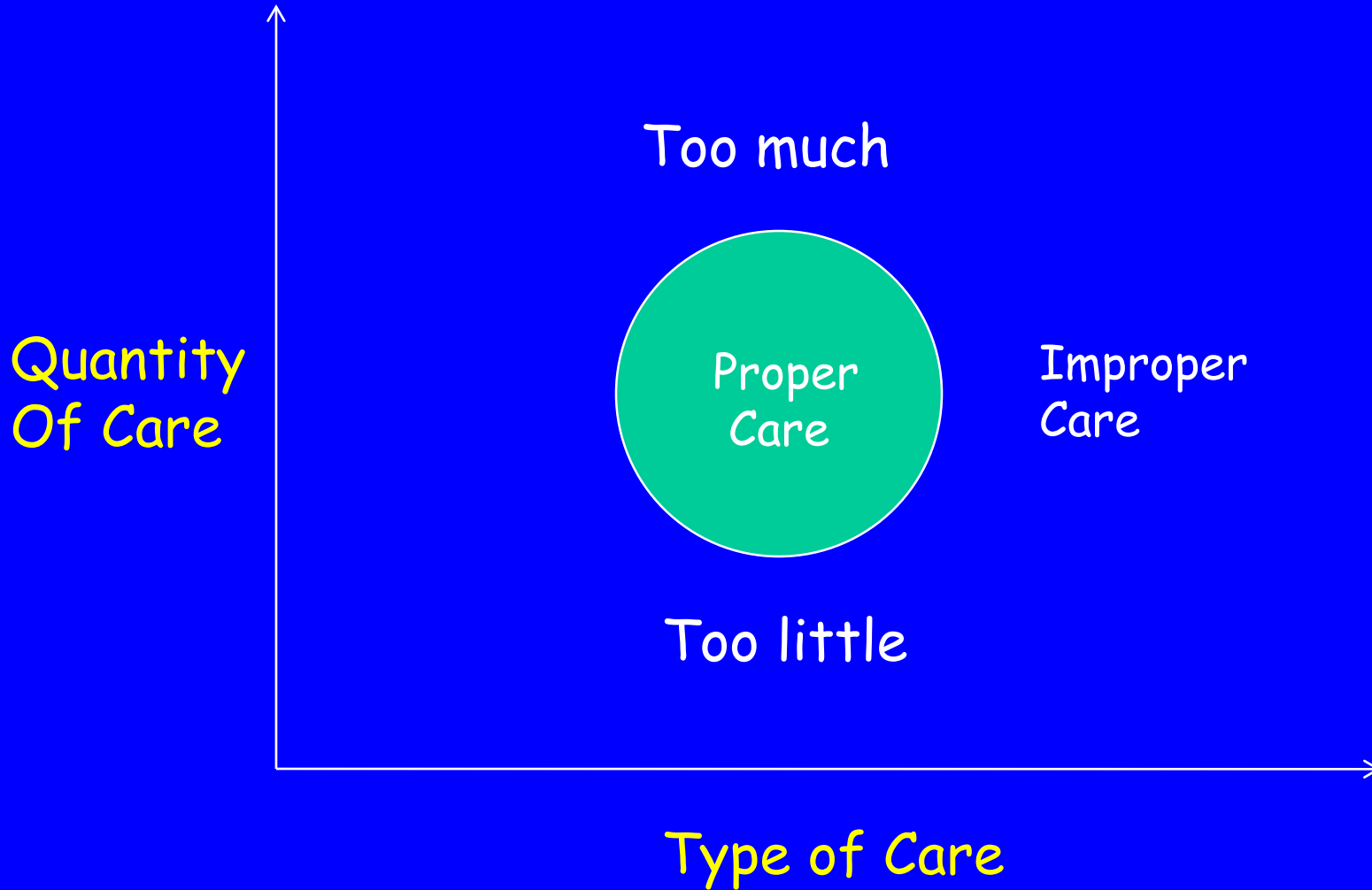
- Diagnosis – incurable/end stage chronic illness
- Prognosis – expected survival, chance of recovery
- Choice – 97yo farmer refuses hospitalization
- Uncertainty – choosing palliative care/hospice cannot depend upon absolute certainty of patient's prognosis, patient understanding and choice inform where prognostic certainty is lacking
- The “surprise question” – would you be surprised if this person died in the next year? If not, then Palliative care team involvement is appropriate, if available

# Too Much Treatment

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- Annals of Internal Medicine 2011, Sirovich et al
- Approx. 600 primary care physicians surveyed
- Ave. responder – 30% too much treatment
- Unnecessary harm and expense
- Reasons:
  - ✓ Malpractice concerns 76%
  - ✓ Meet performance standards 52%
  - ✓ Inadequate time with patients 40%
- 40% felt other physicians would order less tests if no additional revenue was generated

# Appropriateness of Health Care





# EOL Care Time Line

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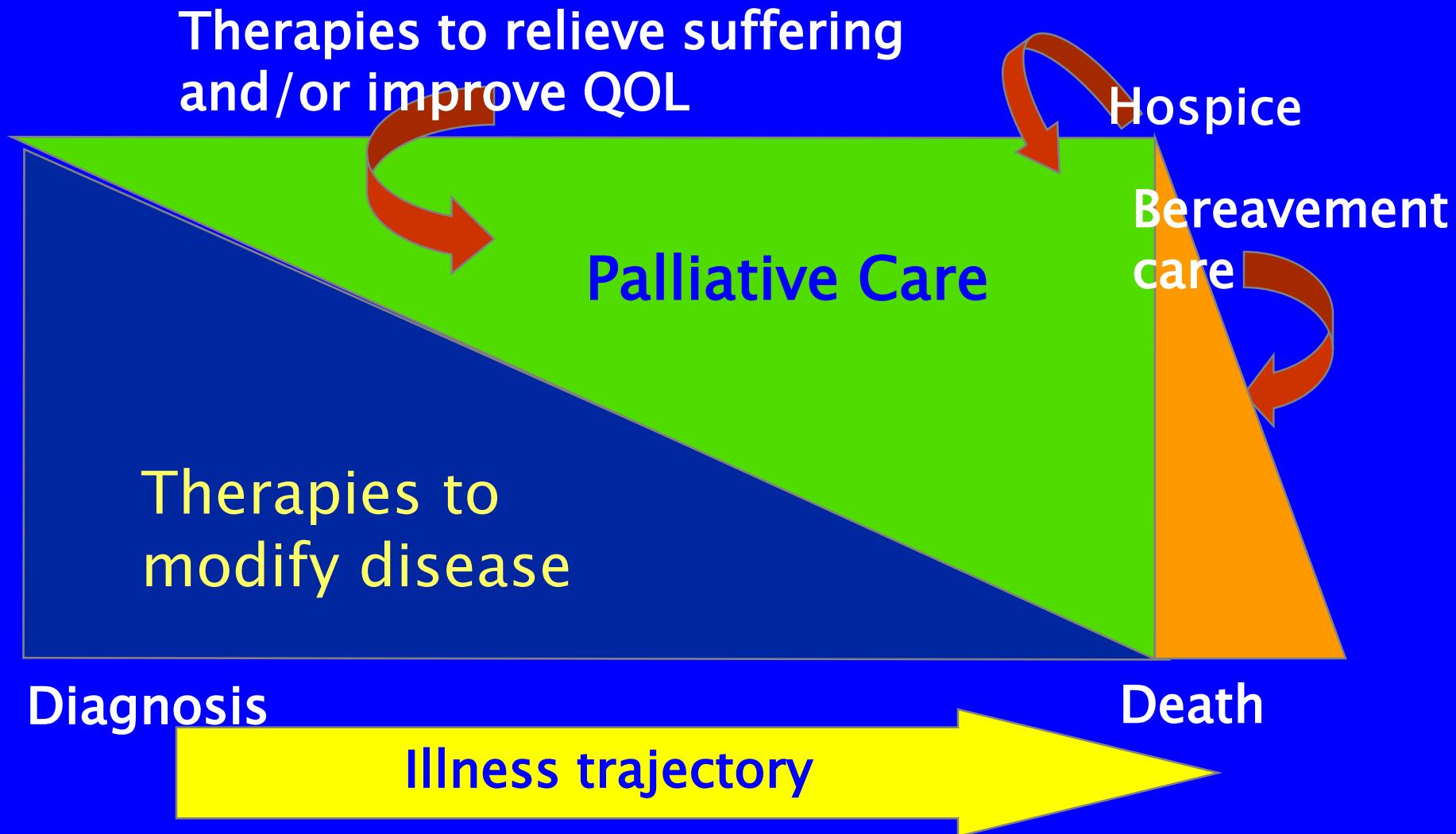
- 1920-1970 -- the Post HPM/Pre HPM era in U.S.
- 1970s -- modern bioethics, right to self-determination (“Whose Life Is It Anyways?”), EKR -- On Death and Dying, hospice “movement” to U.S.
- 1980s -- hospice becomes health care in U.S.
- 1990s -- birth of palliative medicine and palliative care
- 2000s -- corporatization/scrutiny of hospice, palliative care saturation, norm and stagnation
- 2010s – creative destruction in HPM, what will emerge?

# WHO Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

# WHO Model of Palliative Care



# Palliative Care

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- Multidisciplinary treatment of an “incurable” condition (advanced cancer, heart failure, emphysema, dementia)
- Primarily focused on improving symptoms rather than changing the natural history of the disease
- May include surgery, chemotherapy, etc.
- May be life prolonging in some instances
- Excessive toxicity not tolerated
- May require extensive monitoring of lab work or x-rays

# Why Palliative Care?

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- Ethics – good, harm, desire of patient, resources
- Service – growing population
- Quality – best health care for some
- Safety – minimizing harm and burden
- Fiscal Responsibility – to patient, to hospital, etc.
- Why Not? – Strong disincentives: personal, societal, reimbursement structure, time
- Why in the hospital – that is where dying people often are (50-60% die there), where they suffer, where the cost is

# Life-limiting | chronic illness

## Palliative Care Umbrella

Most interventions can be done outside umbrella

Patient decides to receive interventions as part of PC plan

comfort care  
life review  
hospice  
Pall. sedation  
OHDNR  
ADs

chemotherapy  
radiation  
Surg procedures  
transfusion  
hemodialysis  
hospitalization  
IV hydration/Abx  
(not PAS)



# End of Life Care Basic Concepts

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- Identify patients likely near the end of life
- Clarify prognosis and risk/benefit ratio
- Help patient decide if comfort care/palliative care is the best option
- Change plan of care to reflect this decision
- Focus medical interventions on symptom control
- Use aggressive pharmacologic and non-pharmacologic strategies for symptom control
- Use all disciplines to their optimal impact (MD, RN, SW, chaplain, physiatry, volunteer, family)

# Comfort Care

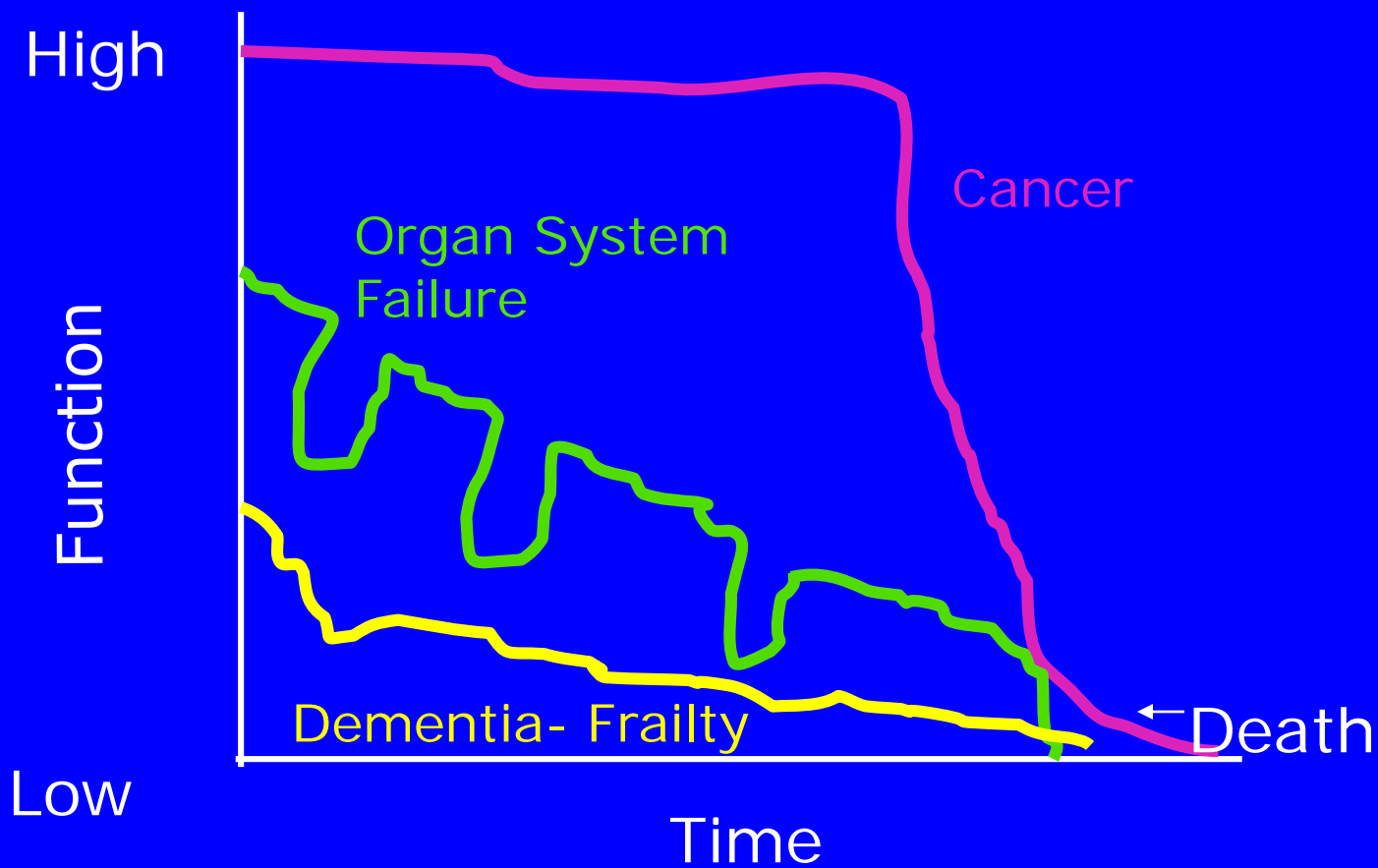
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- Started during terminal phase of incurable illness
- Focus is on person, not disease
- Symptomatic treatment only
- No monitoring of blood tests or x-rays (generally)
- People, equipment, medications
- Deterioration of condition over time is expected
- Quality of life maximized through successive losses

# Hospice

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- A philosophy, not a place
- Optimizing quality of life in the dying person
- Alleviating suffering
- People, equipment, medications
- Physician, nurse, nurse's aide, chaplain, home health aide, physical therapy
- All care in the home/facility
- Generally, no blood tests, xrays, or hospitalization



Trajectories of Function and Well-Being over Time in Eventually Fatal Chronic Illnesses

# Components of a Palliative Care Program

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- Committee/leadership group
- Curriculum/Staff/Education/Outreach
- Consultative Service
- Inpatient Unit or Beds
- Integrated Care Path for Dying Patients
- Liason Effort with Partner Hospices
- Health System Hospice
- Outpatient Palliative Care Program
- Disciplines: medical staff, administration, nursing, social work, chaplaincy, ethics, pharmacy, dietary, physiatry, psychiatry

# PC and Survival

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- Myth – Hospice and PC patients may live better, but will die sooner due to lack of disease-directed Rx
- Truth – one hospice study ('07, JPSM) and one PC study ('10, NEJM) show slightly better adjusted survival for hospice/PC group vs. standard care group in lung cancer
- Explanation – unknown, but likely relating to less burden and less harm in hospice/PC group
- QOL and good communication and patient-centered plan of care more important than survival issues



# The “Who” of Palliative Care



- Physician or team?
- Primary care or specialist?
- Oncologist/cancer team or palliative care specialist/team?
- When to make the transition?
- How to work together?
- Empowering the patient/family
- Solving problems, ensuring satisfaction, enhancing value of care through focus and expertise

# Recent Trends in Hospice

- Percentage of Medicare beneficiaries ever served by hospice increased from 30% to almost 45% in a 15 years
- Lower percent of cancer (still most common approx. 35%) and higher percentage of dementia and heart disease and lung disease
- More NH residents on hospice
- More inpatient hospice beds/facilities
- Cost of hospice slowly creeping up – total and per patient
- For-profit vs. not-for-profit dominance (now >70% FP)
- More regulatory burdens and monitoring of utilization by Medicare (CTIs, FTFs, ADRs)
- Payment “reform” coming soon – in general health care and in home health/hospice, payments will be reduced/remodeled, care does not have to be

# Established Realities 2015

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- Hospice penetration of Medicare population is approaching maximum (60%) under current regulations
- Most referrals are still too late, sometimes too early
- Minorities/disenfranchised persons not yet served enough by hospice
- South U.S., NYC, other places underserved
- Hospice costs are going up, mainly due to more person-days
- Hospice improves health care quality, cost, value, and is adequately paid for, thus costing CMS a lot of money
- Palliative Care does the same, but is not adequately paid for, and thus costs hospitals and clinics a lot of money (FTE) but not CMS yet!
- Both save much more than they cost, are high-value health care

# How is HPC integrating with Cancer Care?

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- Dual-trained physicians and APNs
- ASCO Palliative Care in Oncology Symposium – 3rd Annual 2016
- ASCO/AAHPM cooperative agreement
- ASCO and NCCN guideline contents
- “Choosing Wisely” campaign
- Impact is modest thus far

# What helpful information does PBCD provide?

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- Epidemiology and trends
- Poor prognosis scenarios (type, stage, patient factors)
- Demographic differences
- Burdens of disease besides death

# How can better information earlier impact HPC in Cancer Care?

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- Physician awareness of survival and expected course by stage
- Enhanced formulation of prognosis and sharing of prognosis for patient/family benefit
- Studies of resource utilization can inform cancer practices
- Policy and regulatory change can also be prompted by compelling data



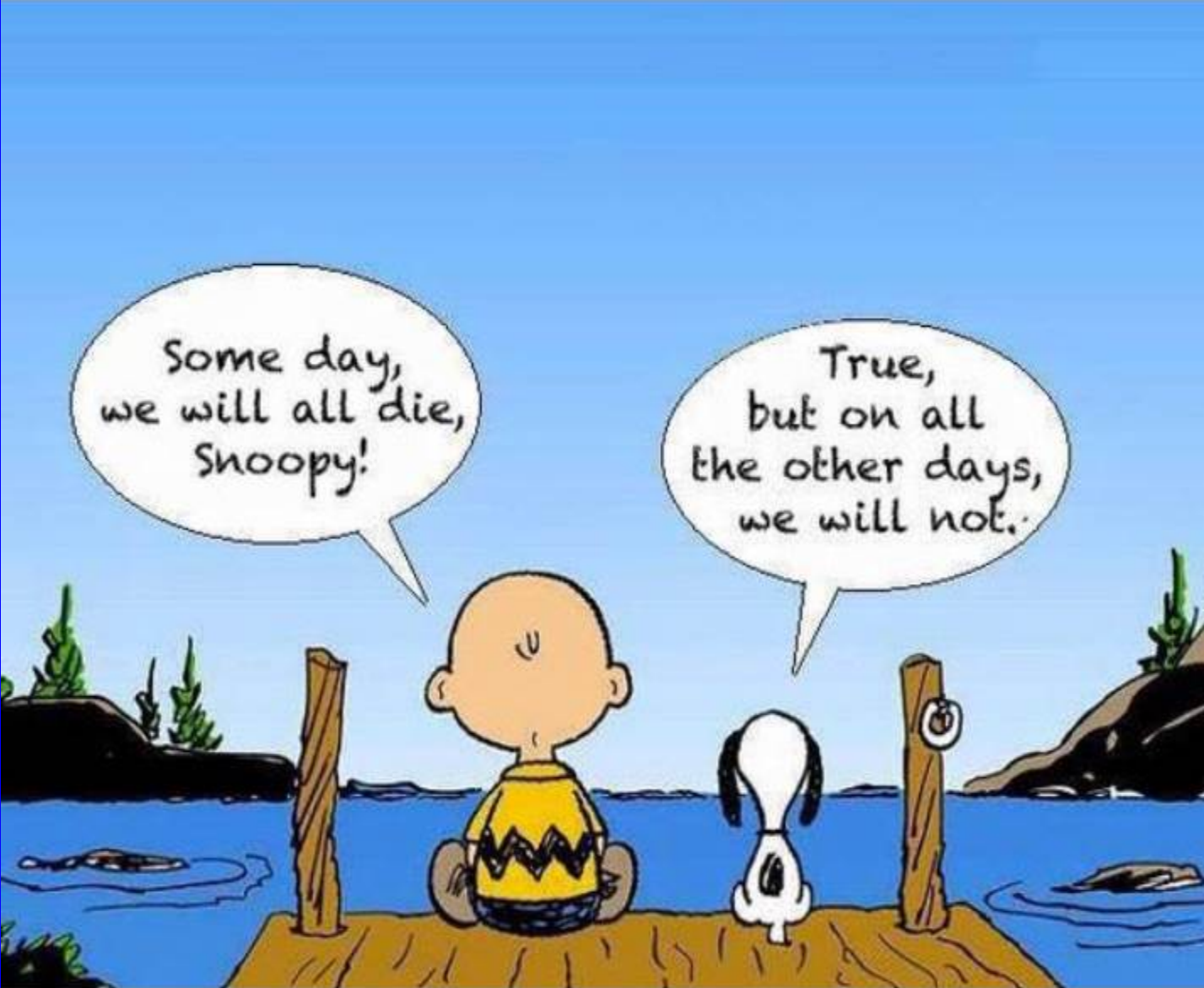
# What would the ideal look like?

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- Disease dialogue (early and often but not too much)
- Data gathering and availability
- Sharing of data
- Informing of guidelines/pathways
- Informing of individual cases (computer prognostic algorithm for patients/families and physicians)

# Conclusion

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- HPC is now recognized as key in cancer care AND cancer control
  - Optimal use of PBCD can improve utilization of HPC in cancer care
  - Cancer registries and cancer epidemiologists need to work with cancer centers to integrate data and information to optimally inform physicians and patients
  - Ideal is within reach, more work and cooperation is needed



Some day,  
we will all die,  
Snoopy!

True,  
but on all  
the other days,  
we will not.