

"Tell Me Doctor, Is It Really That Bad?"

Ethical Considerations Involving Doctor/Patient Communication

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What The Doctor Said

He said it doesn't look good
he said it looks bad in fact real bad
he said I counted thirty-two of them on one lung before
I quit counting them
I said I'm glad I wouldn't want to know
about any more being there than that
he said are you a religious man do you kneel down
in forest groves and let yourself ask for help
when you come to a waterfall
mist blowing against your face and arms
do you stop and ask for understanding at those moments
I said not yet but I intend to start today
he said I'm real sorry he said
I wish I had some other kind of news to give you
I said Amen and he said something else
I didn't catch and not knowing what else to do
and not wanting him to have to repeat it
and me to have to fully digest it
I just looked at him
for a minute and he looked back it was then
I jumped up and shook hands with this man who'd just
given me
something no one else on earth had ever given me
I may have even thanked him habit being so strong

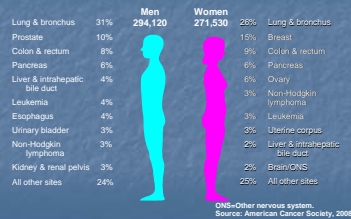
Raymond Carver

Goals For Today

- Describe the communication challenges between a doctor and patient when facing the disclosure of a life limiting diagnosis.

The Changing Healthcare Demographic : Who Are We taking About?

2008 Estimated US Cancer Deaths*



US Mortality, 2005

Rank	Cause of Death	No. of deaths	% of all deaths
1.	Heart Diseases	652,091	26.8
2.	Cancer	569,312	22.8
3.	Cerebrovascular diseases	143,579	5.9
4.	Chronic lower respiratory diseases	130,933	5.3
5.	Accidents (unintentional injuries)	117,839	4.8
6.	Diabetes mellitus	75,119	3.1
7.	Alzheimer disease	71,599	2.9
8.	Influenza & pneumonia	63,001	2.6
9.	Nephritis*	43,901	1.8
10.	Septicemia	34,136	1.4

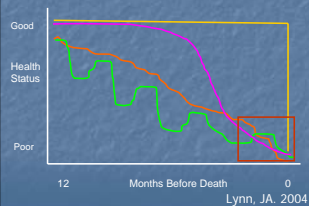
*Includes nephritic syndrome and nephrosis. Source: US Mortality Data 2005, National Center for Health Statistics, Centers for Disease Control and Prevention, 2005.

Chronic Diseases in The United States

- More than 80 percent of people over the age of 65 have one or more chronic disease
- About 5 percent of Medicare beneficiaries account for one third to one half of all health care expenditures
- Account for 7 of the 10 leading causes of death in the US (about 1.7 million persons)

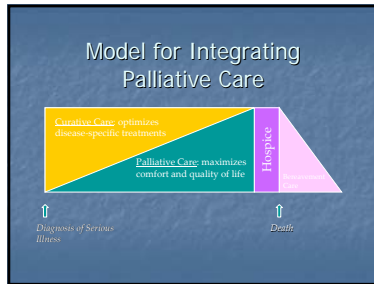
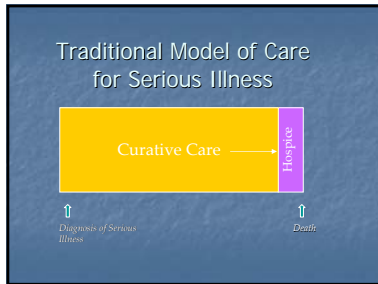
Lynn, JA. 2004

Trajectories: The Course of Illness



How Do Patients and Families Define a Good Death?

- Relief from pain and other physical symptoms
- Attention to emotional, psychological, and spiritual needs
- Compassionate communication
- Involvement in critical healthcare decisions
- Affirmation of personhood and dignity
- Coordination and continuity of care



- ### Principles of Palliative Care
- Affirms life and views death as a normal process
 - Enhances comfort
 - Improves quality of life
 - Active total care of patient whose illness is not curable
 - Defines goals of care

Medical Principles That Guide The Delivery of Health Care

- ### Medical Ethics
- Nonmaleficence
 - Beneficence
 - Respect for autonomy
 - Justice
- Hospice and Palliative Medicine, Core Curriculum and Review Syllabus 1998

- ### Other Traditional Ethical Principles
- Respect for human life and death
 - Principle of therapeutic proportionality
 - Principle of double effect in pain and symptom management
 - Truthfulness in communication

- ### The Principle of The Double Effect
- Is the patient's suffering proportionately severe to warrant the risks of the intervention?
 - Has the patient been fully informed about all likely outcomes of the intervention, both intended and foreseen, and is he or she aware of the reasonable alternatives?
 - Is the intervention the least harmful one available, given the patient's clinical circumstances and personal values?

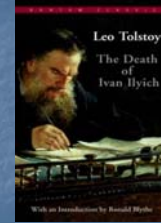
- ### Withholding Information from Patients (Therapeutic Privilege)
- Withholding relevant medical information from patients without their knowledge or consent, in an attempt to minimize potential physical or psychological harms
- American Medical Association, 2006

- ### 1847 AMA Code of Medical Ethics
- Physicians have a sacred duty...to avoid all things which have a tendency to discourage the patient and depress his spirits."
 - Full disclosure would impede patients abilities to render rational decisions or harm them in other ways

2006 AMA Code of Medical Ethics

- Physicians should sensitively and respectfully disclose all relevant medical information to patients. The quantity and specificity of this information should be tailored to meet the preferences and needs of individual patients.
- Physicians need not communicate all information at one time, but should assess the amount of information that patients are capable of receiving at a given time and present the remainder when appropriate.

Communication Challenges When Delivering News



"This deception tortured him—their not wishing to admit what they all knew and what he knew, but wanting to lie to him concerning his terrible condition, and wishing and forcing him to participate in that lie. Those lies—lies enacted over him on the eve of his death and destined to degrade this awful, solemn act to the level of their visitings, their curtains, their sturgeon for dinner—were a terrible agony for Ivan Ilyich."

Leo Tolstoy, *The Death of Ivan Ilyich*

Breaking Bad News

- Unfavorable news in the medical context has been defined as "any news that drastically and negatively alters the patient's view of her or his future."

Breaking Bad News About Cancer: Patients Preferences for Communication

- Content (what and how much information is told)
- Facilitation (setting and context variables)
- Support (emotional support during the interaction)

Parker, PA et al. 2001

Principles of Good Communication: Delivering Bad News

- Health care providers responses to the delivery of bad news
- Information needs of patients
- Communicating prognosis
- The role of hope
- Culture and disclosure of bad news
- Discussing patients emotions and concerns
- Mechanics of delivering bad news

Barclay, JPM 2007

Information Needs of Patients

- To understand their illness and treatment options
- Gain realistic expectations
- Make plans and priorities for the future
- Care for themselves
- Participate in treatment decisions
- Provide a sense of autonomy and control
- As a way of coping with a serious illness

Hope

- Hope is a belief in a positive outcome related to events and circumstances in one's life. Hope implies a certain amount of despair, wanting, wishing, suffering, or perseverance— i.e., believing that a better or positive outcome is possible even when there is some evidence to the contrary.



The Doctor, Sir Luke Fildes, 1891

Suffering

- Suffering occurs when an impending destruction of the person is perceived; it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner.

Eric J. Cassell 1999

Contributors to Suffering

- Beliefs
- Past experiences
- Conflict
- Role function
- Impairment
- Culture
- Spiritual and existential concerns
- Loss of independence and control

The Act of Prognostication

- Formulation (or "foreseeing") is the physician's cognitive or objective estimate of the future course of the patient's illness
- Communication (or "foretelling") is the physician's discussion of the prediction with others

Glare and Sinclair 2008

Studies on Communicating Prognosis

- Doctors emphasize treatment and down play prognosis
- Disclose actual beliefs 34% of the time
- Withhold prognostic information from 25% of patients
- Give deliberately optimistic estimate

Christakis NA. 1999

Opportunities For Improvement



The Training Process

- Young, eager college graduates enter medical school with good intentions and compassionate hearts. They want to help people. They want to alleviate suffering. They want to combat disease. But during those first two years of school, medical students are so inundated by technical details, biological minutiae, and pages of facts that rote memorization and getting through each exam becomes their only concern.

Virginia Morris 2001

End-of-Life Care Content in 50 Textbooks From Multiple Specialties

- Textbooks with highest percentages of absent content were in surgery (71.8%), infectious disease and AIDS (70%), and oncology and hematology (61.9%)
- Textbooks with the highest percentage of helpful end-of-life care content were in family medicine (34.4%), geriatrics (34.4%), and psychiatry (29.6%)

Rabow, M et al. 2000

Improving Communication

- Compassionate communication about prognosis seeks to balance optimism with a gentle respect for patients' right to know the truth about their illness
- Patients and physicians can travel a careful middle ground together, where they "hope for the best, and prepare for the worse."

The single biggest problem in communication is the illusion that it has taken place.

George Bernard Shaw

Cancer Patient

Chemotherapy, radiation, surgery—
All these were options, but giving up was not.
From their conversations, it was hard
To know who wanted the treatment more,
The doctor, the patient, or the family.
They played off each other.
Like cheerleaders, coach, and team:
Beating death was the goal.
And the clinical options were the game plan.
It was a fight to the finish, and they
Weren't finished.

The patient
Had grown tired, but wouldn't let on
To his doctor. After all, he didn't want
To let him down after all he had done for him.
There were days when he wanted to say
"Enough, just let me die now."
But each time he thought of it,
He couldn't bring himself to say it.
Then he began to decide himself:
"Maybe the doctor's right,
There's always one more thing to try."

And so their escalation went on
Month after month, until it had become
Unclear who was treating whom
And who feared death more.

Howard F. Stein, PhD

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Thank you and enjoy the rest of the afternoon !