Spirituality & Cultural Diversity

The patient has a right to, and receives care that is considerate and respectful of his or her personal values or beliefs. Patient assessment considers not only the physiological status but also psychological and social considerations. A patient's cultural and family context are important factors in his or her response to illness and treatment.

- Developing cultural competence begins with self-awareness
- The expression of patient's values and beliefs must be supported
- Patient care should demonstrate an awareness of the spiritual and cultural beliefs of the community served
- Psychosocial and spiritual needs of the patient are met through hospital resources
- Respond to their special needs that may include:
    - Food preferences
    - Visitors
    - Gender of healthcare workers
    - Medical care preferences
    - Gender roles
    - Eye contact and communication style
    - Authority and decision making
    - Alternative therapies
    - Prayer practices
    - Beliefs about organ/tissue donation

Meditation Room

The Meditation Room is located on the first level (South Building) across from the cafeteria.

Pastoral Care Resources can be reached at the following numbers:

Director: (443)-777-7827

Parish Nurse (443)-777-7931

Palliative Care, End of Life Care and Patient Advocacy

Clifford Goldman MD
Director of Pain Management and Palliative Care
Franklin Square Hospital Center

Objectives

- Discuss general principles of palliative and end of life and the need to improve current practices.
- Differentiate palliative care from hospice.
- Describe common issues in pain and symptom management.
- Identify the role of the Patient Care Advocacy Committee

Death and Dying in America Today

- There is a disparity between the way people die & the way they want to die
- Institutions have replaced the home as the common place where death occurs
- Care is likely given by strangers

The Need for Improved Care at the End of Life

- Late 1800's
  - Most deaths occurred at home
  - Extended family provided care
  - Most died within days of onset of illness
- Early to mid 1900's
  - Improvements in living conditions
  - Life-saving & life-prolonging treatments (antibiotics, CPR, anesthesia)
  - Focus of health care shifted from relieving suffering to curing disease

Cause of Death/Demographic and Social Trends

	Early 1900s	Current
Medicine's Focus	Comfort	Cure
Cause of Death	Infectious Diseases/ Communicable Diseases	Chronic Illnesses
Death rate	1720 per 100,000 (1900)	865 per 100,000 (1997)
Average Life Expectancy	50	76
Site of Death	Home	Institutions
Caregiver	Family	Strangers/ Health Care Providers
Disease/Dying Trajectory	Relatively Short	Prolonged

Barriers to Quality Care at the End of Life

- Lack of adequate training of professionals
- Delayed access to hospice/palliative care
- Need for Palliative Care

General Principles during end of life care

- Patient and family as unit of care
- Attention to physical, psychological, social and spiritual needs
- Interdisciplinary team approach
- Education and support of patient and family
- Bereavement Support

Volker, D. (2003). Assisted dying and end of life symptom management. *Cancer Nursing, 26(5)*, 392-398.

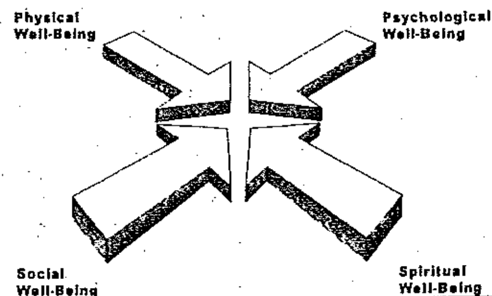
Principles of Hospice & Palliative Care

- Hospice – a program of care provided across a variety of settings, based on the understanding that dying is a part of the normal cycle of life
- Palliative Care - "Interdisciplinary care that aims to relieve suffering and improve quality of life for patients with advanced illness and their families."Center to Ad vance Palliative Care, May 2004

Components of a good EOL and Palliative care:

- Patient and family focused – what does the patient really want?
- Communication – patients and families need honest information and options
- Interdisciplinary team – all disciplines have something to offer
- Non-judgmental support from the health care environment

Model of Quality of Life



Physical Well Being

- Pain
- Multiple other symptoms
- Impact on family caregivers

Pain management

- Comprehensive pain assessment includes: location, intensity, quality, pattern, contributing or alleviating factors
- Address barriers to pain management
- Consider pharmacological and non-pharmacological therapies
- Effective pain management is every patient's right

Principles of pain management

- No ceiling for opioids; may be limited by side effects.
- If one opioid causes side effects, rotate to another, check equianalgesic dosing and start on the low side.
- Need bowel regimen with all opioids.

Principles of Pain Management

- Demerol (meperedine) should not be used routinely; not the most effective opioid and metabolite normeperidine neurotoxic, causes myclonus and seizures.Oral demerol poorly and erratically absorbed.
- Benzodiazepines are much more likely to cause sedation and respiratory depression. If patient on stable dose and concentration correct, look for benzos in the mix.

Principles of Pain Management

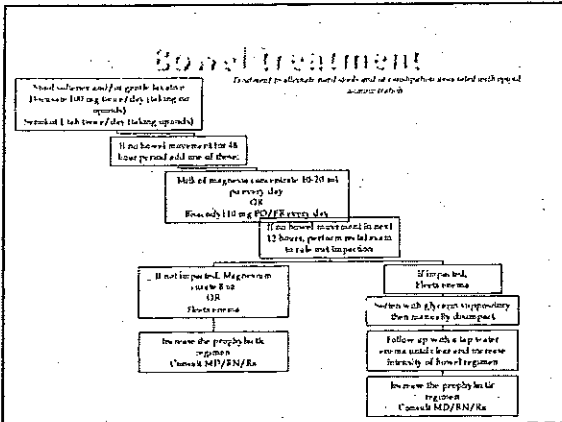
- Keep things simple: stick to one opioid; if using MS Contin, use MSIR (morphine immediate release) for breakthrough.
- For respiratory depression, secure airway, use naloxone 1 vial/10cc ns, 1cc IV at a time (rather than 1 amp all at once).

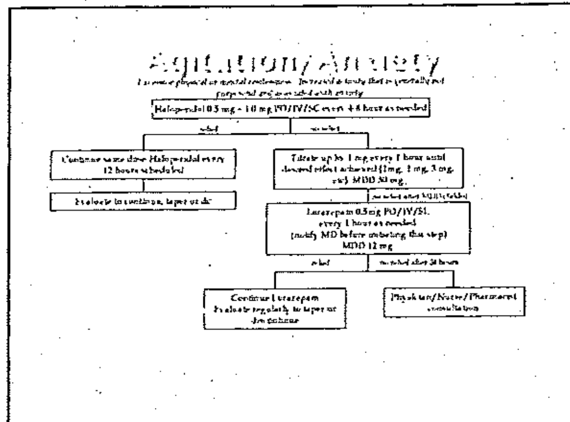
Symptom management: physical and psychological symptoms common at end of life

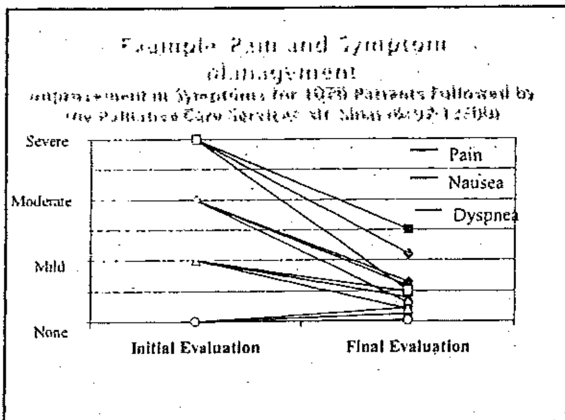
- Dyspnea
- Anorexia
- Fatigue
- Constipation/diarrhea
- Cough
- Depression
- Anxiety
- Nausea/vomiting

Dyspnea

Anorexia







Psychological Well Being

- Wide range of emotions and concerns
- Meaning of illness
- Depression
- Coping
- Cognitive assessment

Communication - families need to know that:

- You will be honest and truthful
- You will not abandon them
- You will explore realistic options
- You will respond to their questions
- You will ask for their input
- You will seek help when you need it
- You will incorporate the entire health care team
- You will take the time to listen

Communication guidelines:

- Chose the right setting: quiet, private, comfortable
- Listen actively
- Encourage patient or family to talk
- Use silence when appropriate
- Don't be afraid to share your feelings
- Avoid misunderstandings
- Give advice sparingly
- Encourage reminiscing

Communication

- Critical at the end of life
- Strong collaboration between health care professionals is a prerequisite to communication with families – we all need to be on the same page!
- Verbal, non-verbal communication, listening and presence are required for effective communication to occur

Social Well Being

- Relationship/role description
- Caregiver burden
- Sexuality concerns
- Impact on children
- Financial concerns

Ethical and Legal Issues

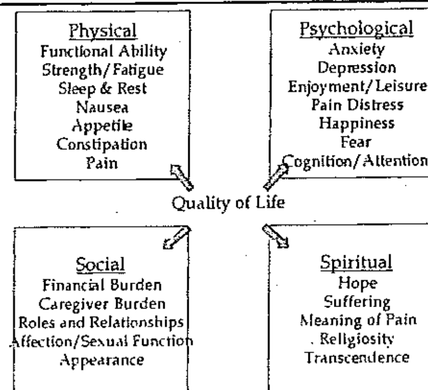
- Ethical issues are inherent in care provided at end of life:
  - Issues of care and comfort
  - Issues of consent and communication
  - Issues of the appropriateness of therapy
  - Issues of needs and resources

Opportunities for Growth

- The last phase of life provides continued opportunities for positive growth in the face of suffering

Life Closure: A Personal Experience

- Completion with worldly affairs
- Completion of community relationships
- Meaning about one's individual life
- Love of self
- Love of others
- Completion of family/friend relationships
- Acceptance of the finality of life
- New self beyond personal loss
- Meaning about life
- Surrender to the unknown
  - "Letting go"



What Palliative Care Does

- Provides expert relief of suffering
- Involves and supports family
- Focuses on complex and advanced illnesses
- Coordinates and rationalizes care
- Helps clarify and set goals with patient & family
- Helps to make system responsive to the patients
- Ends diffusion of responsibility for suffering and end-of-life care
- Provides alternative to purely curative care

What Palliative Care is not

- Does NOT seek to delay or advance death
- Is NOT "Giving up" on a patient
- Is NOT opposed to curative or life-prolonging care
- Is NOT tied to the Medicare Hospice Benefit

Interdisciplinary Team

- Physicians
- Nurses
- Chaplains
- Social workers
- Care coordinators
- Physical and occupational therapists
- Dietitians
- Support staff

Patient Care Advisory Committee

When "what is best for the patient" becomes unclear, the PCAC can help.

- disagreement/uncertainty among medical staff
- disagreement between staff and patient/family
- Uncertainty about the proper decision maker
- Uncertainty about what the law requires

Mayor,S. (2005) Clinicans need better access to ethics advise. *BMJ,330(7504)1345.*

Accessing the PCAC/Ethics Committee

Anyone directly involved in the direct care of the patient can utilize the PCAC (nurses, care associates,chaplains, doctors, therapists, social workers, etc.)

Usually the team decides together.

Contact the PCAC by calling the OPERATORS and asking to be connected with the PCAC physician on call.

How the PCAC/Ethic Committee Advocates

- Creates a safe place for clear communication
- Listens! To medical data and opinion from staff
- Listens! To concerns of patent and family
- Identifies the appropriate decision maker
- Respects the patient's autonomy
- Assists in identifying the facts...and the options
- Identifies laws or ethical principles that apply
- Offers recommendations to the staff & patient

What the PCAC brings to the conversation

- Expertise and perspective from diverse fields (medicine, nursing, social work, education, ethics, pastoral care, nutrition, PT, law, etc.)
- Objectivity
- Knowledge of law, practice with ethical principles
- Process

Patient Advocacy

The Patient Care Advisory Committee / Ethics Committee is an advisory committee.....not a punitive body.

The PCAC has other functions not directly related to patient advocacy.

Any questions?

Resources at FSHC:

- Future Pain and Symptom Management Consult team (Currently contact extension 7180)
- Pain Resource Nurses
- Case management/Social Worker
- Chaplains