# Role of Research in Building A New Discipline: Developing a Science of Psychosocial Care in Cancer

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# Barriers to Psychosocial Research in Cancer

- Diagnosis was not revealed to patient
- Stigma of mental illness attached to psychological issues, even in illness
- Belief that subjective symptoms could not be acutely reported by patient
- Psychological and social issues are “soft science”, not “real” science

# 1970s: Barriers Reduced

- Debates about telling diagnosis
- New optimism about curative cancer treatments
- Cancer survivors began to reveal their diagnosis - Happy Rockefeller and Betty Ford (1975)
- Cancer was “out of the closet”

- Around 1975, patients began to be told their diagnosis and treatment options; their psychological responses could finally be explored
- 1972 – The War on Cancer Act by President Nixon had a wider agenda
- 1$^{st}$ NCI-supported meeting in 1975 – of 25 investigators in San Antonio, TX

# Early Barrier to Research Issue

- Patient self-report was not accepted as a valid measure of subjective symptoms, neither clinically nor in research studies
- Only objective ratings by the physician were considered valid
- No rating scales were available
- First major effort was to develop **reliable** and **valid quantitative** scales to measure subjective symptoms

# 1970-90s: Valid Self Report Scales

- Validated quantitative tools were developed for
  - Health-related QOL
  - Pain
  - Fatigue
  - Anxiety
  - Depression
  - Delirium

These tools permitted evidence-based interventions to be developed and tested

Today, cancer clinical trials use patient self reported symptoms called

Patient-Reported Outcomes (PROs)

# National Comprehensive Cancer Network (NCCN)

1997 – Appointed a multidisciplinary Panel, one person from each center, to evaluate and improve psychosocial care in cancer

- Oncologist
- Nurse
- Social Work
- Psychologist
- Psychiatrist
- Clergy
- Patient

# NCCN PANEL MEMBERS FROM COMPREHENSIVE CANCER CENTERS

| Name | Discipline |
|---|---|
| J. Holland, Chair | Psychiatry |
| C. Benedetti | Oncology |
| W. Breitbart | Psychiatry |
| S. Fleishman | Psychiatry |
| P. Fobair | Social Work |
| G. Foley | Nursing |
| C. Greiner | Psychiatry |
| Rev. Handzo | Clergy |
| J. Herman | Social Work |
| P. Jacobson | Psychology |
| S. Knight | Psychology |
| M. Levy | Oncology |
| M. Loscalzo | Social Work |
| R. McAllister | Psychology |
| Rev. Randall | Clergy |
| M. Riba | Psychiatry |
| J. Shuster | Psychiatry |
| D. Snyder | Oncology |
| A. Valentine | Psychiatry |
| C. van Gunten | Oncology |
| J. Weinberg | Patient Advocate |
| M. Zevon | Psychology |

# PANEL TASK

- FIRST:
  - The label of **“Psychiatric”**, **“Psychological”**, **“Emotional”** are embarrassing and stigmatizing
  - Find a more acceptable term
  - Find word that covers psychological, social, spiritual concerns
- CHOSEN WORD: **DISTRESS**

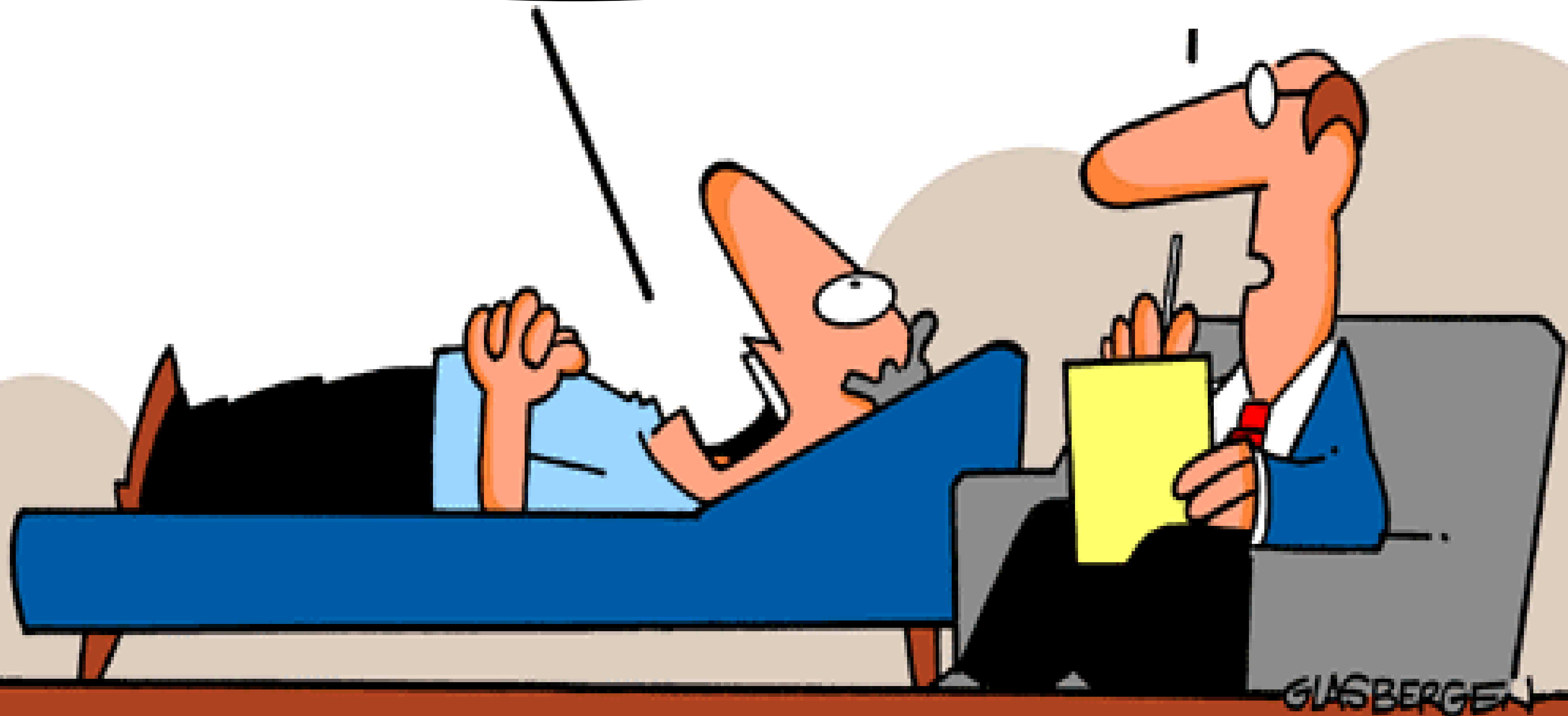
# DISTRESS CONTINUUM

| Normal Distress | Severe Distress |
|---|---|
| Fears | Depression, |
| Worries | Anxiety |
| Sadness | Family |
| | Spiritual |

# Distress is Caused by

- Physical symptoms (pain, fatigue)
- Psychological symptoms (fears, sadness)
- Psychiatric complications (depression, anxiety, delirium)
- Social concerns (for family and their future)
- Spiritual concerns – seeking comforting philosophical, religious or spiritual beliefs
- Existential concerns- seeking meaning in life while confronting possible death

"Don't you have anything better to offer me, Doctor, than **REALITY?**"

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# Standard of Care: NCCN

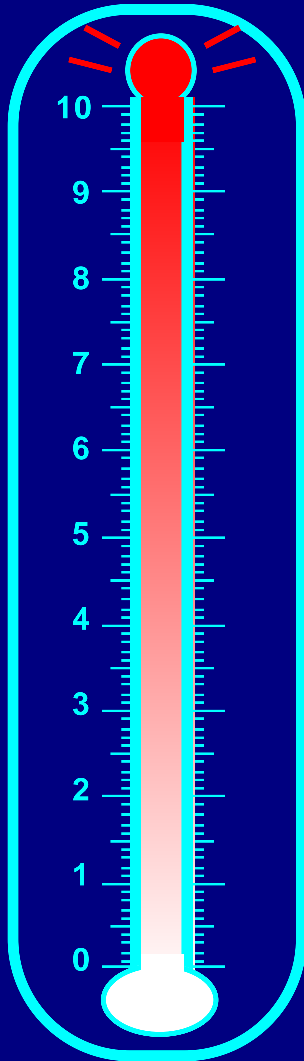
- Distress should be recognized, monitored, documented and treated promptly at initial visit and as clinically appropriate
- Screening should identify the level and nature of the distress and it should be managed by Clinical Practice Guidelines
- An interdisciplinary committee should implement and monitor standard of care

- Developed the NCCN Distress Management Standard of Care and Clinical Practice Guidelines
- Updated annually; evidence-based when possible, otherwise consensus-based by experts

- Task next was how to rapidly identify the distressed patient in a busy oncology office
- Proposed to use the successful Pain Approach:

“How is your pain on a 0 – 10 scale?”

During the past week, how distressed have you been?




Please indicate your level of distress on the thermometer and check the causes of your distress.

Practical problems
___ Housing
___ Insurance
___ Work/school
___ Transportation
___ Child care

Family problems
___ Partner
___ Children

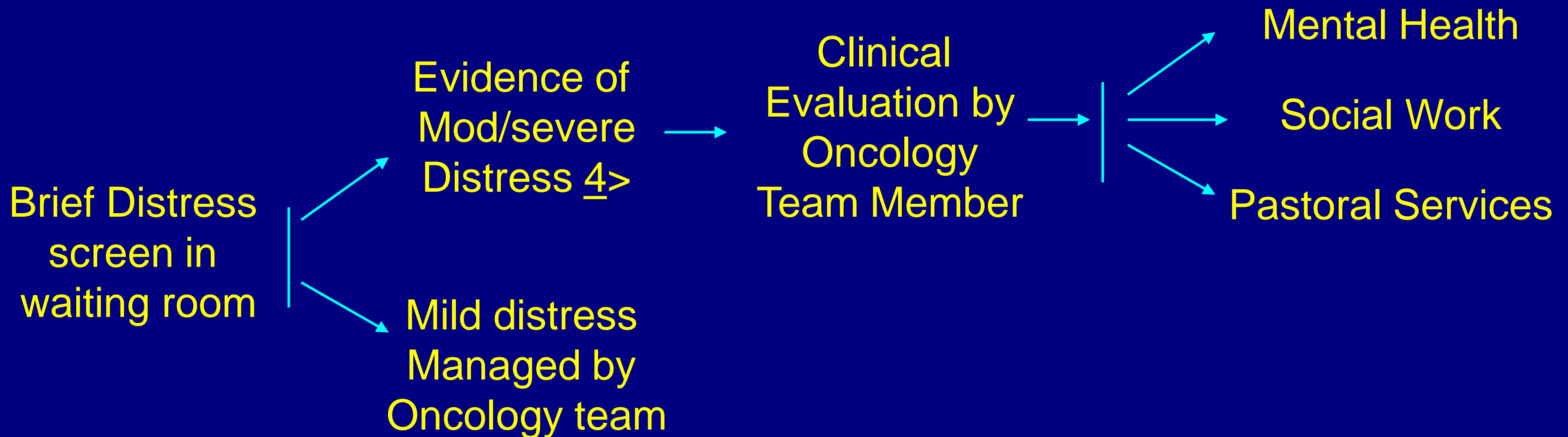
Emotional problems
___ Worry
___ Sadness
___ Depression
___ Nervousness

Spiritual/religious concerns
___ Relating to God
___ Loss of faith
___ Other problems

**Physical problems**
___ **Pain**
___ **Nausea**
___ **Fatigue**
___ **Sleep**
___ **Getting around**
___ **Bathing/dressing**
___ **Breathing**
___ **Mouth sores**
___ **Eating**
___ **Indigestion**
___ **Constipation/diarrhea**
___ **Bowel changes**
___ **Changes in urination**
___ **Fevers**
___ **Skin dry/itchy**
___ **Nose dry/congested**
___ **Tingling in hands/feet**
___ **Feeling swollen**
___ **Sexual problems**

**BRIEF SCREENING TOOL AND PROBLEM LIST**

# NCCN Practice Guidelines



# National Attention to Complaints of Poor Psychosocial Care by Cancer Patients

2005 — $1,000,000 to NIH to study "barriers to psychosocial care for patients with cancer and their families in <u>community</u> settings"

2006-07 — Given to Institute of Medicine to appoint a Multi-disciplinary Committee

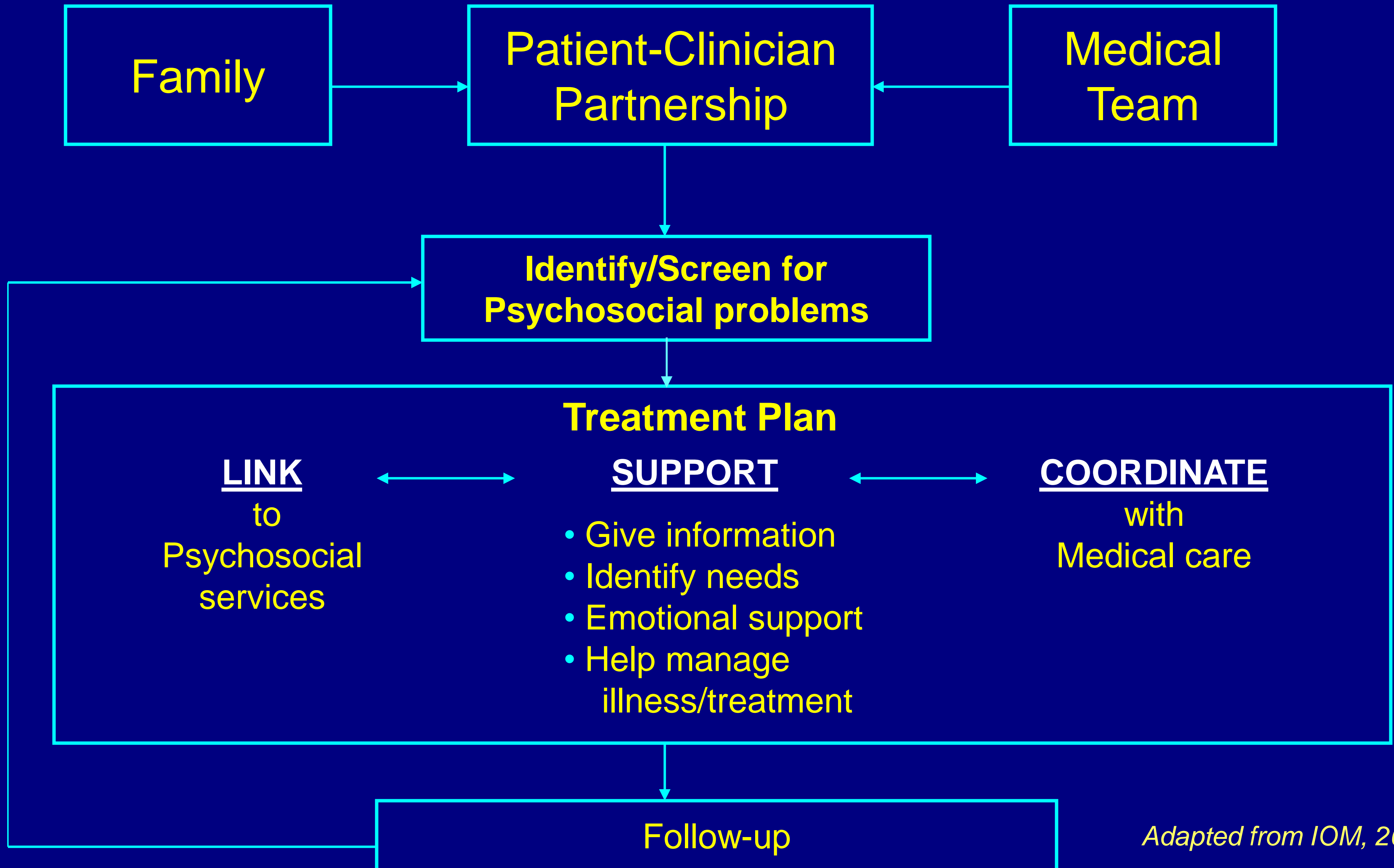
# Result: Strong Evidence Base for Psychosocial Interventions

- Communication: Doctor-Patient
- Psychotherapy/Counseling
- Psychopharmacological
- Self-management (diabetes, CVD)
- Behavior change (smoking)
- Burden of caregiver

# IOM Report: A New Standard of Quality Cancer Care: 2008

- The psychosocial domain must be integrated into routine cancer care

# Model for Psychosocial Services




*Adapted from IOM, 2008*

# 2009 ASCO: Quality Oncology Practice Initiative (QOPI)

- 100 community oncologists have voluntarily audited their practice through QOPI
- Psychosocial quality indicators now included in <u>all</u> QOPI audits
- Quality of psychosocial care can now be assessed; a “report card” can be given

# 2011 American College of Surgeons Commission of Cancer Endorsed

New Standard for accreditation of 1500 cancer centers which requires that the psychosocial domain be a component of routine care by 2015

- How do we implement the new standard into routine care?
- Implementation is the big next step to alter routine practice patterns – HARD JOB!

# International Psycho-Oncology Society

Adapted the IOM Standard:

- **Quality care must integrate the psychosocial domain into routine care**
- **Distress should be identified as the sixth vital sign after pain**

# 2014

IPOS Quality Standard through the International Union Against Cancer (UICC), has been endorsed by 72 affiliated Organizations

**Statement on Standards and Clinical Practice Guidelines in Clinical Care**

**International Endorsement**

# 2014: A Science of Care

- Evidence based interventions and treatment guidelines for care of the whole patient established **a science of psychosocial care**
- Distress screening (recognition, triage and referral of distressed patients) must be part of routine oncology care

# Distress Should Be

Monitored routinely now as the

6th VITAL SIGN

- Pulse
- Respiration
- Temperature
- Blood pressure
- **Pain (0-10)**
- **Distress (0-10)**

***Endorsed by Canada Cancer Council 2005***

# Psychosocial Research Today

- In cancer prevention / detection (smoking, exercise, diet)
- In coping with diagnosis and treatment
- In cancer survivors
- IN PALLIATIVE AND END-OF-LIFE CARE

# Psychosocial Issues in Palliative Care

Two Components

- PAIN
  - Pain
  - Physical symptoms
- SUFFERING
  - Psychological
  - Social
  - Spiritual/Existential

# “Suffering of the Mind”: Distress of Illness

- Physical symptoms (pain, fatigue)
- Psychological symptoms (fears, sadness)
- Social concerns (for family and their future)
- Spiritual concerns – seeking comforting philosophical, religious or spiritual beliefs
- Existential concerns – seeking meaning in life and possible death

**“We are not ourselves when nature, being oppressed, commands the mind to suffer with the body”**

**King Lear, Act II**

**“Psycho-Oncology is the only subspecialty in cancer that is involved in the care of <u>every</u> patient at <u>every</u> visit, irrespective of disease or treatment modality – this is the human side of cancer care”**

*James F. Holland, MD*

*Oncologist and Supportive Spouse*