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

• 1st 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

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<tr>
<th>Name</th>
<th>Department</th>
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<tr>
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<td>J. Weinberg</td>
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<td>M. Zevon</td>
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• 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

Fears
Worries
Sadness

Severe Distress

Depression,
Anxiety
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?”
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
NCCN Practice Guidelines

Brief Distress screen in waiting room

Evidence of Mod/severe Distress 4>
- Mild distress Managed by Oncology team
- Clinical Evaluation by Oncology Team Member

Mental Health
- Social Work
- Pastoral Services
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 community 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

1. **Family**
2. **Patient-Clinician Partnership**
3. **Medical Team**

- **Identify/Screen for Psychosocial problems**

**Treatment Plan**
- **LINK** to Psychosocial services
- **SUPPORT**
  - Give information
  - Identify needs
  - Emotional support
  - Help manage illness/treatment
- **COORDINATE** with Medical care

**Follow-up**

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 all 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!
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
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 every patient at every visit, irrespective of disease or treatment modality – this is the human side of cancer care”

James F. Holland, MD
Oncologist and Supportive Spouse