The New International Standard for Quality Cancer Care: Integrating the Psychosocial into Routine Care

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UICC World Congress, Montreal, Canada
August 29, 2012
Developing a Science of the Care of the Whole Patient
Historical Attitudes Toward Cancer In First Half of Twentieth Century

- Belief was that cancer equals death
- Diagnosis was not revealed to patient; it was considered cruel and inhumane: “they will give up hope”
- Fears of a disease with no known cause or cure.
- Patients with cancer were stigmatized by society (ashamed; a “secret”)
Historical Attitudes Toward Mental Illness/Psychological Issues

• The centuries old fears, negative attitudes and stigma toward mental illness/psychiatric / psychological and emotional problems - even in the context of life-threatening illness - impeded attention to the psychological domain of cancer care.
Psychological Issues in Medical Illness: 1960s

• Interest in the psychiatric complications of medical patients
• Consultation-liaison psychiatry began with focus on medically ill
• Kubler-Ross encouraged talking with dying patients and end-of-life care
• Engel’s biopsychosocial concept expanded Adolf Meyer’s earlier “psychobiology” concept
Attitudinal Barriers Reduced: 1970s

- New optimism about curative treatments and concern about long-term side effects
- Debates about telling diagnosis
- More cancer survivors who revealed their diagnosis
- Cancer revealed by Happy Rockefeller and Betty Ford (1975)
- Womens’ and patients’ rights movements
- Cancer was “out of the closet”
• Around 1975, the stigma of silence began to be broken in the US. Patients began to be told their diagnosis and treatment options; their psychological responses could finally be explored

• Psycho-oncology, psychosocial oncology, behavioral oncology, quality of life research began only in the last quarter of the 20th century
PSYCHO-ONCOLOGY Definition

- Multidisciplinary subspecialty of oncology concerned with the emotional responses of patients at all stages of disease, their families and staff (PSYCHOSOCIAL)

- The psychological, social and behavioral variables that influence cancer prevention, risk and survival (CANCER CONTROL)
Early Research Issue

• Patient self-report was not accepted as a valid measure of subjective symptoms
• Only objective ratings by the physician were considered valid
• Most rating scales available were designed to measure symptoms of mental illness
• First major effort was to develop **reliable** and **valid quantitative** scales to measure subjective symptoms
1970-80s: Early Psychosocial Research

- Validated **quantitative** tools for assessment of subjective symptoms were developed
- Health-related QOL
- Pain
- Fatigue

- Anxiety
- Depression
- Delirium
N = 4,496 Patients by Brief Symptom Inventory (BSI)
Overall prevalence = 35%

By Site:

- Lung 43%
- Brain 42%
- Pancreas 36%
- Head & Neck 35%
- Liver 35%

Zabora, et al., 2001
Managed Care: Today in US

Most cancer care is in overly busy offices and clinics

RESULT: patients psychosocial problems receive little attention
1997 – Appointed a multidisciplinary Panel, one person from each center, to evaluate and improve psychosocial care in cancer

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

Worries

Family

Sadness

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
- Developed the NCCN Distress Management Standard of Care and Clinical Practice Guidelines

- Updated annually; evidence-based when possible, otherwise consensus-based by experts
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
• 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
Clinical evidence of moderate to severe distress or score of 4 or more on screening tool (DIS-A)

Brief screening for distress (DIS-A):
- Screening tool
- Problem list

Unrelieved physical symptoms, treat as per disease specific or supportive care guidelines

Clinical evidence of mild distress or score of less than 4 on screening tool (DIS-A)

If necessary

Primary oncology team + resources available

Mental health services

Social work services

Pastoral services

Referral

EVALUATION
Clinical assessment by primary oncology team of oncologist, nurse, social worker for:
- High risk patients
  - Periods of vulnerability
  - Risk factors for distress
  - Practical problems
  - Family problems
  - Spiritual/religious concerns
  - Physical problems

TREATMENT
Distress Should Be Monitored routinely now as the 6th VITAL SIGN to be checked:

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

Endorsed by Canada Cancer Council 2005
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
- The psychosocial domain must be integrated into routine cancer care
Model for Psychosocial Services

Family → Patient-Clinician Partnership → 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
How do we move from establishing a new standard to implementing it in routine clinical care?
Basic Step: Measure Quality of Care

• Measure quality of psychosocial care in a given practice / clinic

• Pilot project in Florida Quality Care Initiative (5 cancer centers) to audit colorectal cancer care

• Added psychosocial questions to chart audit

APOS Working Committee Chair, Jacobson
Emotional well-being assessed?

(N = 388, Overall = 60%, Range = 6% to 84%)
Pain Assessed?

(N = 388, Overall = 87%, Range = 72% to 98%)
ASCO: Quality Oncology Practice Initiative (QOPI)

- Community oncologists may request an audit through QOPI
- **Psychosocial quality indicators now in all QOPI office audits**
- Quality of psychosocial care can now be assessed; a “report card” can be given
New Standard for accreditation which includes requirement that the psychosocial domain be a component of routine care
Established an international quality standard:

- Quality care must integrate the psychosocial domain into routine care
- Distress should be identified as the sixth vital sign after pain
August, 2012

IPOS Quality Standard through the UICC, has been endorsed by 47 Organizations
Statement on Standards and Clinical Practice Guidelines in Clinical Care

International Endorsement
2012: A Science of Care

- Evidence based interventions and treatment guidelines for care of the whole patient establishes a science of care.

- Distress screening (recognition, triage and referral of distressed patients) must be part of routine oncology care to meet the new international standard of quality cancer care.
Developing a Science of Care was essential, however the humanistic dimension remains critical.
The secret of the care of the patient is in caring for the patient.

Francis Peabody, MD

JAMA. 1927;88(12):877-882
BRISBANE, AUSTRALIA

IPOS 14th World Congress and COSA's 39th Annual Scientific Meeting

11-15 November 2012
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