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

Jimmie Holland, M.D.
Memorial Sloan-Kettering Cancer Center
New York, New York

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

SCREENING FOR DISTRESS – 1

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

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

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
Worries
Sadness

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

- 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

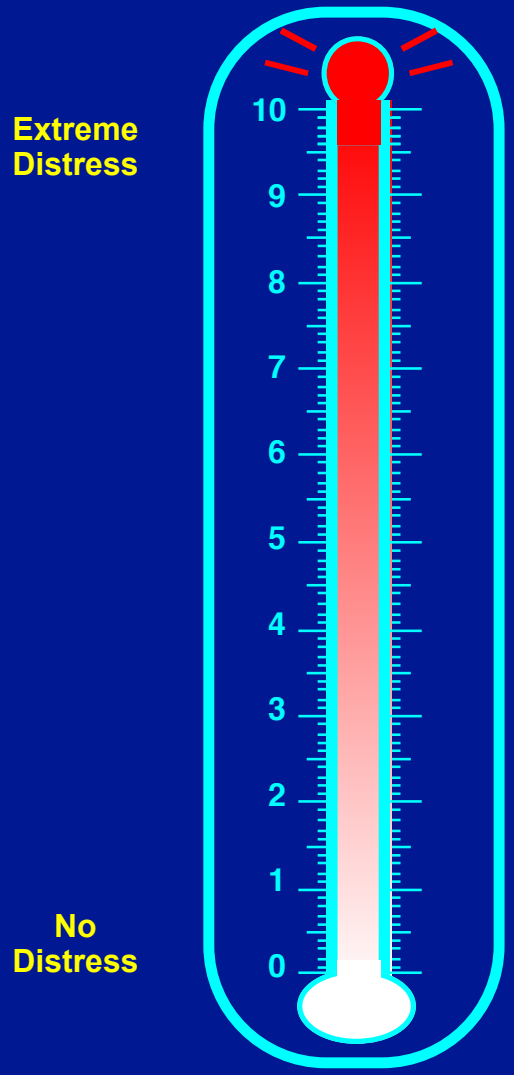
- Distress should be recognized, monitored, documented and treated promptly at initial visit and as clinically appropriate
- Screening should identify the level and nature of the distress and it should be managed by Clinical Practice Guidelines
- An interdisciplinary committee should implement and monitor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

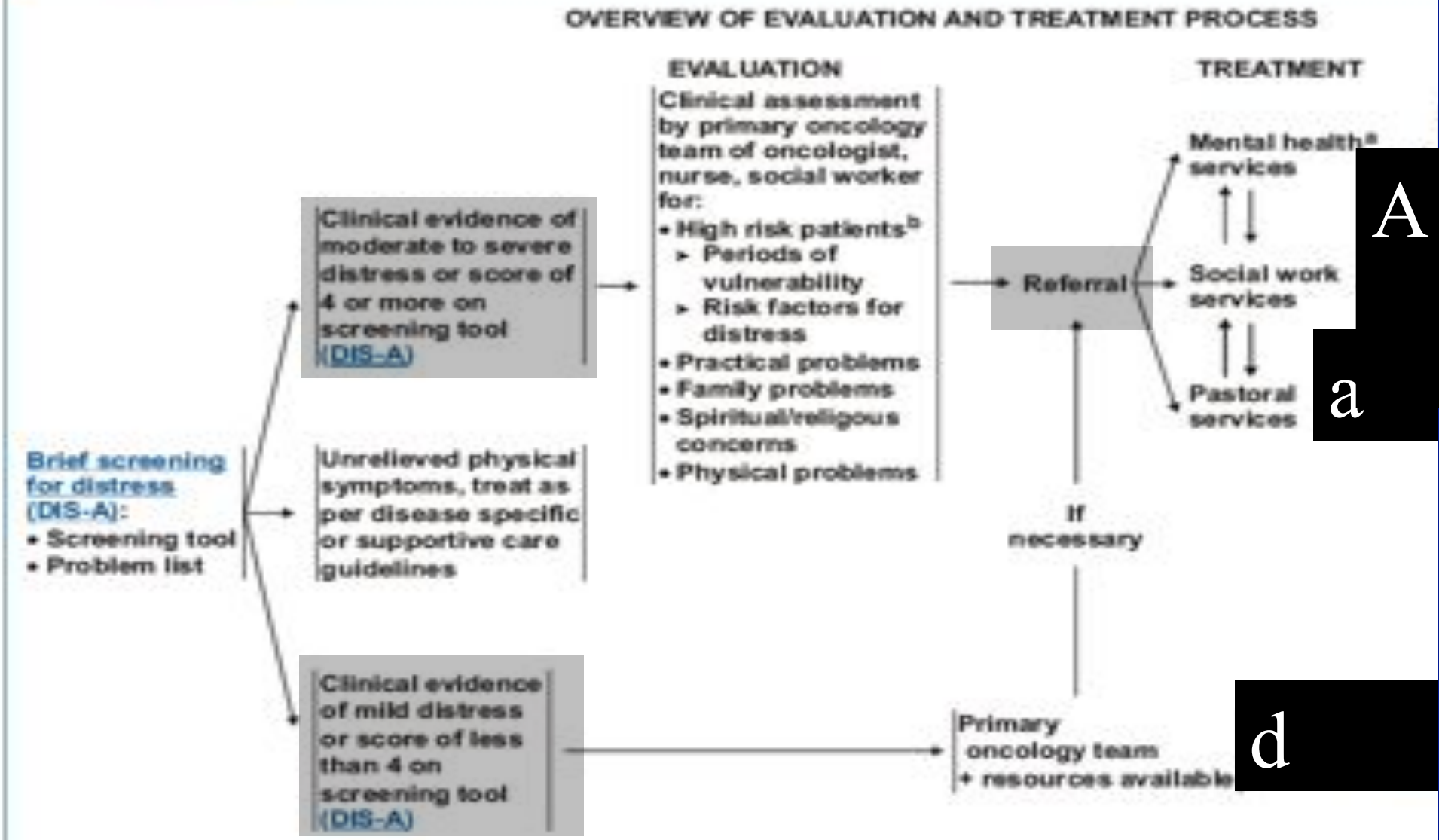
Spiritual/religious concerns
__ Relating to God
__ Loss of faith
__ Other problems

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

NCCN® Practice Guidelines in Oncology – v.1.2007

Distress Management



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

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

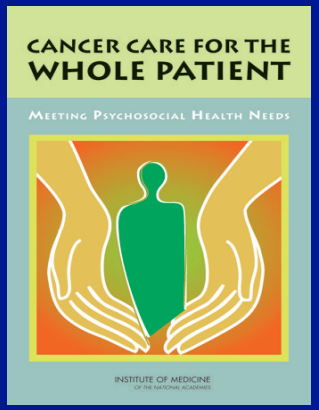
- The psychosocial domain must be integrated into routine cancer care

REPORT

The Institute of Medicine (IOM)

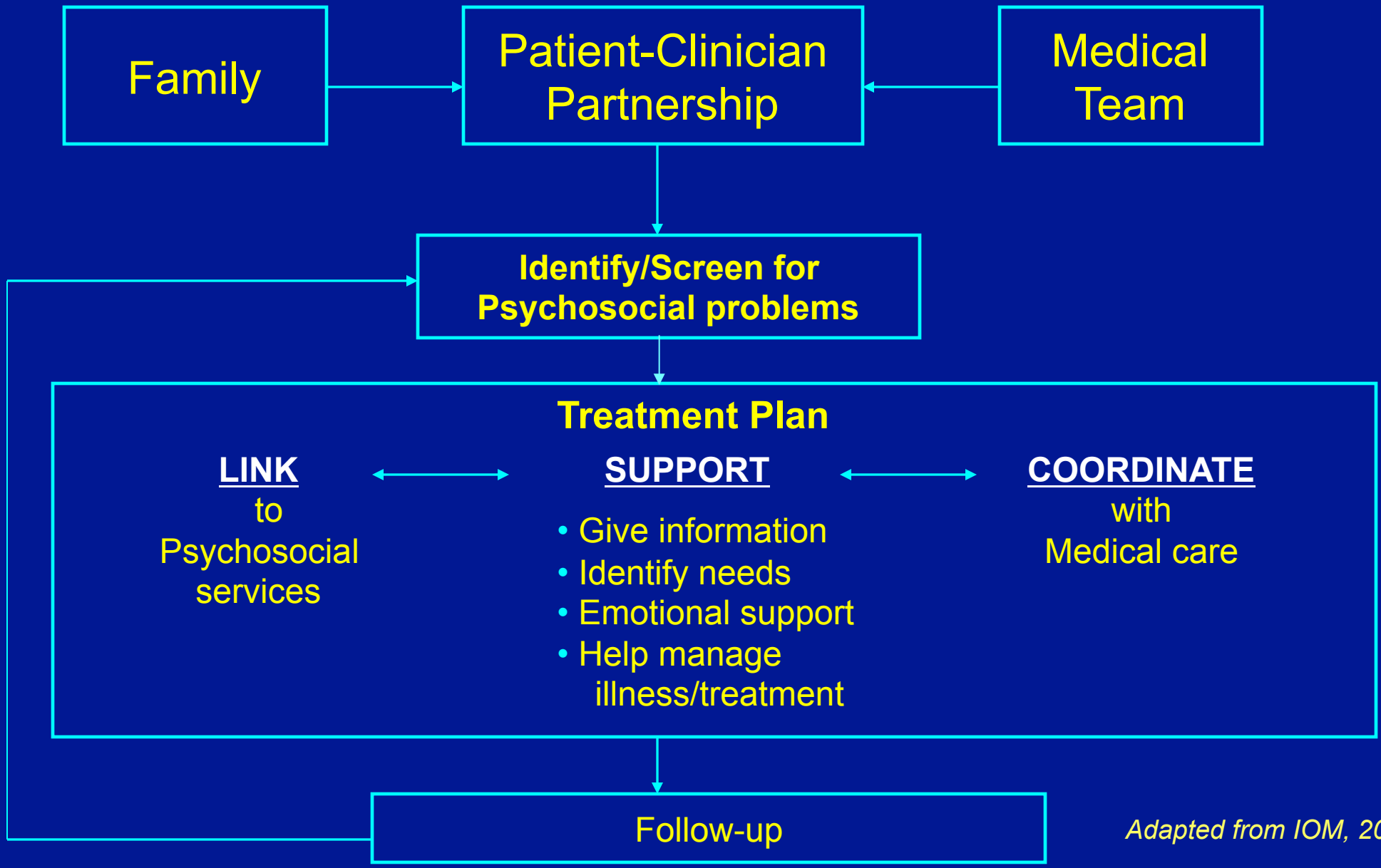
Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs

Released:



Published, 2008

Model for Psychosocial Services



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

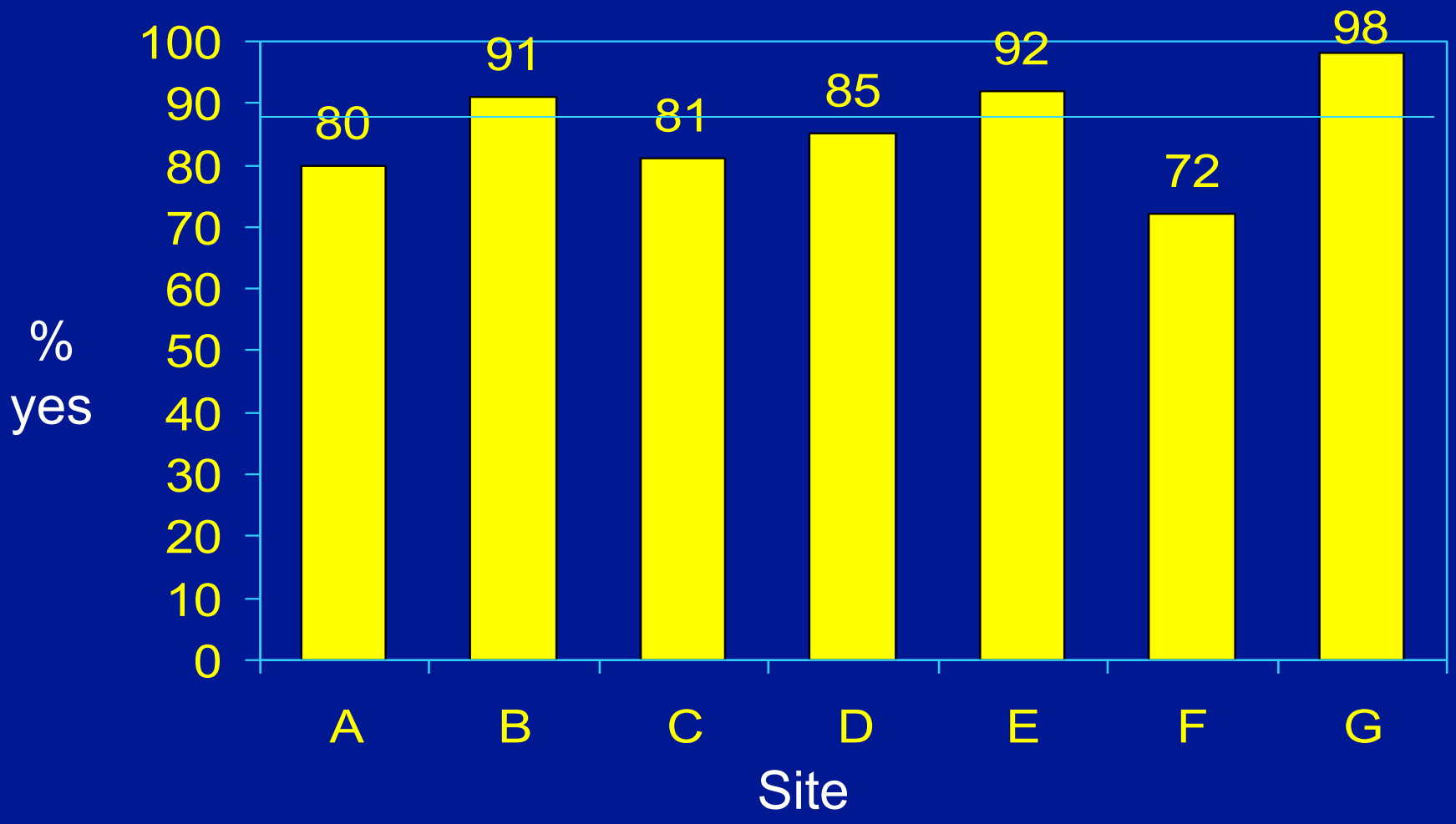
- Measure quality of psychosocial care in a given practice / clinic
- Pilot project in Florida Quality Care Initiative (5 cancer centers) to audit colorectal cancer care
- Added psychosocial questions to chart audit

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 <u>all</u> QOPI office 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 which includes requirement that the psychosocial domain be a component of routine care

International Psycho-Oncology Society

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


Cancer
Council
Victoria


Cancer
Council
Western Australia


Cancer
Focus
NORTHERN IRELAND


CANCER
PATIENTS AID
ASSOCIATION


Clinical
Oncological
Society of
Australia


DUTCH
CANCER
SOCIETY


財團法人
台灣癌症基金會
FORMOSA CANCER FOUNDATION

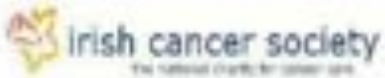

LÖSEV


HOSPIS
MALAYSIA


YAYASAN KANKER INDONESIA


INCTR
International
Network
for Cancer Treatment and Research


SIOP


irish cancer society


LEBANESE CANCER SOCIETY
SOCIÉTÉ LIBANAISE DU CANCER


LIVESTRONG


National
Cancer
Society
Malaysia


neolife


NCRS


PHILIPPINE CANCER SOCIETY

Prostate Cancer Foundation of Australia

PoCoG

REACH FOR RECOVERY
BREAST CANCER SUPPORT GROUP
Reach for Recovery Kenya

REACH TO RECOVERY
INTERNATIONAL

SEPO

Cancerfonden
Swedish Cancer Society

TBCA
中華民國乳癌病友協會
Taiwan Breast Cancer Alliance

Turkish Psychosocial Oncology Association

UICC
global cancer control

V Care
V Care Foundation

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 Care of the Patient

Francis Peabody, MD

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

"The secret of the care of the patient is in caring for the patient."


BRISBANE, AUSTRALIA
IPOS
International Psycho-Oncology Society
IPOS 14th World Congress and COSA's 39th Annual Scientific Meeting
Clinical Oncological Society of Australia
11-15 November 2012
www.ipos-cosa.org