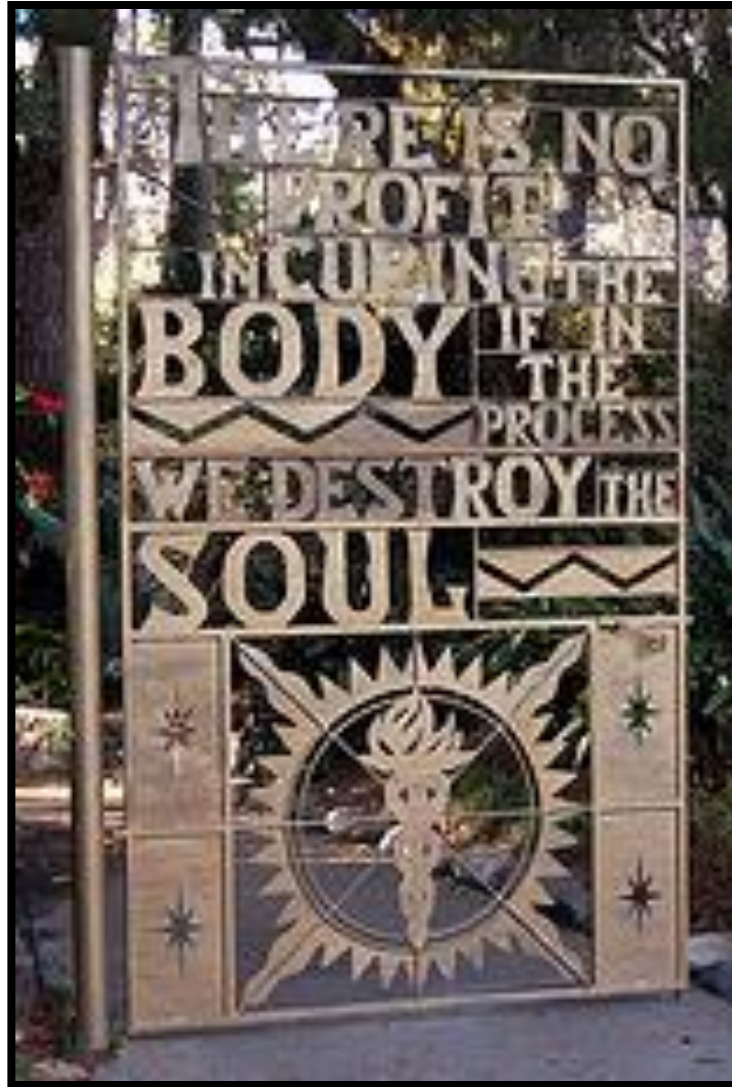


the **MIRACLE** of **SCIENCE** with **SOUL**



“Fostering Partnerships in Oncology and Palliative Care”

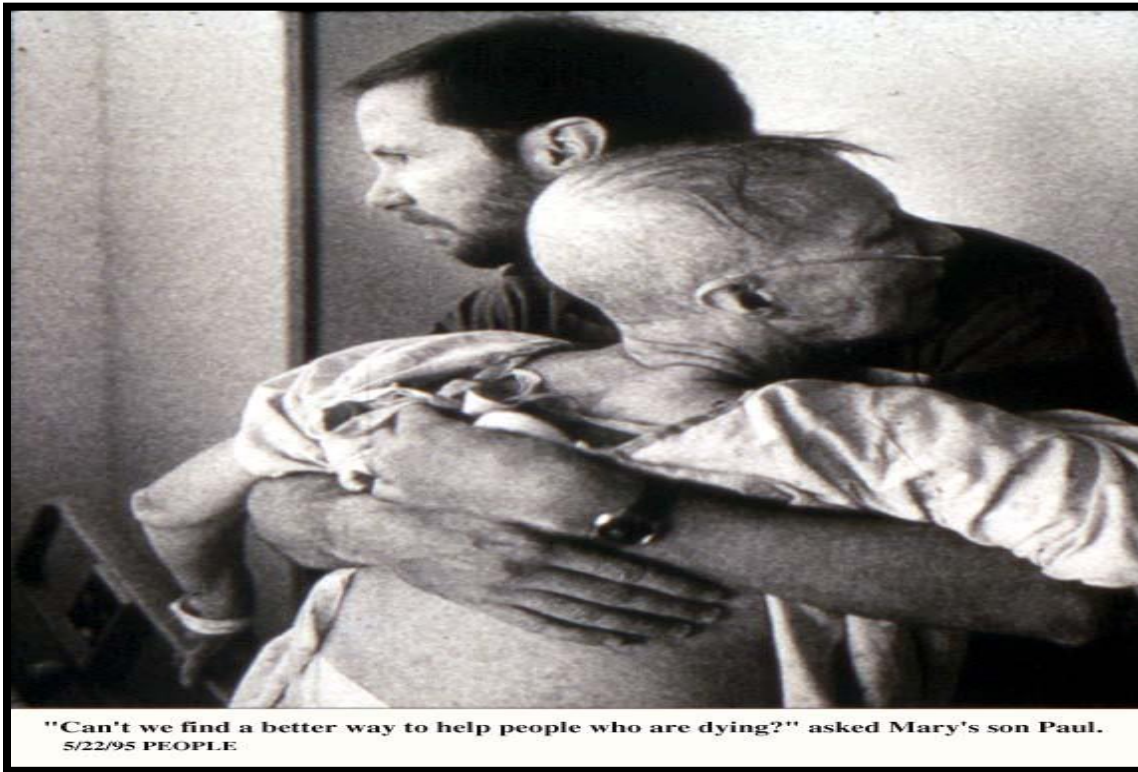
Betty Ferrell, PhD, RN, MA, CHPN, FAAN, FPCN
Professor & Director
City of Hope
National Medical Center
Division of Nursing Research and Education



Objectives

1. Describe the “common ground” of oncology and palliative care.
2. Identify steps in building collaborative relationships.
3. Recognize the value of research, education and practice initiatives in oncology and palliative care.

Why Do Research in Palliative Care?



**"Can't we find a better way to help people who are dying?" asked Mary's son Paul.
5/22/95 PEOPLE**

Death and the Research Imperative

New England Journal of Medicine

**Daniel Callahan, PhD
Hastings Center**

March 2, 2000

From the cellular to the social level,
much remains to be learned about how
people die and how reliably excellent and
compassionate care can be achieved.

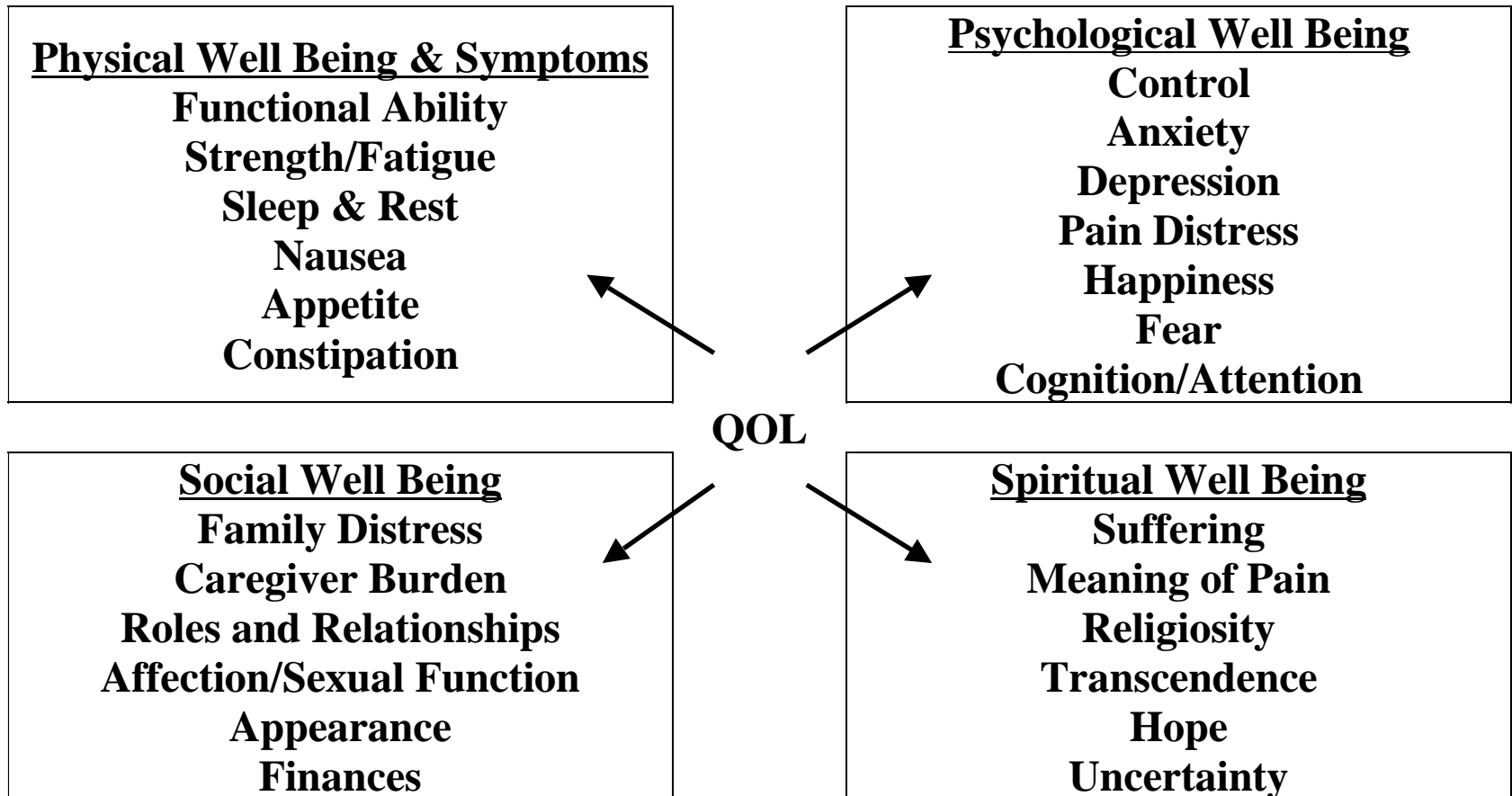
(Cont.)

Important, unanswered questions exist about the fundamental physiological mechanisms of the symptoms that cause so much suffering among dying patients and about the kinds of interventions that will relieve these symptoms.

-Callahan,2000



Dimensions of Quality of Life



Barriers to Research In Palliative Care

- ❖ Overall limitations in funding for research and in the number of palliative care researchers.
- ❖ Research establishment and associated funding has been focused on rehabilitation or cure.

(Cont.)

Barriers to Research In Palliative Care

- ❖ Lack of political or consumer advocates to promote research in end of life care.
- ❖ Limited focus on palliative care in graduate education to promote end of life research.

(Cont.)

Barriers to Research In Palliative Care

- ❖ Rapidly declining status limits subject accrual and opportunity for longitudinal measures.
- ❖ Lack of conceptual frameworks appropriate for palliative care research.

(Cont.)



Barriers to Research In Palliative Care

- ❖ Late referrals to hospice or palliative care programs severely restricts opportunities for accrual to studies.
- ❖ Participation in research interferes with demands of patient care.

(Cont.)

Barriers to Research In Palliative Care

- ❖ Lack of research instruments and methods appropriate for this population.
- ❖ Challenge of conducting research in a sensitive area.

(Cont.)



Barriers to Research In Palliative Care

- ❖ Balancing demands of rigorous research (such as the need for randomization) with awareness of patient needs.

Building a Palliative Care Research Program

- ❖ Identifying the needs
- ❖ Research to fill the gap
- ❖ Clinically relevant research
- ❖ Dissemination to others

Patient and Family Caregiver Studies (1984-1999)

- ❖ Pain Management at Home
- ❖ Family Factors Influencing Cancer Pain Management
- ❖ Pain Education Intervention for Patients and Family Caregivers

(Cont.)

Patient and Family Caregiver Studies (1984-1999)

- ❖ Dissemination of Pain Education in Home Care
- ❖ Family Caregiver Quality of Life

(Cont.)

Patient and Family Caregiver Studies (1984-1999)

- ❖ Cultural Adaptation of Pain Education
- ❖ Cancer Pain Education for Patients & Public (CPEPP)



From Pain to Palliative Care: Pain Education in Home Care



HOPE Project – Home Care Outreach for Palliative Care Education

Phase 1 Development and pilot in 2 agencies (PDIA)

Phase 2 5 local agencies & national conferences (NCI)

Ovarian Cancer / QOL Research

- ❖ QOL Survey 1996
- ❖ “Conversations” Qualitative Analysis
- ❖ Quantitative Survey (11/02)
- ❖ QOL Intervention

CARING.....SHARING.....HOPING.....HEALING.....HELPING.....COPING.....HUMORing



CONVERSATIONS!



The International Newsletter for Those Fighting Ovarian Cancer

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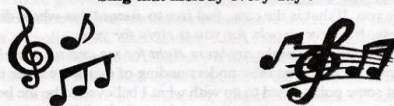
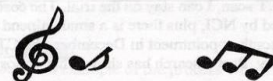
CINDY'S NOTES: This opening thought has been excerpted from a speech by Marguerite Patricia Gilner of MD. The speech was titled, "The HOPE Advantage: How To Thrive While Surviving Cancer".....

"Like other crises, cancer has a way of shifting priorities in our lives. Little changes begin to happen when we are open to the goodness of God and others. With grateful hearts we can appreciate the simple things of life—even in the midst of our difficult times. As we know, cancer does not discriminate. It often attacks without warning and it drastically changes the course of our lives."

"How do we learn to live with the uncertainty and fear caused by our cancer diagnosis? How do we manage to be hopeful? I believe the answer is in striving to live for today and choosing to celebrate life one day at a time. Fear traps us in our pain. Hope gives us the vision to dream impossible dreams and believe they will come true. Even though hope is a positive and affirming word, it is also a word that requires conviction, responsibility, and action. We cannot simply hope and expect change; we need to participate actively in the course of events so we can create that change positively." (Patricia's recipes for HOPE and THRIVING are on the last page of this issue.)

"We all have a song of hope in our hearts.
Listen !

Recognize the melody that resounds in your heart and offers you hope.
Sing that melody every day !"



Explanation of this issue: One of the most difficult questions for any of us who are fighting any type of cancer is determining what treatment options exist and which would work the best for our specific situation. After working through this process with others and for myself, I decided to attempt to put this complex process down on paper. The remainder of this issue is comprised of steps in my process as well as the most useful tools I found. (I apologize for the wrap-around of topics from page to page, but it was necessary to keep the printing and mailing costs down.)

If you have something to add/suggest as well, send it to me for addition.

If you are NOT interested in clinical trials or in finding additional treatments after the initial surgery and treatment, then you might want to skip reading this issue. I'll catch you in March.

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Analysis of “Conversations” Correspondence

- ❖ Correspondence from 1993-2000
- ❖ n=21,806 letters, cards, email
- ❖ Ethnographic methods used to analyze “data” from 2001-2002



Subsequent OVCA Intervention Studies

- Cancer Survivorship
- Pain
- Family Caregiving

Reducing Barriers to Pain & Fatigue Management

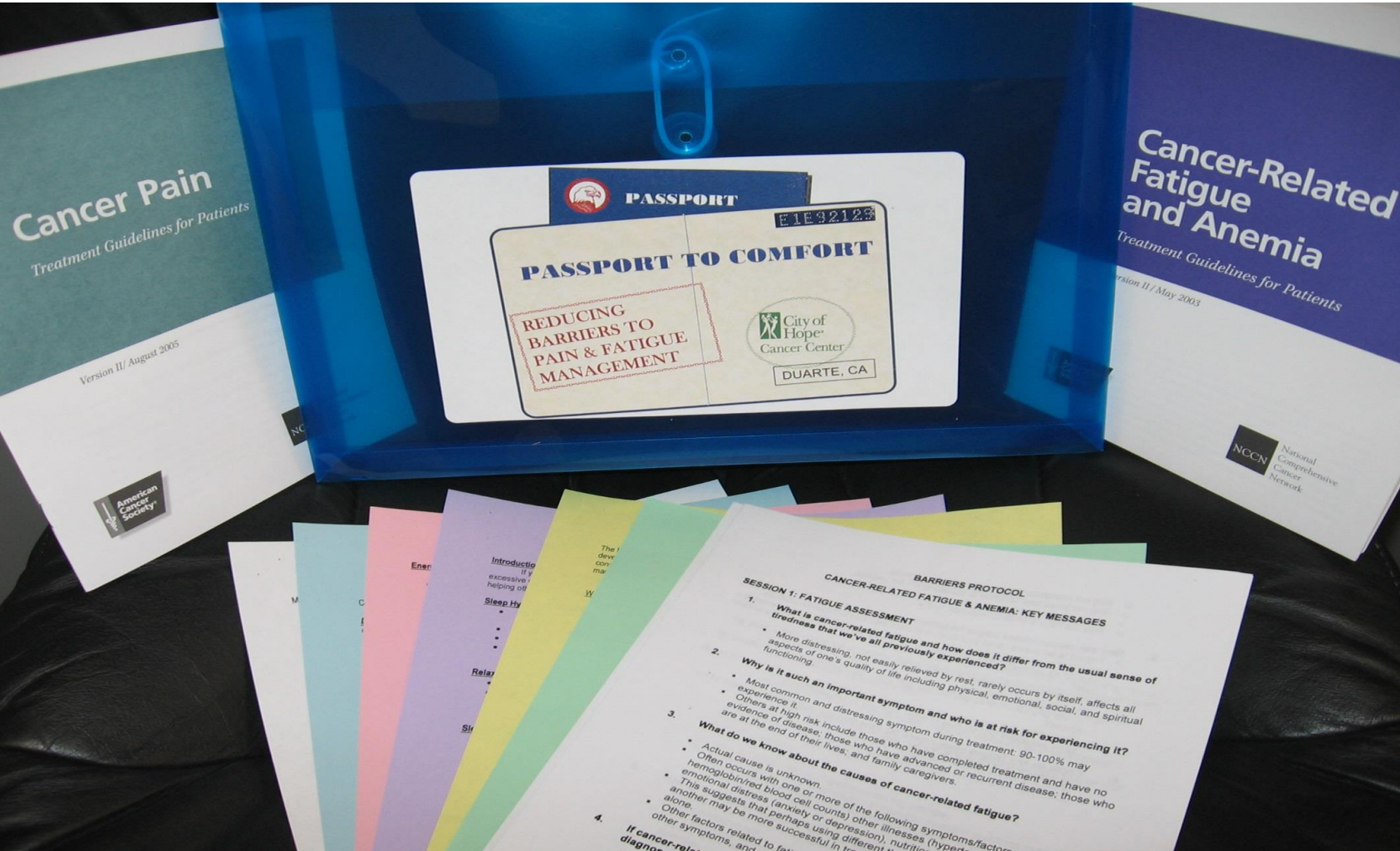
Betty Ferrell, PhD, FAAN, Tami Borneman, RN, MSN, CNS,
Virginia Sun, RN MSN, NP, Marianna Koczywas, MD,
Barbara Piper, DNSc, FAAN

Funded by NCI

Study Phases

Phase 1	Phase 2	Phase 3
Baseline Usual Care	High Intensity Passport Intervention Patient Professional System	Low Intensity Passport Intervention Patient Professional System

Phase II Patient Education Packets



From Pilot to P01

1. Unfunded chart review of lung cancer with a surgical fellow
2. Institutional pilot to develop intervention
3. P01 (11 million funded by NCI)
4. Dissemination (R01 funded by NINR)

Lessons Learned

- ❖ Be focused
- ❖ Think of your research in phases or steps
- ❖ Research only what you care about passionately
- ❖ Don't let the tail wag the dog
- ❖ Interdisciplinary Collaboration

Lessons Learned

- ❖ Seek input liberally
- ❖ Be very, very flexible
- ❖ Value descriptive research
- ❖ Use diverse methods
- ❖ Be realistic
- ❖ Listen to the mission / agenda of others
- ❖ PUBLISH!!!