Cancer Care Outcomes Research and Surveillance Consortium (CanCORS)

3rd International Cancer Control Congress
8-11 November 2009

Cernobbio, Como, Italy

Dee W. West, Ph.D.

Professor of Epidemiology – Health Research and Policy

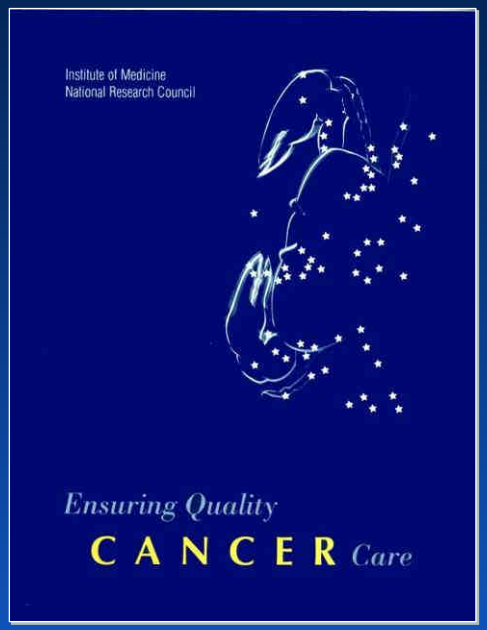
Stanford University School of Medicine

Chief Scientific Officer

Northern California Cancer Center

Disparities in quality of care

"*For many Americans with cancer, there is a wide gulf between what could be construed as the ideal and the reality of their experience with cancer care*." (IOM, 1999)



Studies have repeatedly shown quality of cancer care varies by:

- **Age**
- **Race/ethnicity**
- **Education/income**
- **Geography**

But we don't really know *why* disparities occur

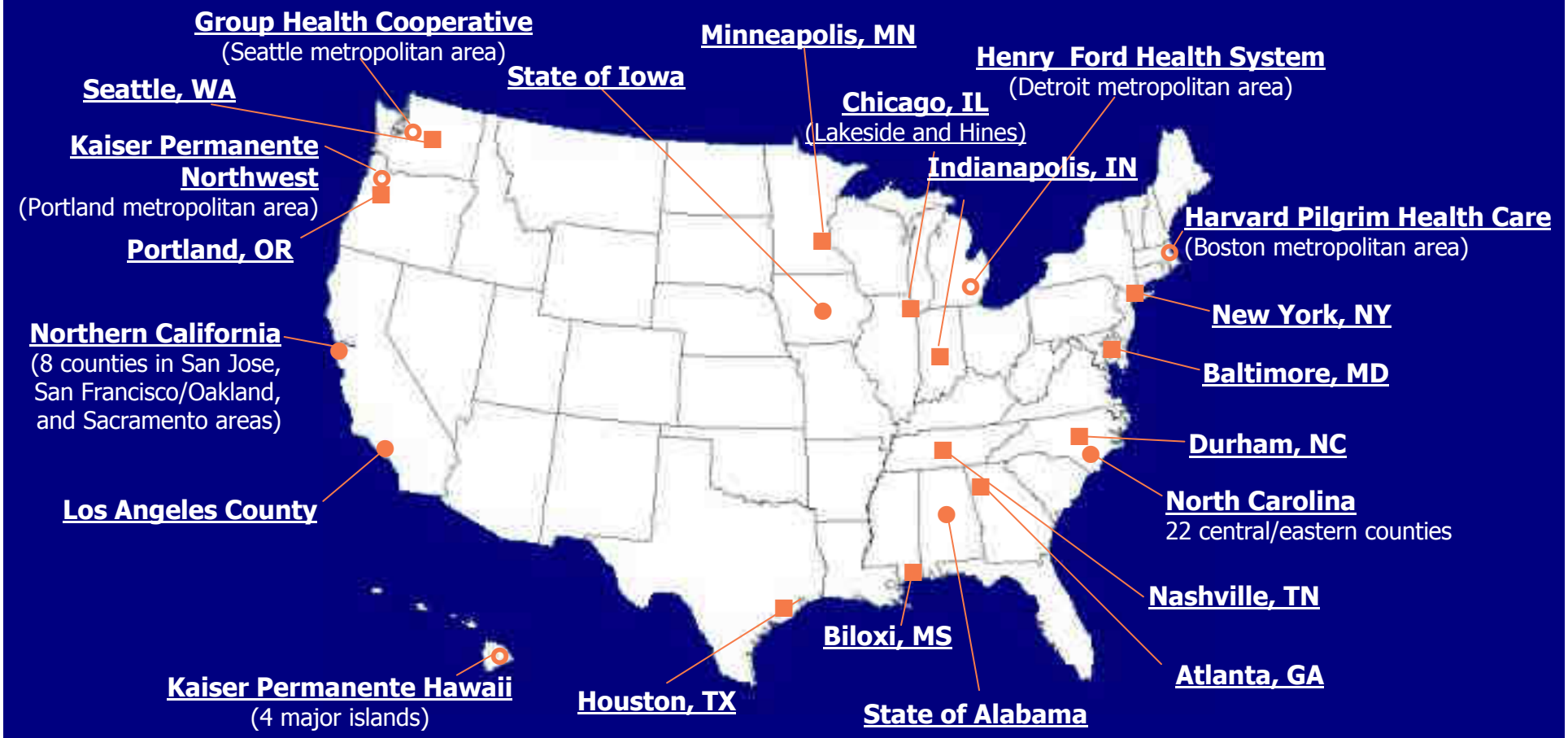
Possible explanations

- **Patients**
  - **Lack of information**
  - **Preferences (Cultural, cost, etc.)**
- **Physicians**
  - **Inadequate knowledge base**
  - **Biases**
- **“The System”**
  - **Inadequate facilities/access**
  - **Poor coordination of care**
  - **Inadequate reimbursement**
  - **Biases**

CanCORS

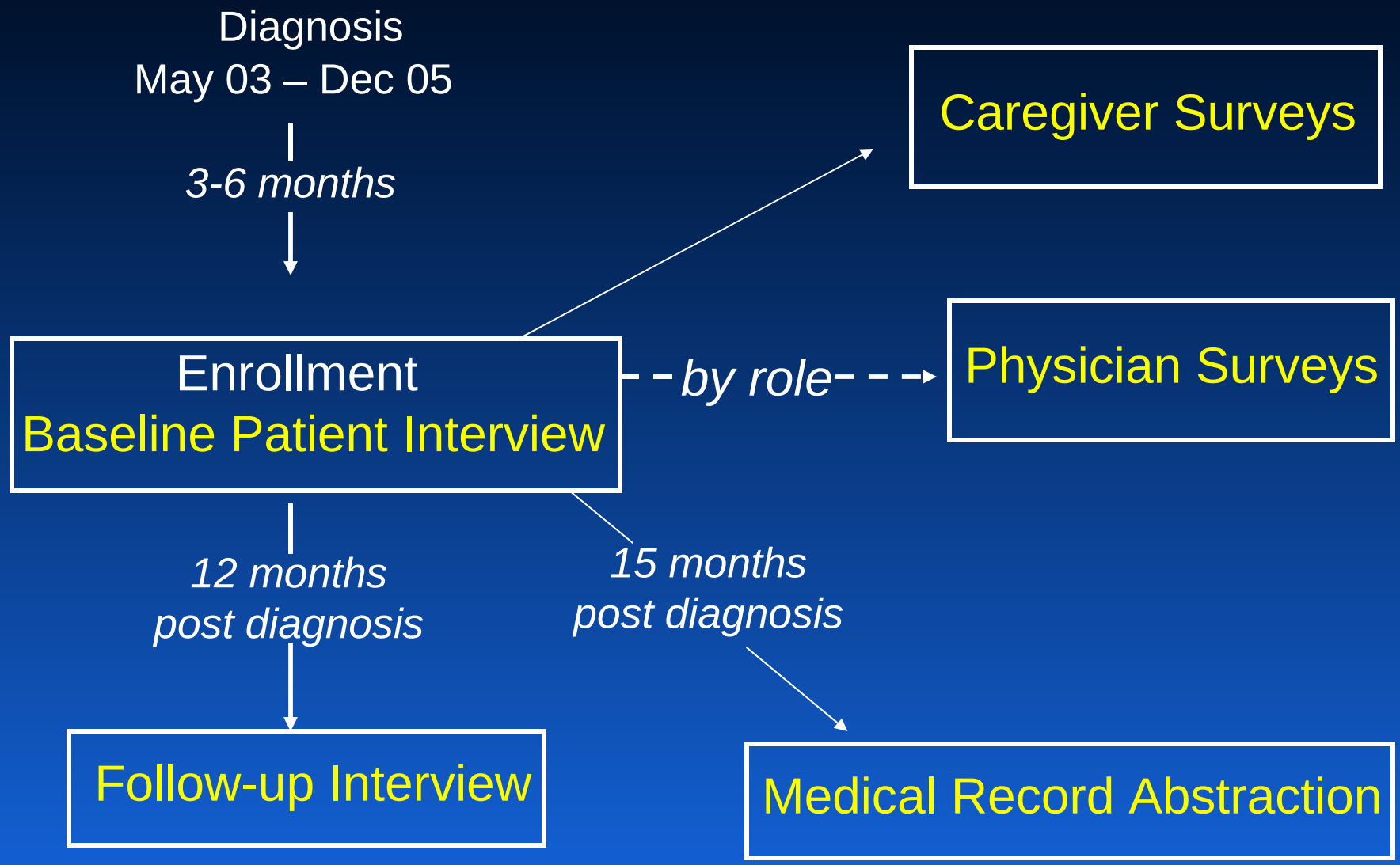
- **Funded in 2000**
- **Scientific Goals**
  - **Examine treatment choice with a special focus on *why* certain groups receive lower quality care**
  - **Characterize the outcomes of treatment in the “real world”**
  - **Develop state-of-the art methods for outcomes research**

CanCORS Sites

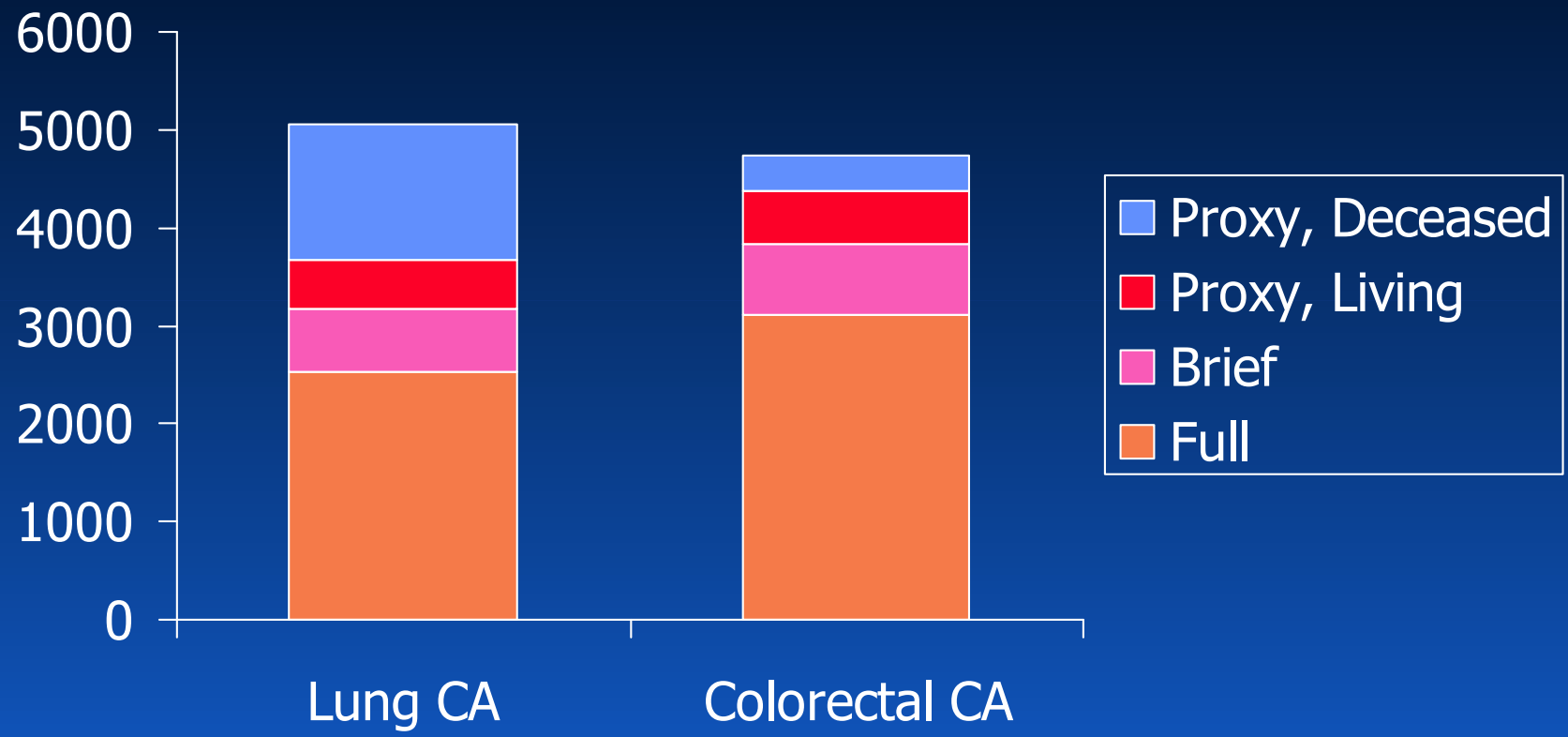


- Patients from population-based cohorts in geographic areas
- Patients from integrated health-care delivery systems
- Patients at Veterans Health Administration hospitals

Data Collection



Types of Baseline Interviews



Enrolling the Elderly

CanCORS vs SEER vs Clinical Trial			
	Colorectal Cancer		
	CanCORS	SEER	ECOG
Median Age at Diagnosis	67	72	63
% Age 75-84	23.3%	29.2%	9.5%
% Age 85+	8.2%	12.6%	0.4%

Quality of care by race and age — what has CanCORS revealed?

- **Some racial disparities in evidence-based cancer care no longer evident: *e.g. adjuvant chemotherapy for stage III colon cancer***
- **But other troubling racial disparities persist:**
  - ***Analysis in progress*: Surgery for early-stage lung cancer: *Black:White adjusted odds ratio 0.38***
- **Pervasive age-related disparities persist**
  - **Insights from CanCORS on the "why" question…**

Adjuvant chemo for stage III colon cancer by age

Age	% Chemo	Unadjusted OR	Adjusted OR*
<55	91%	1.00	1.00
55-64	82%	0.43	0.43
65-74	82%	0.43	0.55
≥75	48%	0.09	0.11

*Adjusted for race, sex, income, education, marital status, region, and severity of comorbidity (medical records)

What else could explain sharp drop in chemo by age?

Access to oncologists?

Among patients who did not receive chemotherapy, most, in all age groups, saw an oncologist :

80% of age <75 vs. 84% of age ≥75

Patients' preferences or oncologists' decisions?

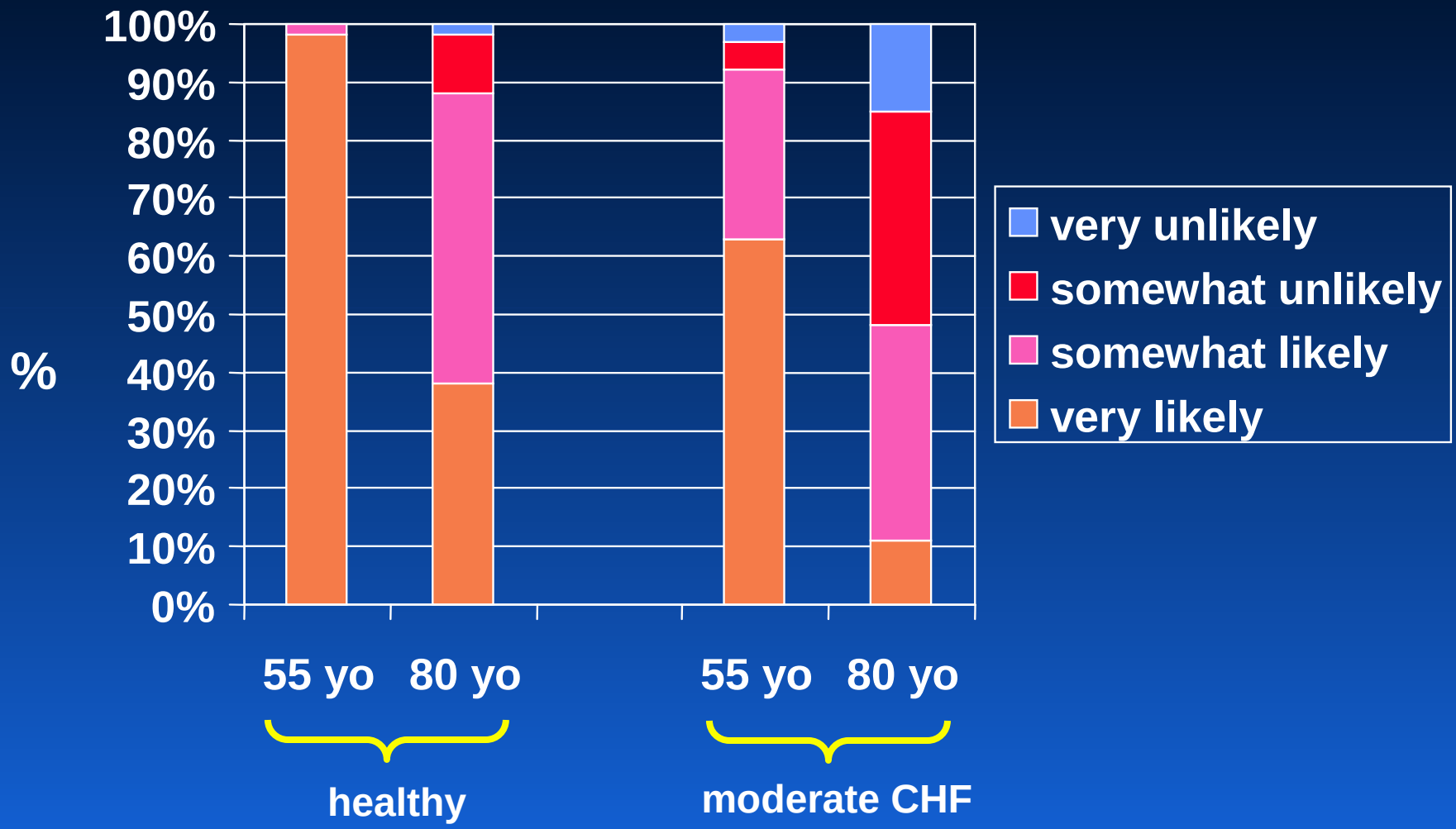
Among patients age ≥75 who did not receive chemo:

33% of patients decided against it

22% made joint decision with oncologist

45% had oncologist recommend against it

Physicians' likelihood of recommending adjuvant chemo



Clinical & policy implications

Physicians follow guidelines to treat patients age <75, but differ widely about treating older patients:

- **Too conservative treatment OR appropriate selection?**

Enhanced information and decision support regarding benefits & risks of adjuvant chemotherapy may help older patients and their doctors make better clinical decisions

Simple RCTs with inclusive eligibility criteria in older patients needed to tailor adjuvant treatment for key group: *~40% of all colon cancer patients*

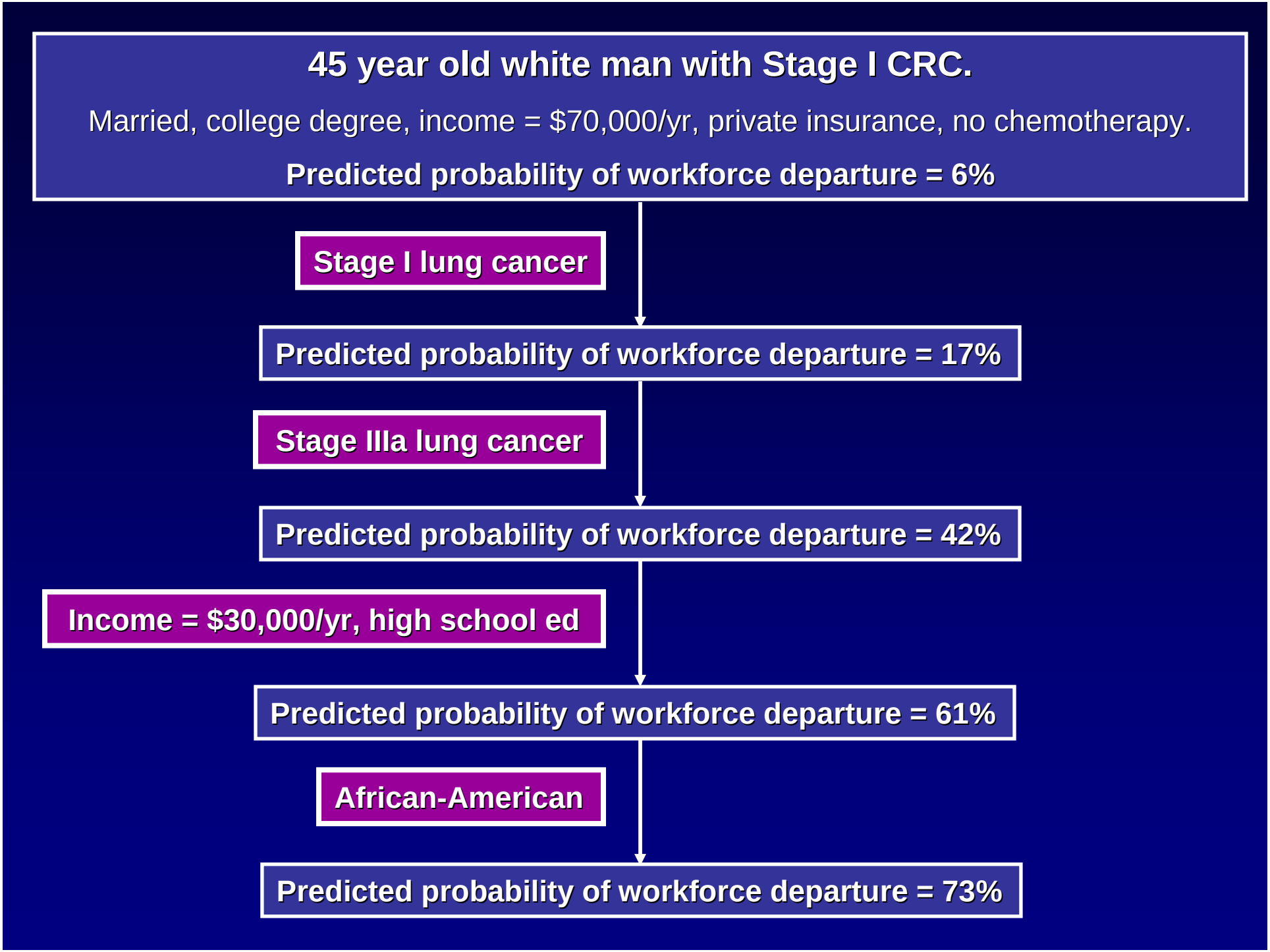
Employment

Results

- **Long-term cancer attributable labor force departures occur in ~16%**
- **Factors significantly associated with *higher* rates of labor force departure:**
  - **Lung cancer (vs. CRC), stage III disease (vs. stage I-II)**
  - **Increased age**
  - **African-American/Hispanic race (vs. White/Asian)**
  - **Lower educational level, lower income**

Results

- **Statistically significant interactions also found:**
  - **Rate of departure much more sensitive to income level among African-Americans/Hispanics than among Whites/Asians**
  - **Married men *less* likely than unmarried to stop working; married women *more* likely than unmarried to stop working**


45 year old white man with Stage I CRC.
Married, college degree, income = $70,000/yr, private insurance, no chemotherapy.
Predicted probability of workforce departure = 6%
Stage I lung cancer
Predicted probability of workforce departure = 17%
Stage IIIa lung cancer
Predicted probability of workforce departure = 42%
Income = $30,000/yr, high school ed
Predicted probability of workforce departure = 61%
African-American
Predicted probability of workforce departure = 73%

The job of caring for ailing loved ones is often daunting. Now, many are asking...

How Can We Help Our Nation's Caregivers?

By Gail Sheehy

"IT'S CANCER."

Those words from my husband's oncologist plunged us into the whirlpool of fear, denial and confusion that suddenly drafts many in middle life into the wars against aging and physical decline. Within the first few days of sharing the news with stunned family members, Googling disease sites, tracking down doctors, comparing hospitals and growing dizzy from conflicting opinions, it began to dawn on me that my life had changed radically. I had a new role: "family caregiver." It's a job nobody applies for. You don't expect it. You won't be prepared.

When I assumed that role, I became part of an unpaid army of 44.5 million Americans who take care of adults. (An additional 6 million provide care

MY TRANSITION TO CAREGIVER began, as it does for many, when it came time for my husband to leave the hospital. A discharge planner may hand you a list of facilities that you have only a day or two to investigate. You learn that Medicare will decree whether or not a patient qualifies for "acute rehab," the type necessary to restore functionality.

A doctor tipped me off that the patient's fate often is determined by the number of steps he or she can take. Less than 12 steps, and the patient is consigned to "long-term care" in a nursing home, where little attention is paid to the possibility of ever becoming independent again. I will never forget

An unpaid army of 44.5 million is caring for our ailing adults.

to build strength. We had gotten as far as six steps.

"Morning, sweetheart. It's showtime!"

He smiled.

"What do I have to do?"

"Twenty steps. Practice."

Later, the physical therapists were left open-mouthed as my husband pushed the walker out the door. Thirty steps! It was the difference between being warehoused in a nursing home and hope.

LIKE MOST NEW CAREGIVERS, I THOUGHT THE CRISIS WOULD RESOLVE ITSELF in six months or a year, and then we would go back to normal. That was 15 years ago. Once as-

Parade Magazine, September 9, 2007

Objective caregiver burden at ~ 6 months post dx

	High Need Patient* (N=475) Mean (sd)	Other (N=272) Mean (sd)
Caregiving hrs/week	26 (29.4)	15 (23.22)
Care tasks/week	8.75 (5.36)	6.32 (5.35)
Clinical tasks/week	3.41 (2.13)	2.40 (2.17)

*Metastatic disease OR severe comorbidity OR cancer treatment within 2 weeks prior to survey

Caregiver training

Did any provider give you training in…	Not needed	Yes	No
…changing bandages?	44%	18%	36%
…administering meds?	32%	22%	46%
…managing nausea?	36%	21%	43%
…managing pain?	29%	28%	42%
…managing fatigue?	24%	29%	47%
…managing other side effects or symptoms?	24%	27%	49%
…any other treatments?	29%	9%	62%

Caregiver Burden

- **Over half of cancer caregivers surveyed must balance work and caregiving tasks; and 1 in 6…**
  - **care for the cancer patient and**
  - **work for pay and**
  - **care for one or more children or other family members**
- **25% report medium to high levels of role conflict and strain**
- **Many caregivers perform "clinical" tasks but at least 25% of these did not receive training**
- **Thus, many cancer patients are receiving clinical care from unpaid, untrained caregivers**

Ongoing analyses

Analyses for >50 manuscripts ongoing, including:

- **Prevalence of under-treated pain and depression**
- **Barriers to clinical trial participation**
- **Access to hospice services**
- **Impact of patient and health system factors on patient ratings of care**
- **Assessment of registry data accuracy**

Overarching conclusions

While these analyses are still being completed, early results suggest:

- **Physician recommendations drive patterns of care**
- **Disparities in care, therefore, largely attributable to MD uncertainty and/or biases**
- **Cancer treatment in the community is surprisingly well tolerated medically**
- **But non-medical effects of cancer & treatment on patients and families have been underestimated**

Implications for research & care

Optimizing treatment of older patients:

- **Assess effectiveness of alternative strategies by following this cohort for survival**
- **Conduct large simple RCTs to define optimal care**
- **Develop decision support tools for patients & MDs**

Implications for research & care

Ensuring access to new therapeutics:

- **Fully characterize the dissemination curve**
- **Identify patient, physician, and system barriers**

Improving outcomes:

- **Examine long-term employment effects**
- **Increase support for caregivers**

CanCORS Investigators and Research Sites

John Ayanian , MD	Harvard Medical School
Elizabeth Chrischilles, PhD	University of Iowa
Mona Fouad, MD	University of Alabama, Birmingham
Patricia Ganz, MD	RAND/UCLA
Katherine Kahn, MD	RAND/UCLA
Catarina Kiefe, MD, PhD	University of Alabama, Birmingham
Dawn Provenzale, MD	Duke University / Veteran's Administration
Michelle Van Ryn, PhD	Minnesota Veteran's Administration
Robert Sandler , MD	University of North Carolina
Robert Wallace, MD	University of Iowa
Jane Weeks, MD	Dana-Farber, Cancer Research Network
Dee West, PhD	No. California Cancer Center, Stanford Univ.