National Cancer Institute

Caregivers of Lung and Colorectal Cancer Patients

Audie A. Atienza, PhD
Behavioral Research Program
National Cancer Institute
National Institutes of Health

On behalf of the Caregiver Supplement Working Group of CanCORS and Cancer Caregiving Collaboration

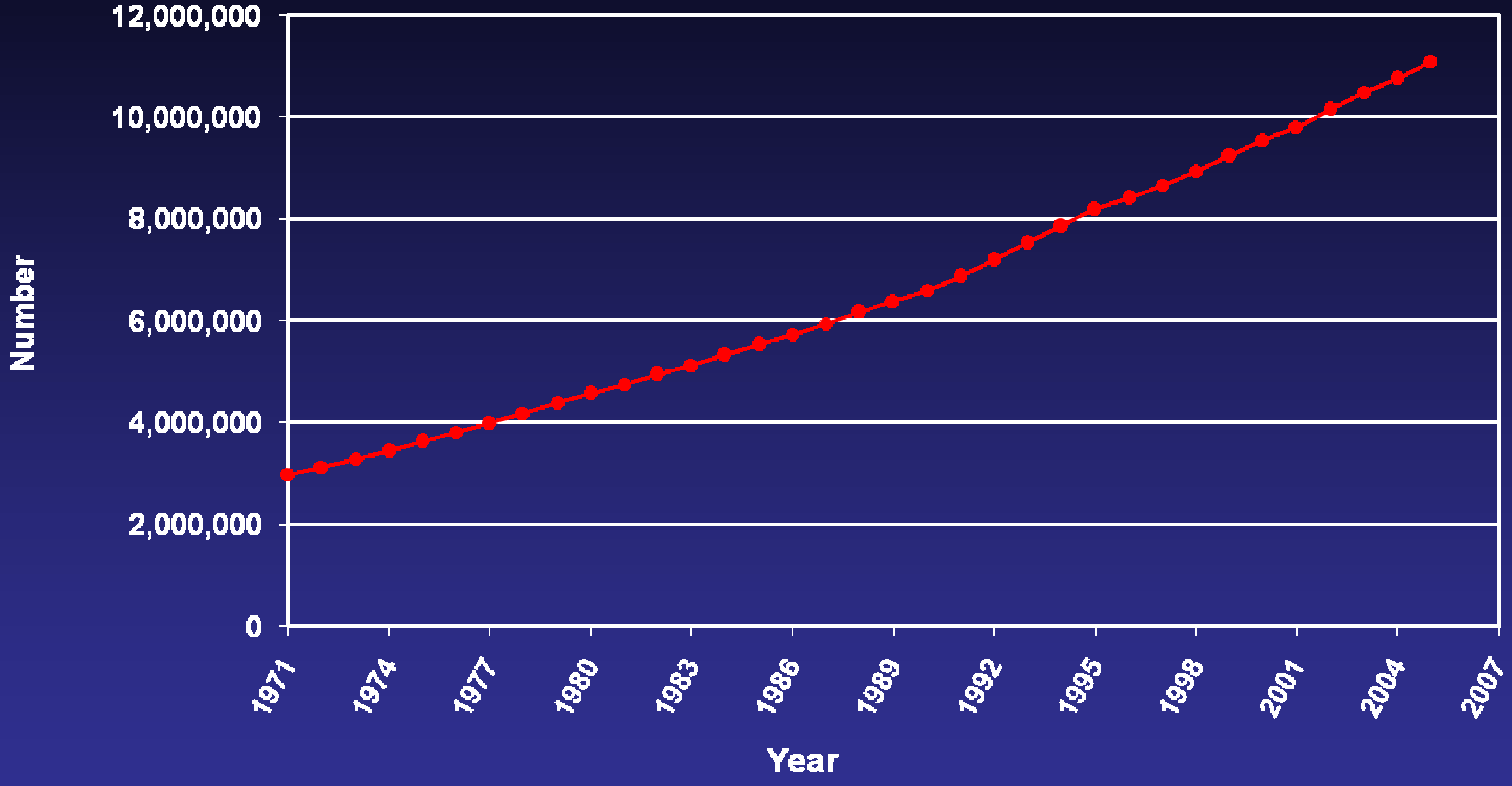
U.S. DEPARTMENT
OF HEALTH AND
HUMAN SERVICES
National Institutes
of Health

"Make the Conquest of Cancer a National Crusade"

National Cancer Act of 1971

President Richard Nixon signs National Cancer Act on December 23, 1971

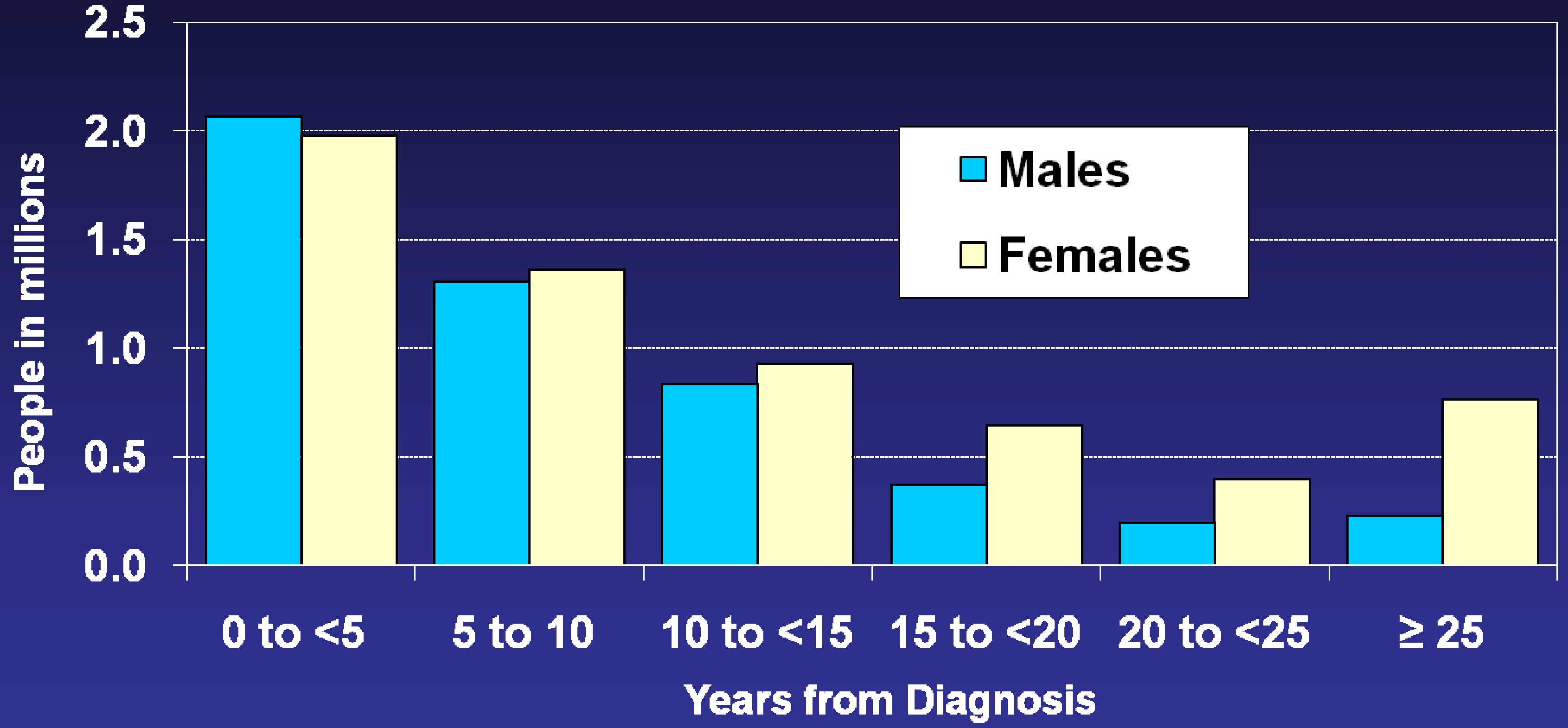
Estimated Number of Cancer Survivors in the United States From 1971 to 2005



Data source: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov). Prevalence database: "US Estimated 30-Year L-D Prevalence Counts on 1/1/2005 by Duration." National Cancer Institute, DCCPS, Surveillance Research Program, Statistical Research and Applications Branch, released April 2008, based on the November 2007 SEER data submission.

Estimated Number of Persons Alive in the U.S. Diagnosed with Cancer on January 1, 2005 by Time From Diagnosis and Gender

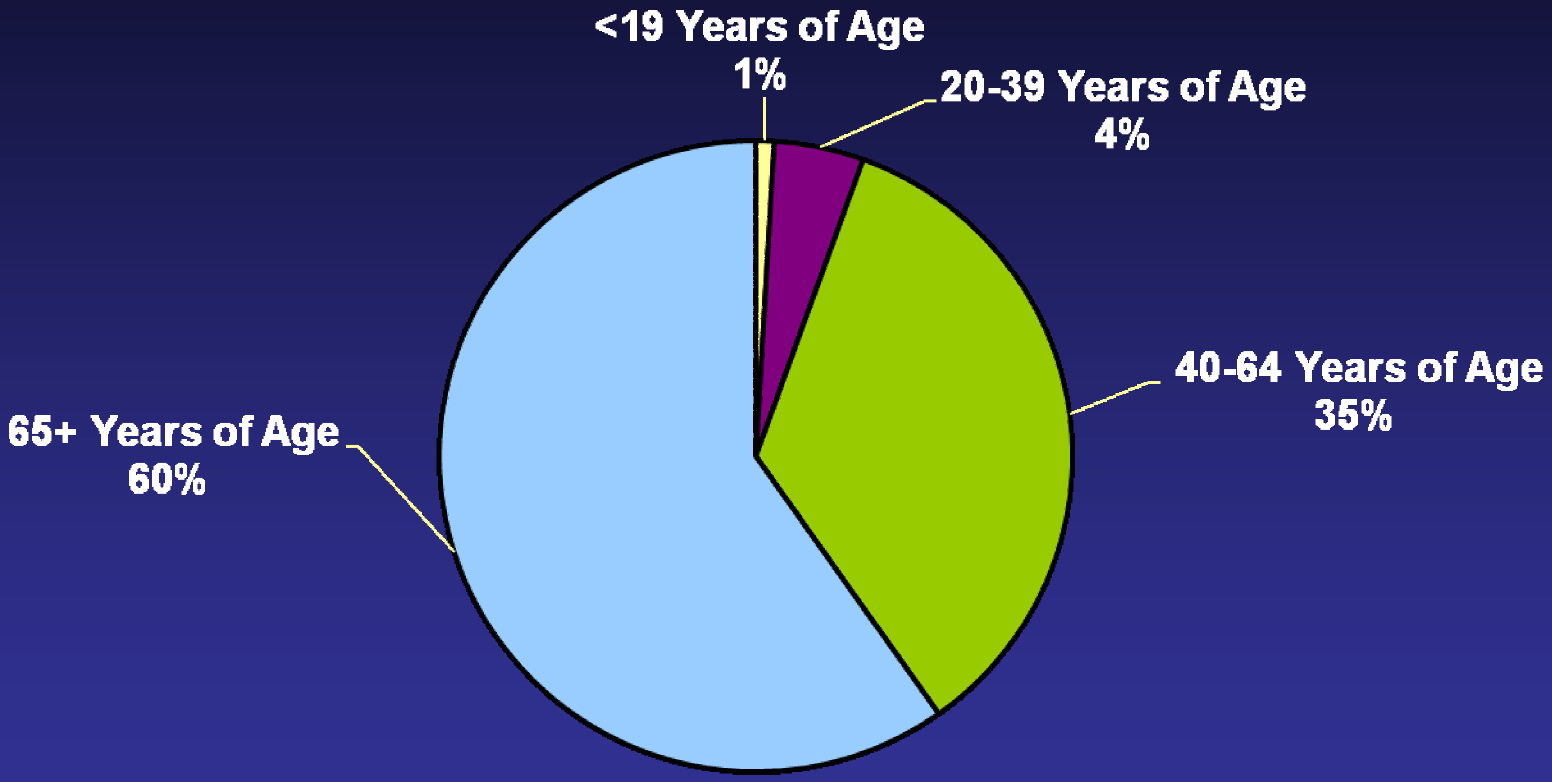
(Invasive/1st Primary Cases Only, N = 11.1 M survivors)



Data source: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov). Prevalence database: "US Estimated 30-Year L-D Prevalence Counts on 1/1/2005 by Duration." National Cancer Institute, DCCPS, Surveillance Research Program, Statistical Research and Applications Branch, released April 2008, based on the November 2007 SEER data submission.

Estimated Number of Persons Alive in the U.S. Diagnosed with Cancer on January 1, 2005 by Current Age

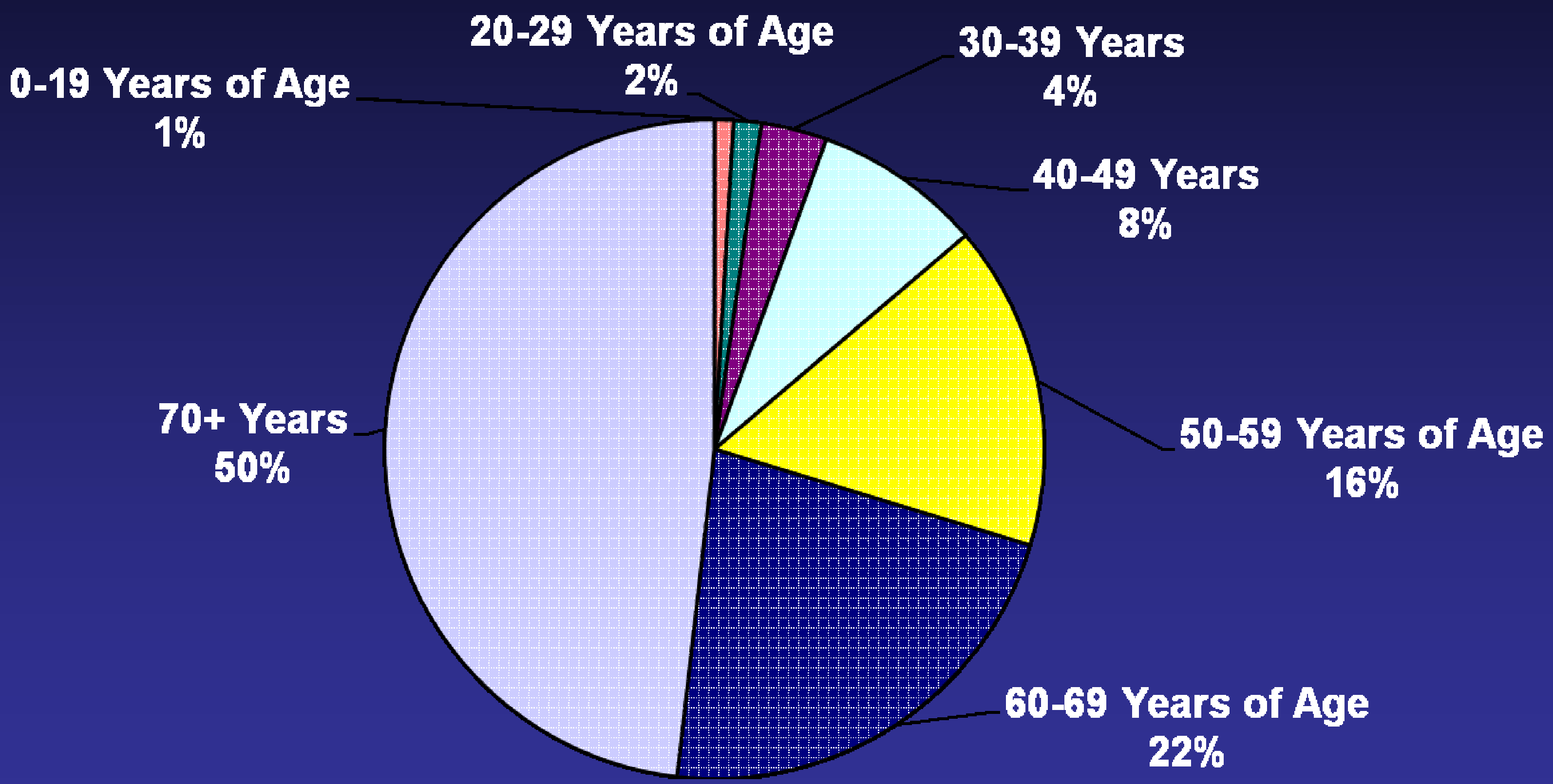
(Invasive/1st Primary Cases Only, N = 11.1 M survivors)



Data source: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov). Prevalence database: "US Estimated Complete Prevalence Counts on 1/1/2005." National Cancer Institute, DCCPS, Surveillance Research Program, Statistical Research and Applications Branch, released April 2008, based on the November 2007 SEER data submission.

Estimated Number of Persons Alive in the U.S. Diagnosed with Cancer on January 1, 2005 by Current Age

(Invasive/1st Primary Cases Only, N = 11.1 M survivors)



Data source: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov). Prevalence database: "US Estimated Complete Prevalence Counts on 1/1/2005". National Cancer Institute, DCCPS, Surveillance Research Program, Statistical Research and Applications Branch, released April 2008, based on the November 2007 SEER data submission.

The Changing Demography of Cancer Survivorship

Cancer is, for most, *a family illness!*

Burden on ‘Secondary’ Survivors: Family and Caregivers

Impact of Cancer on the Family[2]

Three out of every four American families will have at least one family member diagnosed with cancer.

[2] Cancer Facts and Figures 1996. New York: American Cancer Society, 1996

Summary
Cancer Caregiving:
A New and Growing Challenge

- Growing population of cancer survivors: 11.1 million – that will increase with an aging population
- The majority of those diagnosed today can expect to be alive in 5 years; 66% of those diagnosed as adults and 80% of those diagnosed as children (age 19 or younger)
- Treatments for cancer have become increasingly complex and multi-modal
- Most (80-85%) cancer patients receive their care in the outpatient setting, largely in the community (versus big cancer centers)
- Cancer for many has become a chronic illness

What is the Research Telling Us?

General Caregiving in the United States

An estimated 44.4 million caregivers in the U.S. found in 21% of households

Research conducted by AARP (Linda Barrett, PhD) and the National Alliance for Caregiving in Washington, and Belden Russonello & Stewart, Research/Strategy/Management Inc., Based in Washington DC. The project was funded by the MetLife Foundation.

caring and coping

...a caregiver's perspective on cancer

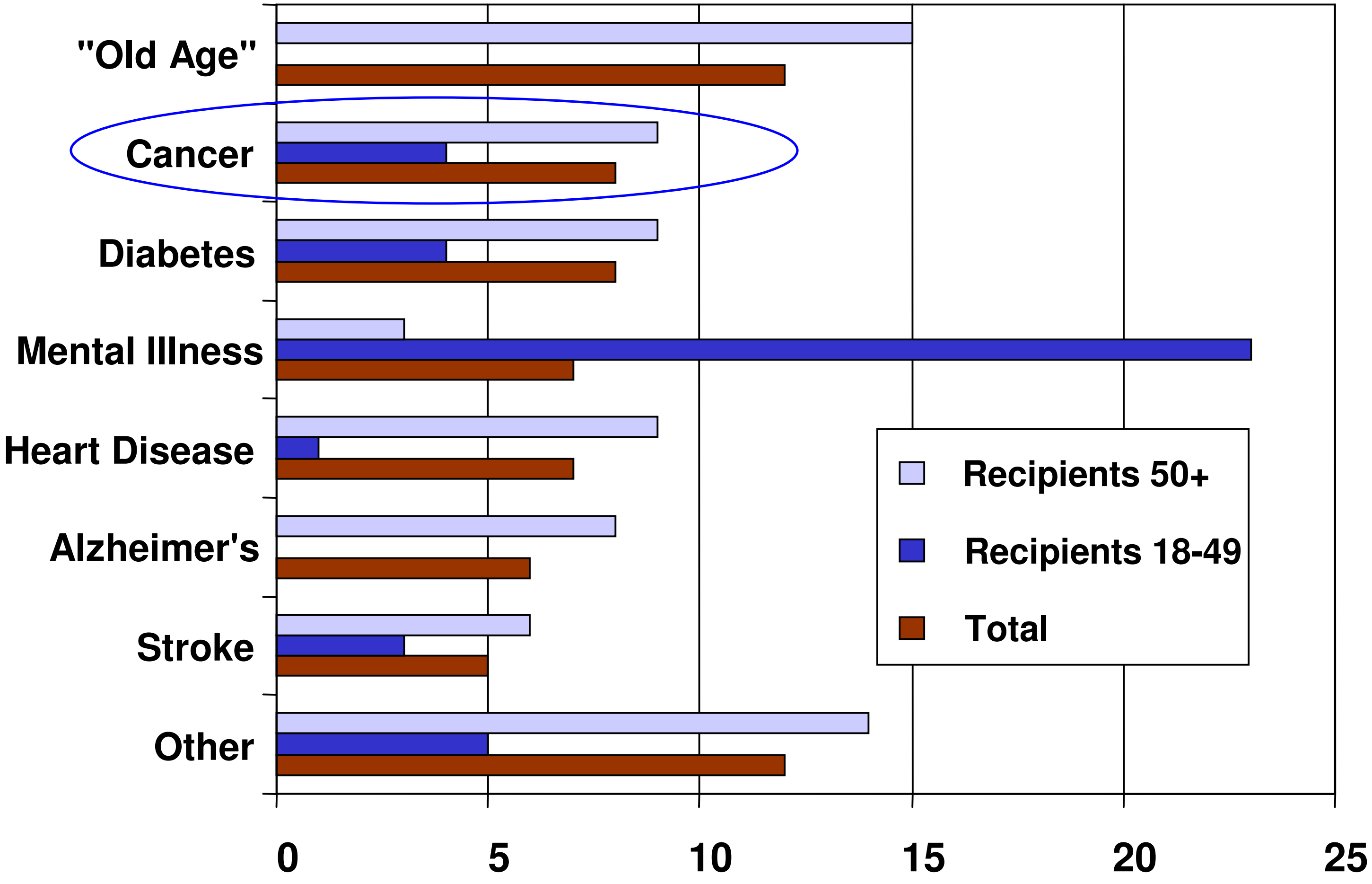
Caregiver Support Program

...helping family and friends care for seniors

National Cancer Institute

Main Illness Or Problem of Care Recipient Identified by Caregiver

(By Percentages) (N = 1,247 U.S. Caregivers)



Data Source: Caregiving in the U.S., National Alliance for Caregiving and AARP, 2004

Profile of Caregiving

70% of the caregivers assist one person, half provide care eight or less hours per week

17% say they provide care more than 40 hours per week

Average length of time caregivers have provided care is 4.3 years

Caregiver Characteristics

60% of these caregivers worked (Male caregivers were more likely to be working full time, whereas women worked part-time)

83% were caring for a family member

61% were women

37% had no other unpaid help in caring for the person

Female caregivers provided more hours of care time and were more likely to indicate that they did not have a choice in assuming the caregiver role.

Cancer Caregiving:
A New and Growing Challenge

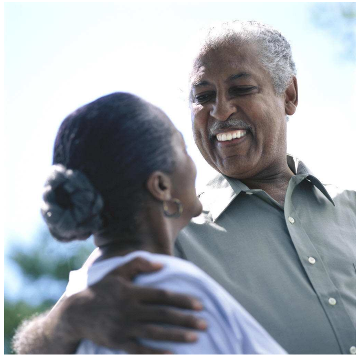
- Estimated 4 million cancer caregivers
- Caregivers are part of the oncology, or cancer care workforce
- But, we have relatively limited information about cancer caregivers and the care they provide
- The effect of caregiver characteristics on patient outcomes is unknown

Leveraging a Unique Opportunity: The CanCORS Caregivers' Study

- In 2001, the NCI established the Cancer Care Outcomes Research and Surveillance Consortium (CanCORS)

  http://grants.nih.gov/grants/guide/rfa-files/RFA-CA-01-013.html

- A research program to understand treatment choices and outcomes of colorectal cancer and lung cancer



Colon Cancer Awareness

Cancer Care Outcomes Research and Surveillance Consortium
CanCORS

Research Teams and Sites

Research Team	**Population**
University of Alabama	State of Alabama
University of Iowa	State of Iowa
UCLA/Rand	Los Angeles County
University of North Carolina at Chapel Hill	22 central/eastern counties
Harvard/Kaiser Northern California	8 counties in San Jose, San Francisco/Oakland and Sacramento areas
Cancer Research Network	Managed care organizations in 5 regions
Veterans Administration	VA hospitals in 10 cities

Research Design

- An observational (cohort) study
- A population-based sample of patients with newly diagnosed cancer (4800 lung and 5300 colorectal cancer) from many regions of the U.S.
- Follow-up for 18 months from diagnosis
- A rich set of variables from patients, providers, medical records, and national datasets

CanCORS Caregivers' Supplement

- In 2004, NCI funded a special supplement to CanCORS to permit assessment of associated cancer caregivers
- Caregivers were identified by the cancer patient during the patient interview.

Instrument

Self administered mailed questionnaire

- Domains:
    - Objective caregiver burden including type of care provided, and cancer care training
    - Subjective caregiver burden
    - Financial burden of caregiving
    - Work and caregiving conflict
    - Social support & quality of relationship with patient
    - Health and quality of life
    - Health behavior and self-care
    - Demographics and health insurance coverage

CanCORS Caregivers Sample

- 2593 consecutive eligible informal caregivers were sent self-administered questionnaires.
  - 828 baseline (~4 mth post diagnosis; T1) (66%)
  - 802 f/u (one year post diagnosis; T2) (61%)
  - *Note: baseline and follow-up samples represent two separate cross-sectional samples*

- 53% were caregivers for patients with colorectal cancer; 47% were caregivers for patients with lung cancer.
- 25% were men and 75% were women
- 73% reported living with patient

Caregiver Sample Characteristics

Relationship to cancer patient

- 60% (981) were spouses of patient.
- 33% (530) were other family members,
  - 3% adult son
  - 12% adult daughter
  - 2% patient's father
  - 8% patient's mother
  - 8% other family.
- 7% (90) were partners, friends or neighbors.

Caregiver Burden
How many days a week?

- 55% provided care every day
- 20% provided care 1-6 days a week
- 25% reported providing care less than 1 day a week

CanCORS: Caregiving Burden

What burdens are experienced by colorectal and lung cancer caregivers?

- Caregivers at T1
  - Average hours/wk providing care = 21.1 hours
  - Average # ADLs (past 2 wks) = 1.3
  - Average # IADLs (past 2 wks) = 3.4

- Caregivers at T2
  - Average hours/wk providing care = 20.1 hours
  - Average # ADLs (past 2 wks) = 1.1
  - Average # IADLs (past 2 wks) = 2.9

van Ryn et al. (in progress)

CanCORS: Caregiving Burden

	T1 Sample	T2 Sample
Changed the patient’s bandages	18%	11%
Helped administer medicine to the patient	32%	29%
Kept track of or watched for side effects	66%	49%
Assist the patient manage or control symptoms (e.g., fatigue or pain)	45%	36%

van Ryn et al. (in progress)

Balancing Work and Caregiving Roles

- ~50% of caregivers reported working for pay
  - 75% of adult children of patient
  - 44% of spouses of patient
- Of those caregivers who worked:
  - 26% scored in the top 50% on an index tapping conflict between caregiving and work demands.
  - 27% reported no role strain at all.

* 3-item index, difficulty balancing work and caregiving, work interferes with caregiving, caregiving interferes with work (alpha=.88, range 1-5).

CanCORS Limitations and Summary

- Limitations
  - Cross-sectional design
  - Caregivers were only eligible to participate if the patient was alive at the time of the survey (i.e., “active caregiving”)
  - Results may not generalize to caregivers providing assistance to patients with other forms of cancer.

Important Questions

- How can we help caregivers be more effective in the care they provide?
- What is/should be their role in augmenting oncology workforce shortfall?
- How can we get a better handle on numbers of individuals who are cancer caregivers to estimate burden and plan for the future?
- What policies need to be proposed to help cancer caregivers manage the burden they may experience?

National Cancer Institute

Thank you!

Audie A. Atienza, PhD
National Cancer Institute
atienzaa@mail.nih.gov
(301) 402-8426