

Survivorship: ***Caring for the 12 Million Surviving Cancer***

Linda A. Jacobs, PhD, RN
Director

LIVESTRONG™ Survivorship Center of Excellence
University of Pennsylvania
Abramson Cancer Center

Survivorship Care

Why now?

- Rapidly growing population of survivors
- Increasing expectations of patients for a better quality of life
- Greater emphasis on patient-centered issues
 - Medical community
 - Advocacy groups
 - Quality & quantity of life

Profile of Cancer Survivors

- Over 12 million in the U.S.
- Over 20 million globally
- 3 out of 4 families will have at least 1 family member diagnosed with cancer
- 66% of adults diagnosed can expect to be alive in 5 years
- 61% of survivors are > 65 years of age

ACS, 2007

Needs of Survivors

Lance Armstrong Foundation LIVESTRONG™ Poll
N=1020

- 53% reported secondary health problems
 - Chronic pain (54%)
 - Sexual dysfunction (58%)
 - Relationship difficulties
 - Fertility issues
 - Fear of recurrence
 - Depression
 - Financial & job related concerns
- 49% reported
 - Non-medical cancer related needs not met

Needs of Survivors

Lance Armstrong Foundation LIVESTRONG™ Poll
N=1020

- 70% reported
 - oncologists did not offer support in dealing with health problems secondary to cancer
- 30% reported
 - oncologists willing to talk about secondary health problems
 - did not have the adequate experience or information to provide guidance

Essential Components of Survivorship Care

- Prevention & detection of new cancers & recurrent cancer
- Surveillance for cancer spread, recurrence, or second cancers
- Intervention for consequences of cancer & its treatment
- Coordination between specialists & primary care physicians to ensure that all of the survivor's health needs are met

Survivorship Issues

- Long Term Effects of Treatment
 - Develop during active treatment
 - Persist for years
 - Neuropathies
 - Weakness, numbness, pain
 - Fatigue
 - Cognitive & sexual difficulties
- Late Effects of Treatment
 - Not present or identified after treatment
 - Develop as a result of treatment
 - Organ systems
 - Psychological process

Hewitt M, Greenfield S, Stovall E. (2006). From Cancer Patient to Cancer Survivor: Lost in Transition. Washington, D.C.: The National Academies Press.

Survivorship Issues

- Follow-up guidelines
- Duration of oncology follow-up care
- Communication among providers
- Knowledge of providers
 - Oncology
 - Primary care
- Information needs of survivors
 - Left in the medical twilight zone

Information Needs of Survivors

- Cancer Survivors Study N=752
 - 6 different cancer sites
 - Bladder, breast, colorectal, prostate, uterine, melanoma
 - 3-11 years post diagnosis
 - Information needs
 - Quality of information received
 - 38% fair to poor
 - Long-term side effects
 - 36% fair to poor

Survivorship Issues

- Variable
 - Risk factors
 - Age
 - Race
 - Co-morbidities
 - Income
 - Access to care
 - Compliance

Caring for Cancer Survivors

- Evaluation of oncology care model
 - Clinical care
 - Research
- Resource assessment & allocation
 - Dedicated staff
 - \$\$
- Goals
 - Short & long-term

Challenges

- Diverse oncology populations
- Workforce issues
 - Oncology
 - Primary Care
- Large patient volumes
- Reimbursement, insurance issues
- HIPAA
- Funding

More Challenges

\$\$\$\$

- Clinical revenue
 - Limited
- Downstream income
 - Institution
 - Other departments
 - labs
 - radiology
 - subspecialists

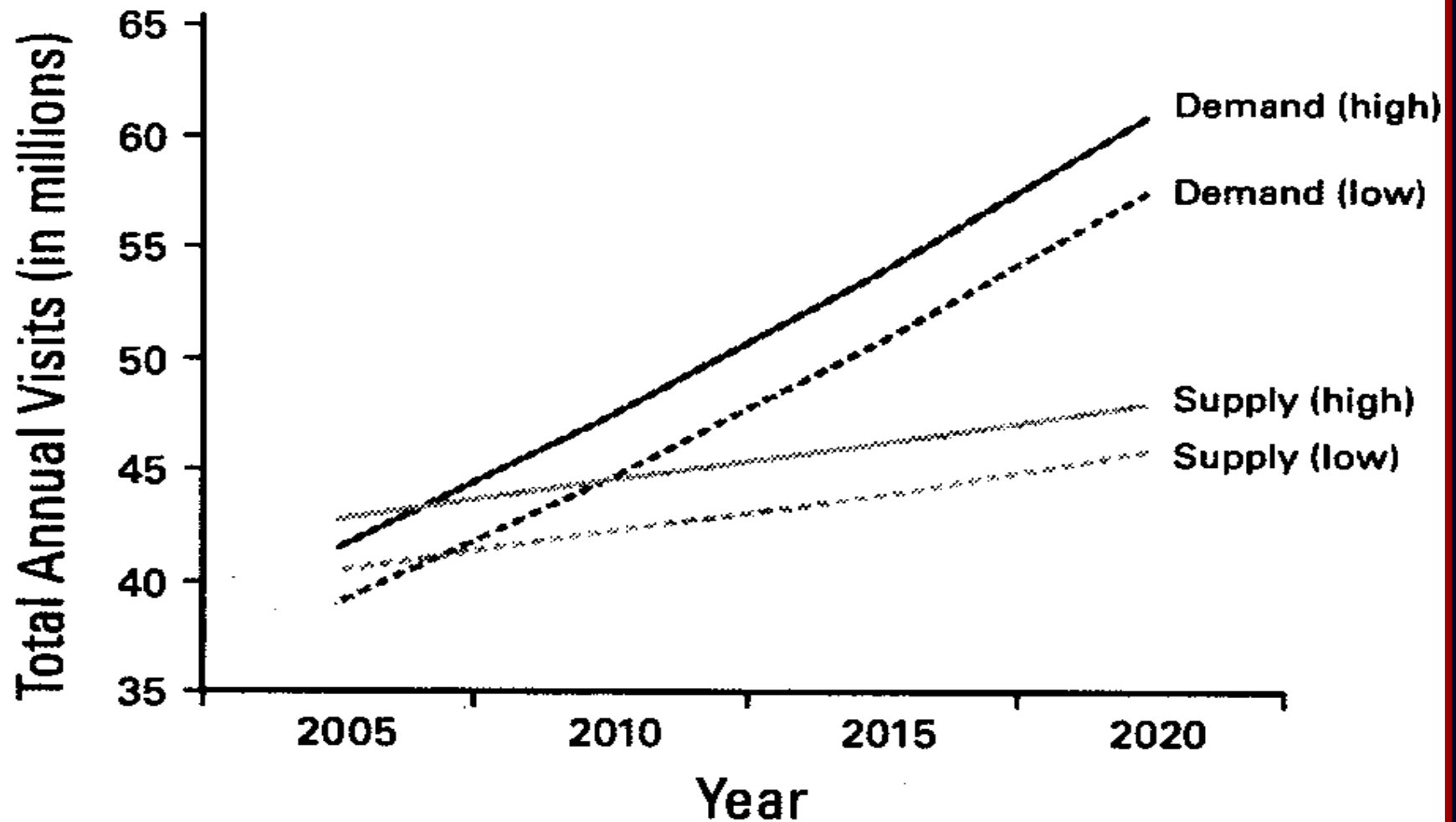
IOM Report 2006

Adult Cancer Survivorship

- How many survivors receive comprehensive survivorship care?
 - Many are “*lost in transition*”
- Transition from active treatment to survivorship care
 - How is this accomplished & by whom?
 - How is the patient prepared for this transition & educated about plan?

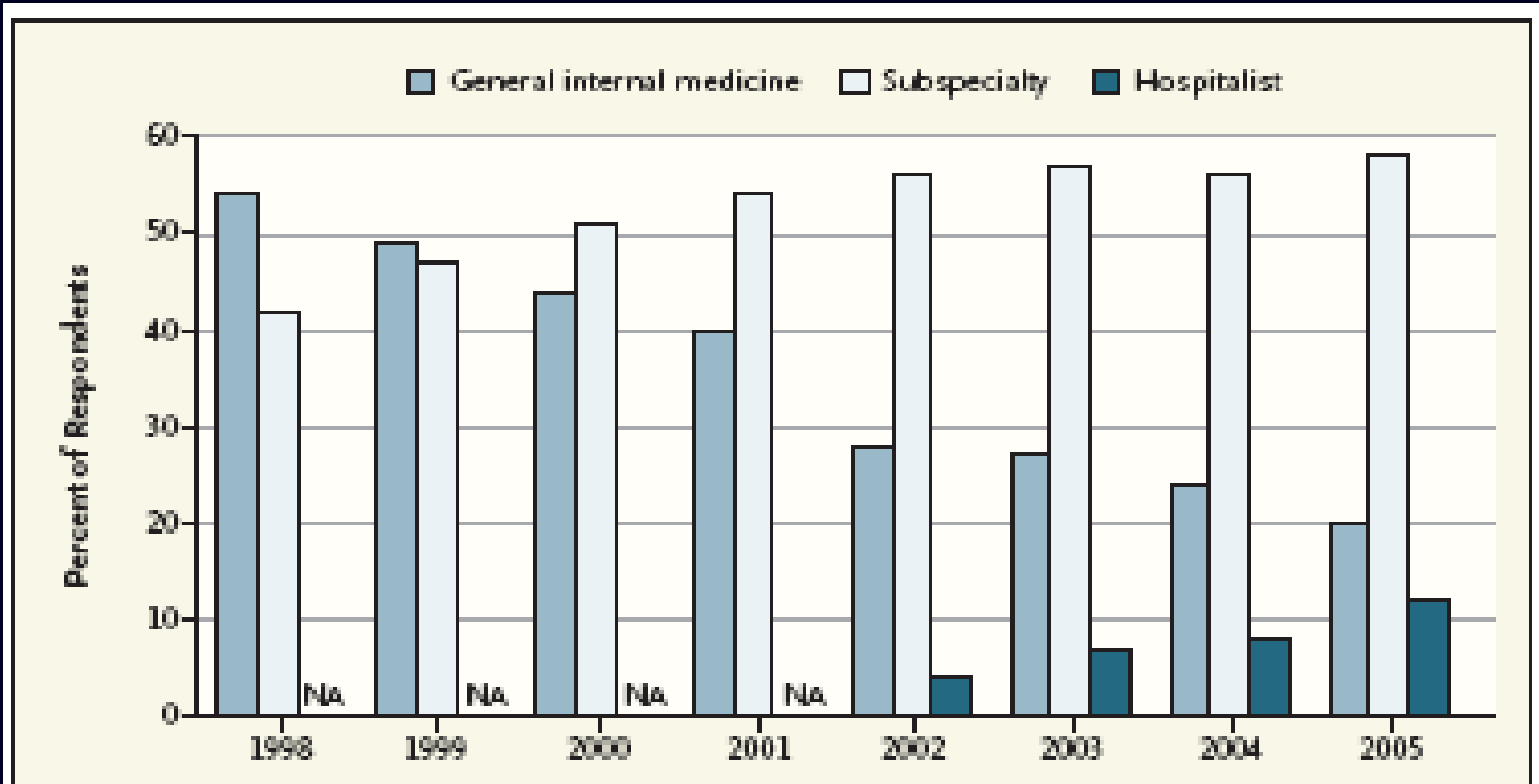
Hewitt, Greenfield, & Stovall (2005). *From Cancer Patient to Cancer Survivor: Lost in Transition*. The National Academies Press: Washington, D.C.

Projected Supply of and Demand for Oncologists



ASCO Workforce Report, JOP, 2007

Proportions of Third-year Internal Medical Residents Choosing Careers as Generalists, Subspecialists, and Hospitalists



Proportions of Third-Year Internal Medical Residents Choosing Careers as Generalists, Subspecialists, and Hospitalists.

Necessary Care for Cancer Survivors

- *Study of quality of non-cancer related health care received by CRC survivors*
- Cases=14,884
- Controls=16,659
- Survivors were less likely to receive recommended care
 - e.g., lipid monitoring in survivors with chronic angina
 - 64.3% cases
 - 69.1% controls

Necessary Care for Cancer Survivors

Survivorship Care N=7465

- Non-cancer-related health needs of cancer survivors are not a priority by oncologists
 - 50% continue with oncologist for follow-up
 - 8% oncologist alone
 - 68% oncologist & primary
- **Primary care alone**
 - Less likely to undergo cancer-related surveillance procedures
 - More likely to receive
 - Eye exams
 - Flu vaccines
 - Cholesterol screening
 - cervical screening
 - DEXA scans
- **Oncologist alone**
 - Worse preventive care

Earle & Neville, 2004

IOM Report 2006

Adult Cancer Survivorship

- “Patients completing primary treatment should be provided with a comprehensive 1) *treatment summary* & 2) *follow-up plan* that is clearly and effectively explained.”
 - Cancer type, treatments, & consequences
 - Timing & content of follow-up care

Models of Care

- Pediatric Follow-up Care Model
 - Multidisciplinary
 - Resource intense, not disease specific
- Adult Follow-up Care Models
 - Multidisciplinary
 - Resource intense, not disease specific
 - Disease specific
 - Survivorship clinic
 - Consultative service
 - One time visit
 - Nurse Practitioner
 - Extension of care continuum
 - Integrated Care Model
 - Survivorship care focused visits
 - Transition to primary care

Integrated Care Model

Survivorship Treatment Summaries & Care Plans

- Survivorship follow-up visits in all oncology collaborative practices
 - NP survivorship visits at the end of treatment/yearly
 - Treatment summary & care plan completed & discussed
- Referral to Primary Care
 - variable timing/disease specific
- Education & information dissemination
 - patients, oncology/primary care providers, sub-specialists
- Outcome evaluation
 - patients & providers

Resource

Survivorship Care Plan

- **OncoLink**
 - **OncoLife**
 - Version 1. released Spring 2007
 - Develop care plans with patients at the end of treatment
 - Late effects of treatment
 - Surveillance guidelines

<http://www.oncolink.com/oncolife>



Caring for the 12 Million Cancer Survivors

- Summary of Survivorship Care Models
- *\$\$, limited number of survivors reached*
- *Dedicated staff, clinic space, resources*
 - Multidisciplinary
 - Disease specific
 - Consultative service
 - Nurse Practitioner
- *Broadest reaching*
- *Treatment summary & care plan*
 - *Communication tool*
- *Transfer to primary care*
 - Integrated Care Model

Caring for the 12 Million Cancer Survivors

- Needs of Cancer survivors
 - Cancer & non-cancer related
- Models of care
 - Treatment summaries & care plans
- Workforce issues
- Reimbursement issues
- Follow-up care guidelines
- Research funding