

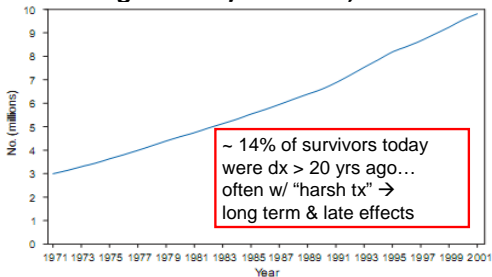
Issues in Cancer Survivorship

Wendy G. Goldberg, MSN, APRN, BC
Josephine Ford Cancer Center and
Consultation-Liaison Psychiatry
Henry Ford Health System
Detroit, Michigan
with assistance from
Teresa Lynch, PhD
Psychooncology Fellow

What are we talking about, & why?

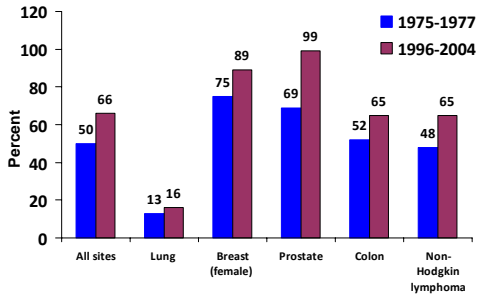
- “Cancer Survivor” – definitions
- 12 million survivors in the U.S.
 - 5,168,889 men (2006)
 - 6,216,003 women (2006)
 - # will double by 2050 (Yabroff, Lawrence, et al, 2004)
- Lifetime: 1 in 3 males & 1 in 2 females
 - > 40% people born in 2008 (Travis & Yahalom, 2008)
- Adults w/ Cancer
- Children w/ Cancer (become adult survivors)
- Elderly

Estimated # of Living Persons Ever Diagnosed w/ a Cancer, 1971 to 2001

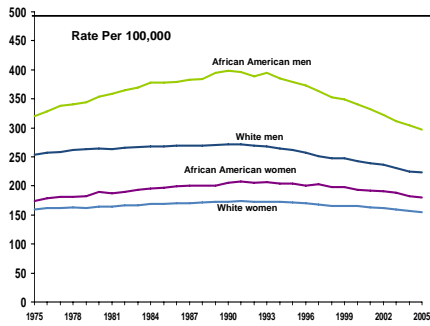


* Estimated by applying U.S. populations to SEER-9 and historical Connecticut Tumor Registry data and adjusted to represent all cancer survivors, January 1 populations were based on average mid-year population estimates from the U.S. Census Bureau.

Trends in Five-year Relative Survival Rate, U.S., 1975-2004

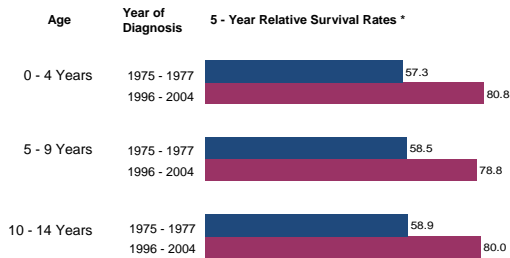


Cancer Death Rates* by Sex and Race, US, 1975-2005

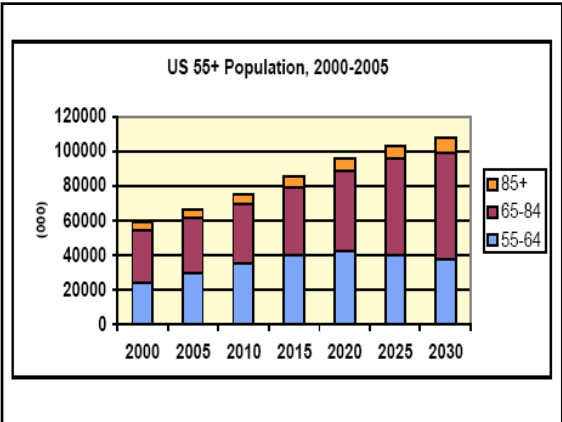


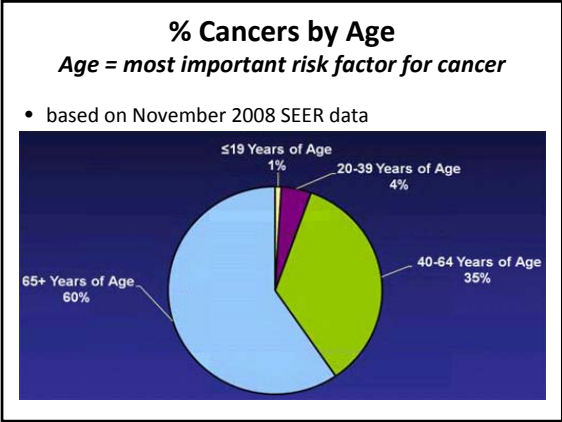
*Age-adjusted to the 2000 US standard population.
Source: Surveillance, Epidemiology, and End Results Program, 1975-2005, Division of Cancer Control and Population Sciences, National Cancer Institute, 2008.

Trends in Cancer Survival by Age Group, Children 0-14 Years, 1975-2004



*5-year relative survival rates, based on follow up of patients through 2005.
Source: Surveillance, Epidemiology, and End Results Program, 1975-2005, Division of Cancer Control and Population Sciences, National Cancer Institute, 2008.





Even as the Survivor Population Increases...

The trend for the HCP Workforce is:

- **Shortage of Oncology Specialists** (physicians & nurses)
- **Shortage of Primary Care Providers**

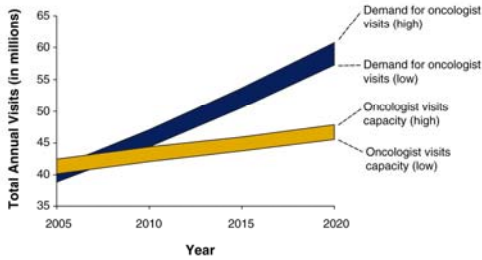
Therefore...

We must learn what we need to know through research & translate this knowledge into clinical programs in order to care for cancer survivors

Oncologist Shortage

Ensuring Quality Cancer Care Through the Oncology Workforce,
<http://www.nap.edu/catalog/12613.html> accessed April 11, 2010

SUPPLY AND DEMAND IN THE ONCOLOGY WORKFORCE



Patient's Voices

From Cancer Patient to Cancer Survivor: Lost in Transition

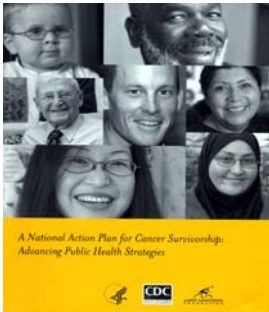
4 Essential Components of Survivorship Care

- 1. Prevention** - recurrent & new cancer, late effects
- 2. Surveillance** - cancer spread, recurrence, 2nd cancers, assess medical & psychosocial late effects
- 3. Intervention** – for sequelae of cancer and cancer tx
- 4. Coordination** – b/ Specialists & PCPs to meet survivors' health needs

Please show DVD

Something must be done – but, what?

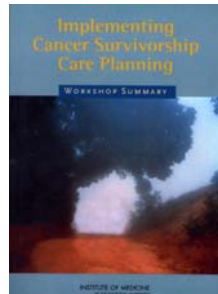
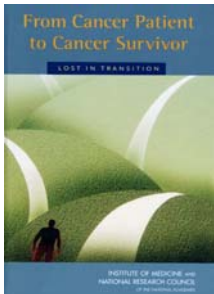
- NCI – Cooperative Groups (1955)
 - NCCS (1986) – use term “survivorship”
 - NCI Office of Cancer Survivorship (1996)
 - LAF / CDC - National Action Plan (2004)
 - IOM Report (2006) ***
 - Distinct phase of care
 - Clinical, Research, Education, & Advocacy
 - 4 Essential Components of Survivorship Care
-
- ASCO and ONS / NCCN Guidelines (1995)



**A National Action Plan for Cancer Survivorship:
Advancing Public Health Strategies
CDC / LAF 2004 www.laf.org**

IOM REPORTS 2006 & 2007

www.nap.edu

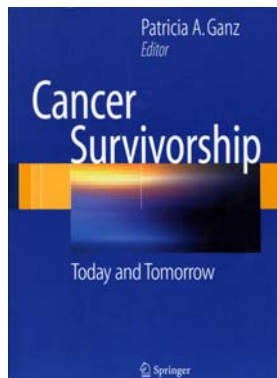


Evolving Standards – Survivorship Care Plan

- Treatment Summary
- Cancer Surveillance
- Long Term & Late Effects – 3P’s
 - (prevent, palliate, promote)
- Health Screening
- Health Promotion
- Biopsychosocial adjustment
- Genetic Counseling PRN
- ID health team roles & responsibilities
- Focus on “patient agency” – what is pt’s role?

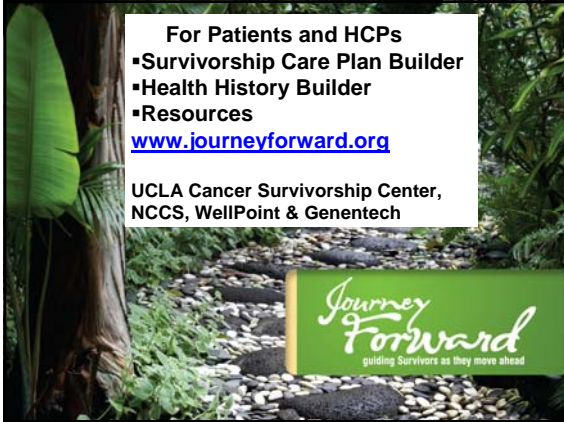
Cancer
Survivorship
Today
and
Tomorrow

Patricia A. Ganz
(Editor)
Springer, 2007



Care Plan Descriptions & Templates

- LAF & CDC, National Action Plan (2004)
 - www.cdc.gov/cancer/survivorship/pdf/plan.pdf
- 2 IOM Reports - www.nap.edu
- ASCO Web Site – generic + 5 specific cancers
www.asco.org/treatmentsummary
- Journey Forward - www.journeyforward.org
- Cancer Survivor’s Prescription for Living –
<http://tiny.cc/SFA83> (by RNs for RNs)
- LIVESTRONG Care Plan (powered by OncoLink)
 - www.livestrongcareplan.org (for patients)



Survivors of Childhood Cancers

- **Children's Oncology Group (COG)**
 - Guidelines for follow-up based on treatment
 - www-survivorshipguidelines.org
- **Lost to follow-up:** < 30% of survivors 20 yrs from diagnosis return for follow-up care
- **Inadequate care:** Survivors who do return for care often do *not* receive proper surveillance

Models of Survivorship Care

- **Shared Care Model**
- **Disease-Specific Clinics**
- **Comprehensive Survivorship Clinics**
 - Consultative Model
 - Advanced Practitioner Clinician-led Clinic
 - Specialized Multidisciplinary Survivorship Clinic
- **Blended Models**

Evolving Standards – Quality of Life Screening

- HRQOL
 - Symptom Prevalence and Intensity
 - Patient-Reported Outcomes
 - Mood (Distress, Anxiety, Depression)
 - Distress Thermometer, GAD-7, PHQ-9
 - Cognitive Function
 - ADL's
-
- Prevalence, Treatment, Cost (time, resources, \$)

Evolving Standards – Transitions in Care

- IOM Focus
- HFHS Primary Care (unpublished study, 2009)
 - ❖ 88% PCPs: Important to understand cancer patients' follow-up plans
 - ❖ > 50% PCPs: "Rely" on patients to inform them of their follow-up plan, yet...
 - ❖ > 80% of providers believe their patients are confused about follow-up

Evolving Standards – Transitions in Care

Research Evidence to support adoption of Cancer Survivorship Care Plans is sparse. Many barriers to implementation remain. Should we continue to pursue?

With **Education & a Treatment Algorithm,**
PCPs can deliver cancer surveillance care
similar to oncologists
for breast & colorectal cancer

(Grunfeld, 2006 & Wattchow, Weller, et al, 2006)

Research Trends & Needs – Quantity AND QUALITY of Life

*Is there a place for survivorship research
in cancer clinical trials???*

Office of Cancer Survivorship, NCI 1996

1. Understand, prevent & reduce adverse physical, psychosocial & economic sequelae of cancer & its treatment
2. Educate HCPs, Survivors & Family

Clinical Trials Cooperative Group Program

- Promote and support clinical trials (research studies) of new cancer treatments
- Explore methods of cancer prevention & early detection
- **Study quality-of-life issues & rehabilitation during and after treatment**

www.cancer.gov/cancertopics/factsheet/NCI/clinical-trials-cooperative-group/ accessed April 3, 2010

Cancer & Cancer Treatment: some possible Sequelae

- | | |
|--|---|
| <ul style="list-style-type: none">• Second primary cancers (3rd or more)• Cardiac disease• Neurocognitive dysfunction• Sexual Function / Infertility• Osteoporosis• Necrosis of <input type="text"/> | <ul style="list-style-type: none">• Neuropathies• Endocrine dysfunction• Lymphedema• Pulmonary disease• Fatigue• Prolonged emotional distress• Benefit-finding & Resilience |
|--|---|

Figure 1. Estimated Number of Cancer Survivors* Alive as of January 1, 2005, and the Number Diagnosed with More than One Primary Site by Site of First Primary

Estimated survivors		Estimated survivors who have been diagnosed with more than one cancer, by site of first primary	
Male	Female	Male	Female
Prostate	Breast	Prostate	Breast
2,106,560 (42%)	2,477,850 (41%)	114,470 (28%)	226,880 (48%)
Colon & rectum	Uterine corpus	Colon & rectum	Colon & rectum
531,880 (11%)	572,620 (9%)	69,500 (17%)	56,140 (12%)
Urinary bladder	Colon & rectum	Urinary bladder	Uterine corpus
384,290 (8%)	563,410 (9%)	52,590 (13%)	45,570 (10%)
Melanoma	Melanoma	Melanoma	Melanoma
349,410 (7%)	349,410 (6%)	27,520 (6%)	25,900 (5%)
Non-Hodgkin lymphoma	Uterine cervix	Kidney & renal pelvis	Lung & bronchus
207,200 (4%)	248,760 (4%)	19,860 (5%)	15,410 (3%)
Lung & bronchus	Non-Hodgkin lymphoma	Oral cavity & pharynx	Thyroid
175,430 (4%)	193,880 (3%)	17,270 (4%)	13,180 (3%)
Oral cavity & pharynx	Lung & bronchus	Lung & bronchus	Ovary
154,100 (3%)	187,660 (3%)	17,270 (4%)	13,090 (3%)
Kidney & renal pelvis	Ovary	Non-Hodgkin lymphoma	Urinary bladder
148,840 (3%)	174,240 (3%)	15,070 (4%)	12,390 (3%)
Leukemia	Urinary bladder	Leukemia	Non-Hodgkin lymphoma
132,780 (3%)	136,660 (2%)	7,660 (2%)	11,960 (3%)
Hodgkin lymphoma	Kidney & renal pelvis	Thyroid	Uterine cervix
80,390 (2%)	104,670 (2%)	5,740 (1%)	9,360 (2%)
All sites	All sites	All sites	All sites
5,012,160 (100%)	6,081,250 (100%)	403,870 (100%)	476,430 (100%)

* Rounded to the nearest 10.

Source: Angela Maiuro, Statistics, Research, and Evaluation Branch, Surveillance, Epidemiology, and End Results (SEER) Program, 17 SEER Registries, 1973-2005, Division of Cancer Control and Population Sciences, National Cancer Institute, 2006.

Table 2. Observed-to-Expected Ratio for Developing Subsequent Primary Cancer after Female Breast Cancer by Age at Diagnosis of First Primary, SEER 1973-2005

Subsequent site	Birth to 39 (N=27,633)	40 to 49 (N=70,941)	50-69 (N=180,355)	70 and older (N=120,028)	All ages (N=398,957)	Observed number	Expected number	EAR
Breast	4.54*	1.98*	1.42*	1.20*	1.55*	18,523	11,922	19.64
Lung & bronchus	1.79*	1.24*	0.99	0.77*	0.96*	5,478	5,684	-0.61
Uterine corpus	1.77*	1.25*	1.32*	1.65*	1.40*	3,552	2,538	3.02
Ovary	4.67*	1.82*	1.16*	0.98	1.29*	1,815	1,408	1.21
ANLL	6.33*	3.31*	1.89*	1.03	1.74*	616	354	0.78
All subsequent cancers†	2.87*	1.49*	1.15*	0.99	1.17*	48,934	41,689	21.59

Note: Excludes the first 2 months after initial cancer diagnosis. Site definitions are based on Appendix 2a and 2b from Curtis RE, Freeman DM, Ron E, et al, (eds.) New malignancies among cancer survivors: SEER cancer registries, 1973-2000. Bethesda, MD: National Cancer Institute, NIH Publ. No. 05-5302; 2006.

EAR = excess absolute risk per 10,000 person years at risk (PYAR); ANLL = acute non-lymphocytic leukemia.

* p<0.05

† All subsequent cancers excludes non-melanoma skin cancer.

OCS Call for Research – 2001 Six target areas

1. Descriptive **epidemiologic data** on outcomes > 1 yr s/p dx
2. **Intervention Studies** - develop & test strategies
 - Prevent or decrease **adverse outcomes**
 - Promote **optimal health** practices
3. Describe & develop **patterns of care** for post-tx

OCS Call for Research – 2001

Six target areas

4. Include **under-represented**: Elderly, low SES, ethnic / cultural minorities, live in remote areas, specific cancers (colorectal, lung, heme)
5. ID or develop **instruments** that accurately demonstrate outcomes for post-tx survivors
6. Describe impact on **family**

(Rowland, Aziz, Tesauro, Feuer, 2001)

OCS Research - "hot off the press"

1. Aging
2. Biobehavioral Interface – persistent & late effects
3. Comparative Effectiveness
4. Adherence
5. Health Promotion & Health Behavior
6. Comorbidities – health care utilization & cost
7. QOPI Standards – Summary Care Plans
8. Caregivers

(Julia Rowland, PhD, Dir OCS, 2/20/2010, APOS Meet the Experts)

Translational Research

- Data Challenges
 - Longitudinal & Prospective
 - Relevant Variables
 - Large Data Sets
 - Diverse populations
 - Use of surrogate biomarkers / genetic markers
 - Confounding Variables & Co-morbidities
 - Accurate measurement (vs. self report alone)

Translational Research

- **Tension between**
 - focus on “cure” and “quality of life”
 - Immediate and long term consequences
- **Medical Record Documentation**
- **Programs that are practical to implement** (Jacobsen)
- **Funding**

**Survivorship Research informs
treatment and follow-up care**

ONS: Survivorship, Quality of Life & Rehabilitation SIG

<http://survivorship.vc.ons.org>

- **Mission Statement:** Promote excellence in nursing care of cancer survivors through education, communication and advocacy and enhance nursing knowledge of evidence based practices in caring for cancer survivors.
- **Newsletters** available by request
- **Networking Meeting** - 35th ONS Congress
Saturday, May 15, 2010 / 4:15-5:45 PM Room 3
- **SIG Poster Displays** – ONS Congress Exhibit Hall

Henry Ford Health System --- Josephine Ford Cancer Center

- **EMR & an integrated health care system**
- **Oncology Social Workers**
- **Support Groups** – children & adults
- **Yoga**
- **EXCITE! Program** – exercise, diet, CAM
- **CMS Project** – screen & follow African Americans through a Medicare-funded program

**Henry Ford Health System ---
Josephine Ford Cancer Center**

- **Psychooncology Services:**
Nurse Practitioner & Psychology Fellow
 - Distress Screening
 - Psychooncology Education for Therapists
 - Study of Primary Care Physicians
 - Survey of Patients and Significant Others attending a Cancer Survivors' Program x 2 yrs
 - GYN Advanced Nurse Practitioner Survivorship Pilot

SWOG Survivorship Studies

Active

- ↓ Ovarian failure s/p CTX early ER/PR (-) breast
- Antioxidant & CAM Use & Survival
- ONJ & Bone Mets – Starting Zoledronic Acid Tx
- Carnitine to Prevent Neuropathy from Taxanes

Closed

- > 70 yo & CTX x 3 trials (urothelial, breast, c/r)
- Older Age & barriers to clinical trials accrual

With appreciation:

*Rose Ermete
Robert Chapman
Tiffany Pearce
Teresa Lynch
Julia Rowland
Patricia Ganz
City of Hope, APOS, IPOS, ONS
Richard Preisman
Our Patients*

What will you do next?
