

*From Cancer Patient to
Cancer Survivor:
Lost in Transition*

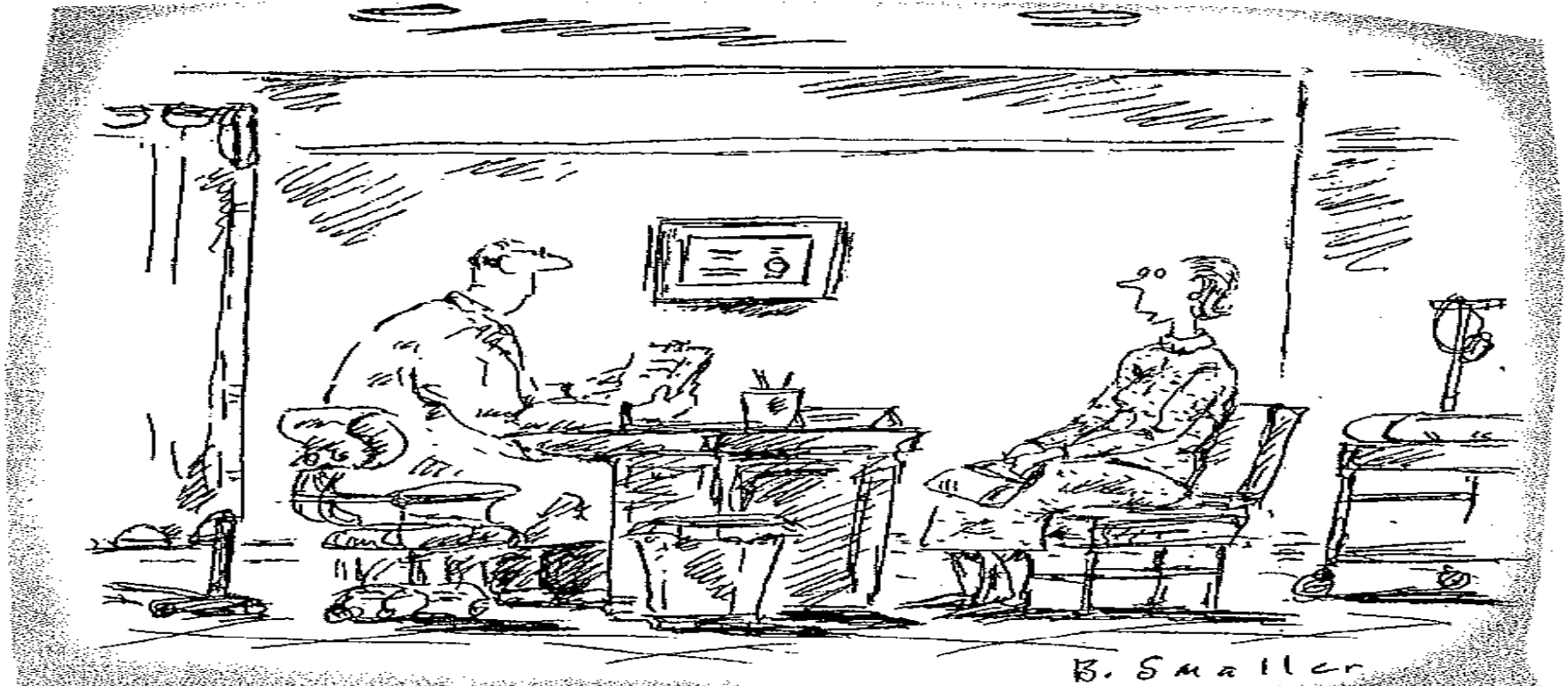
**South Carolina Cancer Alliance Quarterly Meeting
Columbia Conference Center
October 19, 2006**

*Michael Bergin
Chief Operating Officer
National Coalition for Cancer Survivorship*



SCIENCE MAGAZINE

March 24, 2006



“I think the dosage needs adjusting. I’m not nearly as happy as the people in the ads.”

 **NCCCS**

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The power of survivorship. The promise of quality care.

Cancer Survivorship: A Brief History

*The challenge in overcoming cancer is not only to find therapies that will prevent or arrest the disease quickly, but also to map the middle ground of **survivorship** and minimize its medical and social hazards*

1985 NEJM "Seasons of Survival"
Fitzhugh Mullan, co-founder, NCCS
physician/survivor

Cancer Survivorship—a new language

What do we mean by *cancer survivorship* and what is its relation to quality cancer care?

- *“...from the moment of diagnosis and for the remainder of life, an individual diagnosed with cancer is a **survivor**”*
- **Survivorship** is living with, through and beyond a diagnosis of cancer
- Survivors include family, friends and caregivers

Cancer Survivorship

Building the Evidence for Quality Cancer Care

1985 - 2006

- 1985: NEJM "Seasons of Survival" – Fitzhugh Mullan, physician/survivor
- 1986: NCCS founded
Survivorship
Patient Active Concept
- 1987: Cancer Survivor Bill of Rights
- 1993-1990: 350 leaders surveyed Imperatives for Quality Cancer Care
- 1996: NCI Office of Cancer Survivorship
- 2000: IOM Report on Quality Cancer Care
- 2004: IOM Report on Childhood Cancer Survivorship
- 2005: IOM Report on Adult Cancer Survivorship
- 2006: ASCO Survivorship Focus—Survivorship Care Plan



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Cancer Survivor's Bill of Rights - 1987

Survivors have the right to continuous lifelong medical care, as needed.

Professionals involved should make every effort to be:

- **Sensitive** to cancer survivors' lifestyle choices and their need for self esteem, dignity and privacy of the information trusted to them;
- **Careful**, no matter how long these patients have survived, to take symptoms seriously and not to dismiss aches and pains, for fear of recurrence is a normal part of survivorship;



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Cancer Survivor's Bill of Rights - 1987

- **Vigilant** to watch for any long-term and late effects of cancer and its treatment in follow-up clinics and offices;
- **Informative and open**, providing survivors with as much or as little candid medical information as they wish, and encouraging informed participation but not expecting survivors to manage that care on their own;
- **Knowledgeable** about counseling and rehabilitation resources, and willing to refer survivors and their families as appropriate for emotional support and therapy aiming to improve the texture as well as the quantity of time that is theirs to live.



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*Imperatives for Quality Cancer Care[©] ... Advocacy,
Access, Action, and Accountability – 1995-96*

- Defined an integrative medicine model for quality cancer care
- Described physiologic long-term and late effects
- Advocated psychosocial issues of cancer survivorship
- Led to the establishment of the Office of Cancer Survivorship at the National Cancer Institute

1997 – 2006: Building the Case for Quality Cancer Care and Survivorship at the IOM

There is no national cancer care program or system of care in the United States. The National Cancer Policy Board has concluded that 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.

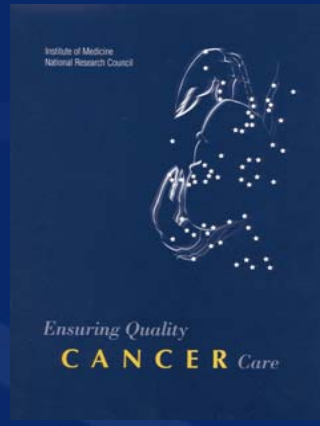
Ensuring Quality Cancer Care

Maria Hewitt, Joseph Simone, MD, editors



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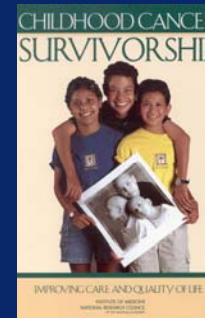
The power of survivorship. The promise of quality care.



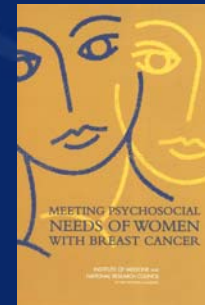
“For many types of cancer, answers to basic questions are not yet available... How frequently should patients be evaluated following their primary cancer therapy, what tests should be included in the follow-up regimen, and who should provide follow-up care?”

IOM: Cancer Survivorship

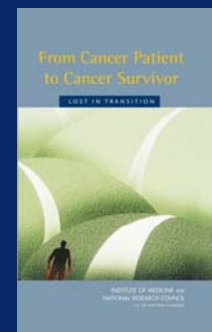
Childhood Cancer Survivorship: Improving Care and Quality of Life (2003)



Meeting the Psychosocial Needs of Women with Breast Cancer (2004)



From Cancer Patient to Cancer Survivor: Lost in Transition (2005)



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Committee Charge

- Raise awareness of the consequences of cancer
- Define quality health care and identify strategies to achieve it
- Recommend policies to improve care and quality of life



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Committee Process

- *17-member committee representing oncology/primary care, urban/rural practice, clinical/health policy research*
- *Met 3 times over 9 months to hear from outside experts, deliberate, and formulate recommendations*

Findings: Survivorship Care

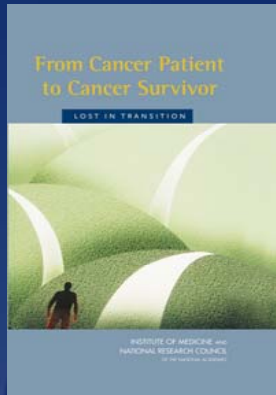
- More than 1 in 3 Americans will be diagnosed with cancer in their lifetime
- 10 million Americans have a personal history of cancer
- The number of cancer survivors will increase sharply

Findings: Survivorship Care

- Survivorship care is a neglected phase of the cancer care trajectory
- Cancer recurrence, second cancers, and treatment late effects concern survivors
- Few guidelines on follow-up care
- Providers lack education and training

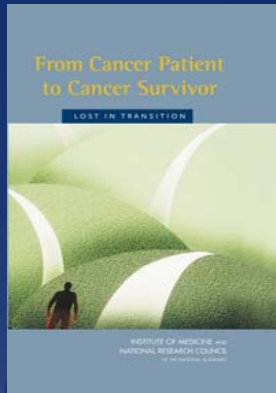
Findings: Survivorship Care

- Survivors may:
 - be unaware of risk
 - have no plan for follow-up
- Opportunities to intervene may be missed
- Cancer care is often not coordinated
- Models of survivorship care not tested



Recommendations

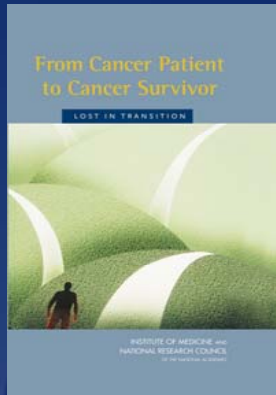
1. Raise awareness of the needs of cancer survivors
 - Establish cancer survivorship as a distinct phase of cancer
 - Act to ensure delivery of appropriate survivorship care



Recommendations

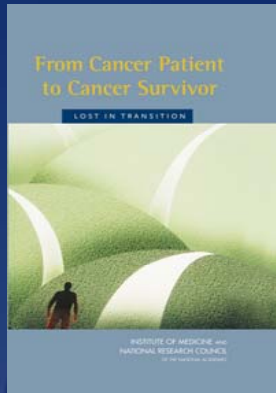
2. Survivorship care plan

- Written by principal oncology provider
- Effectively explained
- Reimbursed by third-party payors



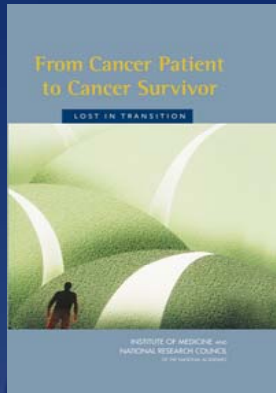
Recommendations

3. Provide survivorship care using:
 - Clinical practice guidelines
 - Assessment tools
 - Screening instruments



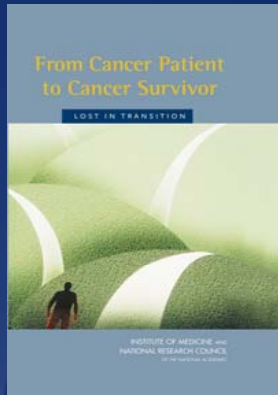
Recommendations

4. Develop quality of care measures and implement quality assurance programs
5. Test models of coordinated, interdisciplinary survivorship care
 - Shared-care model
 - Nurse-led model
 - Survivorship clinics



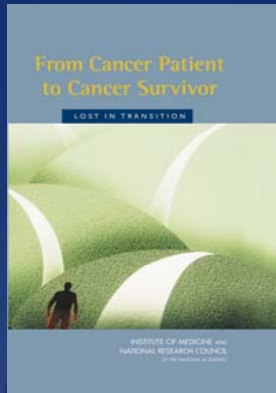
Recommendations

6. Incorporate survivorship into statewide comprehensive cancer control plans and evaluate effectiveness
 - Preventive services
 - Community-based resource guides
 - Professional education and training



Recommendations

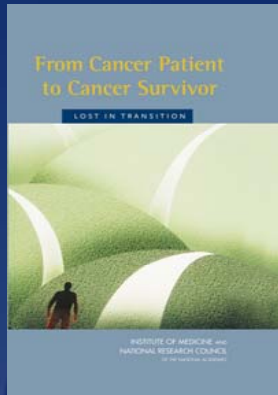
7. Expand educational opportunities for health care providers
 - Oncology and primary care physicians
 - Nurses
 - Social workers and other mental health providers



Recommendations

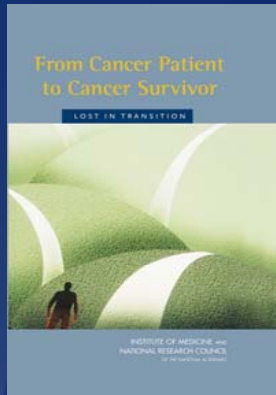
8. Eliminate discrimination and minimize adverse effects on employment

- Finance programs offering information and support
- Familiarize health care providers with employment-related issues and services
- Educate survivors on rights and responsibilities



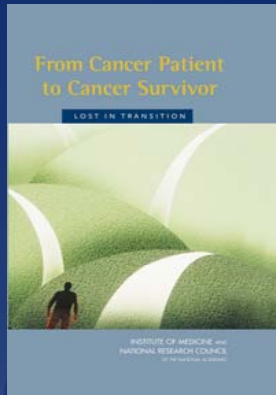
Recommendations

9. Ensure access to adequate and affordable health insurance
 - 11% of survivors age ≤ 65 uninsured
 - Survivorship care is an essential benefit
 - Coverage for evidence-based aspects of care



Recommendations

10. NCI, CDC, AHRQ, CMS, VA, ACS and others should increase survivorship research support
 - Mechanisms of late effects
 - Clinical and psychosocial interventions
 - Clinical trials on surveillance strategies
 - Health services research



Progress to date...

- A symposium was convened in November 2005 to coincide with the release of the report
- NCCS convened a workshop on survivorship care planning in May 2006 with key thought leaders to discuss implementation steps

“Never doubt that a small group of thoughtful, committed people can change the world. Indeed, it is the only thing that ever has.”

Margaret Mead

Legislative Advocacy — What is it and why do we need it?

- It's about making having a voice and making "noise"
- Building relationships with policymakers over time – not a one-time effort
- Speaking up and remaining focused
- The system DOES respond

The March in Washington, DC (1998)

The message – “No More Cancer”



Results: 16% increase in funding for NIH -opened the door to discussing access to care issues

What is Comprehensive Quality Cancer Care?

- Coordinated, integrative evidence-based care, including symptom management and palliation from the time of diagnosis onward. Treatments for nausea, fatigue, pain and depression, other psychosocial needs
- NOT limited to end-of-life care, or hospice-provided care

Comprehensive Cancer Care

- NCCS Goal: move cancer care system toward comprehensive care
 - Earlier and more aggressive palliative care and symptom management
 - Cancer care plan and treatment summary
 - Provider & patient education on symptom management
 - Support for model palliative care programs

Why do we need a survivorship care plan?

- To summarize and communicate what transpired during treatment
- To describe known and potential late effects of treatment with expected time course
- To communicate to the survivor and other health professionals **what has been done and what needs to be done in the future**
- To promote a healthy lifestyle to prevent recurrence and reduce the risk of other co-morbid conditions

Patricia A. Ganz, MD

Cancer Prevention/Epidemiology Track
2006 ASCO Annual Meeting



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Comprehensive Cancer Care Improvement Act of 2006—HR 5465

To provide relief and assure quality cancer care, NCCS:

- Developed the concepts of advocates into a legislative proposal
- Relied on expert advice of NCCS Board to focus the legislative concepts
- Worked with Congress to refine proposal and develop plan for introduction
- Introduced by Lois Capps (D-CA) and Tom Davis (R-VA)—May 2006

Comprehensive Cancer Quality Improvement Act—H.R. 5465

Highlights of Legislation:

- Funding for model programs
- Professional education re: appropriate symptom control
- Refine Medicare payment to ensure treatment plan and care summary

H.R. 5465 — Comprehensive Cancer Care Improvement Act of 2006 – Sec. 2. FINDINGS

The Congress makes the following findings:

- Individuals with cancer often do not have access to a cancer care system that provides comprehensive and coordinated care of high quality.
- The cancer care system has not traditionally offered individuals a comprehensive plan for treatment and symptom management, strategies for updating and evaluating such plan with the assistance of a health care professional, and a follow-up plan for monitoring and treating possible late effects of cancer and its treatment.
- Comprehensive cancer care should include a means for **providing cancer survivors with a comprehensive care summary and a plan for follow-up after primary treatment** to ensure that cancer survivors have access to follow-up monitoring and treatment of possible late effects of cancer and cancer treatment.



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