Survivorship: Caring for the 12 Million Surviving Cancer

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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
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

Institute of Medicine & National Research Council, 2006
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

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

Report from ACS Studies of Cancer Survivors, 2008
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?

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
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

Earle & Neville, 2004
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
“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