Caring for Survivors

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Cancer Survivorship Program
Survivors

• Growing numbers of survivors
  – Convergence of ageing population and numbers surviving cancer
• Greatest number are over 60 years
• Breast, prostate and colon cancers
• Growth of uninsured
• Predicted shortage of providers
How should survivorship care be delivered?

- Integrated, coordinated and multidisciplinary
- Designated individual coordinates care across disciplines with shared responsibility
- Patient-centered

IOM 2005
Barriers to Care Delivery

• Barriers facing survivors
  – Fragmented health care delivery
  – Lack of awareness of late effects
  – Barriers to communication

• Barriers facing providers
  – Fragmented system of care
  – Lack of education and training in survivorship
  – Lack of survivorship standards of care
  – Difficulties in communication between providers
  – Capacity for delivering survivorship care

Essential Components of Survivorship

- Surveillance for recurrence
- Prevention and detection of new cancers
- Interventions for consequences of cancer and its treatment
- Coordination between specialists and primary care providers
- Promotion of healthy behaviors
Cancer Surveillance

- Few guidelines available because of lack of evidence and consensus on follow up recommendations
- Surveillance seems like a good thing
  - Little evidence of improved outcomes
  - Expensive
  - Relapse more commonly detected by signs and symptoms
  - Psychological distress
- Justified for the identification of disease that can be cured or survival prolonged
- Limit unnecessary and harmful care
- Facilitate delivery of necessary care

Survivorship Care
Usual Practice

- Follow-up by oncologists is routine
- Duration of follow-up is variable
- Follow-up guidelines are limited and recent
- Follow-up care focused on surveillance for recurrence
- Limited transfer of knowledge and information to primary care provider
Long Term Follow-up Programs

Rationale

• A need to figure out how to care for the large number of individuals in follow-up
• Greater understanding of the consequences of cancer and its treatment
• Focus on the application of interventions to eliminate/reduce sequelae
• Follow-up care setting can be a platform for research
• Begin to focus on survivorship education and training
Survivorship Care Models
Academic Institutions

- Pediatric programs
  - Long term follow-up clinics
    - 2 years post-treatment
    - Pediatric oncologist and nurse practitioner
  - Free standing
  - Multidisciplinary
  - Not disease specific
  - Risk–based survivor care
Survivorship Care Models
Academic Institutions

- **Adult programs**
  - Disease-specific programs
  - Comprehensive programs
    - Consultative model
      - One time visit
      - Focus on medical summary and systematic plan for surveillance
    - Ongoing care model
      - Nurse practitioner-led clinic
        » Extends the care continuum
        » May be imbedded with the treatment team
      - Multidisciplinary long term follow-up program
        » Follows the pediatric model
Survivorship Care Models
Community Settings

• Setting where most survivors receive care
• No model currently exists for oncology follow-up
• Shared-care is a model to evaluate
  – Already used for the management of chronic diseases
  – Studies demonstrate improved patient outcomes and enhancement of the management of chronic disease
  – A few studies suggest that this model is applicable to the care of cancer survivors

Shared-Care Model
Elements

• Care shared by two or more clinicians of different specialties
• Common understanding of expected components of care and respective roles
• Clear communication between cancer specialist and primary care physician
Shared-Care Models Risk-Stratified Approach

• Low risk individuals
  – Transition early to primary care
• Moderate risk individuals
  – Joint follow-up by oncology team and primary care
  – Transition late to primary care
• High risk individuals
  – Oncology maintains follow-up
  – Primary care manages non-cancer related care
Survivorship Initiative at MSKCC

- Survivorship research and services for all age groups
- Development and evaluation of models of care
- Development of new clinical programs addressing greatest need
- Expansion of the survivorship research community
- Development and dissemination of information
Our Beginnings

• **Original Survivorship Programs at MSKCC**
  
  – Survivors of Childhood Cancer: Long Term Follow-up (LTFU) Program
    
    Charles Sklar, MD Director
  
  – Post Treatment Resource Program (PTRP)
    
    Penny Damaskos, MSW Director
Center Perspective
Survivorship at MSKCC

• Conceptually
  – All living persons who ever received a diagnosis of cancer along with family members, friends and caregivers

• Programatically
  – Extend the continuum of care
  – Focus on the needs of individuals, families and caregivers who have completed treatment
  – Focus on oncology care and services
  – Center wide effort
  – Inclusive of physical, psychosocial, social and spiritual domains
Guiding the Effort
A Federation Approach

• Oversight and management
  – Program Staff
    • Report to Physician-in-Chief
  – Steering Committee
    • Physicians
    • Nurses
    • Social workers
    • Administrators
    • Patients
  – Long-term follow-up clinic leaders
Guiding the Effort
A Federation Approach

• Pilot team leaders
  – Clinical
    • Physician, NP and administrator
  – Research
    • MD and/or PhD

• Ad hoc work groups
  – Patient portal
  – Research data base

• Metrics committee
  – Physicians, nurses and administrators
New and Expanded Patient Services

• Maximize use of current programs and services
  – Support groups and psychoeducational programs
  – Nutrition counseling
  – Smoking cessation
  – Physical rehabilitation

• Establish communication systems
  – Patients
  – Providers

• New services
  – Clinic for adult survivors of pediatric cancer
  – Sexual health program
  – Reproductive medicine and fertility preservation consultation
Survivorship Model of Care at MSKCC

• Shared-care model
  – Nurse practitioners as primary oncology provider
  – Ongoing communication with the community physician

• Risk-based approach
  – Transfer to NP begins when patients have recovered from the immediate effects of treatment and risk of recurrence is reduced
  – Transfer to primary care when feasible

• The NP works within a service/Disease Management Team

• Care provided within disease-specific clinics

• Research is a core element of the pilots
FOLLOW UP CARE OF CANCER SURVIVORS

DIAGNOSIS → TREATMENT → EARLY FOLLOW UP → SURVIVORSHIP POST-TX FOLLOW UP → LONG TERM POST-TX FOLLOW UP

- Cancer recurrence
- Sequelae of Tx
- Screening other cancers
- Health Promotion

Oncology Specialist → APN

Primary Care Provider
Survivor Clinic Model

- Follow-up in close association with oncology physician
- Long term follow-up patients:
  - Early stage patients
  - Past period of highest risk for recurrence
- Independent Nurse Practitioner visit
- Clinical focus
  - Surveillance for recurrence of the primary cancer
  - Evaluation and treatment of medical and psychosocial consequences of treatment
  - Screening for second cancers
  - Patient education about survivorship issues and availability of community resources
  - Health promotion, including smoking cessation and sexual health services
  - Communication with community physician
Adult Clinics
In Operation

- Urology- Prostate, Renal, Bladder Surgery
- Prostate Radiation
- Thoracic Surgery
- Breast Medicine
- Breast Surgery
- Colorectal Surgery
- Allogeneic Transplant
- Adult Survivors of Pediatric Cancers
  - Kevin Oeffinger, MD
<table>
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<tr>
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<th>Cancer type</th>
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## Summary of Cancer Treatment and Follow-Up Plan

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### Treatment Summary

#### Surgery

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Clinic Analysis

- Satisfaction
  - Patient
  - Clinicians
- Demonstrated sustainability and success in facilitating shared care
- >3500 patients currently receiving care in survivorship clinics
Expansion of the Program

- Continued expansion of clinics
- Clinical adaptations of model
- Growing medical and psychosocial research community
- Expanding professional education about cancer survivorship care
- Growing clinical resources
  - Rehab program
Challenges

• Sustainability of clinical programs
• Finding different solutions for different survivor populations
• Reimbursement for services
  – Out of network follow-up care
• Lack of adult follow-up guidelines
• Limited federal research funding
Summary

- Cancer survivorship issues will continue to grow in significance for patients, clinicians, health care systems, and payors
- Lack of guidelines and research create great challenges in responding to needs
- Implementation of strategies recommended by the IOM report are underway
- Models of care are being tested to address how to transition care effectively
Resources

• National Coalition of Cancer Survivors
• Cancer Survival Toolbox
• Lance Armstrong Foundation
• Cancer.Net (ASCO)
• American Cancer Society
• National Cancer Institute Office of Cancer Survivorship
• Fertile Hope
• Legal resources: FMLA and HIPPA
• For professionals: IOM, CDC/LAF, President’s Cancer Panel, NCI