Caring for Survivors

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Cancer Survivorship Program

Survivors

- Growing numbers of survivors
  - Convergance 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

Hewitt, Greenfield, & Stovall (2005). *From Cancer Patient to Cancer Survivor: Lost in Transition.*

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 Survillance

- 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

Earle, C J (2006) *J Clin Oncol* 24:5112-5116; Burstein HJ & Winer E (2000) *NEJM* 343:1086-1094

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

Renders et al: Diabet Med 20:846-852, 2003; Jones et al: Am J Kidney Dis 47: 103-114, 2006; Grunfeld et al: Br J Cancer 49:882-886, 2003; Grunfeld et al: JCO 24:848-855, 2006

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

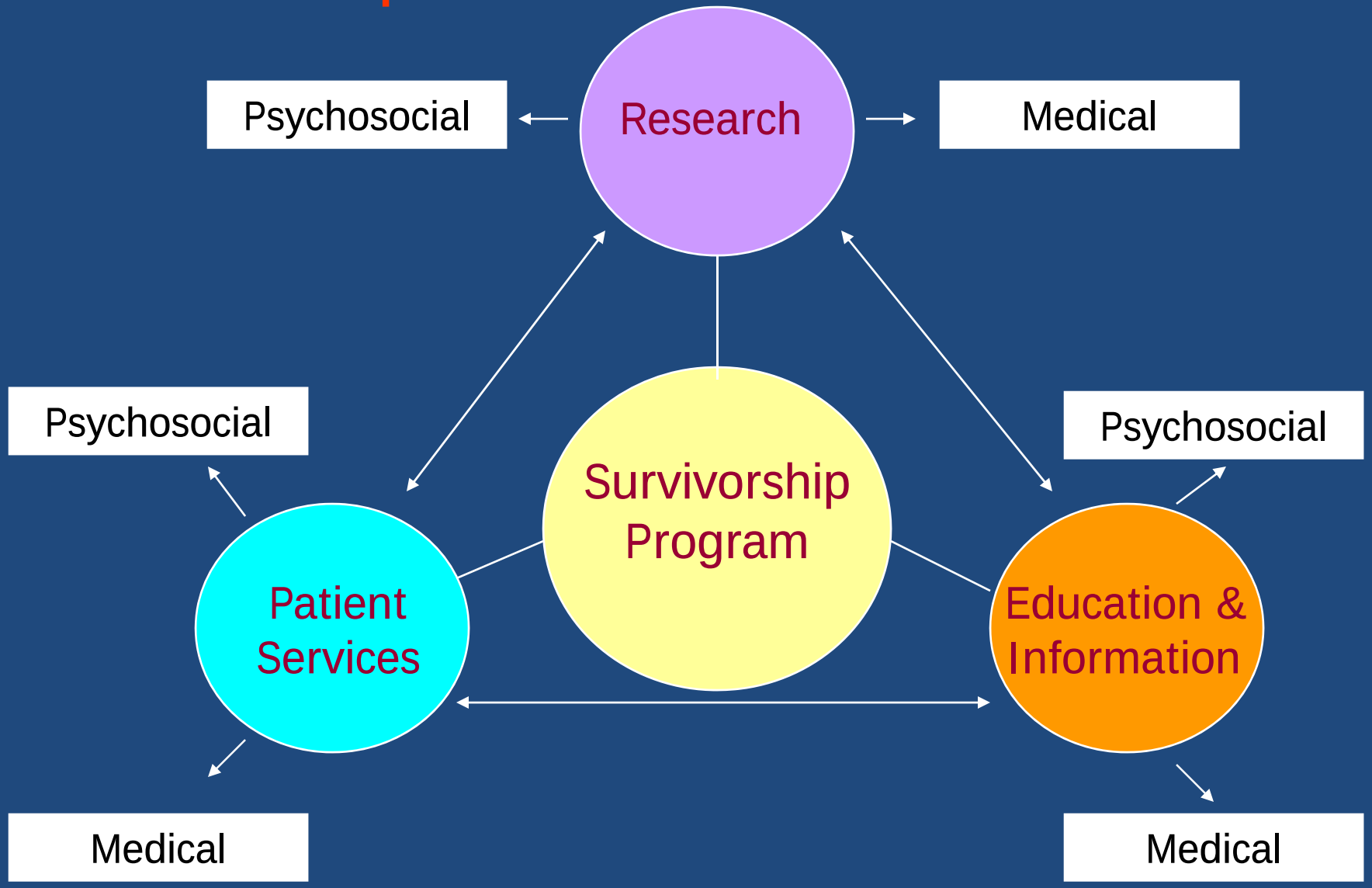
Shared-Care Models Risk-Stratified Approach

- 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

Survivorship Model



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

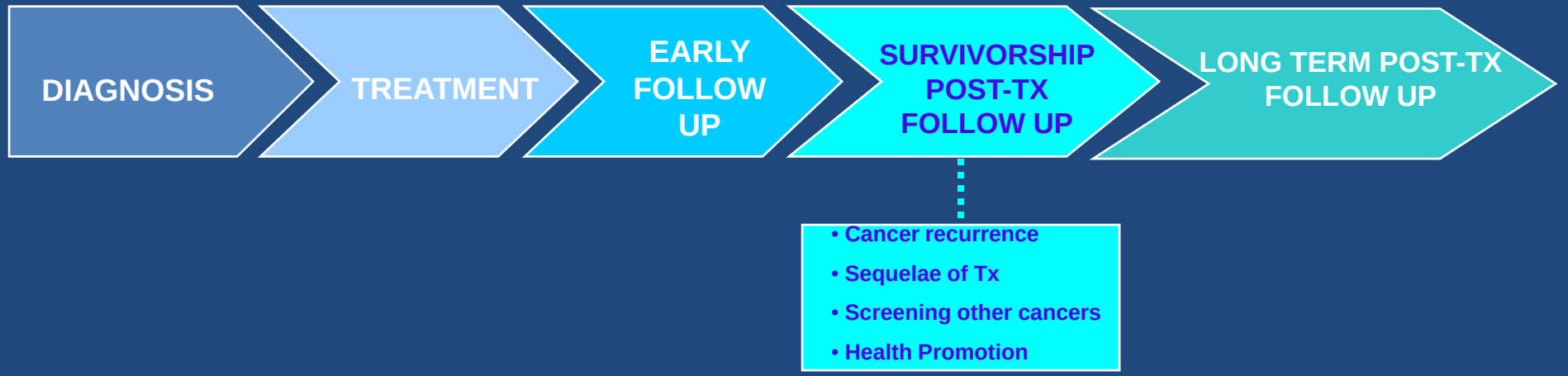
New and Expanded Patient Services

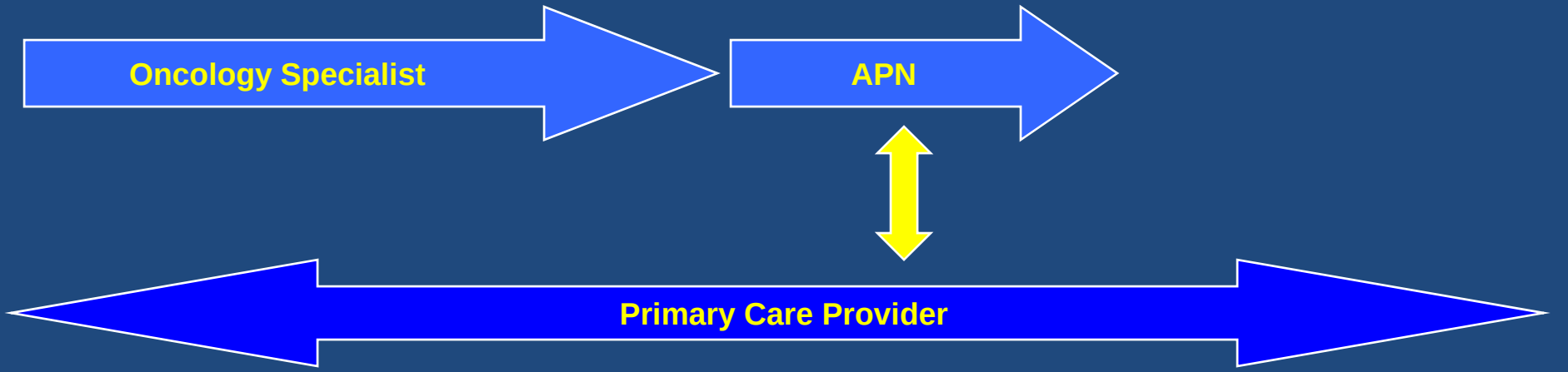
- Maximize use of current programs and services
  - Support groups and psychoeducational programs
  - Nutrition counseling
  - Smoking cessation
  - Physical rehabilitation
- Establish communication systems
  - Patients
  - Providers
- New services
  - Clinic for adult survivors of pediatric cancer
  - 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





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

Survivorship Standard Follow-up Care					
Service	**Cancer type**	**Interval**	**Visit**	**Testing**	**Stage/Primary Provider**
Thoracic	Lung	Year 1	Every 6 months	CT scan w/contrast	Stage I-II/Surgeon
		Year 2	Every 6 months	CT scan w/contrast	Stage I-II/ Nurse Practitioner
		≥ Year 3	Annual	CT scan w/out contrast	
Urology	Prostate	Year 1	Every 6 months	PSA Every 6 months	Year 1- Surgeon ≥ Year 1- Nurse Practitioner
		Year 2	Every 6 months	DRE and PSA Every 6 months	
		Year 3-5	Annual	DRE Annual/PSA Every 6 months	
		> Year 5	Annual	Annual PSA/DRE	
Colorectal	Colon	Year 1-2	Every 4 months	CEA/scope depending on tumor site and CT scan depending on stage	Year 1- Surgeon Year 2- Nurse Practitioner
		Year 3-5	Every 6 months	CEA/scope depending on tumor site and CT scan depending on stage	Nurse Practitioner
		Year >5	Annual	CEA	Nurse Practitioner
	Rectal	Year 1-2	Every 4 months	CEA/scope	Surgeon
		Year 3- 5	Every 6 months	CEA/scope	Surgeon/ Year 5 Nurse Practitioner
		Year ≥5	Annual	CEA	Nurse Practitioner
Breast	Breast Surgery	Year 1-2	Every 6 months	Clinical breast exam, Annual mammogram	Surgeon
		>Year 2	Annual	Clinical breast exam, Annual mammogram	Nurse Practitioner
	Breast Medicine	Year 1-2	Every 3-4 months	Clinical breast exam, Annual mammogram	Medical Oncologist
		Year 3-5	Every 6 months	Clinical breast exam, Annual mammogram	Medical Oncologist
		> 5 years	Annual	Clinical breast exam, Annual mammogram	Nurse Practitioner

Summary of Cancer Treatment and Follow-Up Plan

Diagnosis
Pathology
Date of Diagnosis
Additional Information

TREATMENT SUMMARY

Surgery

Surgeon
Phone

Date	Procedure

Chemotherapy/Biotherapy

Medical Oncologist
Phone
Regimen

Drug	Drug

Regimen

Drug	Drug

Radiation Therapy

Radiation Oncologist
Phone

Date	Type	Field	Dose

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