

Optimizing Cancer Survivorship: A Growing Challenge for Research and Care

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What I will cover...

- Setting the stage for the conversation
- Challenges to life beyond cancer
- Lessons learned along the way
- New directions in survivor's post-treatment care
- Where do we go from here with research and care?

Lessons Learned...

1. Cancer care and how we think about cancer has changed dramatically

(and will continue to do so into the future!)

A Trip to the past: 1971



- Fewer than 50% of those diagnosed with cancer would survive 5 years
- Relatively few treatment options for most cancers; little patient choice (e.g. breast cancer)
- Serious side effects, often poorly controlled (nausea & vomiting, anemia, amputation & functional impairment 2^o to radical surgeries)
- Long hospital stays; largely in-patient based care
- Often lengthy treatment period (*if* patient responded)
- Attitude toward *not* telling the diagnosis
- ***“Survivors” in this earlier period = family!***

The Changing Demography of Cancer Survivorship: 2019

- The majority of those diagnosed today can expect to be alive in 5 years (about 69.7%)*
- Treatments for cancer are often complex and multi-modal and increasingly include oral meds & novel targeted as well as immunotherapies; choices involved!
- Cancer patients receive most of their care in the outpatient setting, largely in the community (versus in-house or in big cancer centers)
- Cancer for many has (or will) become a chronic illness
- Full disclosure & expectation that patients – and their families – will be actively engaged partners in care
- Survivorship is an acknowledged component of care

NIH/DCCPS Model (modified from Abrams)

Cancer Control Continuum

Prevention

Tobacco control
Diet
Physical activity
Sun exposure
Virus exposure
Alcohol use
Chemo-prevention

Early Detection

Cancer screening
Awareness of cancer signs and symptoms

Diagnosis

Oncology consultations
Tumor staging
Patient counseling and decision making
Care planning

Treatment

Chemotherapy
Surgery
Radiation therapy
Adjuvant therapy
Symptom management
Psychosocial care

Survivorship

Long-term follow-up surveillance
Late-effects management
Rehabilitation
Coping
Health promotion

End-of-Life Care

Palliation
Spiritual Issues
Hospice
Bereavement

Cross-Cutting Issues

Communication, decision making, quality of care and health equity, informal caregiving

Lessons Learned...

2. Its' not over when it is over!

The ugly...

Multiple malignancies

- Approximately 19% of new cases of cancer are diagnosed in individuals who already have cancer
- If second cancers were a 'site' of cancer, they (i.e. multiple cancers) would be the most common type diagnosed

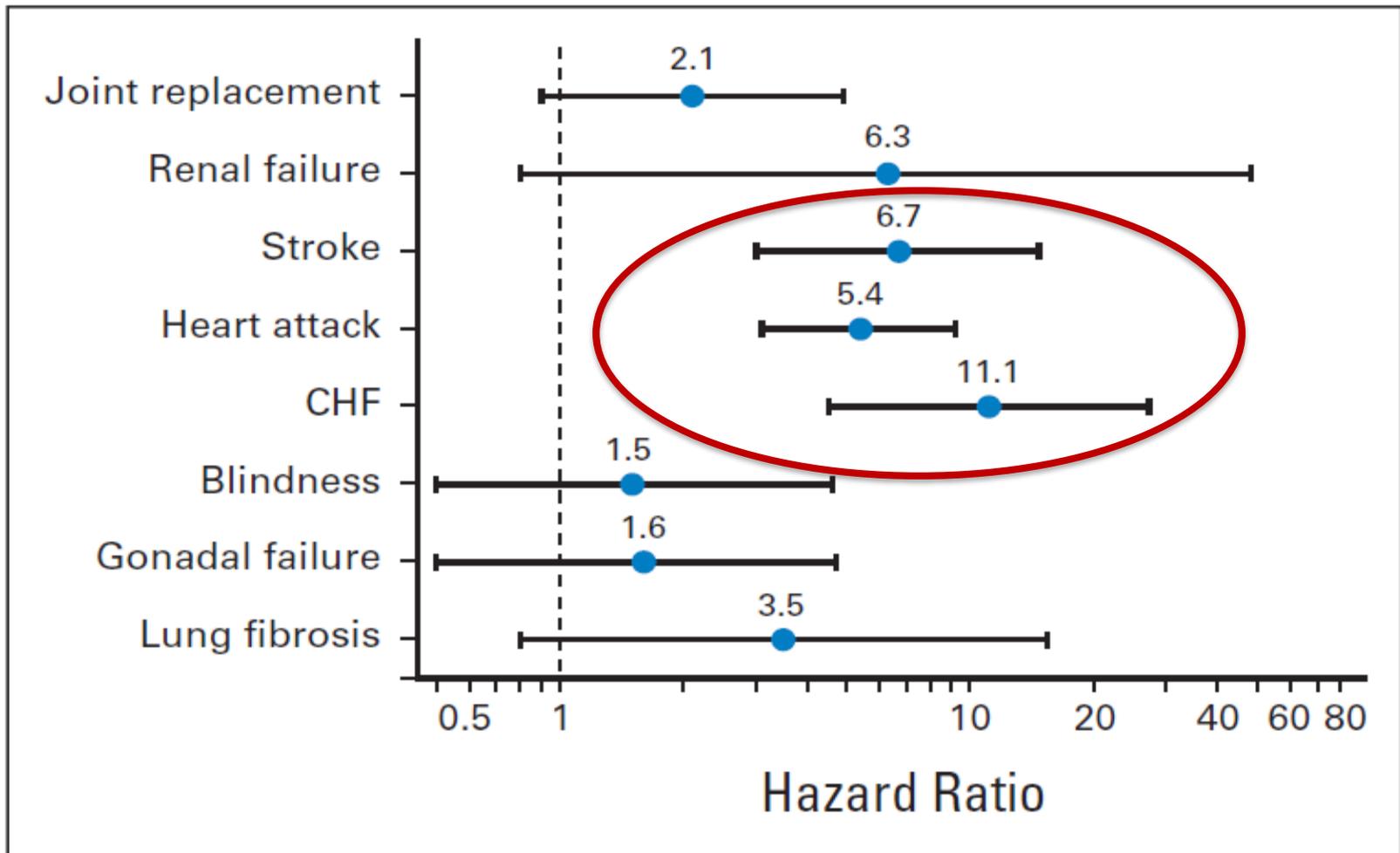


Fig 3. Hazard ratios and 95% CIs of survivors versus siblings for specific chronic conditions that first occurred at or after age 35 years, adjusted for age, race, and sex. CHF, congestive heart failure.

The bad...

Population estimates for poor HRQOL among cancer survivors from the 2010 NHIS as measured by the PROMIS Global 10

Weaver et al, *Cancer Epidemiol Biomarkers Prev* 2012

	Weighted prev Adults without Cancer	Weighted Prev Cancer Survivors	Population Est. for Cancer Survivors (SE)
Physical health score < 1 SD below U.S. population mean	10.2%	24.5%	3,278,000 (184,000)
Mental health score < 1 SD below U.S. population mean	5.9%	10.1%	1,356,000 (122,000)
Physical and mental HRQOL < 1 SD below U.S. population mean	3.5%	7.2%	973,000 (99,000)

The good!

Benefit-finding / Post-Traumatic Growth Research

- **Greater appreciation of life**

“I take time to smell the roses.”

- **Enhanced sense of purpose and meaning**

“My cancer has made me passionate about advocating for others.”

- **Deepened relationships**

“The kindness of friends and strangers was overwhelming and filled my heart.”

- **Heightened self-confidence**

“Getting through cancer was an incredible feat. I am proud of what I accomplished.”

- **Improved health behaviors**

“I take much better care of myself now than before.”

Lessons learned...

3. Planning for recovery and life beyond cancer is important!

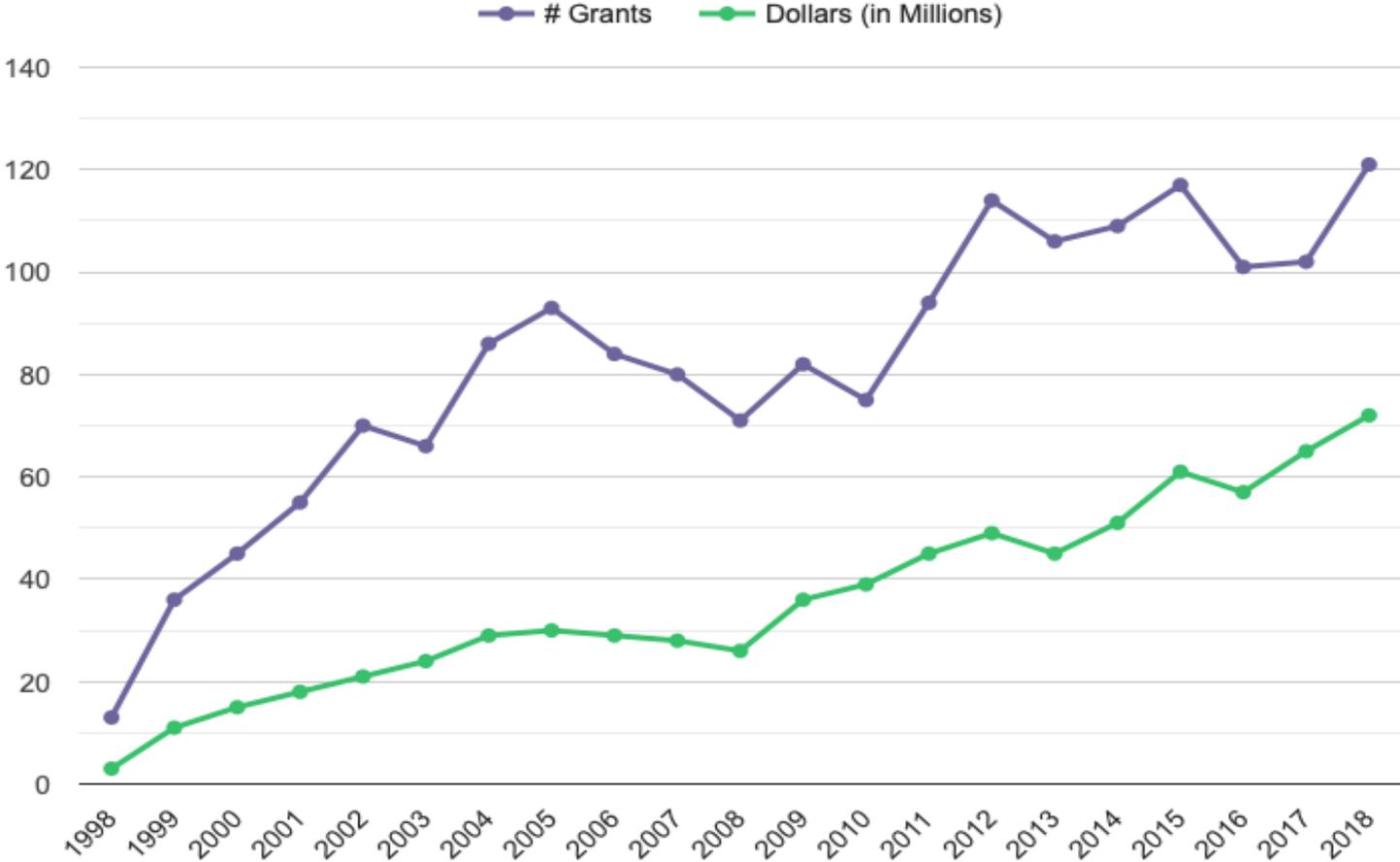
Why is transitioning to recovery so stressful?

- ❖ Fear that the cancer will return
- ❖ Concern about ongoing monitoring
- ❖ Loss of a supportive environment
- ❖ Social demands: 're-entry' problems
- ❖ Diminished sense of well-being due to treatment effects

Lessons Learned...

4. If you build it, they will come

Number of and Funding for Survivorship Grants held by DCCPS: FY98-FY18 (last updated 12.14.2018)

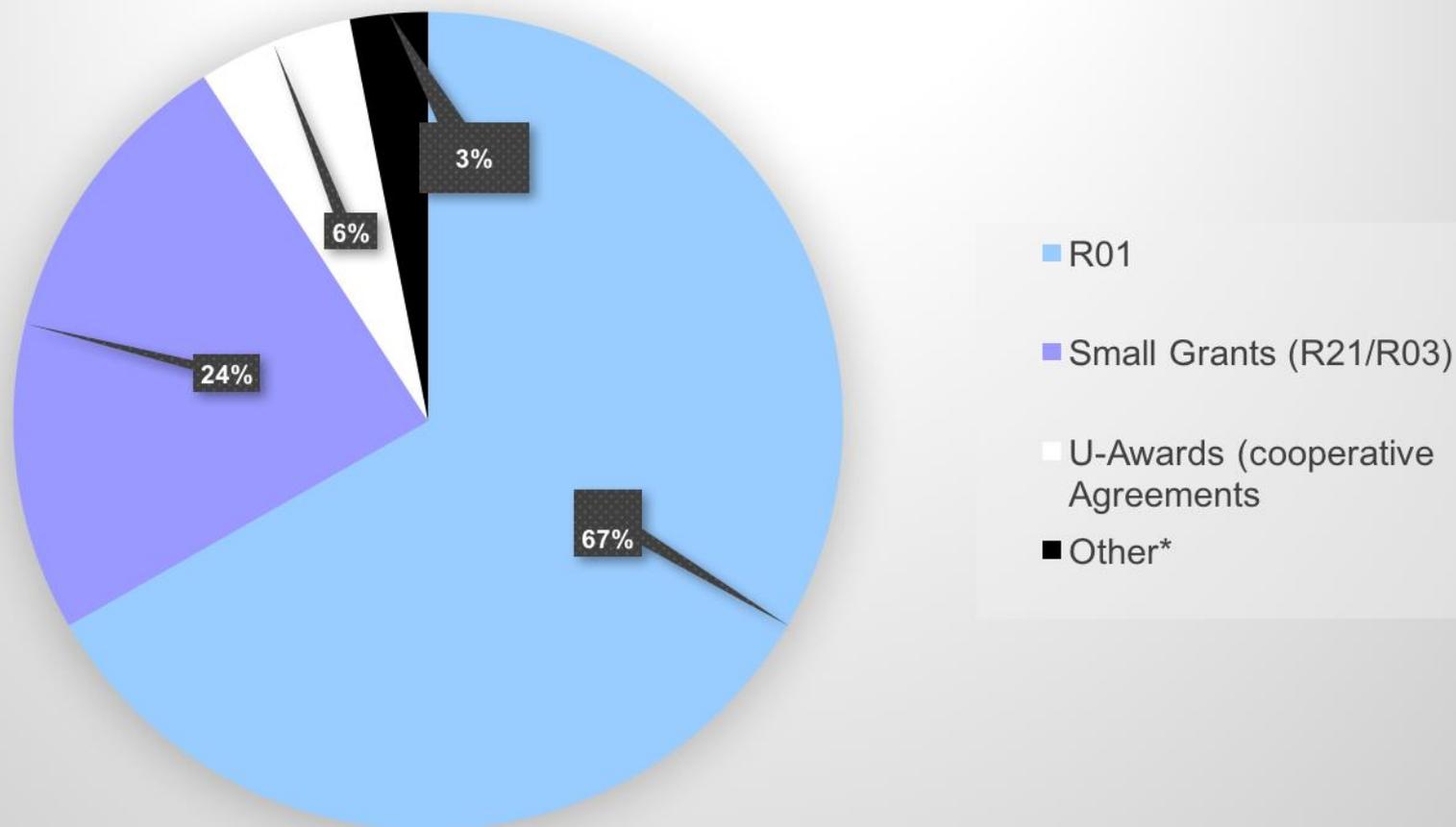


Gap Areas for Pursuit

Lessons learned from the 2016 NIH-wide portfolio analysis of survivorship grants

Rowland JH et al, JNCI J Natl Cancer Inst 2019 111(2):djj208

Distribution of FY2016 Survivorship Grants by Mechanism (N = 165)



*Other includes: R34, R43 (Small Business Grants) and R15 (Academic Research Enhancement Award)

Target Population Characteristics of FY2016 Survivorship Research Grants (N = 165)

Characteristic	n	%
Cancer type ^a		
Breast	78	47.3
Colorectal	25	15.2
Prostate	23	13.9
Hematologic ^c	20	12.1
Gynecological ^b	13	7.9
Lung	10	6.1
Head and neck	9	5.5
Bladder	6	3.6
Other ^d	59	35.8
Pediatric or adult cancer survivors (at time of diagnosis)		
Pediatric survivors	23	13.9
Adult survivors	139	84.2
Both	3	1.8

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^a % does not add up to 100% for cancer type, as some grants included multiple types of cancer. ^b includes lymphomas, leukemias, myeloma. ^c includes cervical, endometrial, ovarian. ^d includes adult not otherwise specified, pediatric not otherwise specified, testicular, renal, bone, soft tissue, Wilms' tumor, basal cell carcinoma, melanoma, brain, retinoblastoma, gastrointestinal

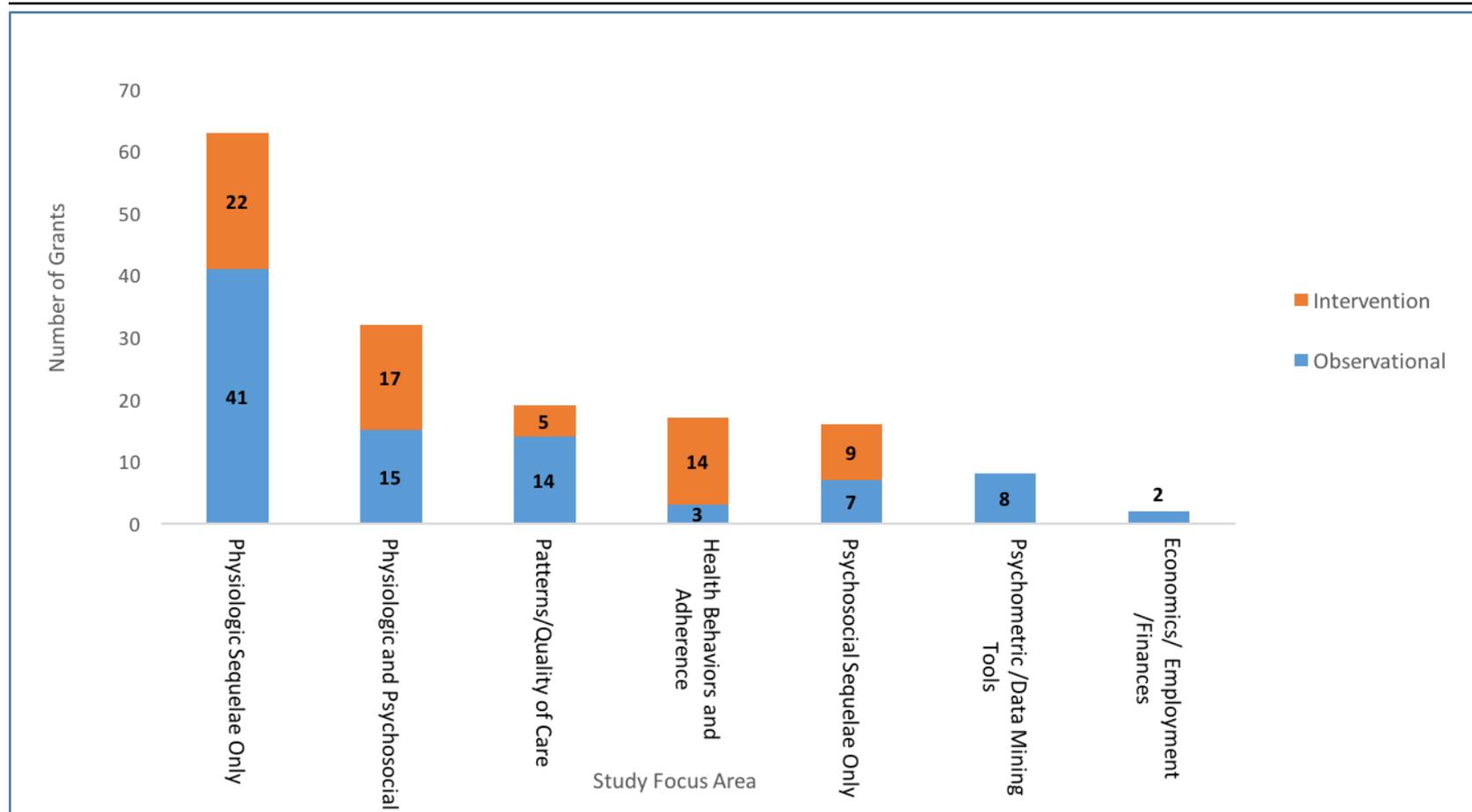
Target Population Characteristics of FY2016 Survivorship Research Grants (N = 165)

Characteristic	n	%
Sex		
Male	9	5.5
Female	71	43.0
Both	85	51.5
Time since diagnosis		
Specified (categories below not mutually exclusive)	127	77.0
<2 years of diagnosis	106	65.2
2 to 5 years after diagnosis	31	18.8
>5 years after diagnosis	27	16.4
Recurrent cancer survivors	2	1.2
Not specified	38	23.0
Special populations		
Adolescents and young adults	11	6.7
Older adults (65 years of age or older)	8	4.8
Rural populations	5	3.0
Families (couples/dyads, parents/siblings)	15	9.1

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^a % does not add up to 100% for cancer type, as some grants included multiple types of cancer. ^b includes lymphomas, leukemias, myeloma. ^c includes cervical, endometrial, ovarian. ^d includes adult not otherwise specified, pediatric not otherwise specified, testicular, renal, bone, soft tissue, Wilms' tumor, basal cell carcinoma, melanoma, brain, retinoblastoma, gastrointestinal

Distribution of FY2016 NIH-Wide Survivorship Grants by Study Focus and Design (N = 157)*



Note: The 8 grants coded as establishment of a cohort are excluded from this figure, as these applications did not lend themselves to coding by a major area of focus.

Perspectives for the Future:

Where do we go from here?

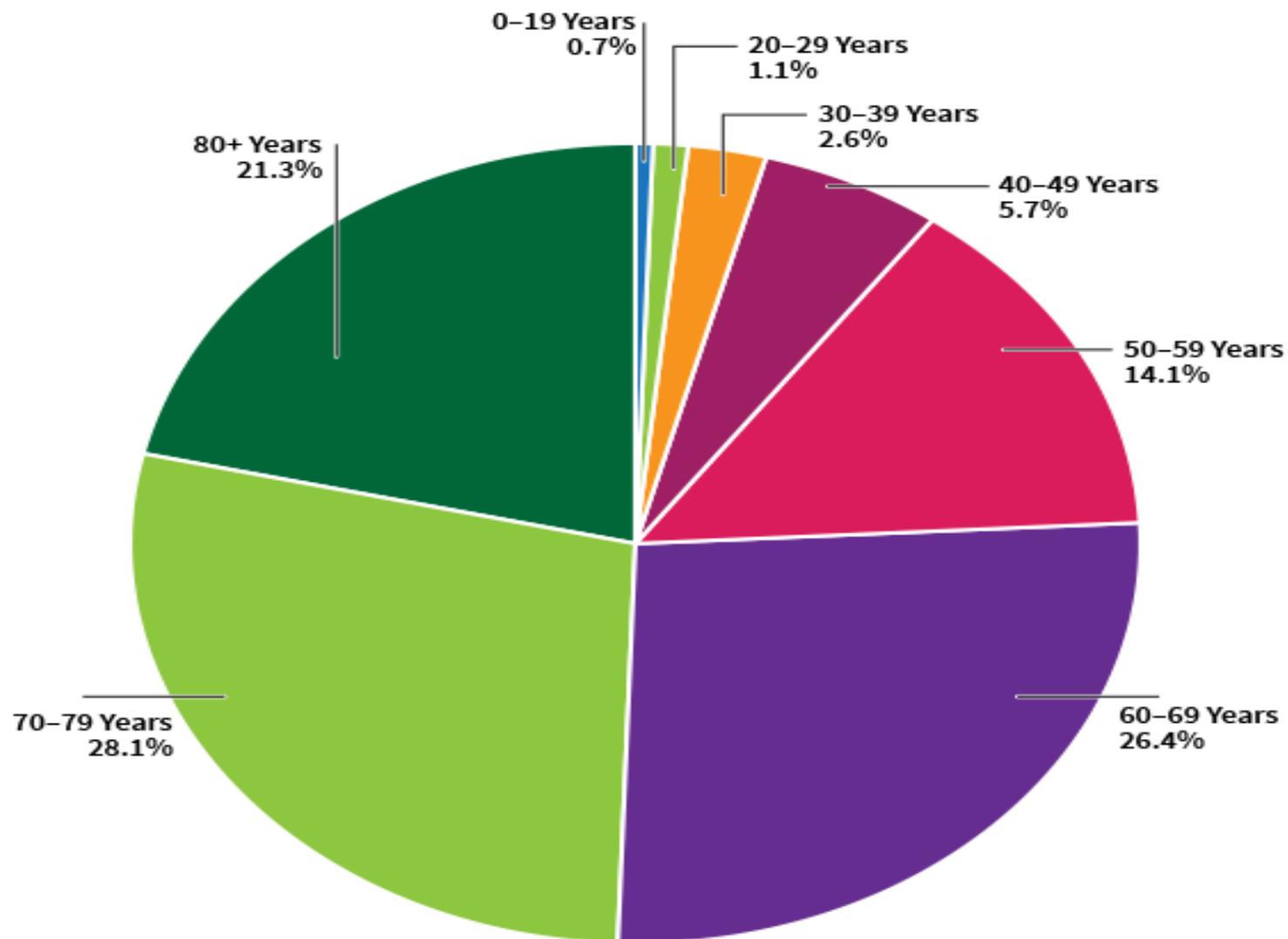
- ❖ **Understand & address emerging long-term and late effects (e.g., targeted therapies, immunotherapies)**

Perspectives for the Future:

Where do we go from here?

- ❖ Understand & address emerging long-term and late effects (e.g., targeted therapies, immunotherapies)
- ❖ **Prepare for an aging population, including understanding the interaction between aging and cancer, *and vice versa***

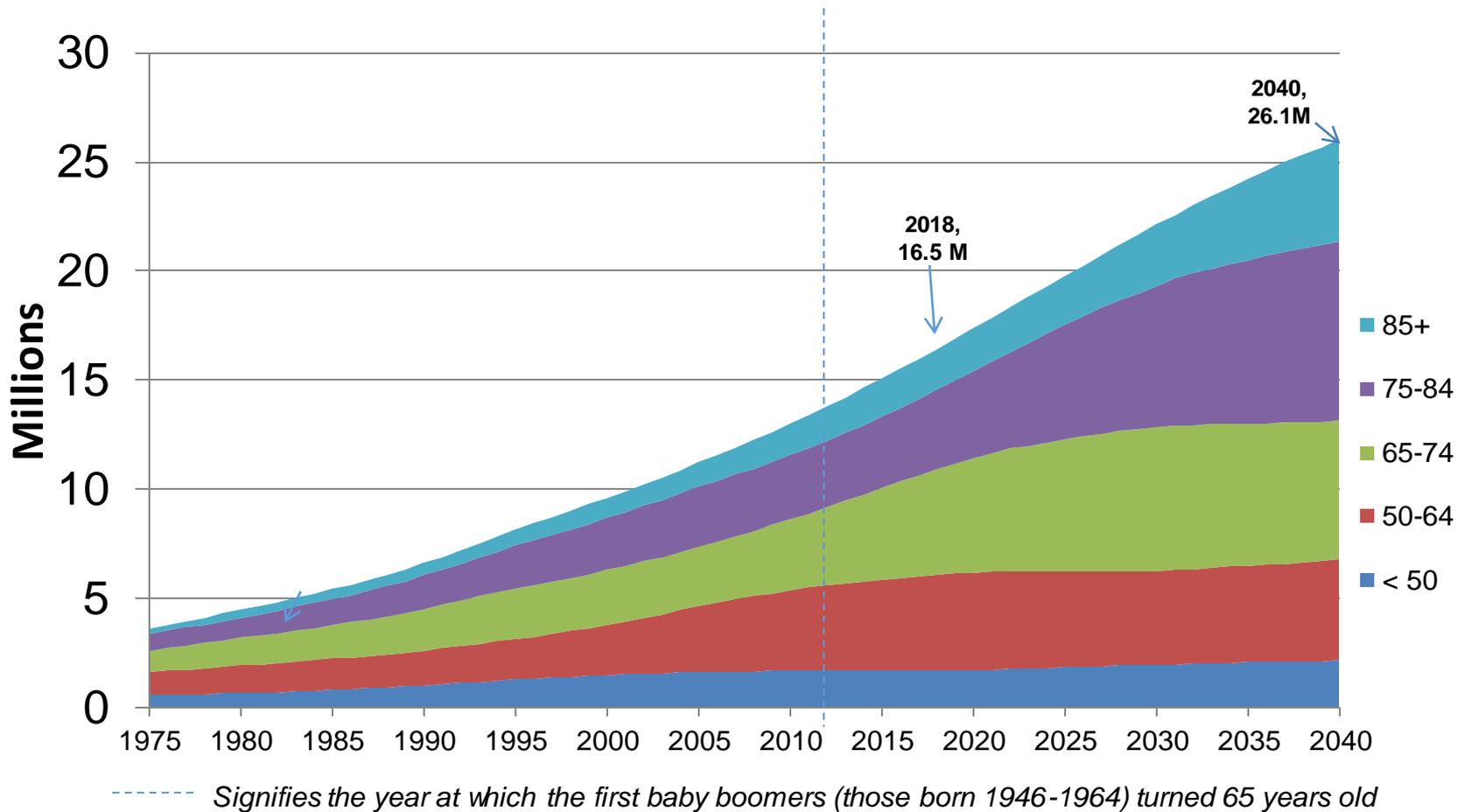
Estimated Number of Cancer Survivors in the U.S., by Current Age – More Detail



REFERENCE: American Cancer Society. *Cancer Treatment & Survivorship Facts & Figures 2016-2017*. Atlanta: American Cancer Society; 2016. Miller, K. D., Siegel, R. L., Lin, C. C., Mariotto, A. B., Kramer, J. L., Rowland, J. H., Stein, K. D., Alteri, R. and Jemal, A. (2016), Cancer treatment and survivorship statistics, 2016. *CA: A Cancer Journal for Clinicians*.

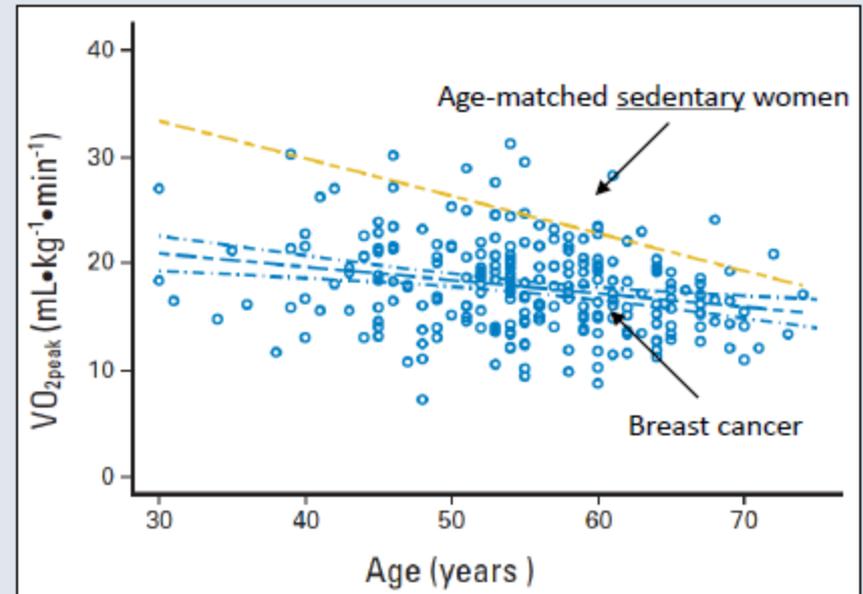
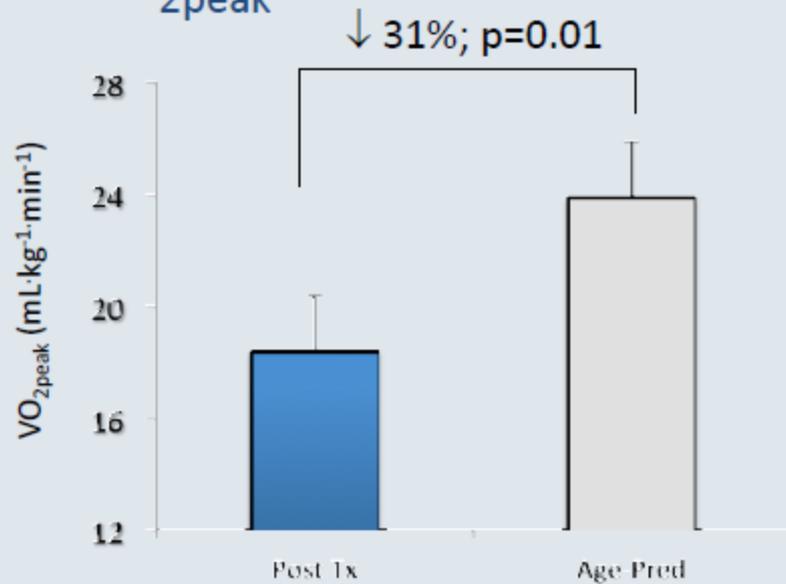
Estimated prevalence from 1975 to 2040 by age (in millions)

Source: Bluethmann, Mariotto & Rowland, *Cancer Epidemiol Biomarkers Prev* 2016



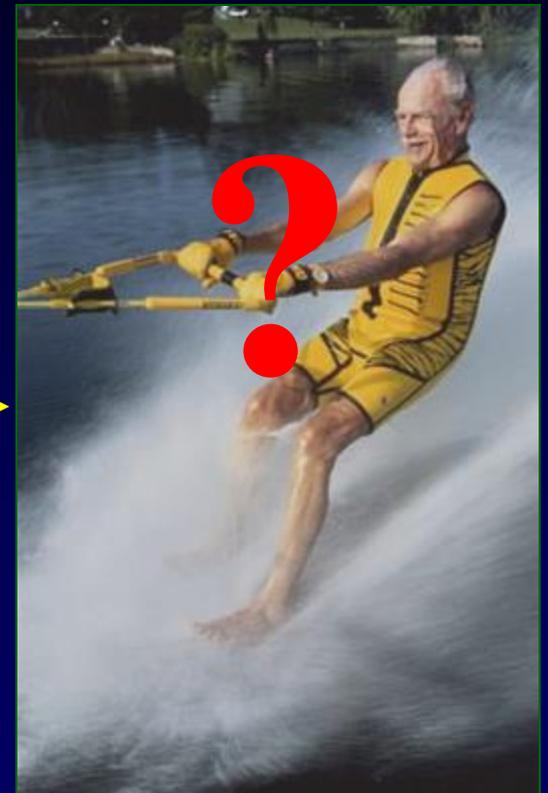
Impact of cancer and its treatment on aging

Breast cancer patients (3yrs post-tx) have marked reductions in VO_{2peak}



Cohort	40yrs	50yrs	60yrs	70yrs
Patients After Therapy (n=140)	21.05	19.51	17.97	16.44
Healthy controls (n=107)	29.82	26.32	22.82	19.32

How does cancer therapy impact aging? “Premature Aging Syndrome”

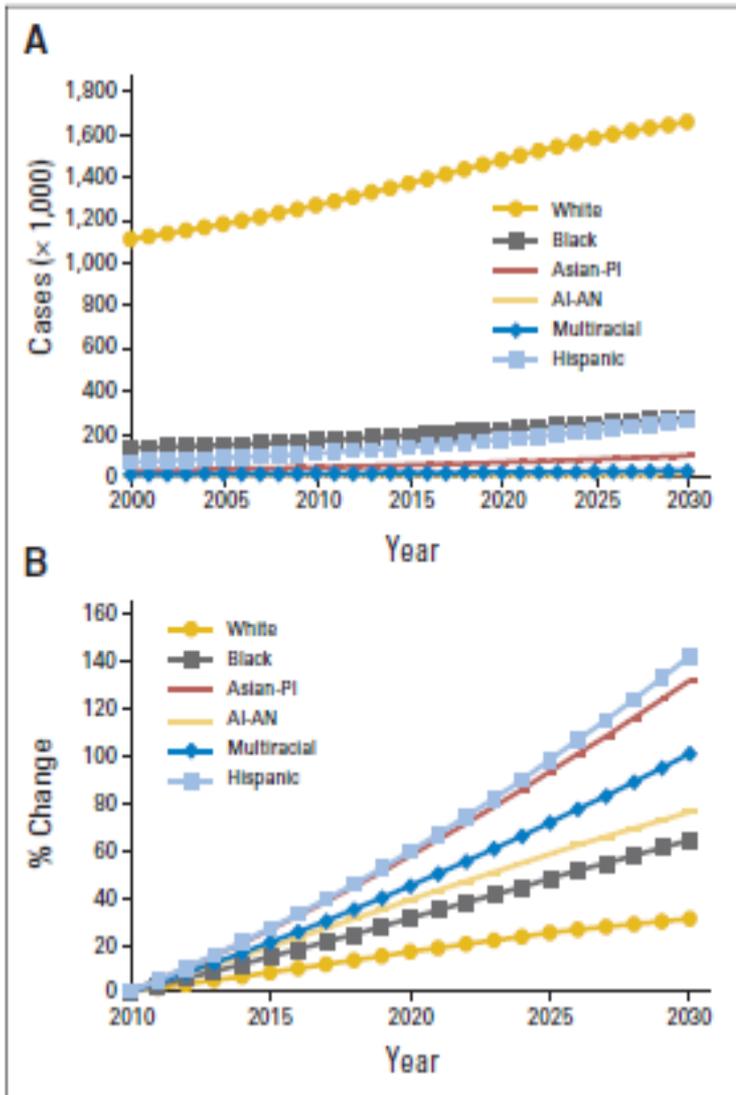


Will I recover?

Perspectives for the Future:

Where do we go from here?

- ❖ Understand & address emerging long-term and late effects (e.g., immunotherapies)
- ❖ Prepare for an aging population, including understanding the interaction between aging and cancer, and vice versa
- ❖ **Study and address the needs of increasingly diverse populations of survivors**
 - Including by cancer site, time since diagnosis, geography, income, and ethnocultural diversity*



- From 2010-30, total cancer incidence will increase from 1.6 to 2.3 million
- A 99% increase is anticipated for minorities, compared with 33% for whites
- Percentage of all cancers diagnosed in minorities will increase from 21% to 28%

Fig 5. Projected cases of all invasive cancers in the United States by race and origin. (*) Nonmelanoma skin cancers were excluded from projections. The Hispanic origin group contains individuals of any race. The race groups white, black, Asian/Pacific Islander (PI), American Indian (AI)/Alaska Native (AN), and multiracial contain only non-Hispanic individuals.

Perspectives for the Future:

Where do we go from here?

- ❖ Understand & address emerging long-term and late effects (e.g., immunotherapies)
- ❖ Prepare for an aging population, including understanding the interaction between aging and cancer, and vice versa
- ❖ Study and address the needs of increasingly diverse populations of survivors
- ❖ **Work on leveraging health behaviors to reduce preventable cancer-related morbidity and mortality**

Lesson Learned...



5. *Cancer presents a ‘teachable moment’*

... a rich opportunity to embrace or rediscover healthy lifestyle behaviors

Why the interest in Survivors' Health Behaviors?

- Growing number of cancer survivors who...
- Are living longer
- Are older, and also aging
- Often gain wt, stop exercising during Rx
- Are at risk for a number of co-morbid health conditions (and may also have a history of others)
- Can benefit from health promoting interventions
- ***Many will not die of cancer!***



Cancer Survivors' Health Behavior

- In 2016, **13.0%** of cancer survivors aged 18 and older were current cigarette smokers (target $\leq 12\%$); but...
- **32.4%** of survivors ages 18 – 44 reported being smokers!
- **31.1%** of survivors age 20 years and older were obese (target $\leq 30.5\%$)
- **34.8%** of cancer survivors aged 18 years and older reported no physical activity in their leisure time (target $\leq 32.6\%$)

Do Survivors Talk with their Physicians about Health Behaviors? (NHIS data)

	Cancer Survivors	Adults without Cancer	p
Diet Discussion	30%	23%	<.0001
Exercise Recommendation	26%	23%	<.005
Smoking Assessment	42%	41%	.41

- Source: Sabatino et al., 2007, *Journal of Clinical Oncology*

Perspectives for the Future:

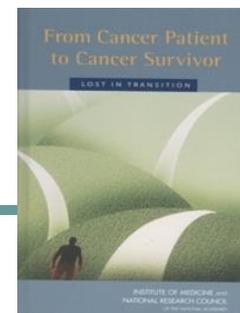
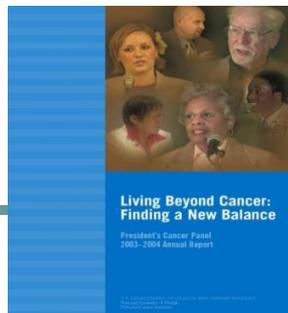
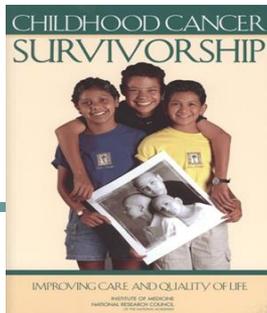
Where do we go from here?

❖ **Design and test best-models for follow-up care**

- ❖ Recommendations for care
- ❖ Evidence-base for this care: Guidelines
 - ❖ Children's Oncology Group
 - ❖ National Comprehensive Cancer Network (NCCN)
 - ❖ American Society of Clinical Oncology (ASCO)
 - ❖ American Cancer Society
- ❖ "Requirements" for care
 - ❖ American College of Surgeons Commission on Cancer
- ❖ By whom and how should this care be delivered?

Components of a Survivorship Care Plan (SCP)

1. **Surveillance** for recurrence/new cancer
2. **Assessment** of and care for long-term/chronic effects of cancer and treatment
3. Evaluation of risk for and **prevention** of late effects, including health promotion
4. **Communication** about and **coordination** among those who will be providing this care



Models for Survivorship Care

Oeffinger & McCabe, *J Clin Oncol*, 2006; McCabe & Jacobs, *Semin Oncol* 2012

- **Multidisciplinary Clinic** Patients seen/evaluated by different providers (e.g., oncology, endocrinology, neuropsychology, social work, etc.)(Peds model)
- **Disease/Treatment Specific Clinic** Survivorship clinic for specific disease category (HSCT); could be used for psychosocial focus only
- **Integrated Care Model** Survivorship visit imbedded in the oncology clinic where the patient was treated; often w/ Nurse Practitioner; ongoing care
- **Shared Care Model Components** Similar to approach to diabetes management
- **Consultative Model** One time visit to establish a plan, make referrals to consultants, identify/return to PCP
- **Tool Kit Visit** Self management

Cancer survivorship

A process for living well with and beyond a cancer diagnosis

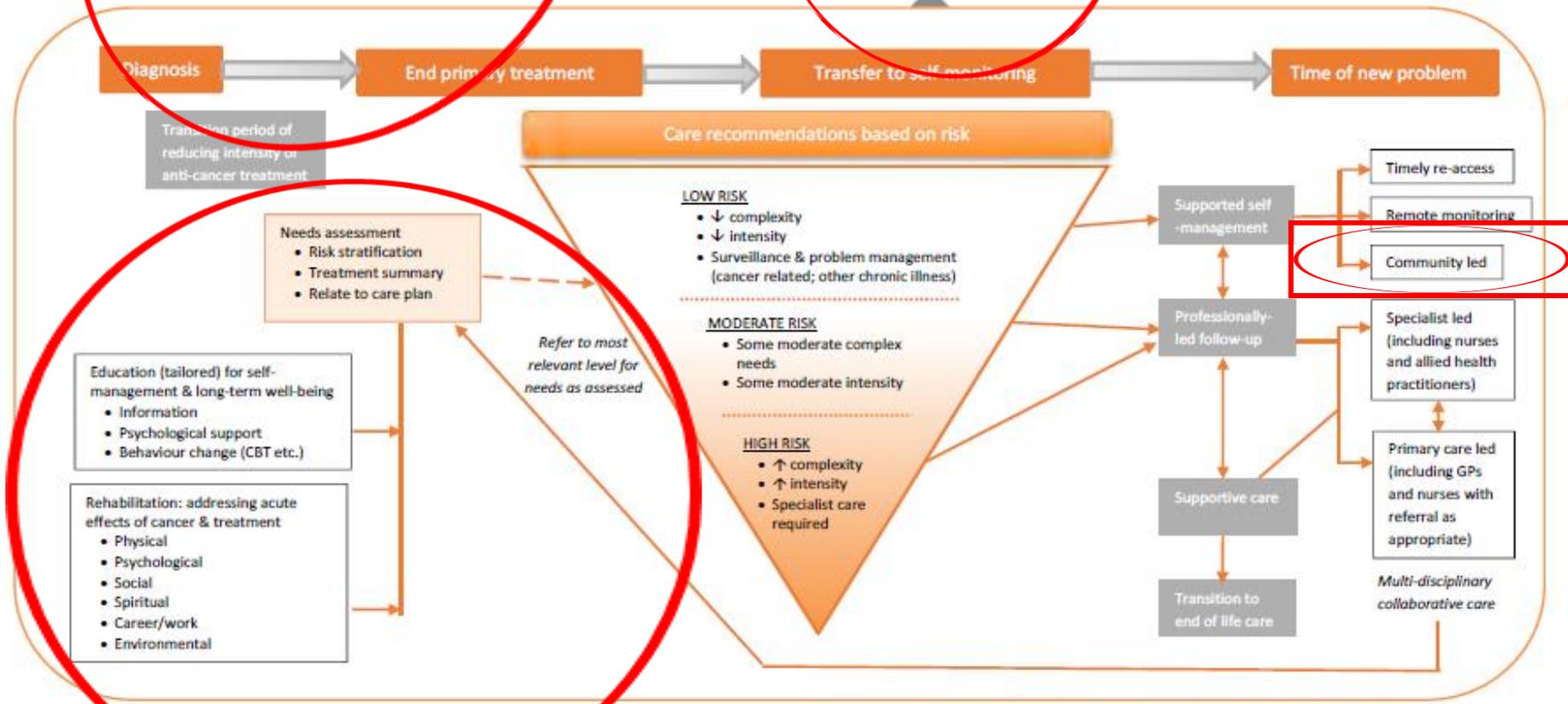
Principles:

How we do it

- Survivor centred (enabling, engaging, empowering)
- Integrated care across all service levels at every time point
- Coordinated care

What we do

- Promote well-being
- Prevent illness
- Manage symptoms and issues



Lessons Learned...

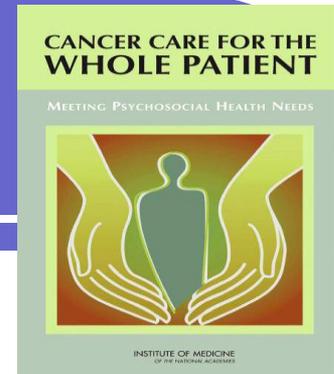
CANCER CARE FOR THE WHOLE PATIENT

MEETING PSYCHOSOCIAL HEALTH NEEDS



6. Addressing psychosocial needs should be an integral part of care

Psychosocial adaptation



Three key points:

- The majority of those diagnosed with and treated for cancer cope well (resilience)
- However, a significant minority (20-30%) struggle and warrant more support
- A variety of psychosocial and/or behavioral interventions are useful in improving quality of life and function of those living with, through and beyond cancer

Meyer & Mark, Health Psychol, 1995; Devine & Westlake, ONF, 1995; Rehse & Newell et al., JNCI, 2002; Stanton, J Clin Oncol 2012; Antoni, Brain Behav Immun, 2013; Faller et al., J Clin Oncol 2013

Perspectives for the Future:

Where do we go from here?

- ❖ Design and test best-models for follow-up care
- ❖ **Figure out how to care for the growing population of cancer caregivers (both formal and informal)!**

Lessons Learned...

7. Cancer affects not just the person,
but also his/her family



What we know about caregivers...

- Family/informal cancer caregivers are 'in the room' with patients, influence decisions and affect care
- They provide vital support as well as direct care, including oversight of medication, visits, wound care
- They often feel ill-prepared for their roles
- Well-being of survivors and their caregivers often parallel one another; dyadic co-dependency
- They often neglect their own health in the process of caregiving
- Their numbers, like survivors, are growing!

Perspectives for the Future:

Where do we go from here?

- ❖ Design and test best-models for follow-up care
- ❖ Figure out how to care for the growing population of cancer caregivers (both formal and informal)!
- ❖ **Design our interventions and models of care for dissemination**



SMITH CENTER FOR HEALING AND THE ARTS

1632 U Street, NW. Washington, DC. 20009



Community



Creativity



Cancer Support⁴⁸

Health & Wellness

Support Groups



“If I had to describe Smith Center in just a few words, I would say it’s warm, nurturing, loving and inspiring.”
- Chu Chu, Program Participant

Yoga & Stress Reduction



Cancer Retreats



Patient Navigation



Cooking & Nutrition



Perspectives for the Future:

Where do we go from here?

- ❖ Design and test best-models for follow-up care
- ❖ Figure out how to care for the growing population of cancer caregivers (both formal and informal)!
- ❖ Design interventions and models of care for dissemination
- ❖ **Identify ways to measure our success in improving survivorship research and care**

<http://progressreport.cancer.gov/>

Perspectives for the Future: *Where do we go from here?*

**What would successful survivorship look like
to you?**

And what will it take to get there?

Thank you!

Ideas, discussion?

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