Life After Cure: Psychological Late-Effects in Childhood Cancer Survivors

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Outline

- Summarize psychological late-effects
  - Prevalence in large cohorts
  - Severity & impairment
- Risk factors
  - Medical late-effects & development
- Consider implications for services

Childhood Cancer Survivor Study

- Multi-center study of 5-year survivors
  - Self-report outcomes on > 7000 adults
  - Parent report on >2900 adolescents
  - Comparison with sibling controls

http://ccss.stjude.org

CCSS: Adult Survivors

- Twice as likely to report significant psychological symptoms—anxiety & depression
- Almost twice as likely to report suicide ideation & impaired mental health
- Four times more likely to report elevated post-traumatic stress symptoms

Hudson et al., 2003. JAMA
Zeltzer et al., 2009. JCO
Recklitis et al., 2010. JCO
Stuber et al., 2010. Pediatrics

CCSS: Adolescent Survivors

- Parent ratings of adolescent survivors show problem behaviors increased compared to siblings
  - 1.5 times > risk of internalizing symptoms
  - 1.7 times > risk of externalizing symptoms

  Similar findings in study of leukemia patients treated with chemotherapy alone

Schultz et al. 2006. JCO
Jacola et al. 2016. Lancet Psychiatry

CCSS: Social Adaptation

- Compared to siblings, adult survivors are:
  - 6 times more likely to report impaired QOL
  - 23% more likely to need special education
  - Less likely to attend college
  - 5 times more likely unemployed due to health
  - 20% less likely to marry

Zeltzer et al., 2009. JCO
Gurney et al., 2009, JCO
Janson et al., 2009. CEBP
Mitby et al., 2003. Cancer
Kirchoff et al., 2010., Medical Care

Other Large Cohort Studies

- Educational impairments
  - Swiss Childhood Survivors Study
  - Dutch, Danish and Canadian cohort studies
- Limited social attainment & QOL
  - Dutch & British cohorts
- Increased psychological distress
  - Swiss Childhood Survivors Study

Michel et al., 2010. JCO
Stam et al ., 2005. Psycho-Onc
Langeeld et al., 2002. Psycho-Onc
Frobisher et al., 2007. IJC
Lorenzi et al., 2009. Cancer
Koch et al, 2004. BJC

Summary: Prevalence

CCS are at increased risk for:

- Psychological **symptoms**
- Impaired education, work, social, & QOL outcomes

However, most survivors adapt well

- 60-75% have no psychological sequelae
- Vast majority do marry & find employment
- Almost half report little impact of cancer
- Many report positive consequences of cancer

Zeltzer et al., 2009. JCO
Gurney et al., 2009, JCO
Janson et al., 2009. CEBP
Kirchoff et al., 2010. Medical Care
Willard et al., 2017. Cancer
Brinkman et al., 2016. JCO
Gunst et al., 2016. SCCancer
Mertens & Marchak. 2015, COAYA

Symptom Severity

- Symptom scales don't tell the whole picture
  - Not necessarily tied to impairment or diagnosis
- Adult survivor studies find higher prevalence of symptoms but not psychiatric diagnoses
- Increased major mental illness in young survivors suggests risk limited to brain tumor survivors

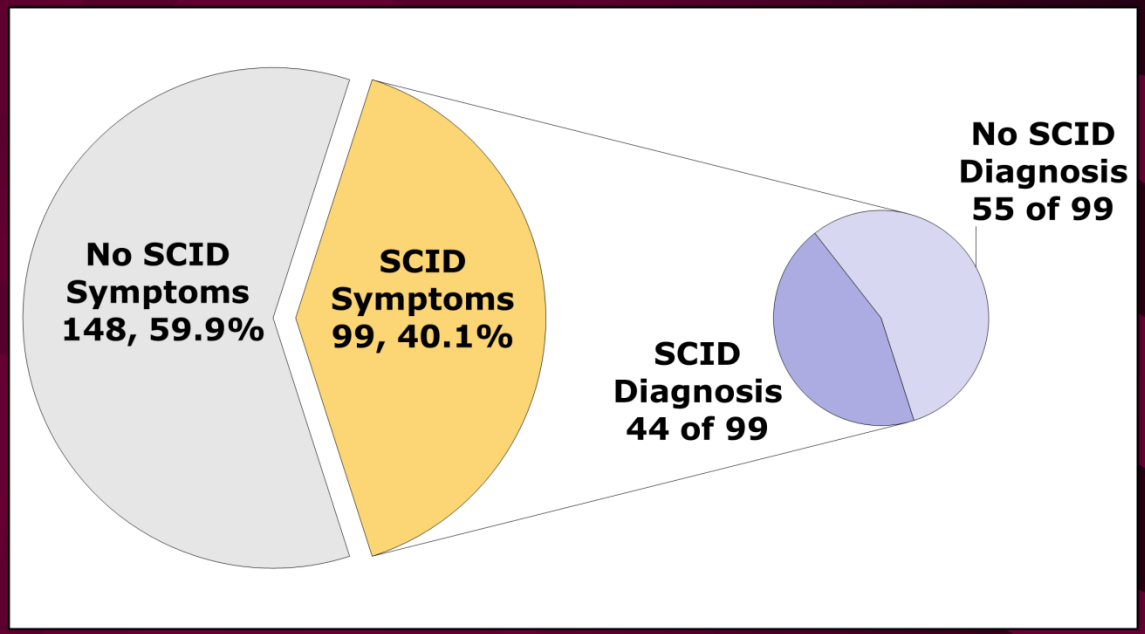
➢ Most CCS with symptoms do not have a diagnosis

Pirl et al., 2009. JCO
Sanchez-Varela, et al., 2013. Psych-Onc
DėLaage et al., 2016. PHOnc

Ross et al., 2003. NEJM
Rasic et al., 2008, Psych-Onc

Symptoms vs. Diagnosis

- 247 survivors age 18-39
- SCID diagnostic interviews: depression & anxiety
- Significant symptoms & diagnosis



Recklitis et al., 2015; Cancer

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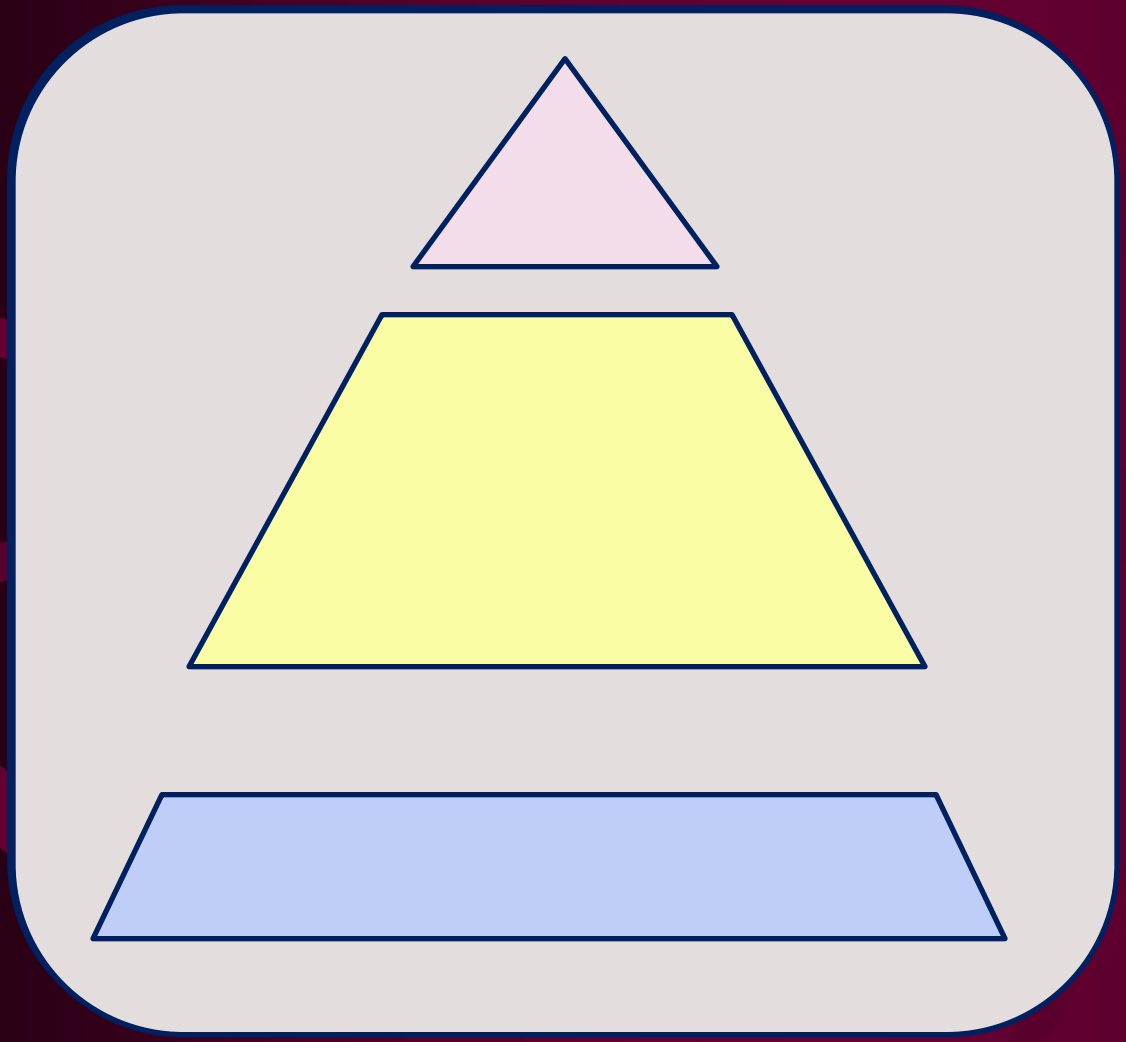
Distress Severity



High Distress
- Clinical range
- Significant Impairment

Mild Distress
- Moderate impairment

Low Distress
- No impairment

Model & figure adapted from Kazak. 2013. PBCancer

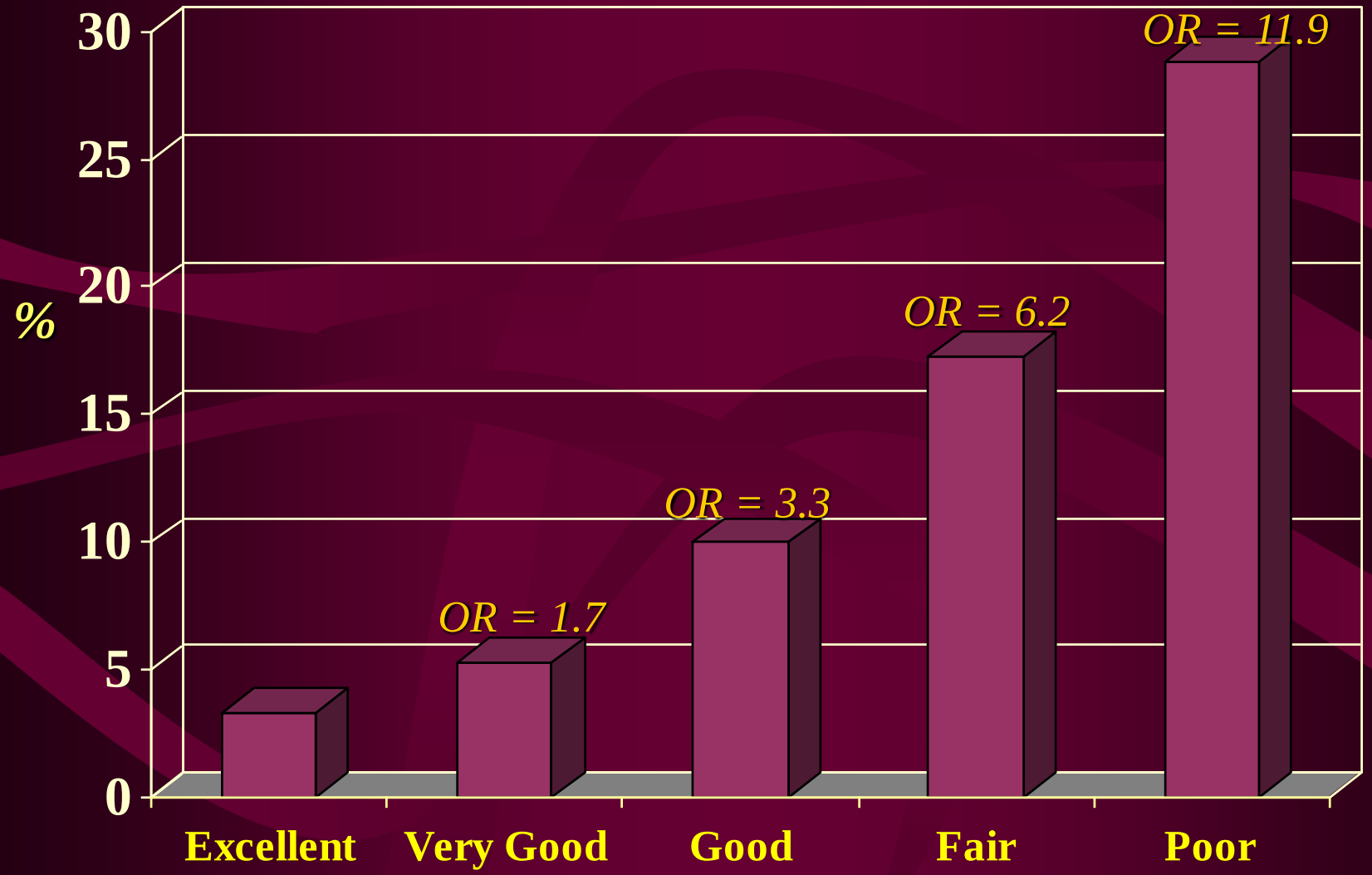
Risk Factor: Medical Late-Effects

- Poor global health, pain, disfigurement, obesity, & other chronic conditions associated with poor psychosocial outcomes
  - CCS with multiple symptom types more likely to report poor health (OR= 32) & pain (OR= 4)
- CNS treatment & brain tumor survivors particularly at risk for poor psychosocial outcomes

Gurney et al. JCO 2009;27(24).
King et al., 2017, Neuro Oncol.
Schultz et al. JCO 2007;25(24).
Vuotto et al., 2017 Cancer.

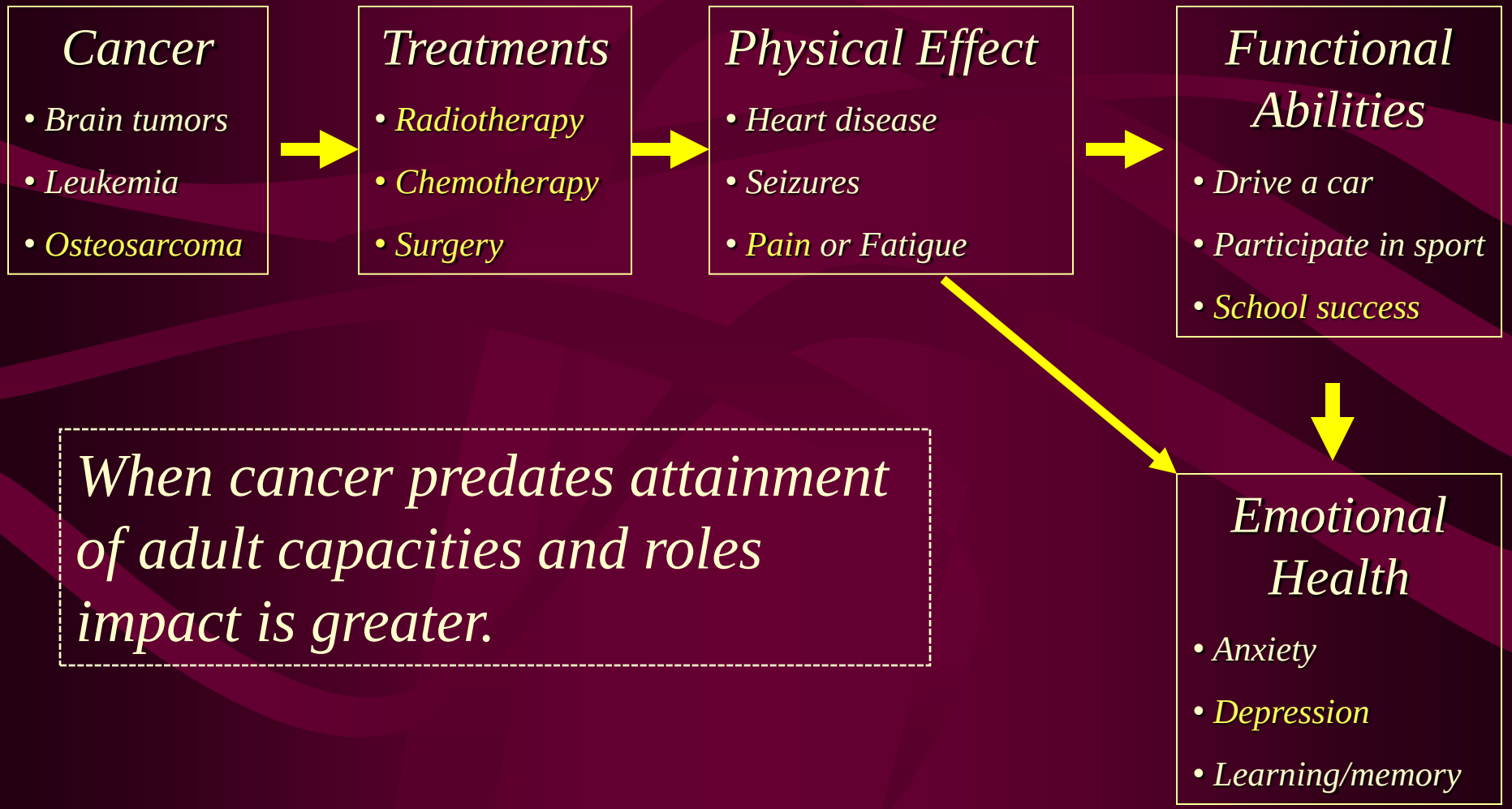
Zeltzer et al., 2008, CEBP
Brinkman et al. 2016. JCO
D'Agostino et al. 2016.Cancer
Kinahan, et al., 2012. JCO

Suicide Ideation & Health Rating



Recklitis et al (2010), JCO Vol 28

Cancer and Distress: A Conceptual Model



John—20 years old

Medical History

- Osteosarcoma in his arm at 15
- Ongoing problems with a bone graft
- Has not finished high school
- At 20 is told he needs a new bone graft

What is wrong with John?

- He has medical late-effects
  - Pain, limited function, & upcoming surgery
- He has emotional late-effects
  - Depressed mood, worry about surgery
- He has school, work & financial limitations
- He has social limitations
  - Does not keep up with most friends
  - Feels “like a loser”

Vulnerable Periods: Life Transition

- Health Changes
  - New symptoms or diagnosis
  - New screening or medical needs
- Move to a new environment
  - Loss of special status
  - Question of disclosing cancer history
- Career changes
  - Questions about insurance and employability
- Intimate Relationships
  - Questions about disclosing cancer history
  - Concerns about body image, sexuality and fertility

Liptak et al., 2016; Coscarelli et al., 2011

Outline

- Consider implications for services
  - Clinical challenges
  - Integration behavioral health into survivorship care

Challenges: What should we prepare for?

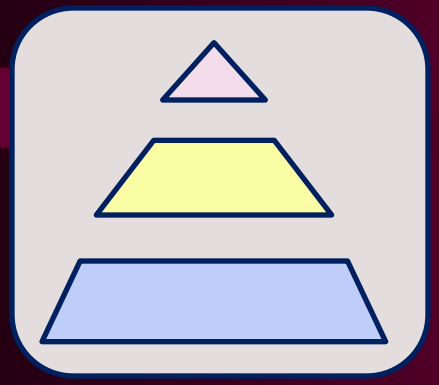
- 25-40% of CCS may have psychosocial needs
- Symptoms across the spectrum, but predominantly mild to moderate symptoms
  - Anxiety, depression, behavior problems, stress
  - Social attainment and QOL limitations
  - Episodic presentation at critical periods
- Impact of physical health on mental health & QOL
- Disruptive effects of cancer on development

Implications: Challenges

- Systemic– including work force & cost
- Technical—
  - Need to include psychiatric models and measures but not be limited to them
  - Identification of survivors in need
  - Development of appropriate interventions
- Conceptual– setting, models of care, integration

Treatment in Cancer Settings:

- Survivorship setting **may** provide optimal care
  - Access to survivor
  - Understanding of treatment & late-effects
  - Integration with medical care
- Survivor setting **may not** provide optimal care
  - Lack of expertise, resources
  - Distance & availability are barriers
  - Plays into denial or resistance to treatment
  - Maintains dependence



Treatment

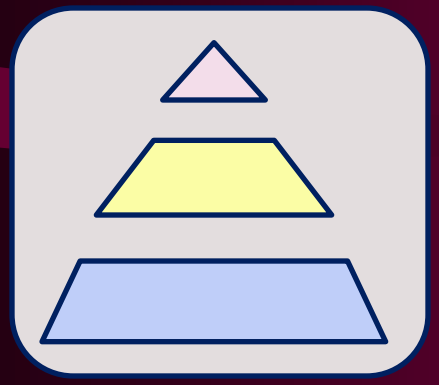
Low Distress
- No impairment

- Routine Supportive & Preventive Care
  - Monitoring, education & information
  - Reassurance & anticipatory guidance
  - Self-help & support resources

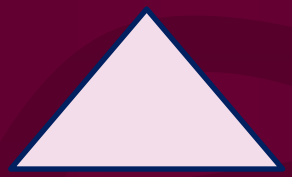
➢ Care planning can comprehend much of this

➢ More programs, staff, consistent delivery across groups and geography

Husson et al., 2011. Ann Onc
Stanton, 2010. JCO
Jacobsen, 2009. JCO
Recklitis & Syrjala, 2017. Lancet Onc



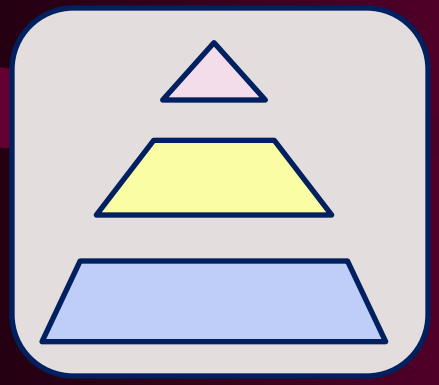
Treatment



High Distress
- Clinical range
- Significant Impairment

- Specialized Mental Health Care
  - May have past/present care team
  - May need referral for new or additional care
  - Evaluate need for ongoing communication/consultation
  - Assist with case-management

Kearney J, et al., 2016



Treatment

Potentially most complex

Mild Distress
- Moderate impairment

- Routine Care
  - Monitoring, education & information
  - Reassurance & anticipatory guidance
  - Self-help & support resources
- Triage & Targeted Care
  - Further evaluation
  - Problem solving
  - Symptom focused care
    - Mental health care
    - Self-help supportive
    - Integrated mind/body

Triage

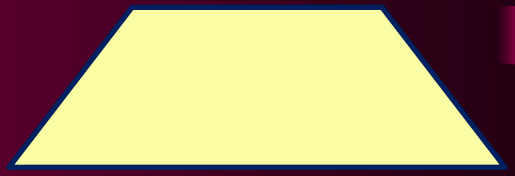
- Evaluate symptoms
  - Duration, severity, impairment
  - Critical symptoms
- Differentiate from physical symptoms
  - Hormonal, cardiac, neurological, anemia, nutrition
  - Medication effects

Identification/Screening

- Identification through multiple means
  - Medical encounter
  - Health history forms
  - Self-report screening forms
- Screening forms alone may not be reliable
  - Existing screens may miss 20-40% of young survivors with psychiatric diagnosis
  - Screening forms may inform evaluation but not stand alone as the evaluation

Recklitis et al. 2016. Cancer
Recklitis et al. 2017. Psych Assess
Salmon et al. 2015. PsychOnc

New Interventions



- Range of intervention options:
  - Low & high intensity—stepped-care
  - Cancer center, community, & mobile
- Range in focus:
  - Social activities, social support & survivor activism
  - Mental health & coping with medical illness
  - Biopsychosocial: sleep, fatigue, sexuality
- Work to understand commonly observed modest uptake

Recklitis & Syrjala. 2017. Lancet Onc
Andersen et al., 2014. JCO
Stanton., 2012. JCO; Stanton et al., 2015 JCO
Alfano & Rowland, 2006. CancerJ

How Can We Help John?

- Medical late-effects
- Emotional late-effects
- School & work limitations
- Social limitations

➢ Integrated care in the survivorship setting

➢ Coordinated care with outside providers

Primary Care Behavioral Health: (PCBH)

PCBH addresses the broad spectrum of behavioral health needs among PC patients, with the aims of

- Early identification
- Quick resolution of identified problems
- Long-term problem prevention
- "Wellness promotion"

Integrated Primary Care Behavioral Health Services, Operations Manual, VA Health Care Network

Robinson & Reiter. 2007
Funderbirk et al. 2013. FS Health

PC Behavioral Health Components

- Integrated systems
  - Co-location, single medical record, joint conferences
- Flexible care
  - Point-of-care; warm-handoffs & check- ins
  - Brief visits & flexibly scheduled
  - Mental health & education, support, referral
  - Low-intensity & group interventions

Robinson & Reiter. 2007
Funderbirk et al. 2013. FS Health

Survivorship Behavioral Health Model

- Support the medical provider in identifying & treating survivors with behavioral problems
- Temporarily co-manage survivors requiring focal BH services, as part of survivorship care
- Resolve some problems in the survivorship context, but refer most to community supports or specialized behavioral care as needed

Adapted from: Integrated Primary Care Behavioral Health Services, Operations Manual, VA Health Care Network

Survivorship Behavioral Health Model

Support medical provider in identifying & treating behavioral problems

- Medical providers as front line "universal screen"
  - Collaborate on identification methods
- Consult on problems cases in real time
- Provide urgent/emergent back-up

Behavioral Health in the Survivor Setting

- Interventions
  - Assessment of referred survivors
  - Consultation & education
  - Supportive care & limited treatment
  - Case management
  - Referral

Consultation & Education

- Available to providers & survivors
  - Reassure and normalize concerns
  - Anticipatory guidance
- Education on common problems
  - Learning disabilities, school/social adjustment
  - Going away to college, relationships & dating
  - Sexuality, sleep, fatigue, infertility

Treatments in Survivor Setting

- Short-term focal problem treatment
  - Extended consultation or brief treatment
  - Limited number of brief encounters
- Survivorship issues
  - Co-management of current medical challenge
  - Reworking of cancer-related issues

➢ Resist the call to provide all care to all survivors

Resolve problems in the community

Referral & Case-management

- Connect survivors with community resources
- Understand & address barriers to care
- Promote development & integration with community--work/school/peers/health
- Educate outside providers on cancer late-effects

Towards Integrated Care

- Questions & challenges
  - *Who will come? Who will pay? Who will educate the workforce? Care location? What interventions work?*
- Existing integrated care models may be adapted o meet the needs of CCS
  - Primary Care Behavioral Health Model
  - Illness Self-Management Model
  - Chronic Care model
  - Patient Centered Medical Home

Recklitis & Syrjala. 2017. Lancet Onc
Bodenheimer et al., 2002. JAMA
Coleman K. 2009. Health Aff
Sia et al, 2004. Pediatrics

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