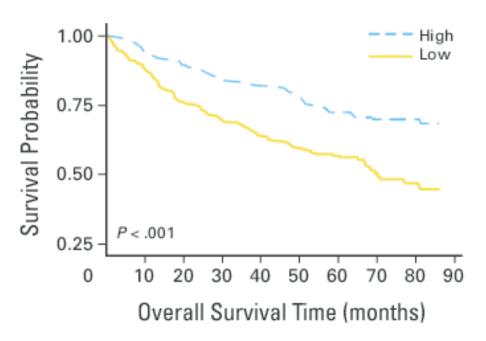
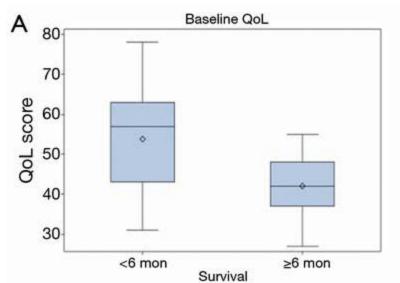
# Psychosocial Care for Cancer Survivors:

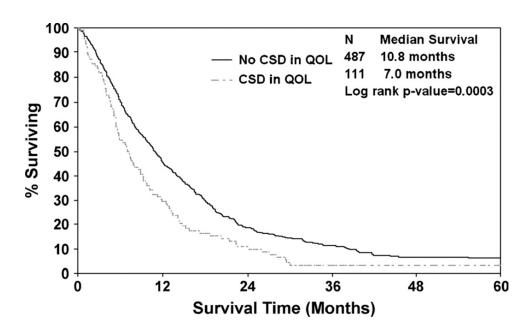
Identifying and managing psychological and social aftereffects of cancer treatment

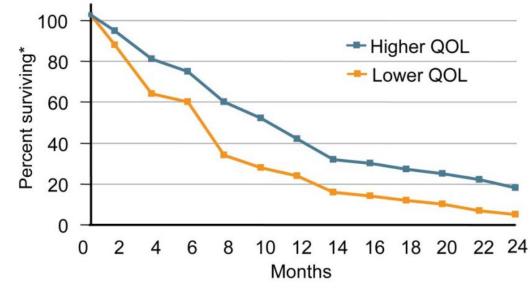
Charles Kamen, PhD, MPH
Assistant Professor
University of Rochester









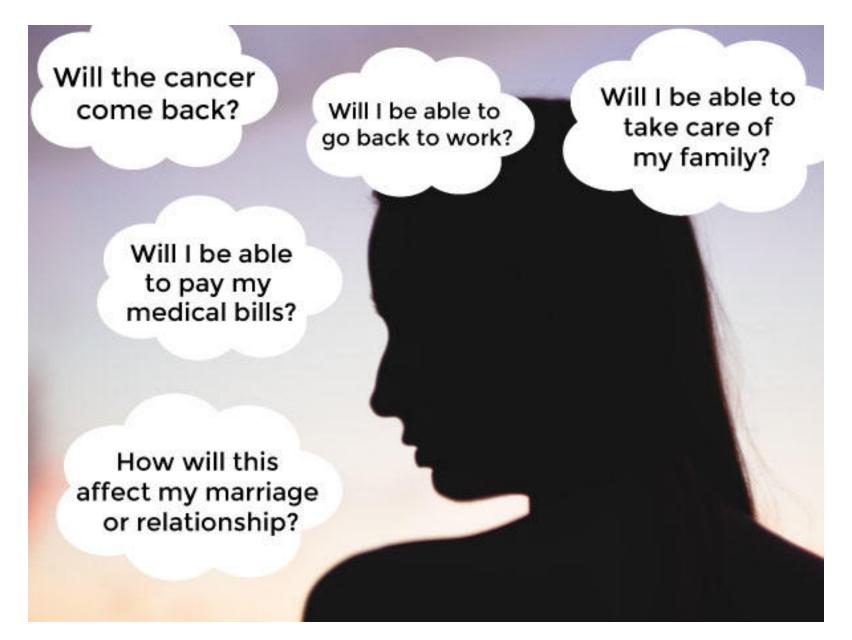




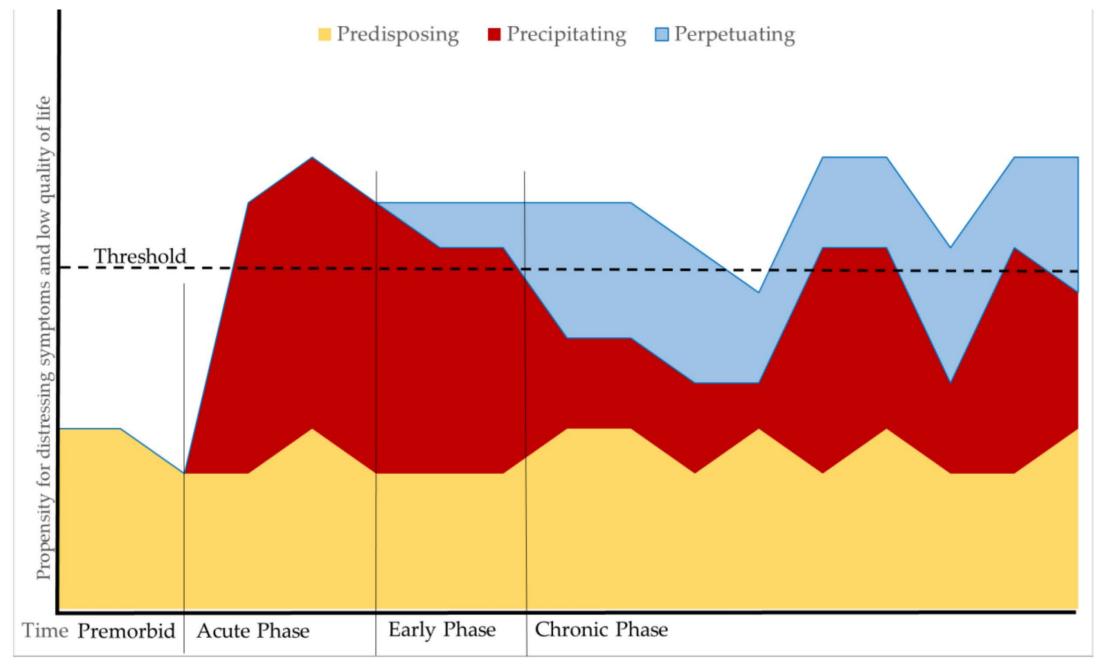
### **Objectives**

- Identify key psychosocial effects of cancer treatment
  - Psychological, social, and emotional short and long term outcomes
- Manage key psychosocial effects of cancer treatment
  - Psychosocial needs across the life course and in minority/underserved cancer survivors
  - Mental health and community support specialists who can help address psychosocial needs after cancer









### Psychosocial Adjustment After Cancer

Psychological distress

Changes in role or identity

Changes in behavior

Mental health disorders



### Psychological Distress

- The majority of survivors adjust well post-treatment
- Between 15% and 40% of survivors experience lasting distress
  - Fear of recurrence
  - Anxiety and depression
  - Post-traumatic stress
  - Guilt and spiritual concerns
- Typically less severe, acute, or sub-clinical issues



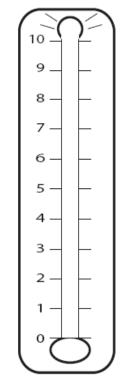


#### **NCCN Distress Thermometer for Patients**

#### SCREENING TOOLS FOR MEASURING DISTRESS

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

#### Extreme distress



Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

#### **YES NO Practical Problems** □ Child care Appearance

- Housing Insurance/financial
- Transportation Work/school
  - Treatment decisions

#### Family Problems

- Dealing with children
- Dealing with partner Ability to have children
- Family health issues

#### **Emotional Problems**

- Depression
- Fears
- Nervousness
- Sadness
- Worry
- Loss of interest in usual activities
- Spiritual/religious concerns

Other Problems:

- YES NO Physical Problems
- Bathing/dressing
- Breathing
- Changes in urination
- Constipation Diarrhea
- Eating
- Fatigue
- Feeling Swollen
- Fevers
- Getting around
- Indigestion
- Memory/concentration
- Mouth sores
- Nausea
- Nose dry/congested
- Pain
- Sexual
- Skin dry/itchy
- Sleep
- Substance abuse
- Tingling in hands/feet

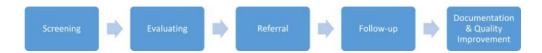
- Hospital Anxiety and Depression Scale (HADS)
- Brief Symptom Inventory (BSI)
- Center for Epidemiological Studies – Depression Scale (CESD)
- Patient Health Questionnaire (PHQ9 or PHQ2)
- Outcome Ouestionnaire 10 (OQ10)



No distress

### Managing Psychological Distress

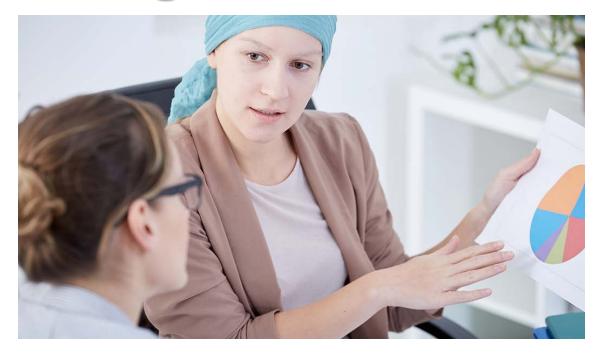
Perform assessments in real time



- Designate cutpoints for moving from assessment to intervention
- Establish triage pathways when a cutpoint is met
- Include psychosocial specialists in care (where possible)
- Provide access to results for survivors and other providers to improve patient—provider communication



# **Changes in Role or Identity**







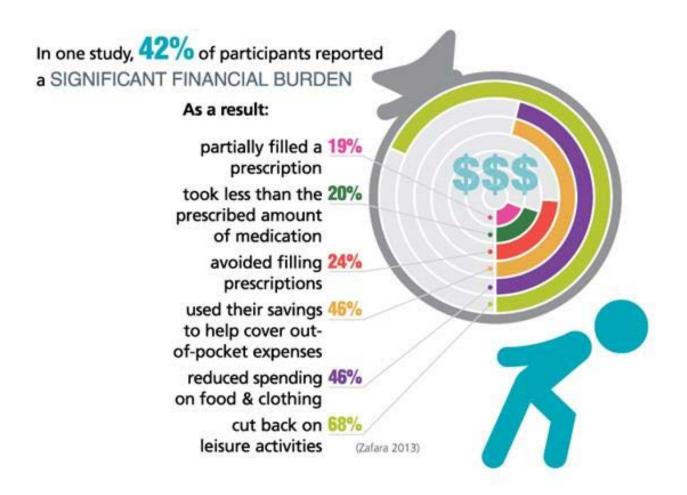


## Relationship and Employment Roles

- 10-15% increased risk of relationship difficulties after cancer
  - Often due to predisposing factors
  - 33% of childhood cancer survivors and 84% of prostate cancer survivors report sexual difficulties after treatment
- 30-40% of cancer survivors have difficulty returning to work
  - 15-35% of survivors experience chronic fatigue
  - Up to 60% of survivors experience cognitive impairment 6 months after chemotherapy, with some recovery thereafter



## **Financial Toxicity**



- Comprehensive Score for Financial Toxicity (COST)
- 3 item screen:
  - Ever skipped medication due to cost
  - Enough income for food and housing
  - Enough income for clothing, transportation



## Changes in Behavior

- Teachable moment for cancer screening
- Teachable moment for other healthy lifestyle behaviors:
  - Diet
  - Physical activity
  - Smoking cessation
- Psychosocial interventions to change behavior most often tested in the survivorship phase



#### Mental Health Disorders

- A rare consequence of cancer and treatment
  - Up to 25% of survivors have a history of mental health diagnoses
  - Those with serious mental illness (SMI; schizophrenia, bipolar, major depression) are two to four times more likely to die from their cancer
  - Up to 22% of cancer patients experience symptoms of Post-Traumatic
     Stress Disorder (PTSD)
- Management of SMI
  - Involve psychiatry early and often!



#### Psychosocial Effects Across the Life Course

Time Early Treatment Post-Treatment Survivor Survivor Early Post-Treatment AYA Identity AYA Identity End-of-Treatment Survivor Identity Survivor Identity Connectedness Connectedness Relationships Relationships Parents Parents Siblings Siblings Peers Peers Healthcare Providers Healthcare Providers **Parental Distress** Parental Distress

#### Survivorship Outcomes

- Participation in long-term follow-up
- Secondary/tertiary prevention of late effects
- Optimal Emotional-Behavioral Adjustment
- Achievement of AYA developmental outcomes

l	Evidence-based Issues for AYA &
l	Parent

- 1. Feeling abandoned by health care providers
- 2. Feeling unsupported, unsafe, and unprepared for survivorshi[
- 3. Lack of knowledge & preparation
- 4. Fear of recurrence

Table 3 Utility of Assessment Tools for Incorporation in Geriatric Assessment That Met Consensus (N=30)					
Domain	Assessment	IQR <sup>a</sup>	% of Panel <sup>b</sup>		
=	Both ADL/IADL	2	93%		
Functional status	Gait speed	2	90%		
	IADL	2	80%		
	ADL	2	40%		
	Mini Mental State Examination	2	80%		
Cognition	Montreal Cognitive Assessment	2	80%		
	Blessed OMC	3	75%		
	Caregiver burden/support	2	87%		
Social support	Medical Outcomes Study Survey	3	72%		
	Social support from medical history	3	67%		
	Gait speed	2	93%		
Objective physical performance	Timed Up and Go	2	90%		
	Short Physical Performance Battery	3	85%		
	Geriatric Depression Scale	3	83%		
Psychological status	Hospital Anxiety & Depression Scale	3	72%		
	Mental Health Inventory	2	63%		
Nutrition	Weight loss	1	90%		
	Mini Nutritional Assessment	3	79%		

Abbreviations: ADL, activities of daily living; Blessed OMC, Blessed Orientation-Memory-Concentration; CARG, Cancer and Aging Research Group; CRASH, Chemotherapy risk Assessment Scale for High-Age Patients; IADL, instrumental activities of daily living; IQR, interquartile range; VES-13, Vulnerable Elders Survey-13.



<sup>\*</sup>Interquartile range, or the 75th percentile minus the 25th percentile. Consensus defined as ≤2 units.

 $<sup>^{\</sup>circ}$ Percent of respondents that chose a utility rating of ≥7 for that item, where 0 = not at all important and 10 = the most important. Consensus defined as ≥66.7%.

## Disparities in Psychosocial Adjustment



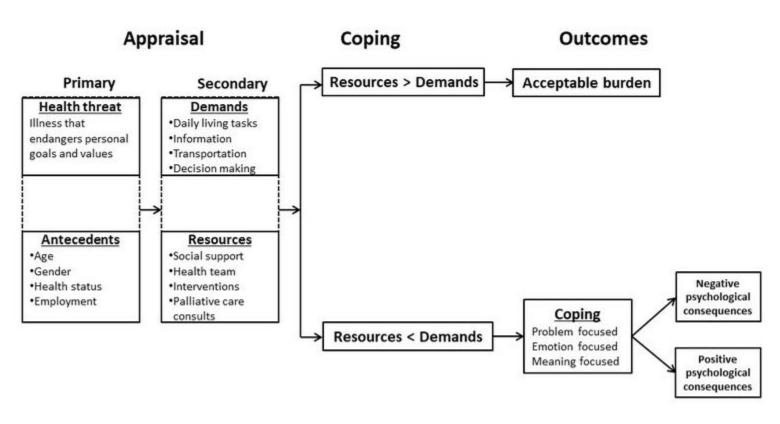
Should I talk about [having breast cancer]? Because how many things could I have? You know black, lesbian - I'm like, I can't be the poster child for everything. At least with the LGBT issues we get a parade and a float and it's a party.

— Wanda Sykes —

AZ QUOTES



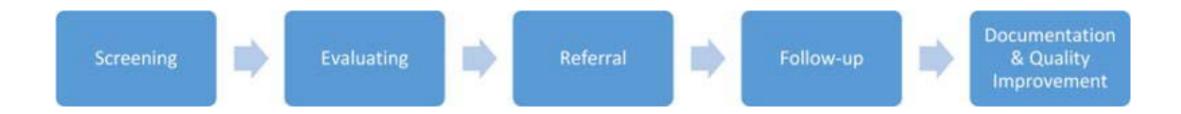
## **Including Caregivers in Care**



- 50% of caregivers
   report high distress
- Some caregivers may be more distressed than survivors!
- Different caregivers experience different stressors



### Addressing Psychosocial Adjustment



- 1. Routine assessment
- 2. Risk stratification
- 3. Self-help recommendations
- 4. Referral



## **Including Community Resources in Care**

- Understand cancer CBOs in your area
  - Gilda's Club, American Cancer Society
- Understand mental health CBOs
  - Mental Health America (MHA), National Alliance on Mental Illness (NAMI), hotlines
- Include in a resource guide



## THANK YOU!

Any questions?



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