CANCER SUPPORT COMMUNITY™

A Global Network of Education and Hope

Psychometric Properties of a 47-item Distress Screening Tool for Older Caregivers of Cancer Patients

Alexandra Zaleta, PhD
Director, Research
Cancer Support Community
February 18, 2017

Disclosures

- Dr. Zaleta: No Disclosures

Presentation Objectives

- Discuss development of the Cancer Support Community's distress screening and referral program for caregivers

- Review validation of CancerSupportSource® Caregiver distress screening tool among older adult caregivers to individuals with cancer

Why Distress Screening and Referral for Cancer Caregivers?

- Caring for people with cancer is accompanied by psychosocial distress and poorer health-related quality of life, which is associated with poorer outcomes for caregivers and patients
- Some caregivers experience especially elevated emotional distress
  - Early identification important given that distress is likely to persist without intervention
- While caregiver burden measures exist, there are limited validated distress screening and referral programs for cancer caregivers

(Litzelman & Yabroff, 2015; Northouse et al., 2012; Reinhard et al., 2015; Sherwood et al., 2008)

Older Caregivers: Unique Risk Factors and Needs

- Older caregivers are themselves at increased risk for health problems
- Cancer caregiving is demanding, and older caregivers more likely to provide care for older cancer survivors, who may have complex health needs and comorbidities
  - Projected 67% increase in cancer incidence anticipated for older adults by 2030
- Older caregivers more likely to report that providing care is a burden on their finances

(Rowland & Bellizzi 2014; Sherwood et al., 2006; Smith et al., 2009)

Cancer Support Community

- CSC has, since its inception in 1982, embraced both individuals with cancer and their families
- CSC provides programs and support to patients, families, children, caregivers, friends
- CSC is unusually positioned to address caregiver distress because we serve caregivers directly

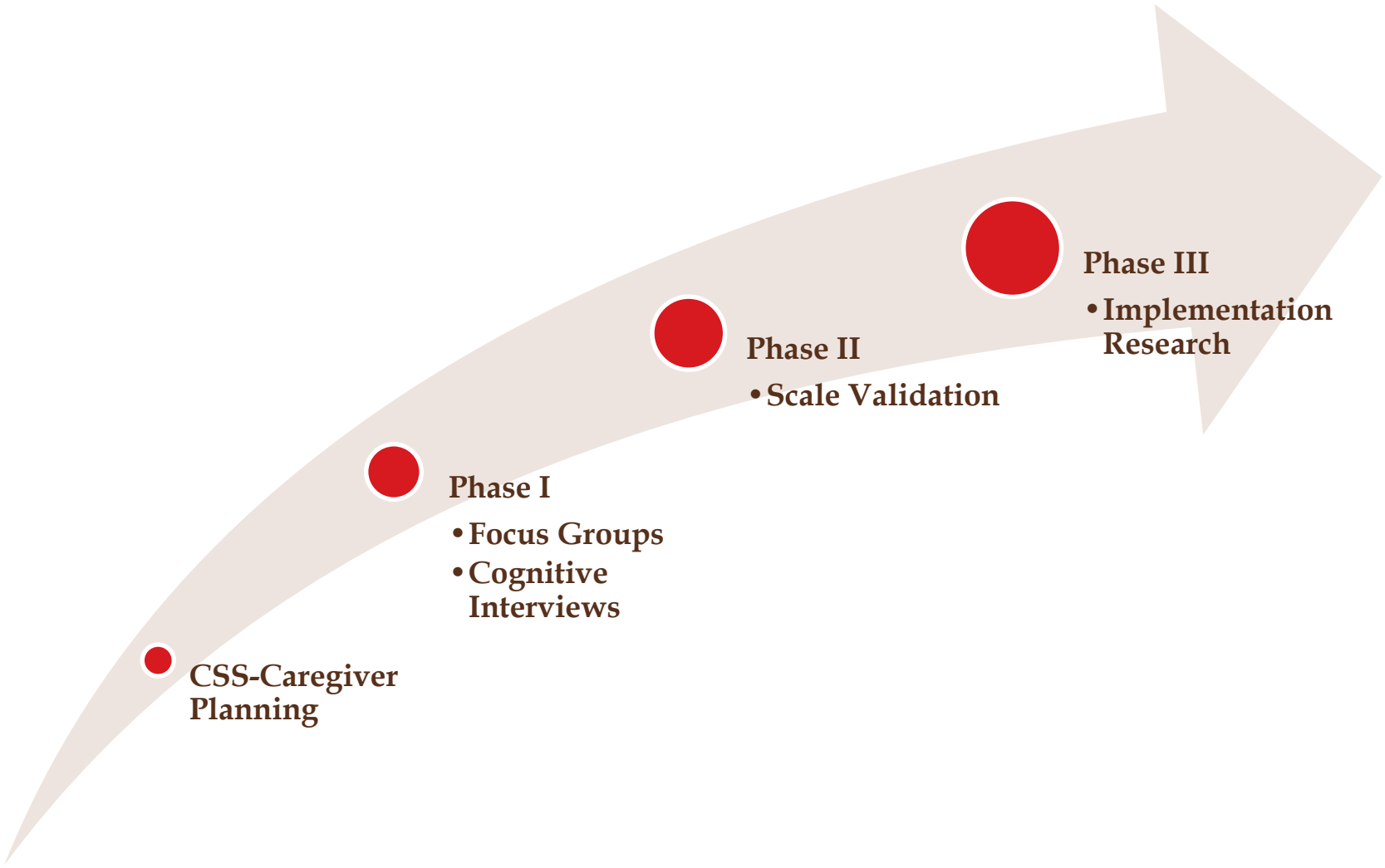
CancerSupportSource®

- Screening program to evaluate level of distress and need, and identify individuals desiring help and follow-up care
- Developed in part due to recommendations for integrated psychosocial care from IOM, PCORI, ASCO, etc.
  - In 2015, American College of Surgeons Commission on Cancer required that its 1,500 accredited institutions that see 70% of all new cancer diagnoses in US implement patient-centered standards

CSS-Caregiver Study Objectives

- To identify relevant concerns of cancer caregivers and to determine those which are most distressing
- To validate CancerSupportSource for caregivers against relevant existing psychosocial instruments
- To test the psychometric properties of CancerSupportSource Caregiver for use with older caregivers facing unique challenges associated with aging

Study Trajectory



Phase I: Focus Groups and Cognitive Interviews

- 3 focus groups and cognitive interviews
- Modified instructions and identified new items, e.g., feeling guilty
- Resulted in 47 items to be tested with caregivers

Caregiver Distress Items Address Three Broad Themes

- Caregiver emotional concerns/self-care
- Caregiving tasks
- Patient well-being

Sample Items and Question Format

Today, how CONCERNED are you about the following for yourself?	Please let us know how we can help you … (please select all that apply)
Eating and nutrition 0 Not at All 1 Slightly 2 Moderately 3 Seriously 4 Very Seriously	☐ Have a staff person talk with you. ☐ Provide me additional information. ☐ No action needed.

Today, how CONCERNED are you about the following caregiving roles or tasks (i.e., ways you help)?	Please let us know how we can help you … (please select all that apply)
Talking with the patient's doctors and health care team 0 Not at All 1 Slightly 2 Moderately 3 Seriously 4 Very Seriously	☐ Have a staff person talk with you. ☐ Provide me additional information. ☐ No action needed.

Today, how CONCERNED are you about the following for the person you are caring for?	Please let us know how we can help you … (please select all that apply)
The patient's pain and/or physical discomfort 0 Not at All 1 Slightly 2 Moderately 3 Seriously 4 Very Seriously	☐ Have a staff person talk with you. ☐ Provide me additional information. ☐ No action needed.

CSS Caregiver: Testing

- 47 items tested with 246 caregivers at 10 national CSC affiliate sites via web-based and paper surveys:
  - GC Chicago
  - GC Quad Cities
  - CSC Greater St. Louis
  - GC Kansas City
  - CSC Central Ohio
  - GC Madison
  - GC Louisville
  - CSC Delaware
  - CSC San Francisco Bay Area
  - CSC Greater Philadelphia
- Participants also completed:
  - NCCN Distress Thermometer (DT)
  - Center for Epidemiologic Studies Depression Scale (CES-D)
  - 12-Item Short Form Health Survey (SF-12)
  - Zarit Burden Interview Short Form (ZBI-12)
  - Caregiver Reaction Assessment (CRA)

CSS-Caregiver Validation with Older Adults

- Of 246 caregiver participants, there were **115** adult caregivers age 55 years and older that are the focus of this presentation

Caregiver Characteristics

N = 115	Frequency (*n*)	%
Age	Mean = 64 years (*SD* = 7)	Range: 55-83
Gender (*n*=114)		
Male	41	36%
Female	73	64%
Race/Ethnicity (*n*=109)		
Non-Hispanic White	101	88%
Hispanic or Latino	4	3%
Black	2	2%
Asian	1	1%
AIAN	1	1%
Household income (*n*=85)		
<$40K	19	17%
$40K-79.9K	33	29%
≥$80K	33	29%
Region (*n*=114)		
Urban	19	17%
Suburban	74	64%
Rural	21	18%

Caregiving Role

N = 115	Frequency (*n*)	%
Care recipient is: (*n*=112)		
Spouse/partner	79	69%
Child	17	15%
Parent/in-law	6	5%
Sibling/in-law	10	9%
Active treatment in past 2 years		
Yes	97	85%
No	13	11%
N/A	5	4%
Hours of care provided weekly (*n*=113)		
≤20	70	61%
21-80	27	23%
>80	16	14%
Self-Rating of General Health		
Excellent	16	14%
Very good	49	42%
Good	32	28%
Fair	17	15%
Poor	1	1%

Cancer of Person Receiving Care

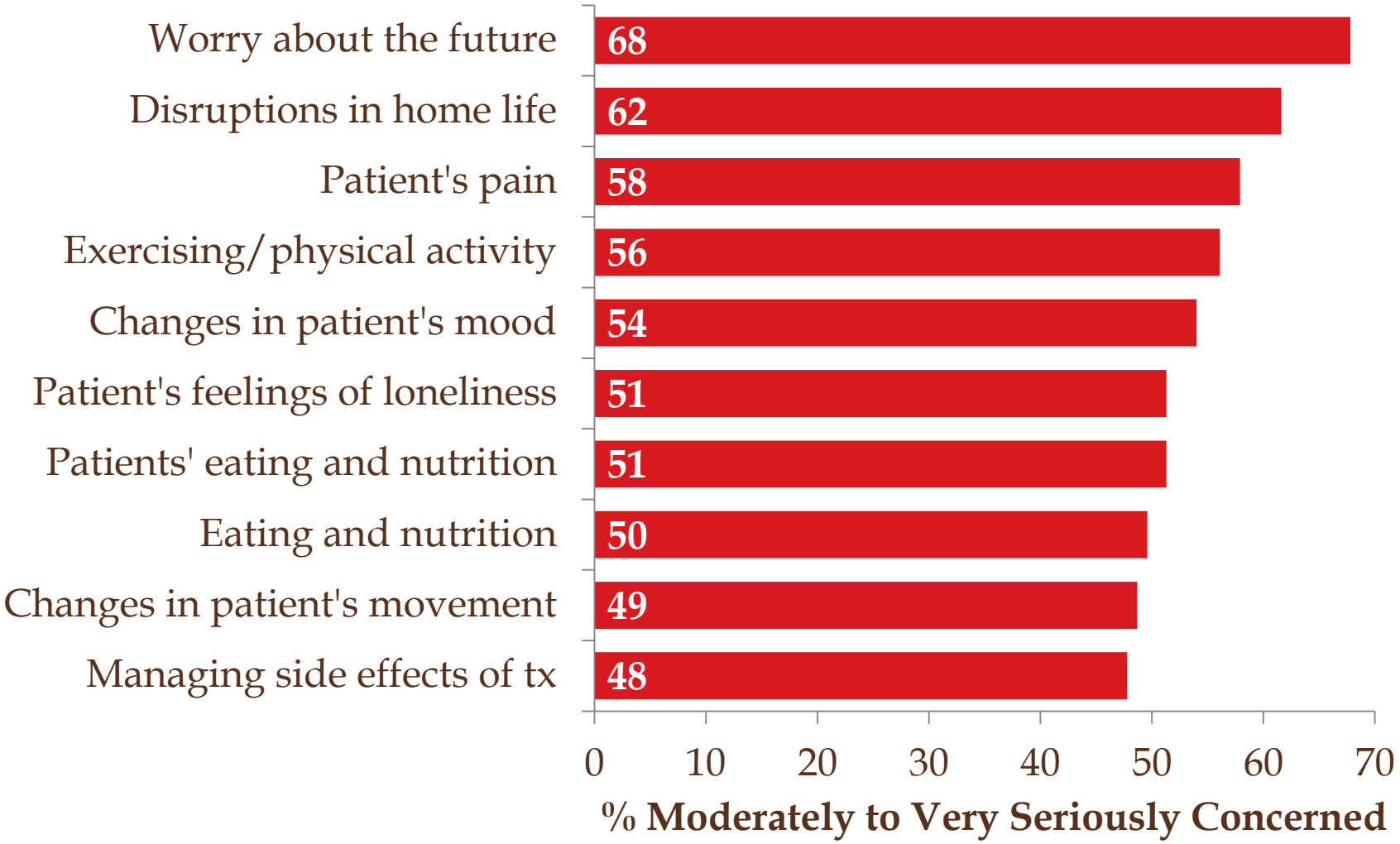
	Frequency (*n*)	%
Breast	22	19%
Blood	21	18%
Lung	10	9%
Brain	9	8%
Colorectal	9	8%
Prostate	7	6%
Ovarian	6	5%
Bladder	3	3%
Kidney	3	3%
Melanoma	2	2%
Pancreatic	2	2%
Endometrial	1	1%
Other	19	16%

Methods for Validation

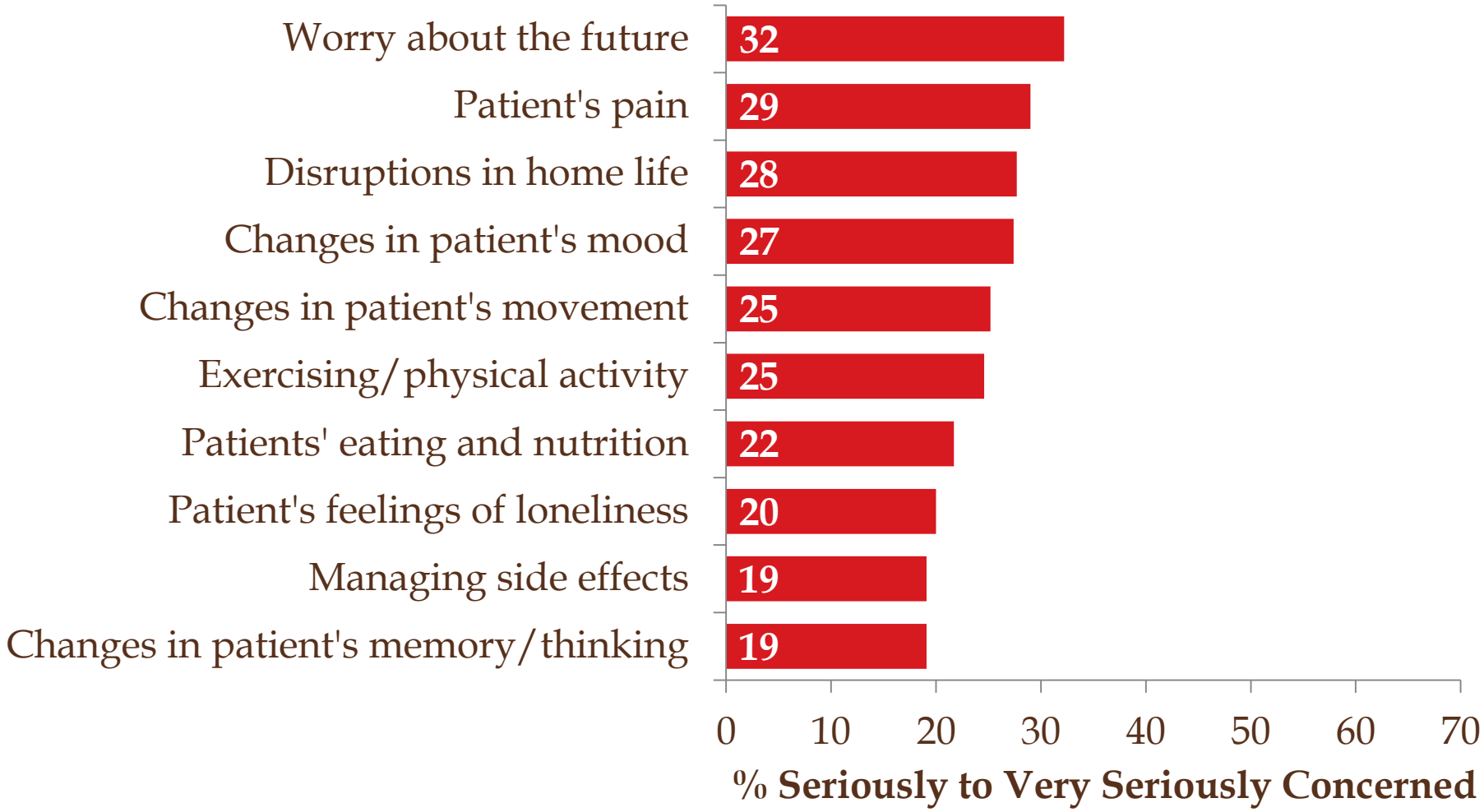
CONSTRUCT VALIDITY	CONCURRENT VALIDITY
Internal consistency reliability Cronbach's alpha (≥ .80 acceptable)	Pearson correlations Distress Thermometer CES-D SF-12 ZBI CRA ROC curve analysis
TEST-RETEST RELIABILITY	**DISCRIMINANT VALIDITY**
Intra-class correlation coefficient (ICC) (Subsample of 53 caregivers)	Known groups validation Analysis of variance *Item discrimination index*

Results

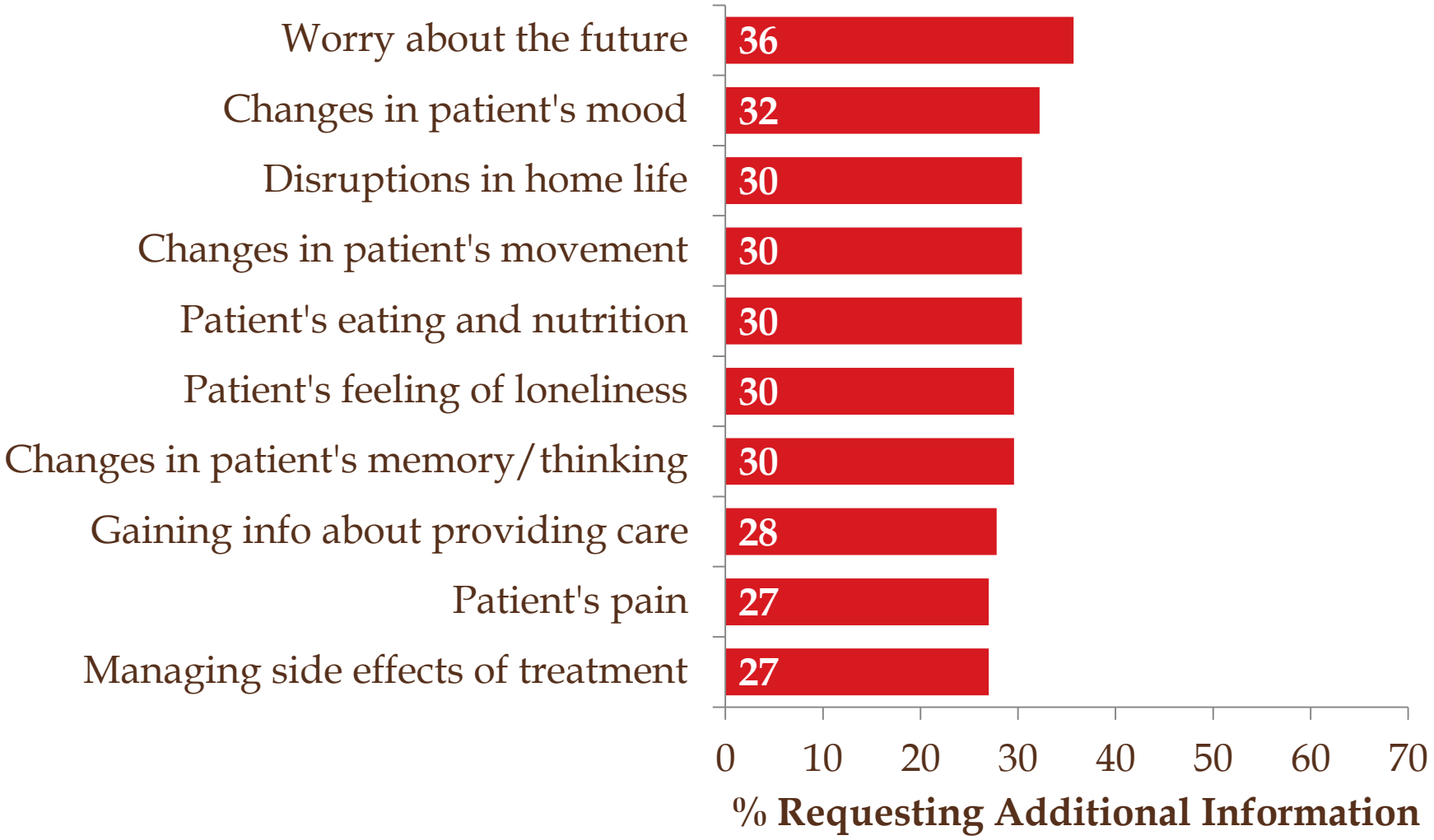
Top Caregiver Concerns



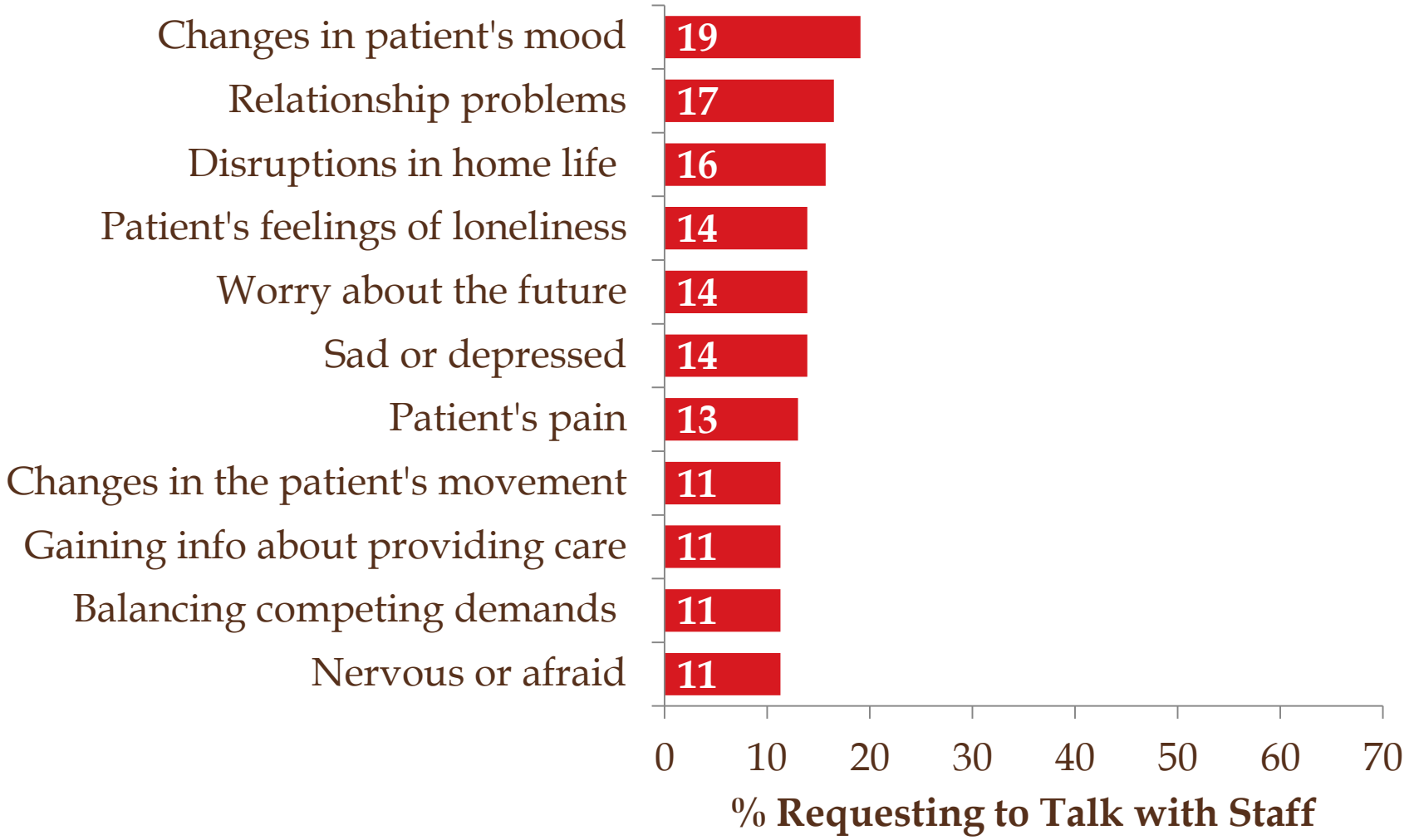
Top Caregiver Concerns



Request for Information



Request to Talk with Staff

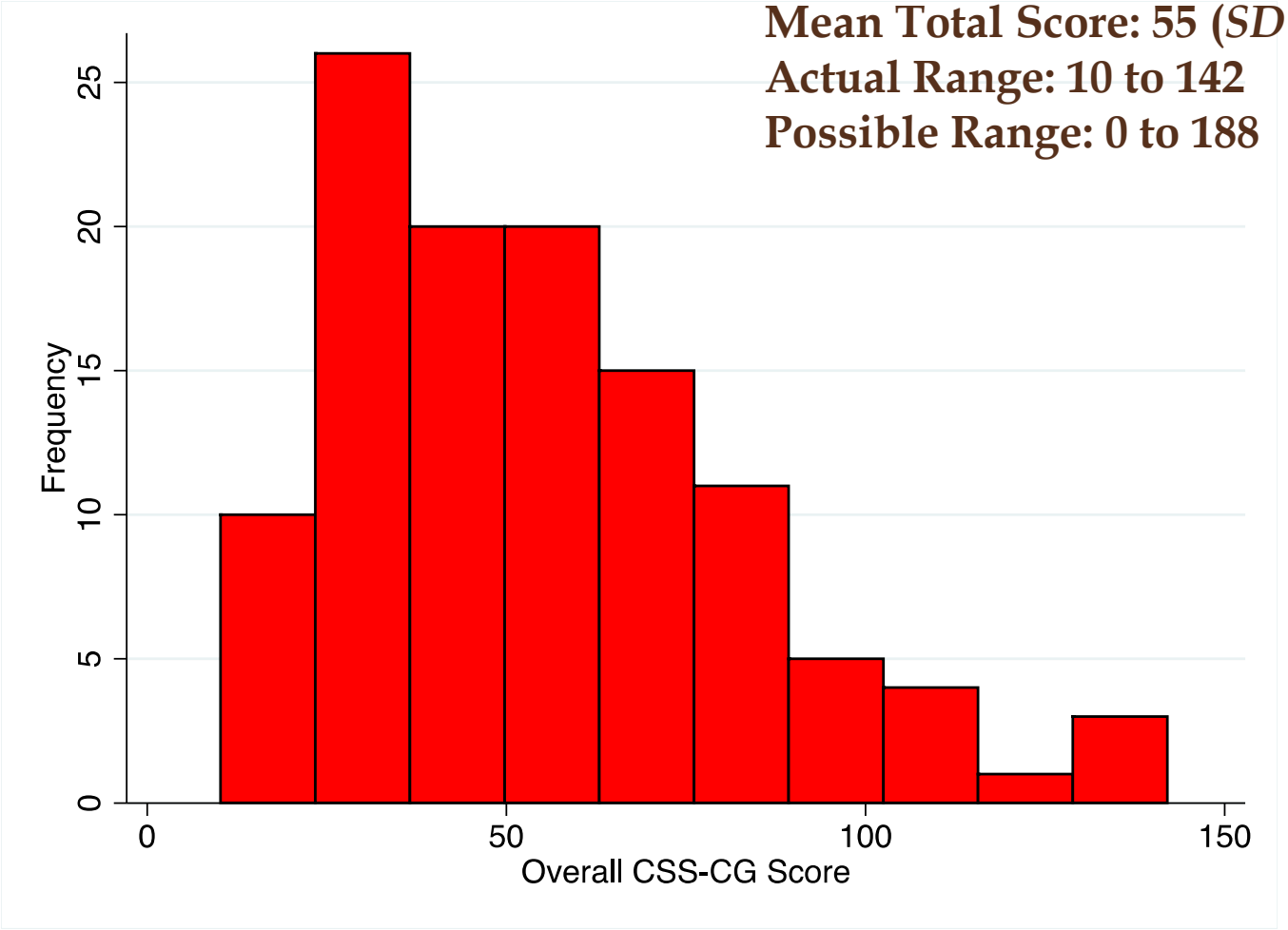


Concern Ratings vs. Requests to Talk to Staff

CSS-Caregiver Item	≥2 (%)	Talk (%)
Relationship problems with care recipient	23	56
Changes in patient's mood and/or behavior	54	31
Feeling unappreciated	24	30
Feeling that I'm always "on"	31	29
Feeling angry or resentful	19	27
Feeling sad or depressed	47	27
Feeling lonely or isolated	30	27
Gaining information about providing care	35	26
Talking with patient's doctors and HCT	22	25

Note: ≥2 indicates rating of "moderately" to "very seriously" concerned

Distribution of CSS-Caregiver Total Distress Scores for Ages 55+



Internal Consistency Reliability for Caregivers Ages 55+

	# items	Cronbach's alpha
Total Distress Score	47	0.95
Subscales		
Emotional/Self-care	27	0.91
Caregiving roles	11	0.90
Concerns about patient care	9	0.87

CSS Caregiver Total Distress Score: Correlation with Validated Measures

Validated Measure	*r*	*p*
NCCN Distress Thermometer	.49	<.001
Center for Epidemiological Studies Depression Scale (CES-D)	.54	<.001
Zarit Burden Interview (ZBI)	.48	<.001
Caregiver Reaction Assessment (CRA)		
Health Problems	.40	<.001
Disrupted Schedule	.36	<.001
Financial Problems	.27	<.01
Lack of Family Support	.20	<.05
Caregiver Esteem	-.18	.052
General Health Survey (SF-12)		
Mental Component Summary Score	-.44	<.001
Physical Component Summary Score	-.28	<.01
General Health (1 item)	-.35	<.001

Note: r = Pearson correlation coefficient

Differences in Total Distress

	Mean (*SD*)	*p*
Caregiving hours/week		
<10 hours (n=51)	46.6 (23.4)	**<.01**
≥10 hours (n=62)	61.9 (30.6)	
General health		
Very good or excellent (n=65)	46.3 (22.6)	**<.001**
Poor, fair, or good (n=50)	66.0 (31.1)	
Annual income		
≥$40K (n=66)	52.2 (24.7)	.19
<$40K (n=19)	61.7 (35.2)	
Gender		
Male (n=41)	51.3 (23.3)	.35
Female (n=73)	56.5 (30.8)	

Test-Retest Reliability

Good to Excellent, ICC ≥0.60	Fair, ICC 0.40-0.59	Poor, ICC<0.40
41 items	**4 items**	**2 items**
Examples…		
My financial well-being	Maintaining appearances or keeping it all together in front of others	Worry about family, children, and/or friends
The patient's weight change (gain or loss)	Managing household or family activities (cleaning, yard work, cooking, child care, etc.)	Changes or disruptions in home life
	Pain and/or physical discomfort	
	Managing side effects of treatment (nausea, swelling, etc.)	

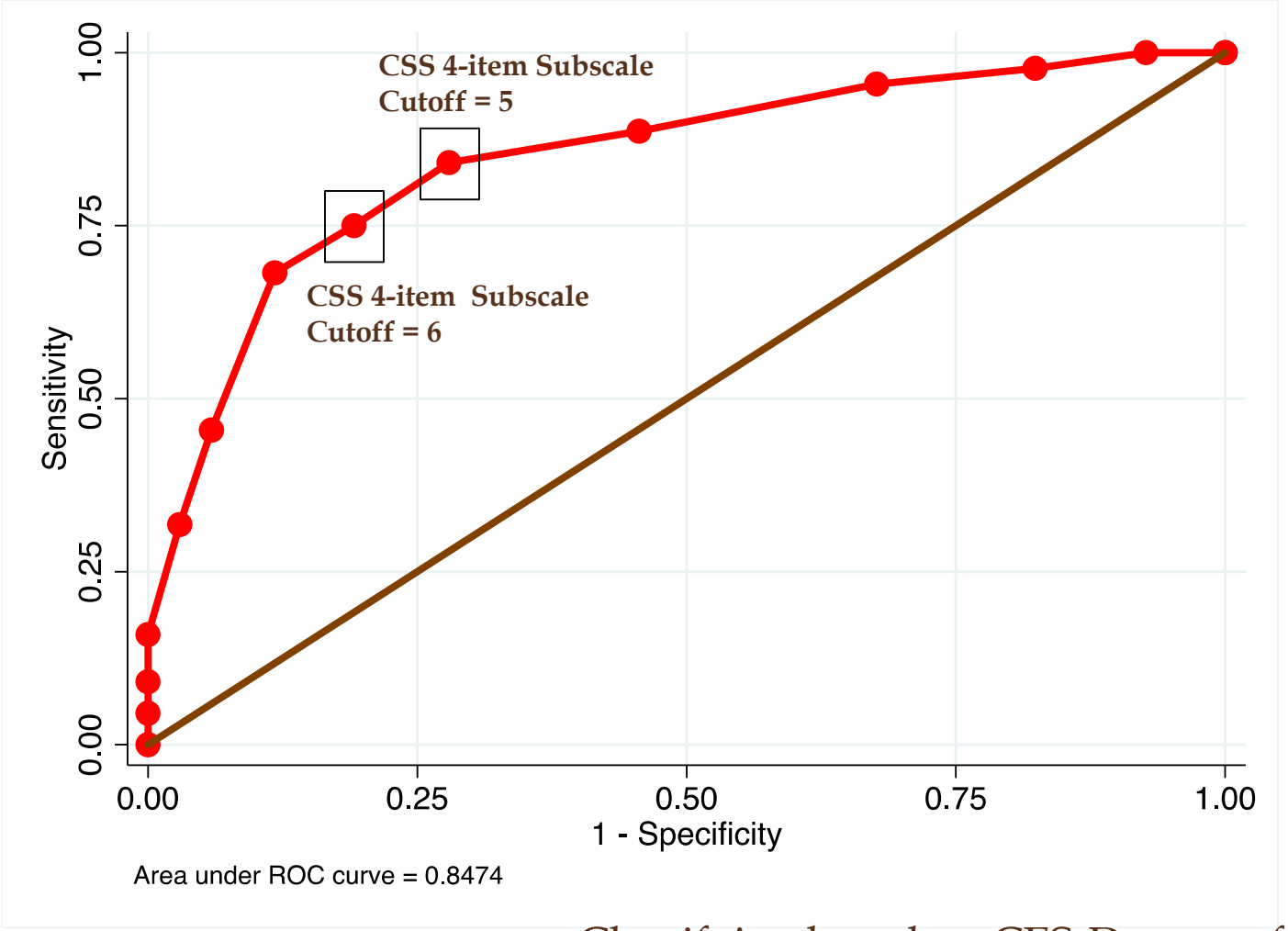
Note: Test-retest conducted in subsample; n = 53

Risk for Depression Subscale

- Secondary goal: Identify those caregivers at risk for clinically significant levels of depressive symptoms
  - People with depression at risk for poorer outcomes; our goal is to triage caregivers to appropriate care

- Adaptation of CancerSupportSource 4-item risk for depression subscale

Risk for Depression Subscale & CES-D



Classifying based on CES-D score of ≥16

Risk for Depression Subscale: Sensitivity and Specificity for Ages 55+

CSS-CG Items	α	AUC	Cutoff	Sensitivity	Specificity
Feeling sad or depressed Feeling lonely or isolated Feeling nervous or afraid *Feeling too tired to do the things you need or want to do*	.76	0.847	6	.75	.81
			5	**.84**	**.72**
Feeling sad or depressed Feeling lonely or isolated Feeling nervous or afraid *Worry about the future and what lies ahead*	.81	0.835	6	.84	.71
			5	.89	.57

α = *Cronbach's alpha*

50% of caregivers were at risk for depression

Next Steps Towards Implementation

- Reduce number of items in CSS 47-item caregiver tool through factor analysis and item discrimination index
- Validate shortened tool in diverse settings
- Develop appropriate educational materials
- Implement CSS Caregiver within same digital platform as CSS Patient
  - Opportunity to look at dyadic distress profiles
- Where and when to implement caregiver screening outside of CSC?

Thank you!

Alexandra Zaleta, PhD
azaleta@cancersupportcommunity.org

With gratitude to:

Joanne Buzaglo, PhD
Vicki Kennedy, LCSW
Mitch Golant, PhD
Margaret Longacre, PhD
Melissa Miller, MPH, PhD

And all of our participating caregivers and CSC affiliates…