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A Global Network of Education and Hope

Symposium Overview:
Implementing Community-Based Distress Screening for Cancer Patients

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Senior VP Research & Training

The Challenge of Cancer Care Today

Growing Numbers

- Today there are more than 13 million cancer survivors in the US
- There will be more than 1.5 million new cases this year alone
- There are more than 77 million baby boomers in the US today

Growing Complexity

- More screening, diagnostic, and biomarker tools with complex results
- More treatment choices than ever before
- Multiple bouts, recurrence

Growing Need

- More people are in need of more services
- Great financial strain in this challenging economic environment

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Emotional & Social Care is Undertreated

87%

Rated at least one social, emotional or physical issue as a moderate to very severe problem

-CSC Cancer Survivor Registry

CANCER SURVIVOR REGISTRY
THE BREAST CANCER M.A.P. PROJECT

$8,400

In a Department of Defense analysis, depression was associated with significantly higher annual health care utilization and costs, costing an average of $8,400 more than costs for individuals without depression

-Jeffery, D. D., and Linton, A., Impact of Depression and PTSD on Health Care Use and Costs Among Persons With Multiple Chronic Conditions in the Department of Defense and Veterans Affairs, Annual Conference of the American Psychological Association, August, 2001.

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Striving for Complete Cancer Care

"Health is a state of **complete physical, mental and social well-being** and not merely the absence of disease or infirmity."

–WHO Definition of Health

World Health Organization

+

"All cancer care should include appropriate **psychosocial support**."

– IOM Report: Cancer Care for the Whole Patient

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

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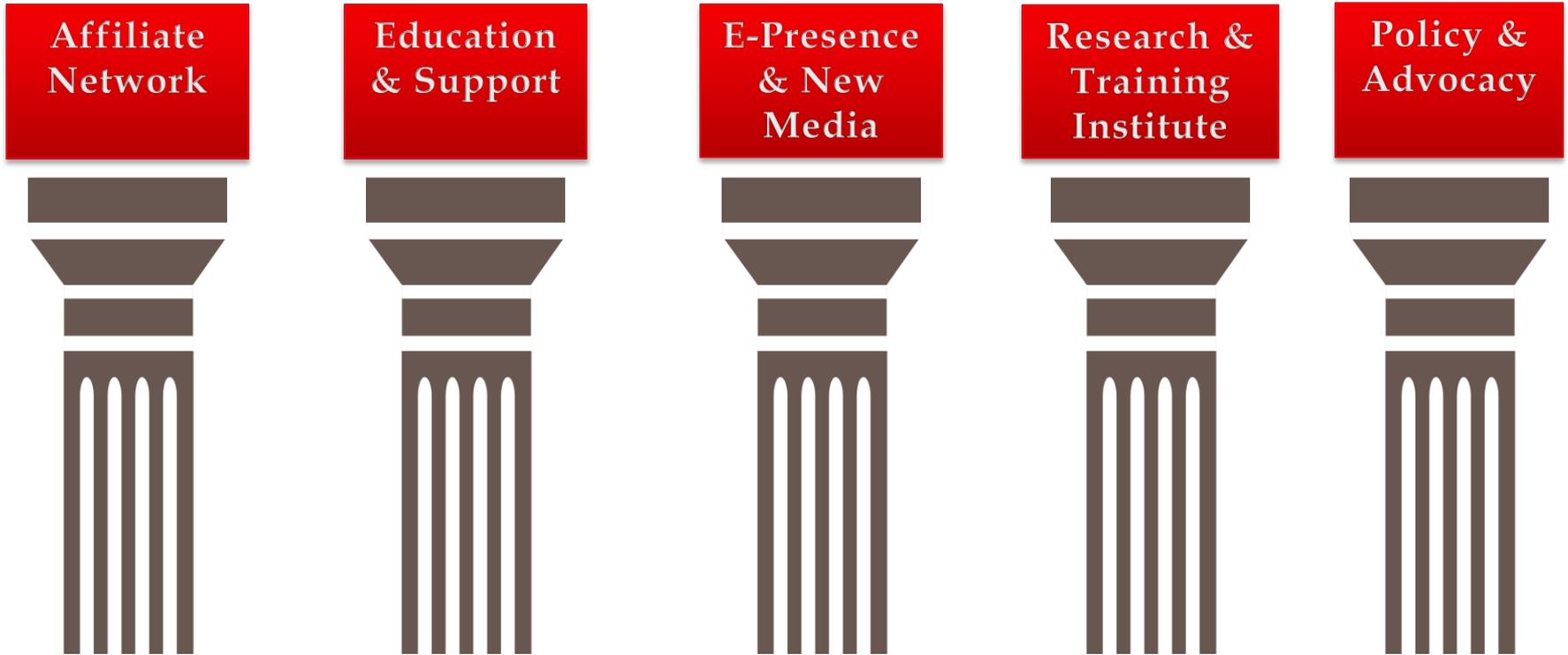# Striving for Patient-Centered Care

- **IOM Report** – *Cancer Care for the Whole Patient*

- **PCORI** – Patient-Centered Outcomes Research Institute

- **American College of Surgeons Commission on Cancer New Patient-**Centered Standards

- **ASCO QOPI Program** – psychosocial care and distress screening added to QOPI

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Enter The Cancer Support Community

Our Mission

To ensure that all people impacted by cancer are empowered by **knowledge**, strengthened by **action**, and sustained by **community**

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CSC's Five Pillars

Affiliate Network

Education & Support

E-Presence & New Media

Research & Training Institute

Policy & Advocacy

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I. Affiliate Network

In the US:

Phoenix, AZ
Cathedral City, CA
Pasadena, CA
Redondo Beach, CA
Santa Monica, CA
Walnut Creek, CA
Westlake Village, CA
Wilmington, DE
Washington, DC
Ft. Lauderdale, FL
Miami, FL
Sarasota, FL
Atlanta, GA
Chicago, IL
Indianapolis, IN
Davenport, IA
Louisville, KY
Salisbury, MD
Ann Arbor, MI
Detroit, MI
Grand Rapids, MI
St. Louis, MO
Bozeman, MT

Bedminster, NJ
Eatontown, NJ
Hackensack, NJ
Linwood, NJ
Buffalo, NY
New York, NY
Rochester, NY
White Plains, NY
Cincinnati, OH
Columbus, OH
Bethlehem, PA
Philadelphia, PA
Pittsburgh, PA
Warminster, PA
Knoxville, TN
Nashville, TN
Dallas, TX
Seattle, WA
Madison, WI
Middleton, WI

Internationally:

Simcoe Muskoka, Ontario
Greater Toronto, Ontario
Tel Aviv, Israel
Tokyo, Japan

In Partnership:

ARC Cancer Support Centre
Dublin, Ireland

Hope & Cope,
Montreal, Canada

Maggie's Center
United Kingdom

The Carewell Community,
Manila, Philippines

V Care,
Mumbai, India

In Development:

Paso Robles, CA
Denver , CO
Branford, CT
Evansville, IN
Greenville, NC
Hanover, MA
Minneapolis, MN
Kansas City, MO
Dayton, OH
Austin, TX
Southeastern Ontario

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I. Affiliate Network (cont'd)
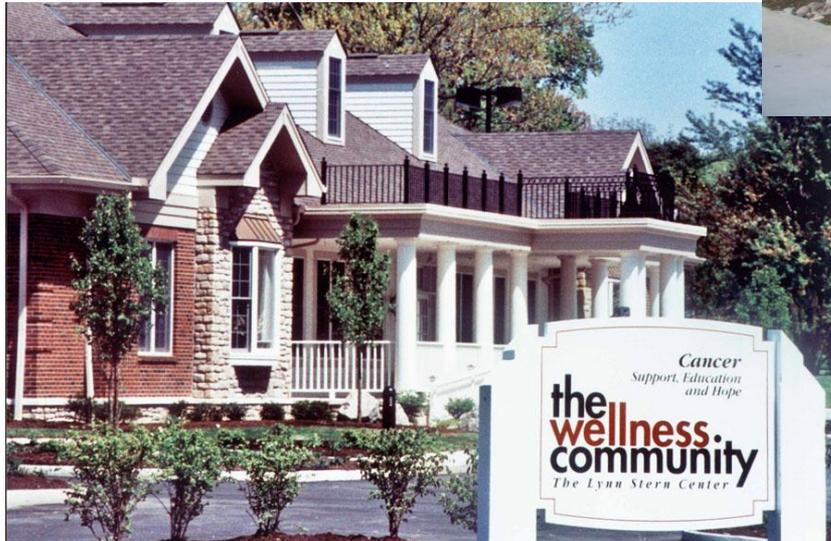
Screening Demonstration Project

Distress screening for patients in the community is largely non-existent

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The Real World

Given:

Most people are not seen in Comprehensive Cancer Centers

Need Tools targeted to diverse populations and settings

True Integration of care across systems does not exist

Key Question:

Can Distress Screening (Referral and Follow-up) Care lead to systemic de-silofication by creating a common language?

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Demonstration Project

To bridge this gap, the Cancer Support Community (CSC) in collaboration with City of Hope (COH) tested the feasibility and effectiveness of community-based, comprehensive screening for cancer patients.

The Beginning
Philadelphia, February 22-24, 2010

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CSC Team

Wendy Ballou & Sally Werner

Melissa Wright & Claudia Robinson

Joanne Buzaglo, Melissa Miller, Vicki Kennedy, Julie Taylor, Kasey Dougherty

CancerSupportCommunity.org

Distress Screening

Is distress screening feasible in the community and will it…..?

- Be user-friendly & welcoming

- Provide members/patients with vital information

- Provide objective tools to plan/deliver programs

- Validate individual needs while deepening their connection in Community

CancerSupportCommunity.org

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Validity and reliability of a 36-item problem-related distress screening tool in a community sample of 319 cancer survivors

Melissa Miller[1], Joanne Buzaglo[1], Kasey Dougherty[1], Vicki Kennedy[1], Julie Taylor[1], Karen Clark[2], Matt Loscalzo[2], Mitch Golant[1]

[1]Cancer Support Community [2] City of Hope

Uniting The Wellness Community and Gilda's Club Worldwide

Background

There are a number of validated measures to screen for distress and identify areas of unmet need

Screening program was chosen because:

- Automated touchscreen interface
- Ability to tailor referrals
- Option to provide summary and print material in real time
- Patient-friendly screening tool

Screening tool had not been validated

Presented a unique opportunity to test psychometric properties in a community sample

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Screening tool

How Much Of A Problem Is This For You? **Sleeping**

| Not a Problem | Mild Problem | Moderate Problem | Severe Problem | Very Severe Problem |

| Prefer not to answer | Do not know |

How Can We Best Work With You On This Problem?

| Provide Written Information | Talk with a Member of the Team | Written Information and Talk with Team Member | Nothing Needed at This Time |

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Phase 1: Refined 53-item tool

350 cancer patients

Process used statistical and theoretical criteria

Reduced and refined City of Hope 53-item tool to meet community needs

- 19 items dropped
- 6 items revised
- 2 items added

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Phase 2: Validated 36-item tool

Sample included 319 cancer survivors across 14 CSC affiliate sites

Pen-and-paper survey

- 36-item screening tool
- FACT-G
- CES-D
- Distress thermometer
- Socio-demographic and clinical questions

Subsample of 101 completed the 36-items a second time

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Statistical Methods

Internal reliability

- Cronbach's alpha coefficient

Concurrent validity

- Pearson correlation coefficient (R^2 reported)
- ROC curve analysis

Known groups validation

- Wilcoxin rank-sum and Kruskal-Wallis tests

Test-retest reliability

- Intraclass correlation coefficient
- Percent agreement

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Sample characteristics

Median age: 61 years

84% female

83% white, 8% Hispanic/Latino

25% <$40K total annual income

45% breast cancer, 12% blood, 9% gynecologic, 5% lung, 5% prostate

20% <1 y from cancer dx, 33% 5 y+

70% active tx for cancer within 2 y

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Top 5 items rated moderate to very severe problem
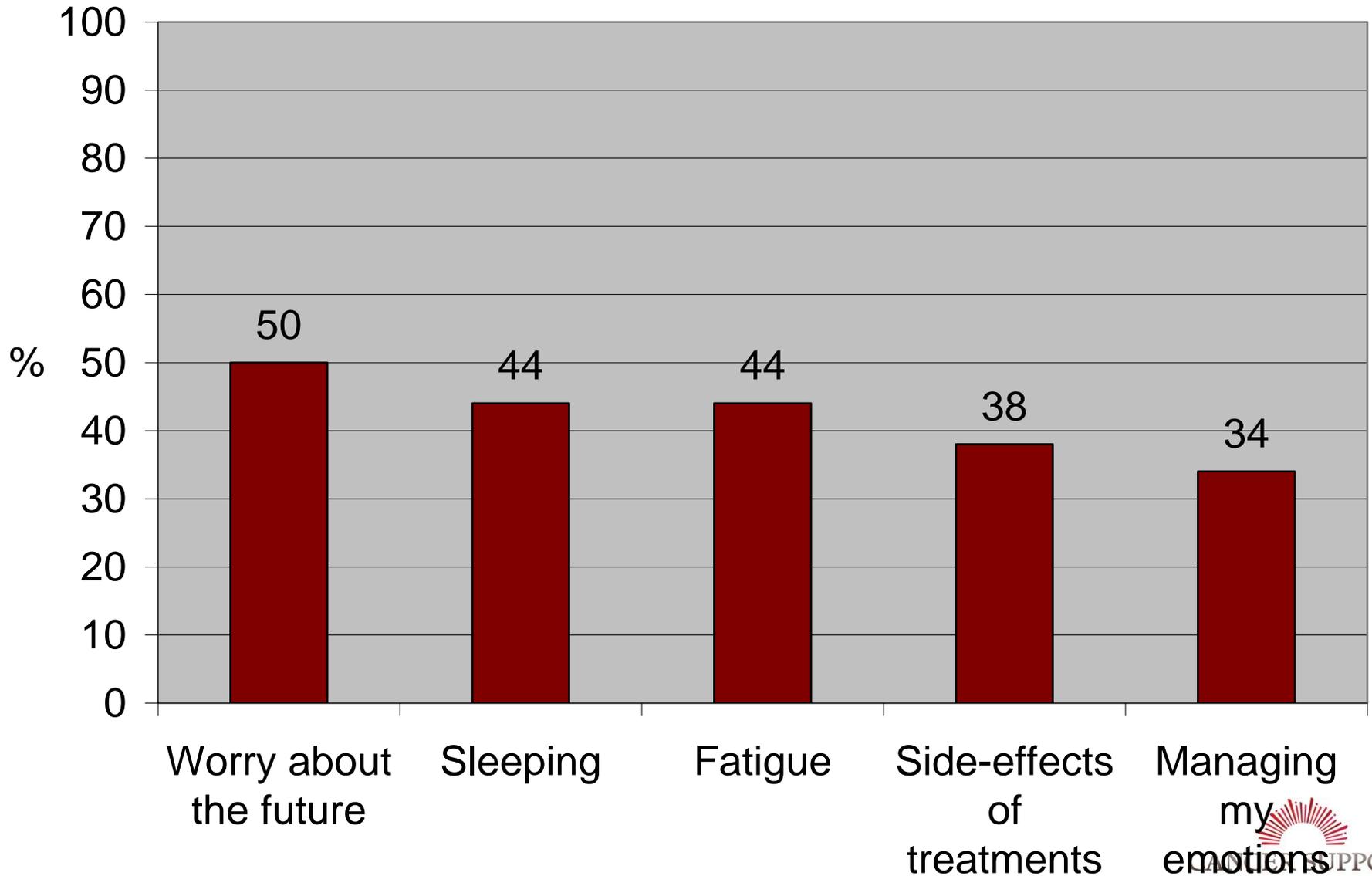
Top 5 items for which assistance was requested
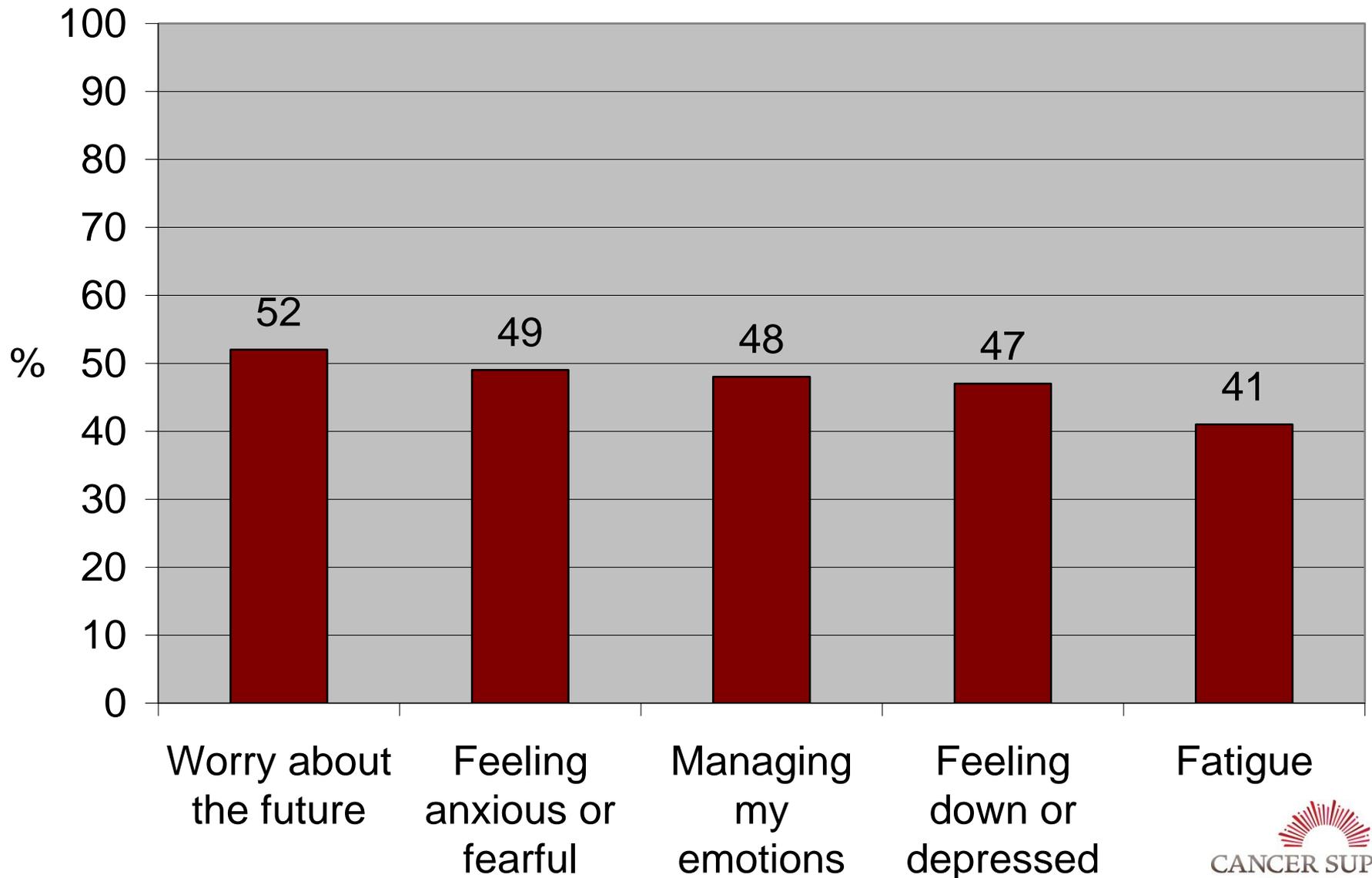
Summary scores

The median number of items rated moderate to very severe problem was 6

Half (52%) did not rate any item as a severe or very severe problem

14% rated 1 item; 10% rated 2 items severe or very severe

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Internal reliability

A 6-item depression subscale was calculated as the sum of the following:

- *feeling down or depressed*;

- *feeling anxious or fearful*;

- *managing my emotions; worry about the future; feeling isolated, alone or abandoned*;

- *feeling irritable or angry.*

Cronbach's alpha

- 0.91 for 36 items

- 0.88 for 6 depression items

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Concurrent validity

Correlations (R^2) between the screening tool and the FACT-G, the CES-D and the DT

Summary Scores	FACT-G					CES-D	Distress Therm.
	Overall	Emotion	Physical	Function	Social		
Summary of problem ratings	0.58	0.34	0.42	0.34	0.23	0.48	0.35
Depression subscale	0.50	0.49	0.21	0.30	0.23	0.50	0.37
Count of items≥3	0.50	0.32	0.41	0.28	0.18	0.44	0.34
Count of items≥4	0.31	0.14	0.26	0.17	0.15	0.30	0.22

R^2≥0.49: strong

$0.49 > R^2$≥0.16: moderate

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Receiver Operating Characteristic curve for the count of screening items rated moderate to very severe problem compared to the CES-D (≥16)

Count=4; Se=0.93; Sp=0.49

Count=8; Se=0.73; Sp=0.78

Area under ROC curve = 0.8289
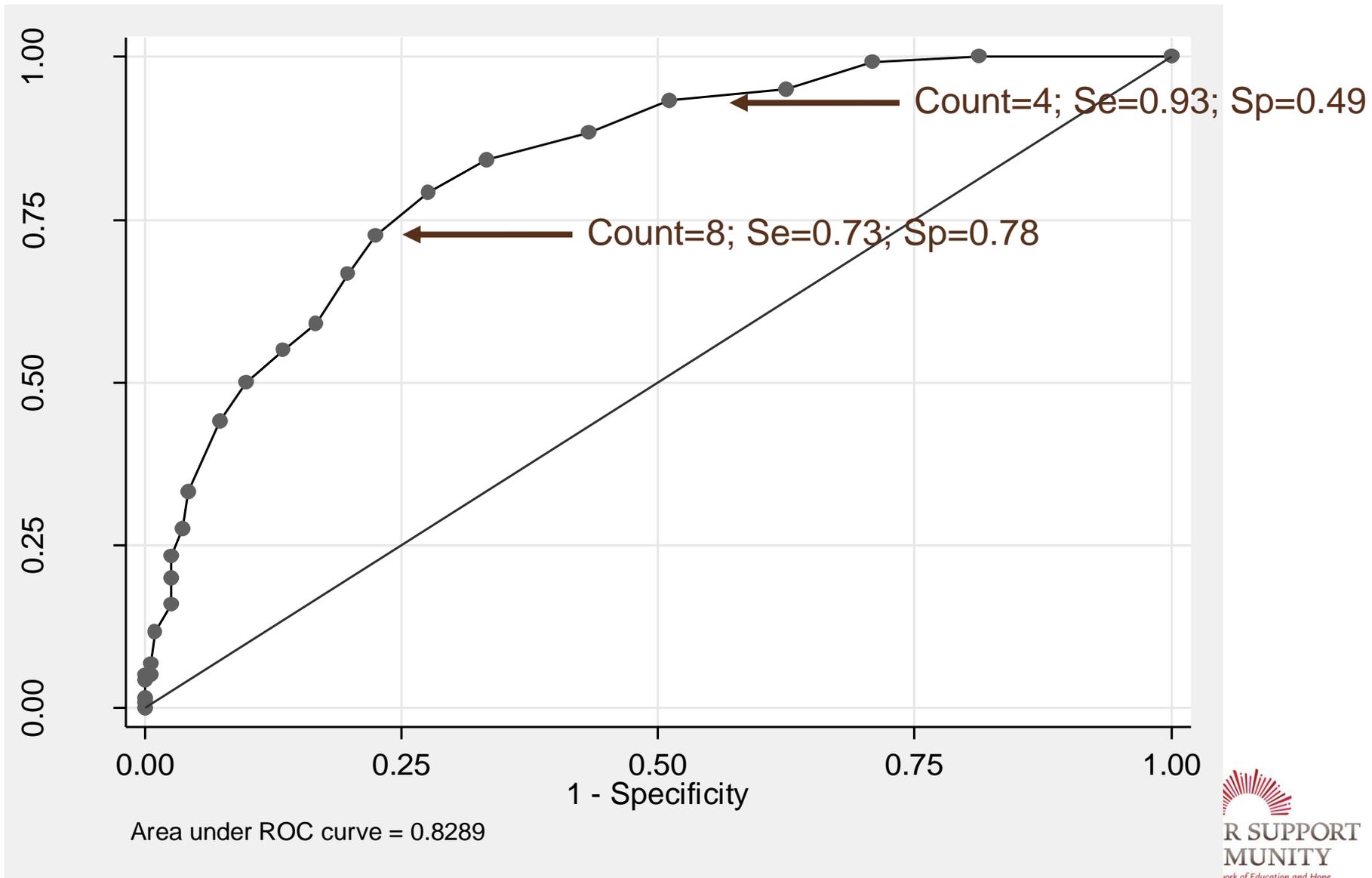
Known groups validation

Characteristic		*n*	Number of items severe or very severe (mean ± SD)	p-value
Depression	CES-D<16	192	0.8 ± 1.7	
	CES-D≥16	120	3.4 ± 4.0	<0.0001
Distress	DT<4	151	0.6 ± 1.5	
	DT≥4	141	2.9 ± 3.5	<0.0001
Active tx for cancer	≥2y	96	1.3 ± 2.9	
	<2y	220	2.1 ± 3.1	0.002
	<5 mo	19	2.4 ± 3.4	
	5 mo-1 y	44	2.2 ± 3.3	
	1 – 2 y	57	1.9 ± 2.5	
	2 – 5 y	84	1.5 ± 2.5	
Time since cancer dx	≥ 5 y	101	1.9 ± 3.7	0.35

Test-Retest Reliability

Percent agreement between test and retest responses was high for all 36 items ranging in value from 71-99%.

The Intraclass Correlation Coefficient (ICC) was ≥0.75 for all 36 screening items except *ability to have children*.

There was 98% agreement for *ability to have children* with 86 of 89 (97%) participants rating the item as *not a problem* at both test and retest.

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Conclusion

Strong psychometric properties in a community sample of cancer survivors.

- Strong internal reliability, discriminant validity and test-retest reliability

- Moderate concurrent validity

Study begins to demonstrate feasibility of systematic screening for distress in the community.

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