



CANCER SUPPORT COMMUNITY

A Global Network of Education and Hope

Distress Screening: Essential Quality Care

Patient Quality of Life Coalition

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Cancer Support Community

OUR MISSION:

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



Cancer Support Community



Affiliate Network

- 50+ centers
- 120+ satellite locations
- Deliver support groups, educational, health and wellness programs
- Hospital-based CSCs



"It is just the greatest place; I have found support, friends and new ways to meet the challenge of having cancer."

Cancer Support Helpline®

- Staffed by licensed mental health professionals
- Serving thousands of people touched by cancer no matter where they live
- Home to *Open to Options*® – Treatment Decision Counseling Program and *CancerSupportSource*™ Distress Screening Program

CANCER SUPPORT SOURCE SM

A PROGRAM *of the* CANCER SUPPORT COMMUNITY 



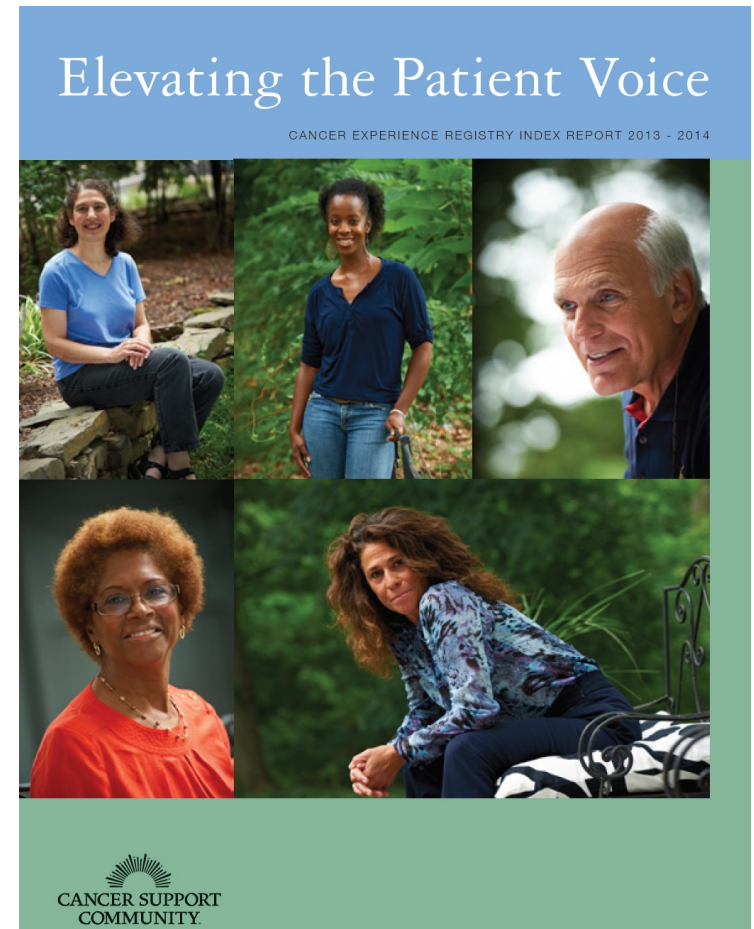
Research and Training Institute

Experts in the Cancer Patient Experience



Cancer Experience Registry®

- First cancer registry in the world focused on understanding and addressing the psychosocial and survivorship needs of **anyone** ever faced with a cancer diagnosis
- Currently 7,000+ participants
- Goal >10,000 (all cancers) in 2014
- www.cancerexperienceregistry.org



Cancer Policy Institute

- Formally launched on June 19, 2013
- Experienced CSC policy team
- Uniting direct patient and family engagement with research to shape the future of quality cancer care

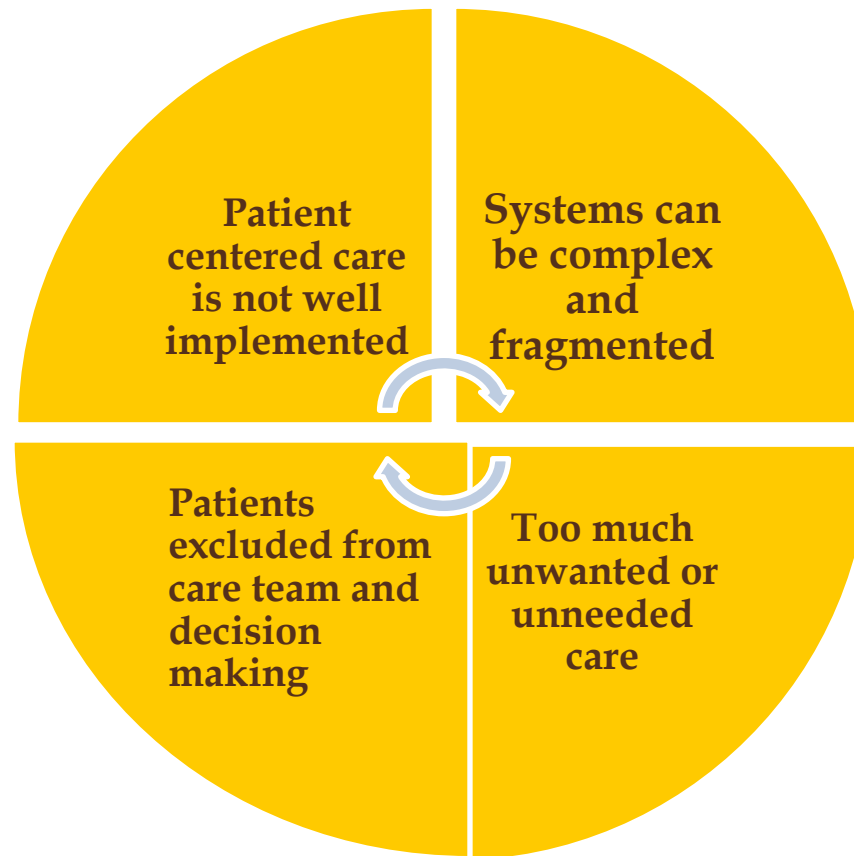


The Cancer Policy Institute *at the*
CANCER SUPPORT COMMUNITY



Distress Screening, Referral and follow-Up: Transforming Quality Care

Issues Identified by the Institute of Medicine



Delivering High-Quality Cancer Care: Charting a New Course for System in Crisis
Institute of Medicine September 2013

Striving for Patient-Centered Care

- Institute of Medicine (IOM)
 - *“Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs”*
 - *“Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis”*
- Patient-Centered Outcomes Research Institute (PCORI)
- American College of Surgeons Commission on Cancer
2012 Patient-Centered Standards
- American Society of Clinical Oncology
Quality Oncology Practice Initiative (QOPI)
- Community Oncology Alliance
Medical Home



**All include distress screening
and psychosocial care**

Definition of Distress in Cancer

“Distress extends along a continuum, ranging from common normal feelings of vulnerability and sadness to problems that can be disabling, such as depression, anxiety, panic, social isolation and existential and spiritual crisis.”

National Comprehensive Cancer Network: 1999, 2001, 2004, 2007, 2010

Today's Reality

Psychosocial distress can be correlated with poorer physical function

“...41% of patients score above the threshold for psychological distress and poorer physical function is associated with increased distress levels.” (Hurria, et al. 2009. JCO)

The cost of care increases alongside distress

- \$8,400 more per individual, per year with depression (Jeffrey, et al. 2010. APA)

35% -50% of women were never asked about distress (Findings from Metastatic Breast Cancer Registry Data, ASCO, 2014)

What is Distress Screening?

- A **brief** method for prospectively identifying and triaging cancer patients **at risk** for illness-related **psychosocial complications** that undermine the ability to fully benefit from medical care, the efficiency of the clinical encounter, satisfaction and safety.

...Personalized medicine requires personalized psychosocial care!



Commission on Cancer New Distress Screening Standard 3.2

- *S 3.2: “The cancer committee develops and implements a process to integrate and monitor on-site psychosocial distress screening and referral for the provision of psychosocial care.”*
- Committee defines patient population to be screened:
 - The timing of screening, the methods, tools, assessment and referral, and documentation
 - Examples of screening tools listed in the standard
 - A psychosocial representative oversees & reports on activity



CANCER SUPPORT SOURCESM

A PROGRAM *of the* CANCER SUPPORT COMMUNITY 

- Web-based, CSS-15/CSS-25 screening Program
- Validated with CES-D, FACT G, & DT
- Password protected, HIPAA compliant
- Patient empowered to report concerns AND what kind of support is needed
- **Real-time reports** created for both patient and clinical team
- Customized information/resource links automatically generated
- Can be integrated into e-scheduler and EHR
- Aggregate data reports for research, program planning, staffing, etc



16

CSS Distress Screening

http://samplehospital.mycarereport.com/patient/pati HealthCare Center Survey



1/17



6%

Test, Joe

Today, how **CONCERNED** are you about... Making a treatment decision?

Please select one of the choices below, then press the NEXT button to continue.

Not at all

Slightly

Moderately

Seriously

Very Seriously

PREVIOUS

NEXT

CSS Distress Screening





HealthCare Center Survey

Sample Hospital

1/17 6% Test, Joe

Making a treatment decision: please let us know how we can help you.

Please select as many of the choices below as apply, then press the NEXT button to continue.

<input checked="" type="checkbox"/>  Have a staff person talk with you	<input type="checkbox"/>  Connect you with online resources	<input checked="" type="checkbox"/>  Give you written information	<input type="checkbox"/>  No action needed
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PREVIOUS NEXT

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CSS My Support Care Report©

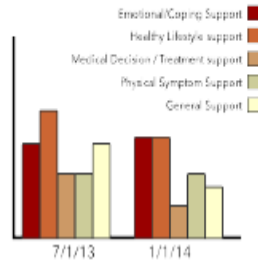
My Care Report

Name: Jane Doe
Date of Birth: 01/01/1980
Date of Survey: 01/01/2014
Your distress score: 75 / 100

Thank you for completing your CancerSupportSource™ Survey on 11/13/2013. As an important next step in your cancer treatment plan, the Cancer Support Community is committed to helping you create a Personal Support Care Plan to assist you in getting the help you need during your cancer journey. Below you will find a summary of your responses. Please note: This is a summary of what you reported on CancerSupportSource™; this is not based on information from your medical records. Please use the information below to talk with your health care team, Cancer Support Community staff person, or other support person about what would be most helpful to you at this time. *(this text is customizable per provider)*

Distress Score History

Our records show that you've taken this distress test before. The following chart shows how your distress level has evolved.



For info about the following items please refer to:

- Emotional/Coping Support: page 2
- Healthy Lifestyle support: page 3
- Medical Decision / Treatment support: page 4
- Physical Symptom Support: page 5
- General Support: page 6

Emotional/Coping Support

Your emotional distress score
15 / 20

Here goes a short description of the category. Many of these changes are physical and/or emotional. For some people diagnosed with cancer these changes will be more spiritual or existential in nature causing them to question the meaning

Spirituality Problems

A diagnosis of cancer brings many changes. Many of these changes are physical and/or emotional. For some people diagnosed with cancer these changes will be more spiritual or existential in nature causing them to question the meaning of their lives and what really matters. Questioning the meaning of one's life by those diagnosed with cancer is quite normal. Spending some time thinking about this topic may help you to discover new goals, priorities and possibilities. *(customized per question per provider)*

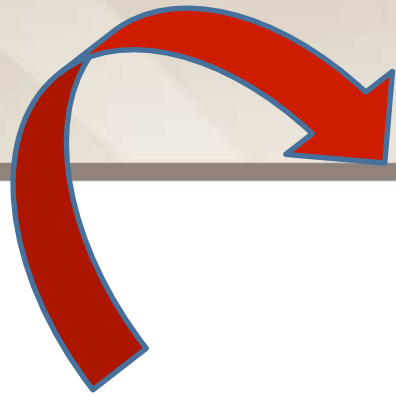


Here are some related online resources that you may want to check:

Frankly Speaking About Cancer - Spirituality Problems fact sheet
1-888-793-9355
<http://www.cancersupportcommunity.org/finding-meaning-and-purpose>

Spirituality in Cancer Care
National Cancer Institute
1-800-4-CANCER
<http://www.cancer.gov/cancertopics/pdq/supportivecare/spirituality/Patient>

Resources and educational information are customizable per provider



Clinical Distress Management Report integrated into the EHR

Distress Screening Report

Name: **Doe Jane** (Female)
Date of Birth: 01/01/1990
Date of Screening: 05/19/2014
Distress score: **30/60**

Survey Results

Concern	Screening 05/19/14	Action Required
Feeling irritable	1. Slightly	Information
Sleep problems	0. Not at all	
Changes or disruptions in work, school or home life	4. Very Seriously	Talk
Feeling sad or depressed	3. Seriously	Information, Talk
Pain and/or physical discomfort	3. Seriously	Information
Body image and feelings about how you look	3. Seriously	Information, Talk
Feeling nervous or afraid	1. Slightly	Talk
Worrying about the future and what lies ahead	2. Moderately	Information
Making a treatment decision	0. Not at all	
Feeling lonely or isolated	1. Slightly	Information
Health insurance or money worries	2. Moderately	Talk
Feeling too tired to do the things you need or want to do	4. Very Seriously	Information
Worrying about family, children and/or friends	2. Moderately	Information, Talk
Exercising and being physically active	2. Moderately	Talk
Finding meaning and purpose in life	2. Moderately	Information

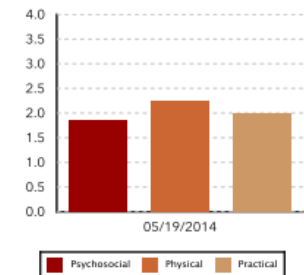
Risk for Depression 9/16
 Feeling too tired to do the things you need or want to do 4
 Feeling sad or depressed 3
 Feeling lonely or isolated 1
 Feeling nervous or afraid 1

Top 5 Concerns

Feeling too tired to do the things you need or want to do 4
 Changes or disruptions in work, school or home life 4
 Body image and feelings about how you look 3
 Pain and/or physical discomfort 3
 Feeling sad or depressed 3

Staff Requests

Changes or disruptions in work, school or home life
 Feeling sad or depressed
 Body image and feelings about how you look
 Worrying about family, children and/or friends
 Exercising and being physically active



Survey Useful: Yes
Comments:
Cancer Diagnosis: Lung cancer
Other type of cancer:
Stage of cancer : Stage IV
Learned about Cancer: 01/01/2012
Active Treatment: No
Age in years:

In Summary...

Distress Screening, Referral and Follow-up:

- ✓ Helps patients better understand and communicate their needs to providers
- ✓ Relieves suffering and improves communication across the care continuum
- ✓ Improves QOL
- ✓ Generates cost savings
- ✓ Improves patient satisfaction



Distress Screening: ACTION NEEDED

-RESEARCH

Document cost effectiveness of screening, referral and follow-up
Assess the applicability & impact of screening in other serious diseases

-IOM

Drive update to *Cancer Care for the Whole Patient*

-HHS

Monitor and advise on ACA implementation
Advocate for coverage of distress screening

-FDA

Ensure a more patient-centered approach to review
Advocate to keep pace with science and innovation

-NCI

Partner to incorporate distress screening in clinical trials
Secure more dollars for psychosocial research

-Capitol Hill

Ensure patient-centered approach to cancer legislation