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CANCER SUPPORT COMMUNITY

A Global Network of Education and Hope



The Reality of Cancer Care Today

- Increasing Numbers
- More Complexity
- Rising Costs
- Growing Social and Emotional Needs



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



Program and Service Delivery

- Affiliate Network
- Cancer Support Helpline[®]
- CancerSupportSourceSM
- Open to Options[®]
- Frankly Speaking About Cancer[®]
- Online Support: The Living Room[®]

Affiliate Network

- 46 centers
- 120 satellite locations
- Hospital partnerships
- Delivering innovative support and educational programming



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

Affiliate Network Hospital Partnerships

- Greenville Health System - Greenville, SC
- UF Health Cancer Center at Orlando Health - Orlando, FL
- Monmouth County Medical Center - in Monmouth County, NJ
- Presbyterian Kaseman Hospital - Albuquerque, NM
- OSF St. Francis Hospital - Peoria, IL
- Whitman-Walker Health* - Washington, D.C.
- Whittier Street Health Center* - Boston, MA

*Indicates Federally Qualified Health Center



Cancer Support Helpline®

- Toll-free, 9 am – 9 pm eastern
- Staffed by licensed mental health professionals
- Open to Options® – Treatment Decision Support Counseling Program
- CancerSupportSourceSM - Distress Screening and Personal Support Care Planning
- In- and outbound call capacity for ongoing follow up and intervention
- Live chat feature
- Active partnerships with industry patient assistance programs and advocacy organizations
- Coming Soon! Subject matter experts in nutrition, financial matters and nursing

CancerSupportSourceSM

- Web-based program that integrates distress screening, referral and follow-up care
- Developed and validated by CSC's research team in partnership with hospitals and cancer centers
- Designed to help institutions meet the new American College of Surgeons Commission on Cancer accreditation standards
- Commitment to measuring the impact of distress screening, referral and follow-up on quality of life, health outcomes and the cost of care

 **CANCER SUPPORT SOURCE**SM

A COMPLETE DISTRESS SCREENING PROGRAM

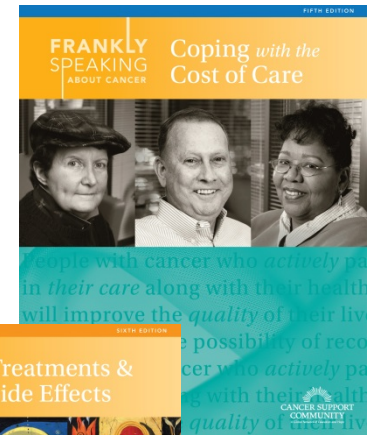
Open to Options[®]

- Evidence-based, shared decision-making program that helps patients prepare a highly personalized list of questions, concerns and goals to share with the MD as part of the treatment decision-making process
- Resulting in:
 - Reduced distress and anxiety
 - Increased confidence in asking questions
 - 9% of eligible patients enrolling into a clinical trial
 - Physicians reporting a more productive appointment



Frankly Speaking About Cancer®

- High quality, evidence-based educational programming
- Topic areas include:
 - Clinical trials
 - Treatment decision-making in partnership with your health care team
 - Managing the cost of care
- Multi-channel delivery
 - In-person workshops
 - Publications (print and eBook)
 - Online (videos, webinars and weekly radio show)



Online Support: The Living Room[®]

- Real-time professionally facilitated online support groups
- 24/7 discussion boards on topics like cancer type, living after treatment and caregiving
- Mind-body practices and links to resources



"The CSC taught me the importance of taking a proactive role in my decision making."

Sharista, Breast cancer survivor

Research and Training Institute

Experts in the Cancer Patient Experience



Research and Training Institute

- The first and only *Institute* in the U.S. dedicated to psychosocial, behavioral and survivorship research and training
- Led by a PhD behavioral psychologist and staffed by a multidisciplinary team of clinical and research professionals
- Delivers one-on-one interviews, focus groups, patient surveys, registries and other peer-reviewed research

Cancer Policy Institute

- Formally launched on June 19, 2013
- Uniting direct patient and family engagement with research to shape future of quality cancer care
- Committed to ensuring **Access** to comprehensive cancer care for all patients, **Quality** as a central theme and **Research** as a critical priority



Cancer Policy Institute

Unique Activities

- Research
- Education
- Collaboration
- Activation



Cancer Policy Institute Education



Insight into Patient Access to Care in Cancer



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

The Cancer Policy Institute at the
CANCER SUPPORT COMMUNITY



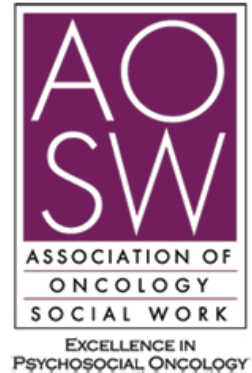
Working with Regulators: A Focus on CMS

An Educational Program of the Cancer Policy Institute at the Cancer Support Community in Partnership with Uniting a Community (UaC):
Policy, Advocacy, Education and Action Network



Tool Kit: A Guide for Patient Advocates

Friends of the Cancer Policy Institute



Friends of the Cancer Policy Institute



University of California
San Francisco



Philip R. Lee Institute
for Health Policy Studies



free to breathe
a partnership for lung cancer survival





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Disparities in Cancer Care

Cancer Health Disparities

- Compared to the general population, medically underserved -low-income, minority, and uninsured- in the United States are disproportionately affected by illness and death from cancer
- Research also shows that individuals from medically underserved populations have lower rates of participation in recommended screenings, and are more likely to be diagnosed with late-stage diseases that might have been treated more effectively or cured if diagnosed earlier

Source: National Cancer Institute. Surveillance, Epidemiology, and End Results (SEER) Program.

Factors Contributing to Cancer Health Disparities

- Complex and interrelated factors contribute to the observed disparities in cancer incidence and death among medically underserved groups
- The most obvious factors are associated with a lack of health care coverage and low socioeconomic status (SES)
- Studies have found that SES factors are associated with an individual's or group's risk of developing and surviving cancer
- SES factors include access to education, certain occupations, health insurance, and living conditions – including exposure to environmental toxins

Source: <http://www.cancer.gov/about-nci/organization/crchd/cancer-health-disparities-fact-sheet#q1>

Examples of Incidence and Outcomes by Race

- Although cancer deaths have declined for both Whites and African Americans/Blacks living in the United States, African Americans/Blacks continue to suffer the greatest burden for each of the most common types of cancer. For all cancers combined, the mortality rate is 25 percent higher for African Americans/Blacks than for Whites
- African American/Black women have a lower incidence of breast cancer than the population as a whole, but a mortality rate that is 30 percent higher
- Native Americans have the lowest 5 year cancer survival rate of any group in the United States

Source: National Cancer Institute. Surveillance, Epidemiology, and End Results (SEER) Program.

Examples of Incidence and Outcomes by Race

- Vietnamese American women have an incidence of cervical cancer 5 times that of White American women
- African American/Black men have the highest incidence rate for prostate cancer in the United States and are more than twice as likely as white men to die of the disease. The lowest death rates for prostate cancer are found in male Asian/Pacific Islanders
- Americans in poor counties (20% below the poverty line) have a 13% higher mortality rate from cancer than Americans in wealthier counties (<10% below the poverty line). This increase in mortality, associated with poverty, is also seen when one controls for race

Source: National Cancer Institute. Surveillance, Epidemiology, and End Results (SEER) Program



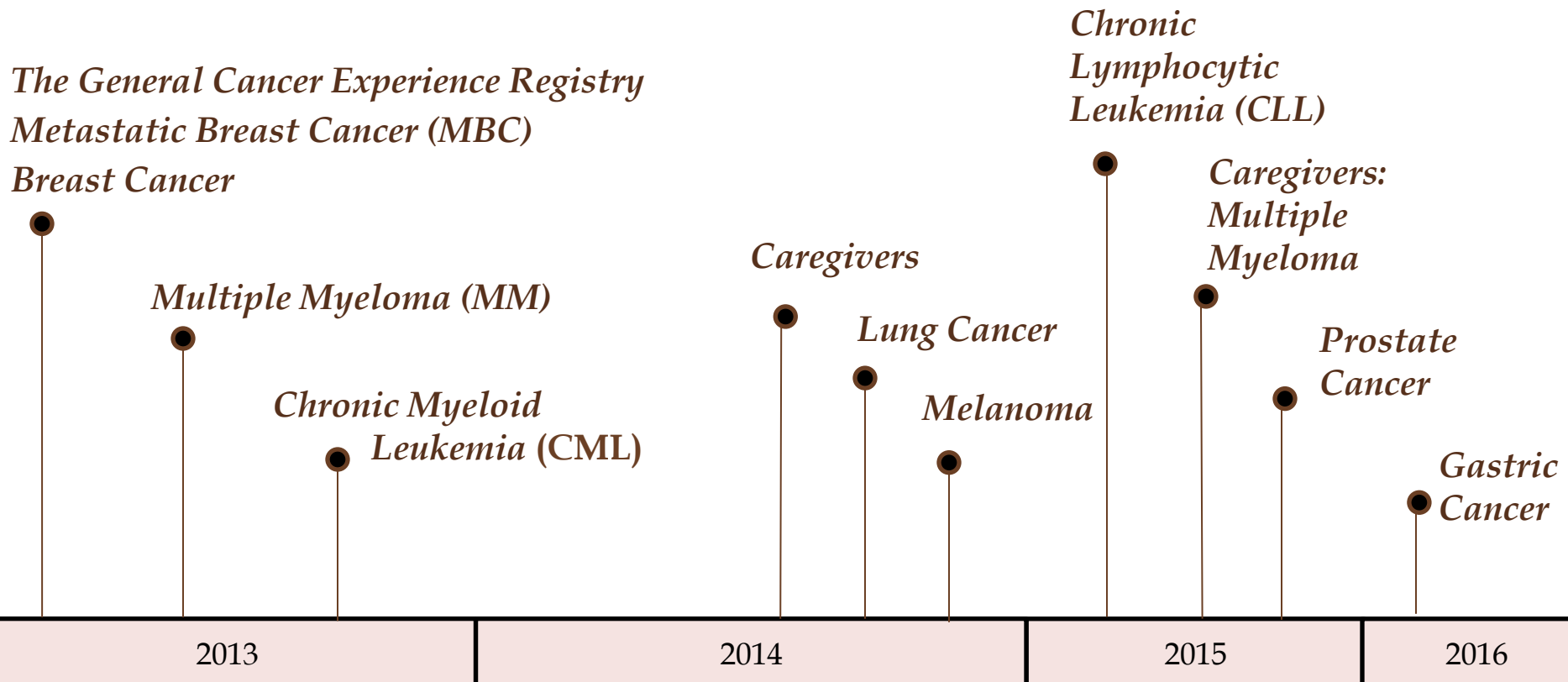
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CSC Data on Disparities

Cancer Experience Registry®

- First cancer Registry in the world designed to:
 - Gain insights into the social and emotional needs of patients, families and caregivers throughout the cancer journey
 - Connect patients and caregivers to one another
 - Advocate as active members of the community and health care system
 - Accelerate and enhance the productivity of research and treatment to improve the lives of those living with cancer
- Currently 9,200+ participants
- CancerExperienceRegistry.org

The Evolution of the Registry: Specialty Registries



Health Disparity Among Diverse Racial Ethnic Groups

- American Psychosocial Oncology Society (APOS), 2016
- Compare needs across the largest racial-ethnic groups in the Cancer Experience Registry Sample.
 - Non Hispanic White - 2165
 - Black or African American - 99
 - Latino or Hispanic - 76
 - Asian - 36
- Latinos reported greater distress than whites and blacks
- Latinos reported higher risk for depression than whites
- Latinos were less likely to receive information than whites, blacks and Asians.

CANCER SUPPORT SOURCESM

A PROGRAM *of the* CANCER SUPPORT COMMUNITY 

- Web-based, CSS-15/CSS-25 screening Program
- Validated against the 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 resource links auto-generated
- Can be integrated into e-scheduler and EHR
- Aggregate data reports for research, program planning, staffing, etc
- English/Spanish
- Coming soon: Caregiver screener, Pediatric/Teen – *Checking In*©



Identifying Distress in Patients at Risk for Depression

- National Comprehensive Cancer Network, 2016
- Identifying those at highest risk for distress + Depression to allow rapid triage
 - 842 patients surveyed
- Top three causes of increased distress in patients at risk for depression
 - Pain + physical discomfort
 - Making a treatment decision
 - Finding meaning
- Compared to white patients/survivors, Latinos were at significantly greater risk for depression
- Patients with household incomes less than \$40K were at greater risk for depression than those of \$100K or more

Cancer related Distress Among Different Racial – Ethnic Groups

- Society of Behavioral Medicine, 2016
- Compare needs across racial –ethnic groups using Cancer Support Source
 - Non- Hispanic White – 629
 - Black or African American – 79
 - Latino or Hispanic – 85
- Latinos had significantly higher levels of distress than whites
- Latinos had higher risk for depression than whites and blacks
- Latinos were significantly more concerned than whites and blacks about feeling lonely or isolated
- Latinos were significantly more concern about making a treatment decision than whites and blacks
- Latinos were significantly more concerned about health insurance or money worries than whites



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Federally Qualified Health Centers

Federally Qualified Health Centers

What are FQHCs?

- FQHCs are private nonprofit or public health care organizations located in or serving federally-designated medically underserved areas or populations
- These health care providers, as defined by Medicare and Medicaid statutes, include all organizations receiving grants under “Section 330” of the federal Public Health Service Act, which defines federal grant funding opportunities for organizations to provide care to underserved populations

How many FQHCs are there?

- As of 2013 (the most recent available data), there are 1,202 FQHCs across the country
- These FQHCs serve approximately 21,726,965 patients and employ roughly 156,000 full-time employees

Who do FQHCs serve?

- Primarily socioeconomically disadvantaged and uninsured or underinsured patients
 - The majority (i.e., 72 percent) of patients have incomes at or below the FPL
 - 42 percent of patients are enrolled in Medicaid
 - 35 percent of patients are uninsured
 - 62 percent of patients are members of minority groups (35 percent Hispanic/Latino and 24 percent African American)

What services do FQHCs provide?

- An array of primary and preventative services, including:
 - Medical services
 - Dental services
 - Enabling services (e.g., translation or transportation to the health center)
 - Mental health and substance abuse services
 - Arranging/coordinating hospital and specialty care (e.g., health center providers must have admitting privileges at one or more hospitals located near the health center or establish other arrangements to ensure care continuity for hospitalized health center patients)

FQHC Pilot

- Open a CSC inside of a FQHC
- Whitman Walker Health – Washington, DC
- Launched in 2015
- Deliver CSC's innovative support and educational programs inside of an FQHC
- Work with the community partner to adapt CSC's programs to be culturally applicable and sustainable
- Study reimbursement of CSC's services



Cancer Support Community

So that no one faces cancer alone[®]

