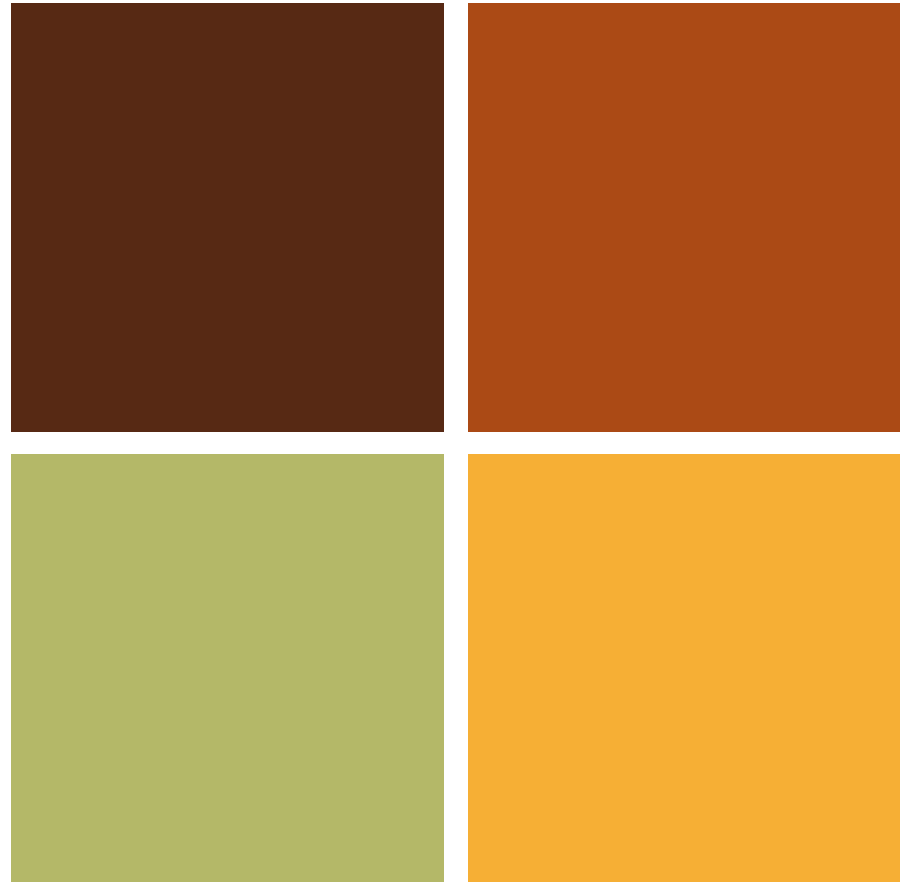


Survivorship Care in Low Resource Settings: Addressing Psychosocial Needs



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Presentation Overview

A brief overview of psychosocial needs in cancer

Examples of programs that address psychosocial needs in low resource settings

- African American survivors – rural and urban
- Older & rural survivors
- Latinas
- Young survivors

Lessons Learned, Strategies & Recommendations



Acknowledgment

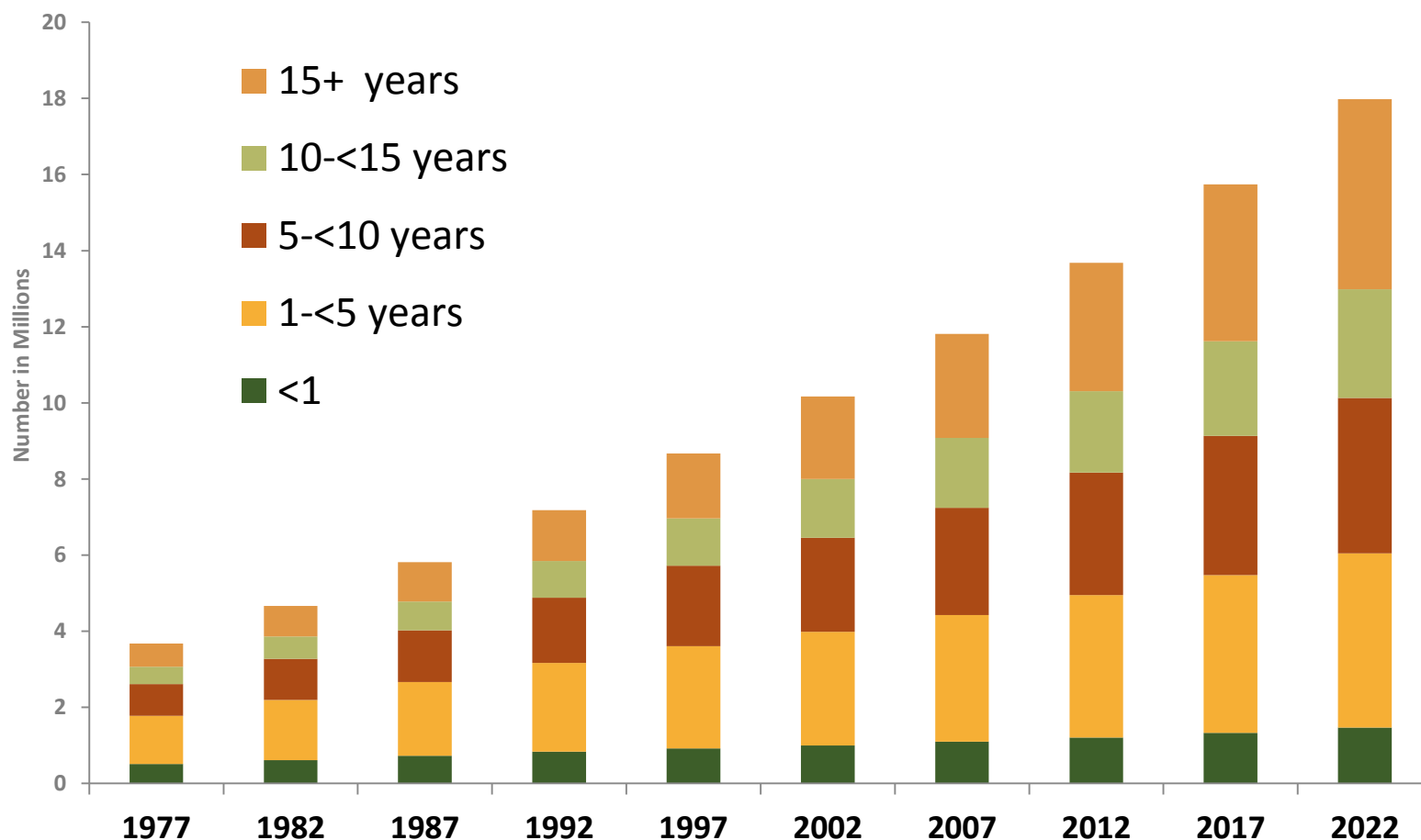


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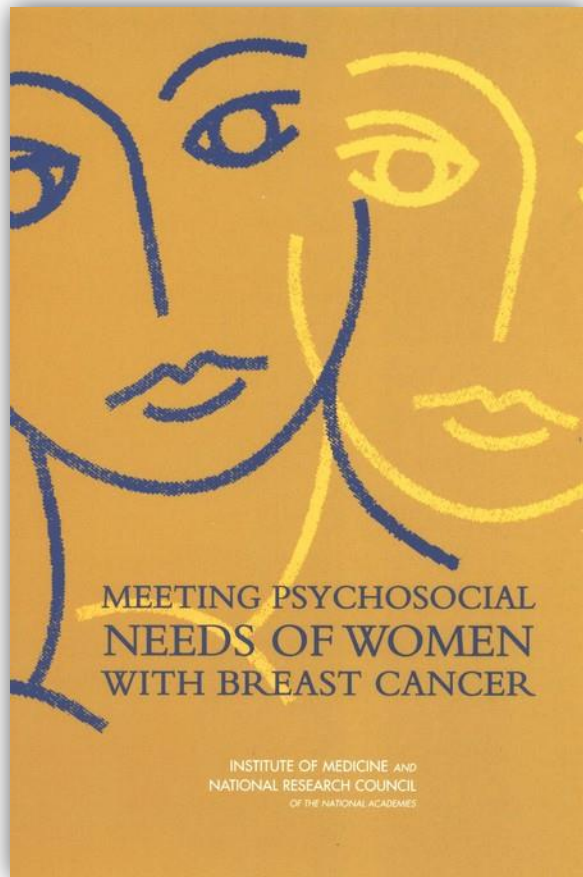
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Projected Number of Cancer Survivors in the US



Source: de Moor et al, *CEBP* 2013

Meeting the Psychosocial Needs of Women with Breast Cancer (IOM, 2004)



- Quality of life framework:
 - Physical: fatigue, sleep, pain, sexual function
 - Psychological: anxiety, depressive symptoms, intrusive thoughts
 - Social: body image, work and family
 - Spiritual and existential concerns
- Distress evaluation
- Interdisciplinary management (e.g., nurses, social workers, psychologists, physicians)

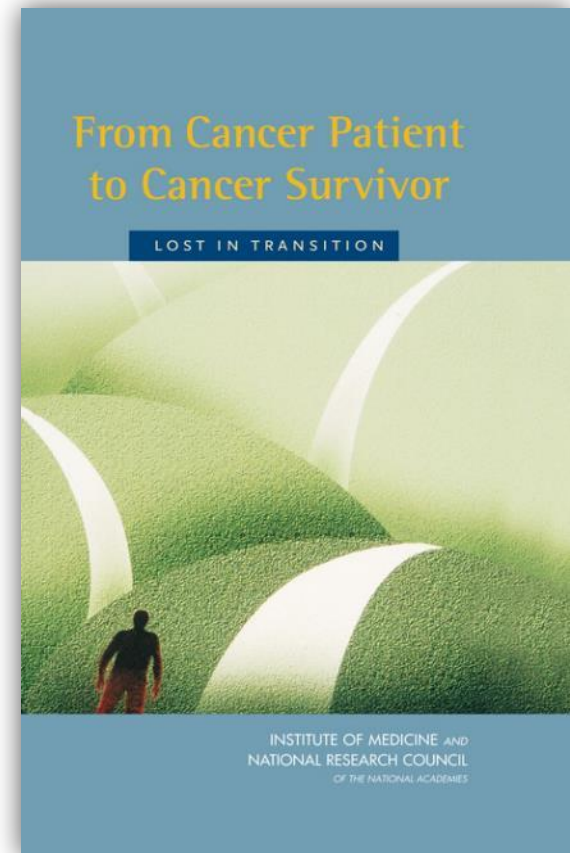


From Cancer Patient to Cancer Survivor: Lost in Transition (IOM, 2006)

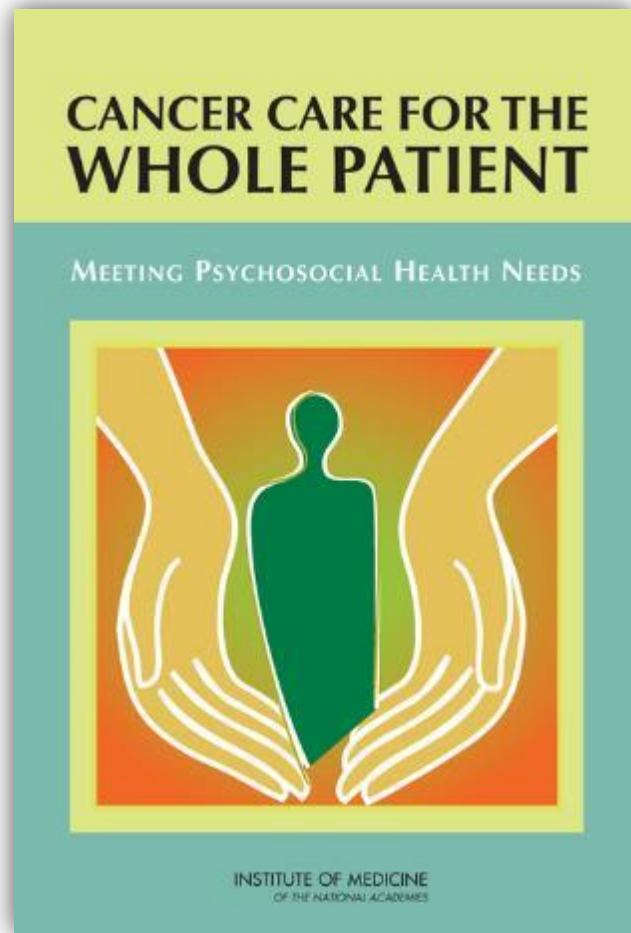
All patients should receive a survivorship care plan

Essentials:

1. Treatment summary
2. Assess and manage psychosocial, family and work
3. Plan for healthy living (physical activity and nutrition)
4. Plan for follow up care with specialists and/or primary care



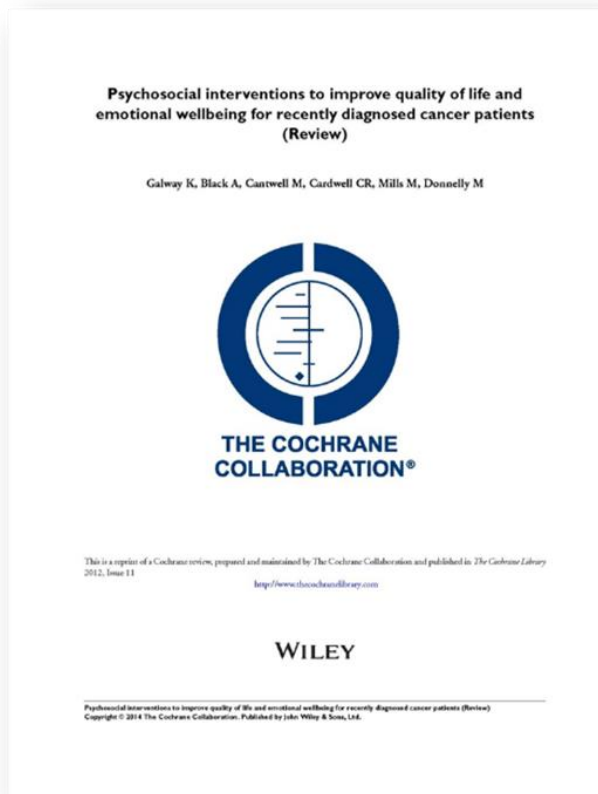
Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs (IOM, 2008)



- *“Psychological and social problems can prevent individuals from receiving needed health care, complying with treatment plans, and managing their illness and recovery.”*
- Expanded assessment of social determinants of health (e.g., access, insurance, literacy, poverty)
- Shared vision



Psychosocial interventions to improve quality of life and emotional well being for recently diagnosed cancer patients (2013)



Six studies showed
QoL improvement

Nurse-delivered
psychoeducation
had beneficial
impact

Considerations in Low-Resource Settings



Are interventions appropriate and feasible?

- Resource restraints
- Infrastructure requirements
- Social and cultural norms
- Can the community deliver downstream cancer care?

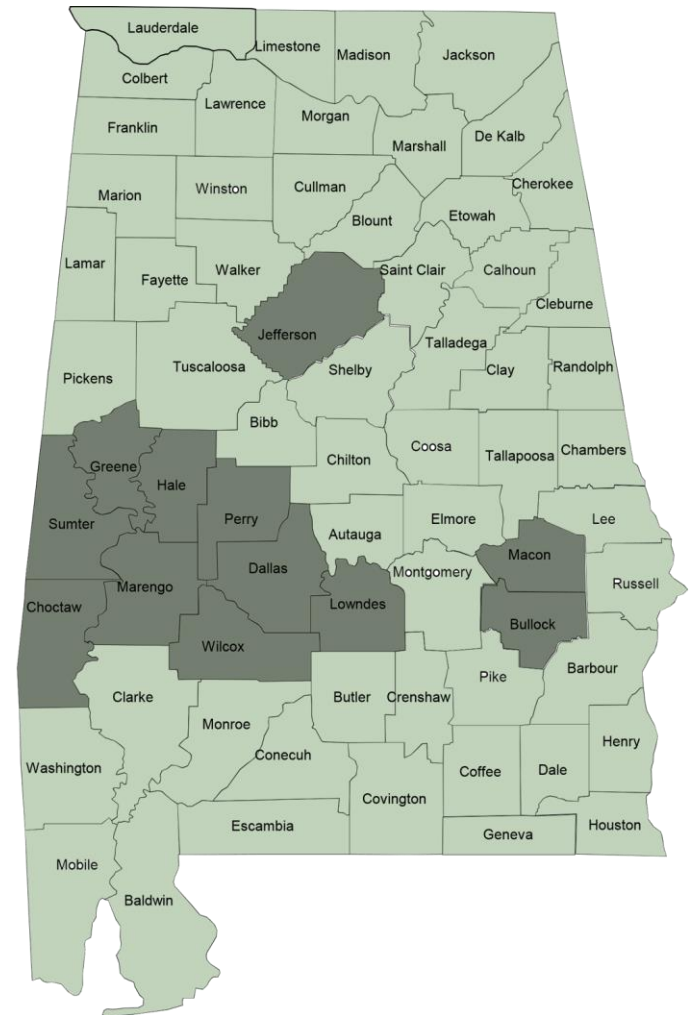
Lesson 1: Leverage partnerships to deliver psychosocial interventions

■ Partnership



Deep South
Network for
Cancer Control

- Community-Based Participatory Research
 - Eliminate barriers to screening & detection of cervical and breast cancer
 - Community Health Advisors
- Can we leverage partnership to improve access to survivorship education, support?
- Qualitative focus groups & in-depth interviews with AA breast cancer survivors in 4 Black Belt counties



Lesson #2: Address Social Stigma and Cultural Beliefs About Cancer

Fatalism

- *“Cancer to me wasn’t cancer to my mom and my sisters. To them cancer was, oh Lord, let’s start making arrangements.”*

Fear

- *“I didn’t share my diagnosis with anybody. I just kept it a secret.”*

Denial

- *“When I first went to the doctor he wanted to take the breast off, but I was in denial and I told him no.”*

Silence

- *“Everybody don’t open up when they’ve been diagnosed... my cousin had been through it for a year before I knew. She didn’t even tell me.”*
-

Gradual Acceptance over Time (2013 – present)

In 2013, survivors organized “Black Belt Survivors Group”

Informal support

Did not use the word ‘cancer’

Preferred face to face meetings within their respective county



Increase in recognition and awareness of survivorship needs

Program on ‘chemobrain’ and cognitive health

Welcomed partnership in survivorship

Requested more information on psychosocial support and side effect management



Church & Family Engagement (n>500)



Large African American urban churches with medical and hospitality ministry

“ThinkWell” cognitive health programs

Twice as many co-survivors attended with survivors

Request for cancer screening and early detection; and survivorship across other cancers

Lesson #3: Adapt Survivorship Programs

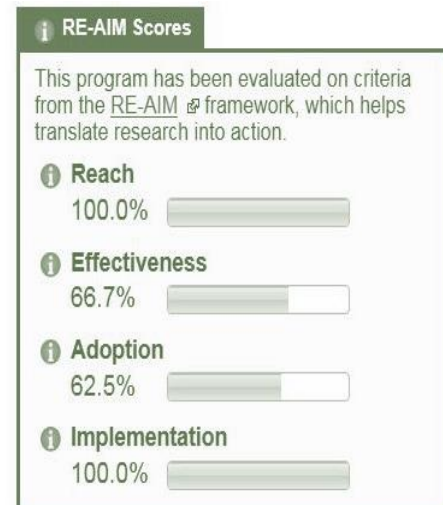
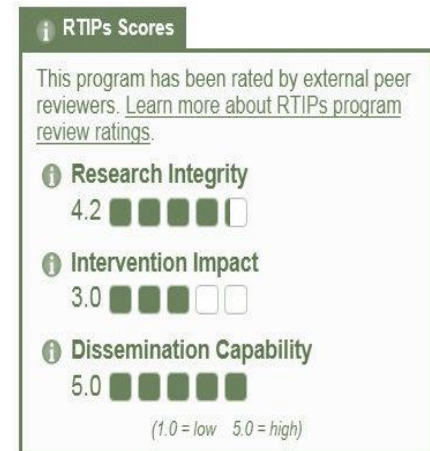
Research Tested Interventions to Practice (RTIP) is a searchable database of cancer control interventions and program materials funded by NIH

172 programs of which 15 are psychosocial, survivorship, and/or supportive care interventions

Guidelines for choosing and adapting programs

- <http://rtips.cancer.gov/rtips/index.do>

Breast Cancer Education Intervention:



Disseminate and Implement Statewide

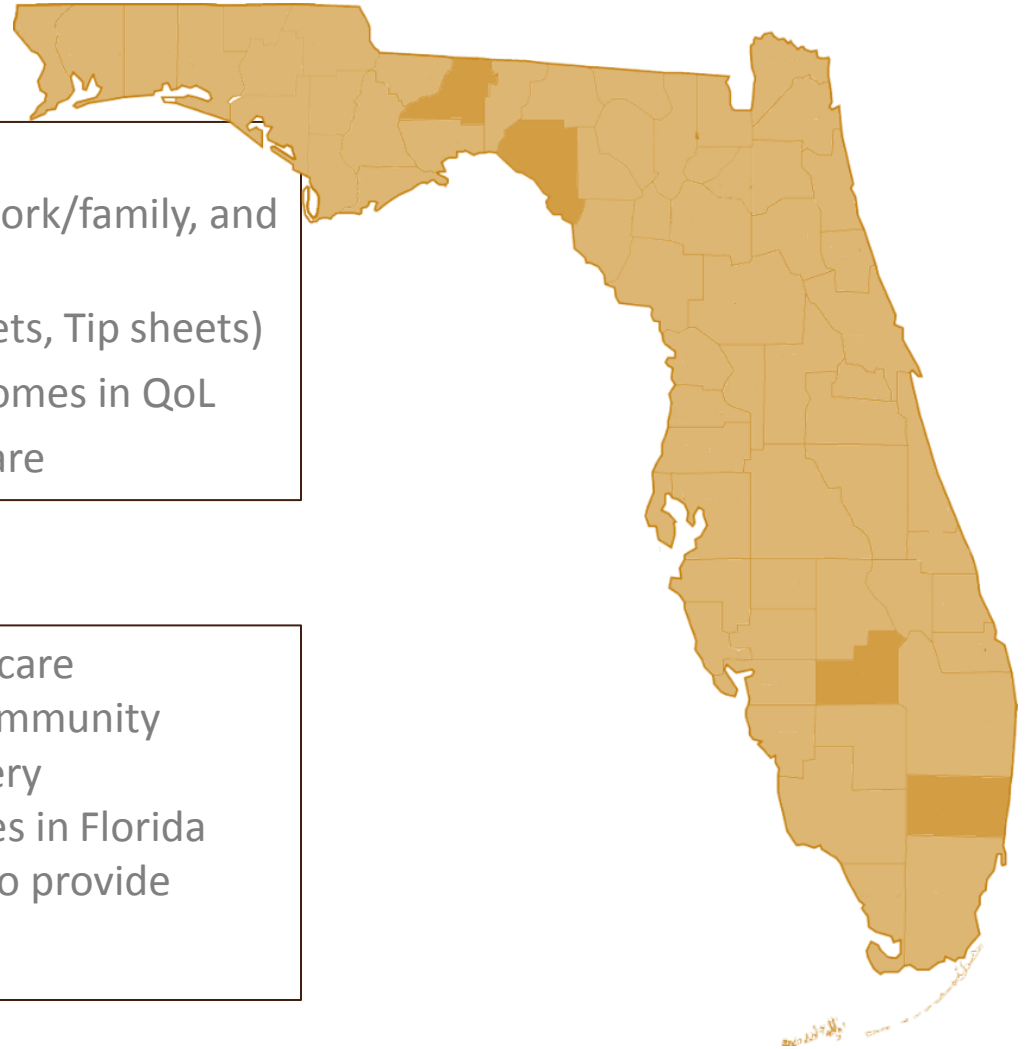
BCEi

QoL Survivorship Intervention

- Physical, psychological, social, work/family, and spiritual education, and support
- Tailored interventions (Worksheets, Tip sheets)
- Improved patient-reported outcomes in QoL
- Strong adherence to follow up care

Older rural survivors

- Barriers to access psychosocial care
- Reluctance to talk with rural community
- Preference for telephone delivery
- Dissemination: 63 of 67 counties in Florida
- Variation in resources needed to provide survivorship care



Financial Toxicity Among Older Rural Survivors



“My COBRA ends next month. How can I have my 6 month mammogram?”



“I will buy my breast cancer pills even if it means I won’t eat.”



“I can’t afford over the counter vitamins or other tests like a bone density.”



“I didn’t know I needed a pelvic exam.”



Lesson #4: Adapt for Latinas



Translated & Customized Program

US Census Bureau Guidelines

- Certified Spanish translation
- Language of Basic broadcast Spanish
- Cognitive interviews for cultural relevance
 - *Personalismo, familismo, marianismo*

Fry Readability Index

- 6th grade reading level of written materials

Telephone Delivery

- 40 Latina breast cancer survivors in FL
 - Cuba, Puerto Rico, Colombia, Costa Rica, Honduras, Venezuela, Mexico, Guatemala, Argentina, Panama, Peru, Dominican Republic
- Bilingual with preference for Spanish at home
- Trained bilingual Latinas to deliver interventions
- Challenges in telephone delivery



Lesson #5: Partner with Young Survivors



Educate



Support



Network



NETWORK & PARTNERSHIP

Interprofessional collaborative partnership
among health disciplines, advocates and
organizations that care for and about young
breast cancer survivors

Expand Reach Via Social Media: Gulf States



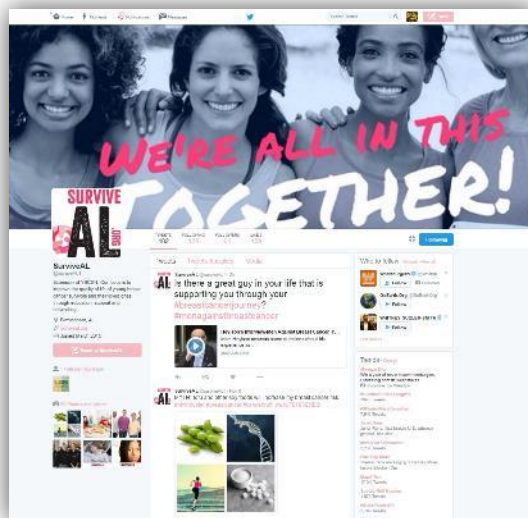
Website



Twitter



Facebook



News and upcoming events

Relevant blog posts

Breast cancer facts & figures

Where to go for local resources

Stories of survivorship

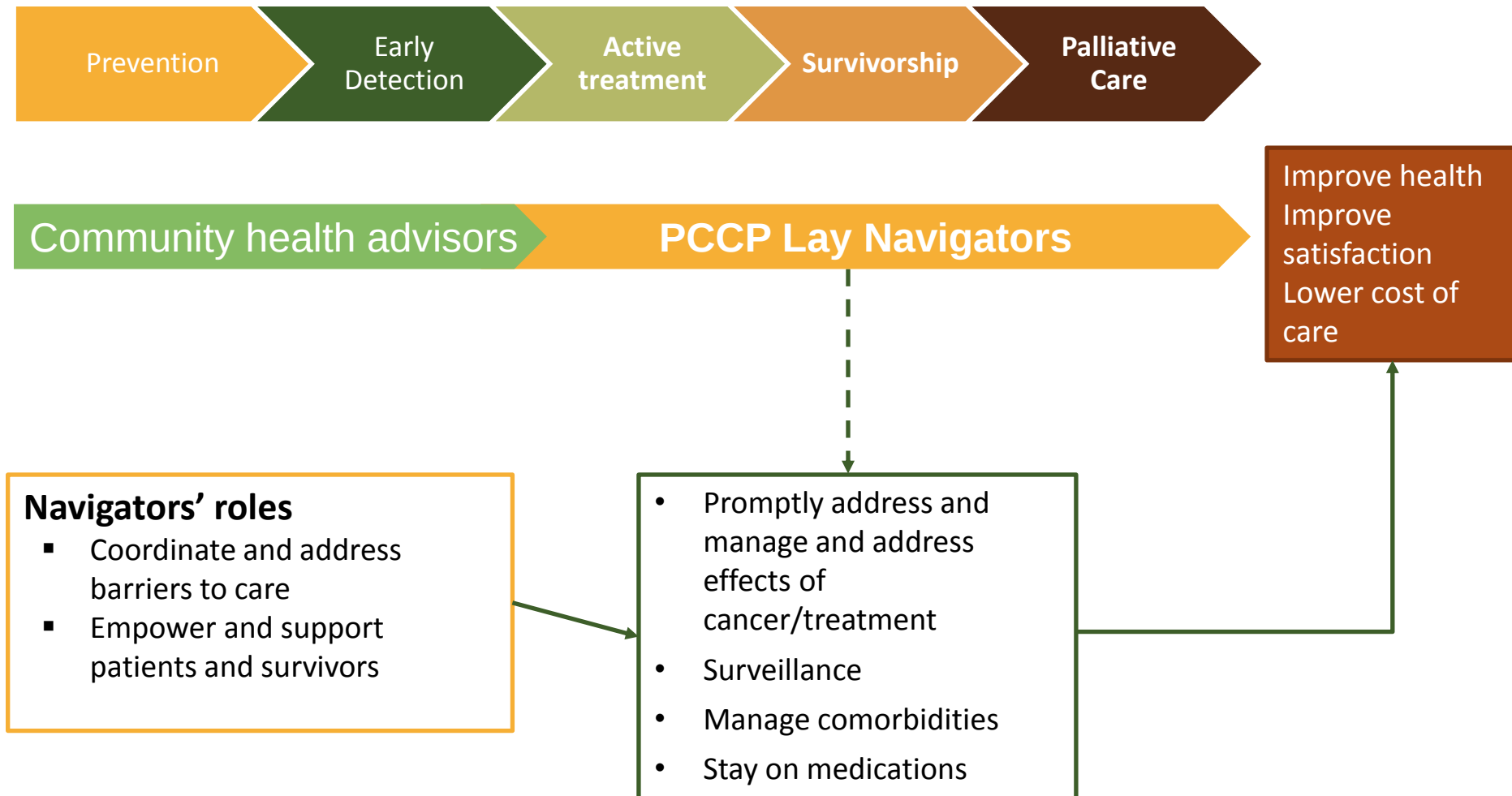
Announce available survivorship research studies

Evidence-based answers

Links to health resources

Re-posts of credible health messages

Lesson #6: Lay Navigation Works



Lesson #7: Mentor our Next Generation



Strategies that Worked

Collaborate, Partner, Collaborate, Partner....Repeat

Use framework of community-based participatory research to build cancer survivorship programs in low resource areas

Evaluate community readiness for survivorship programs

Identify survivorship champions

Strategies that Worked

Use efficacious survivorship intervention programs

- Disseminate and implement survivorship care

Customize and repackage your programs

- Incorporate sociocultural values
- Survivors' preferences: "have it your way"
 - Face to face, telephone, social media

Ask survivors for feedback

Focus on high areas of need in low resource areas

- Aging population in the United States
- Younger working population in low resource countries

Support patient navigation programs to implement survivorship care planning and distress evaluations

Mentor and train the next generation of health disparities/health equity research scientists

Bring psychosocial and survivorship care to the community

