

Survivorship and the Family

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Be Well Stay Healthy
Be Well Stay HealthyKIDS!
Be Well Stay Healthy Families

Cancer Survivor

- **An individual is considered a survivor from the time of diagnosis through the balance of his or her life**

Cancer Survivor

- **An individual is considered a survivor from the time of diagnosis through the balance of his or her life**
- **Family members, friends and caregivers are also impacted by the survivorship experience and are therefore included in this definition**

Office of Cancer Survivorship;

Adapted from the National Coalition for Cancer Survivorship

CLAIRE



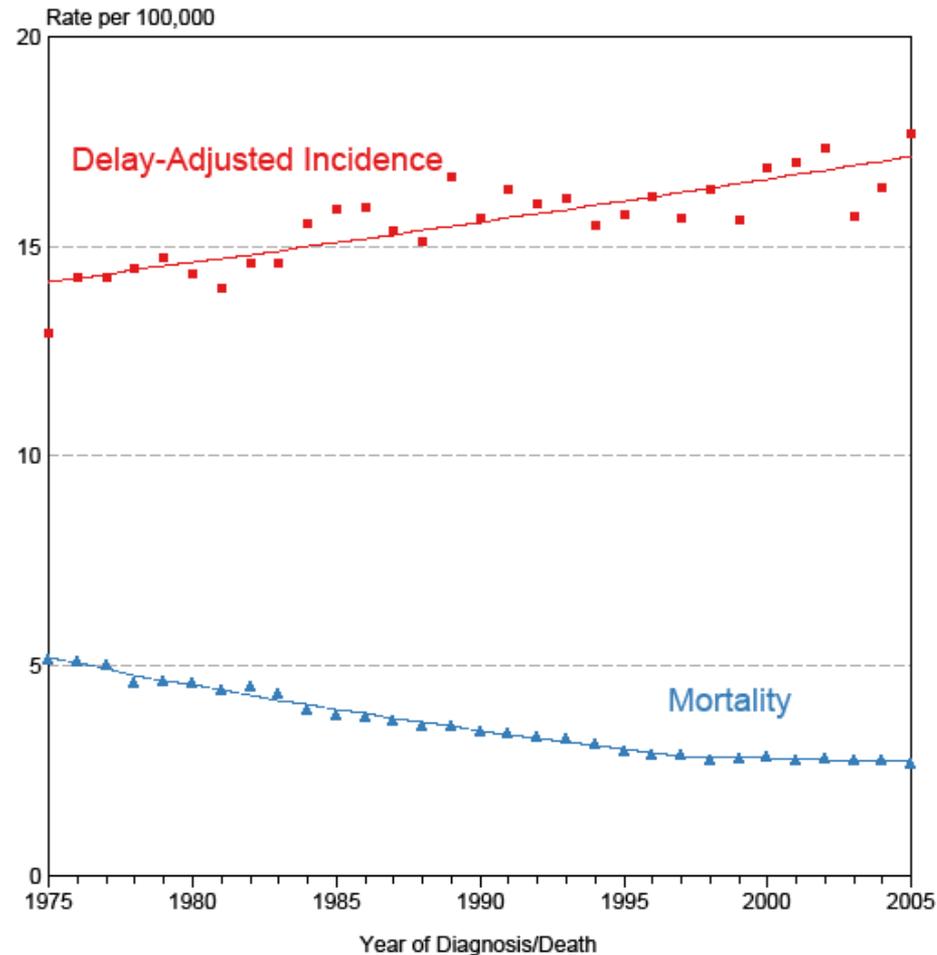
View from the other side

- **Communication**
 - Who was in charge- never clear
 - Care plan was reactive –not proactive –
 - Fragmented care
- **Transitions**
 - Discharge – hurry up to wait
 - Home care- abysmal
 - Future – “time bomb”
- **Support**
 - “Like being thrown into water – better learn to swim fast”
- **System served system – not patient**
- **Exhausting**
- **Stress: “constant on guard” – errors**
- **Financial stressors: coverage; work**

Total Care

**Patient & Family
Centered Care**

SEER Delay-Adjusted Incidence and US Mortality All Childhood Cancers, Under 20 Years of Age Both Sexes, All Races, 1975-2005

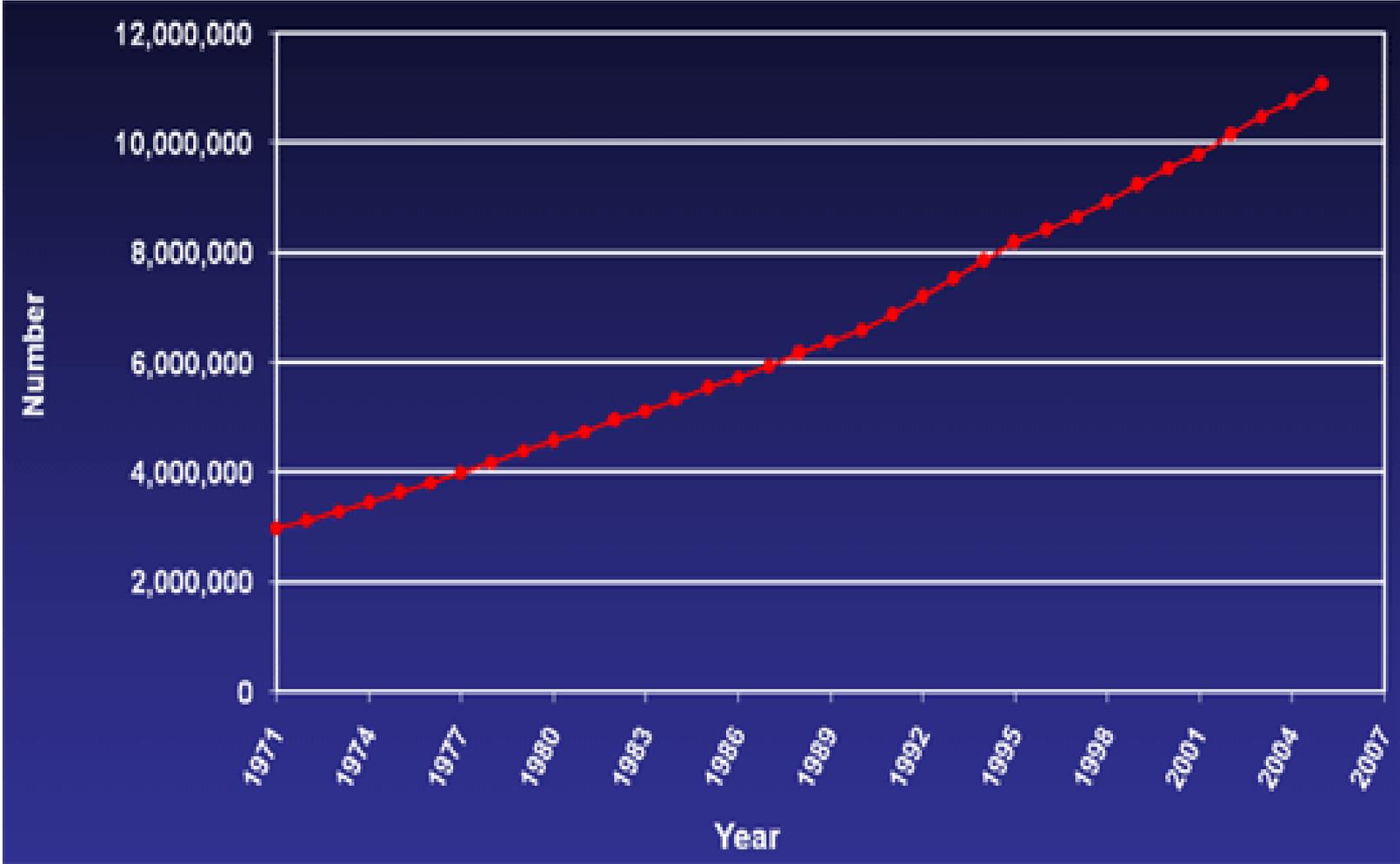


Source: SEER 9 areas and US Mortality Files, National Center for Health Statistics, Centers for Disease Control and Prevention. Rates are age-adjusted to the 2000 US Std Population (19 age groups - Census P25-1103). Regression lines are calculated using the Joinpoint Regression Program Version 3.3, April 2008, National Cancer Institute.

Childhood Cancer

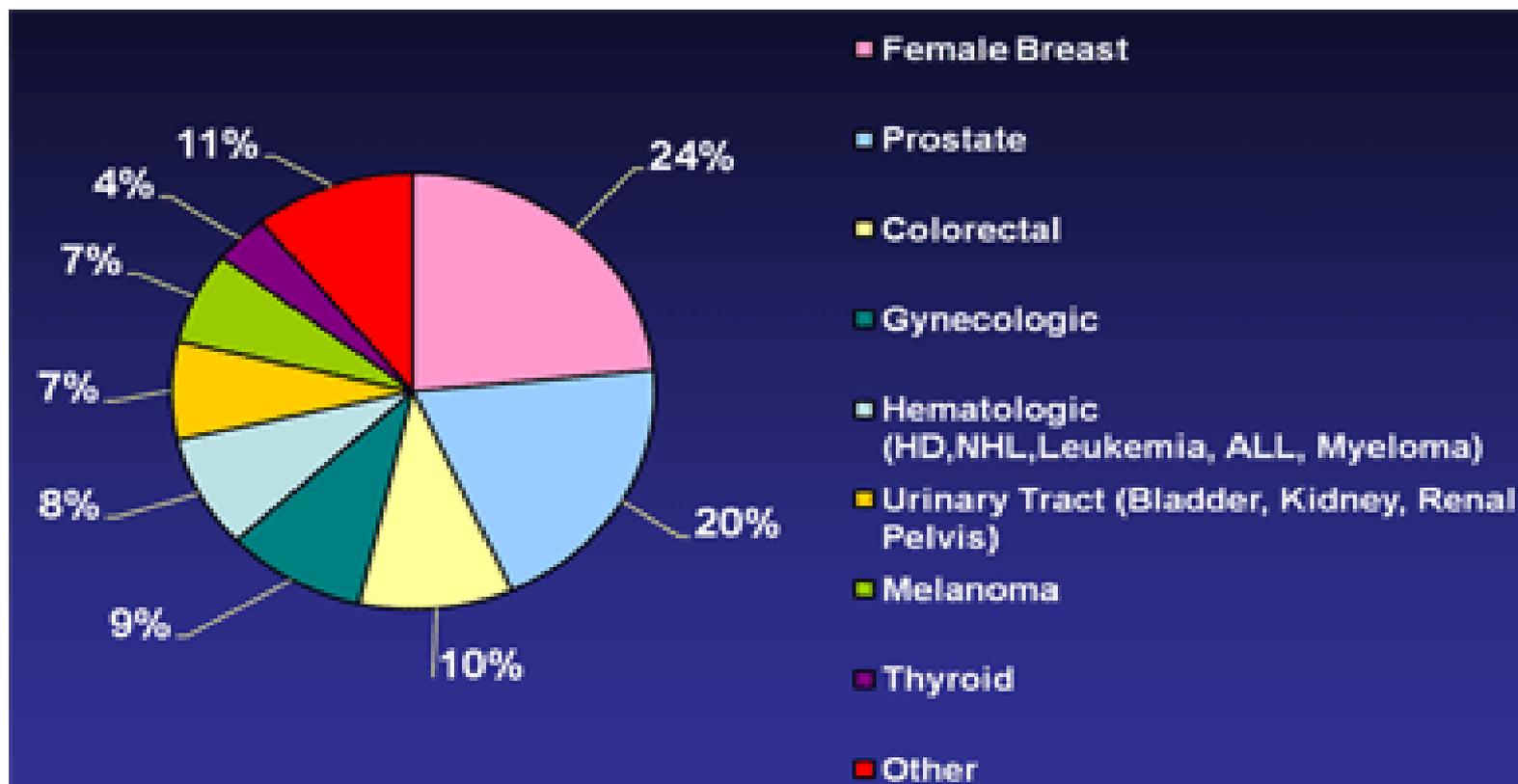
- **5 yr survival rate increased from 20% in 1950-54 to 80% in 2000**
- **~270,000 survivors in U.S.**
- **Long term treatment effects**
 - **66% with at least 1 chronic or late-occurring effect**
 - **50% diminished health status**
- **Challenge of follow-up care**
- **Long term impact and care**

Estimated Number of Cancer Survivors in the United States from 1971 to 2005



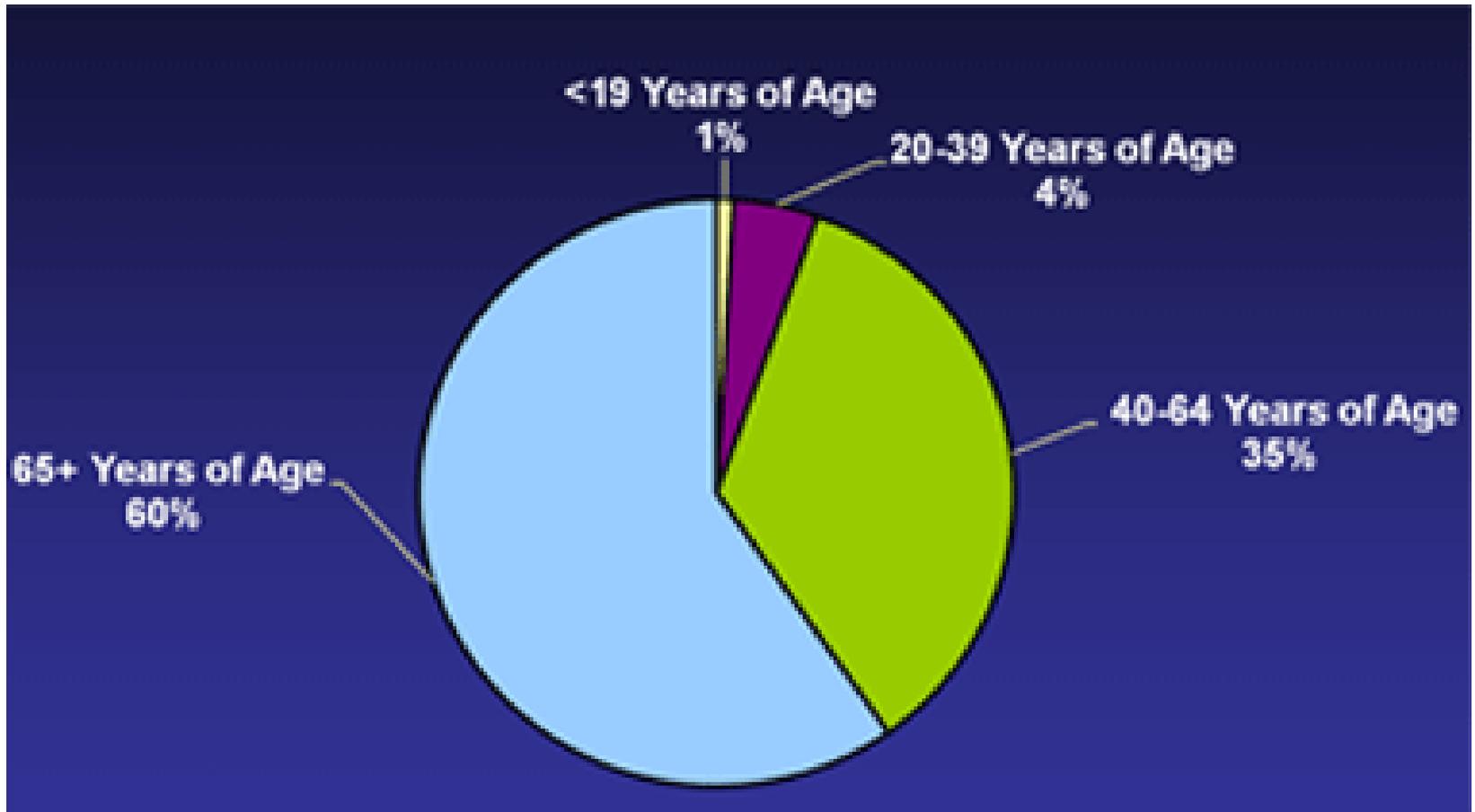
Source SEER DATA, Ries et al Cancer Statistics Review, 1975-2005

Estimated Number of Cancer Survivors in the U.S. on January 1, 2005 by Site (Invasive/1st Primary Cases Only, N=11.1M Survivors)

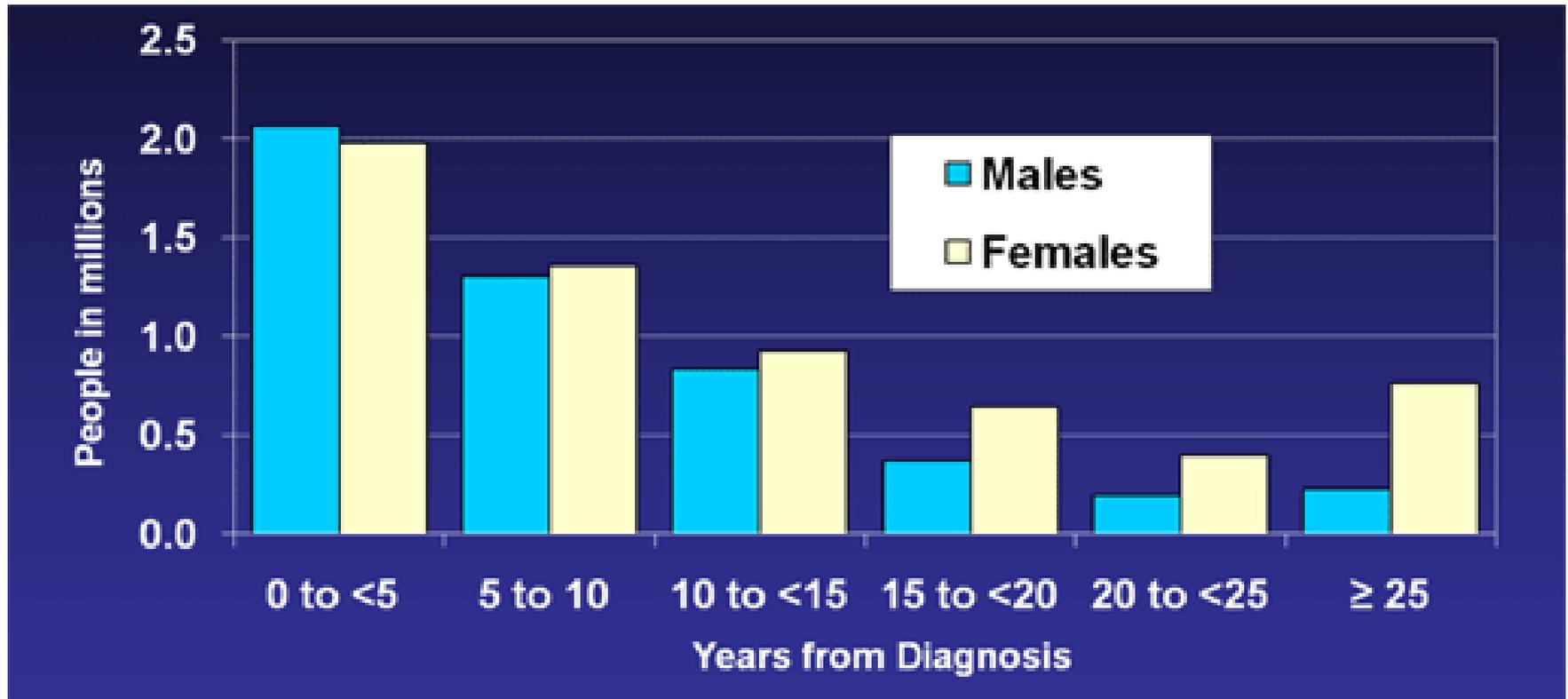


Source SEER DATA, Ries et al Cancer Statistics Review, 1975-2005

Estimated Number of Cancer Survivors in the U.S. on January 1, 2005 by Current Age (Invasive/1st Primary Cases Only, N=11.1M survivors)



Estimated Number of Cancer Survivors in the U.S. January 1, 2005 by Time From Diagnosis and Gender (Invasive/1st Primary Cases Only, N =11.1M survivors)



Possible Late Effects Of Treatment

- **Radiation**

- **Coronary artery dis**
- **Pulmonary fibrosis**
- **Neuropsychological**
- **Short stature/bone**
- **Bladder**
- **Second cancers**
- **Hypothyroidism**
- **Sterility**
- **Premature menopause**
- **Cataracts**

- **Chemotherapy**

- **Cardiomyopathy**
- **Pulmonary fibrosis**
- **Neuropathy**
- **Hearing loss**
- **Myelodysplasia**
- **Bladder effects**
- **Sterility/Infertility**
- **Premature menopause**
- **Cataracts**

From Cancer Patient to Cancer Survivor: Lost in Transition- National Academy of Sciences Report

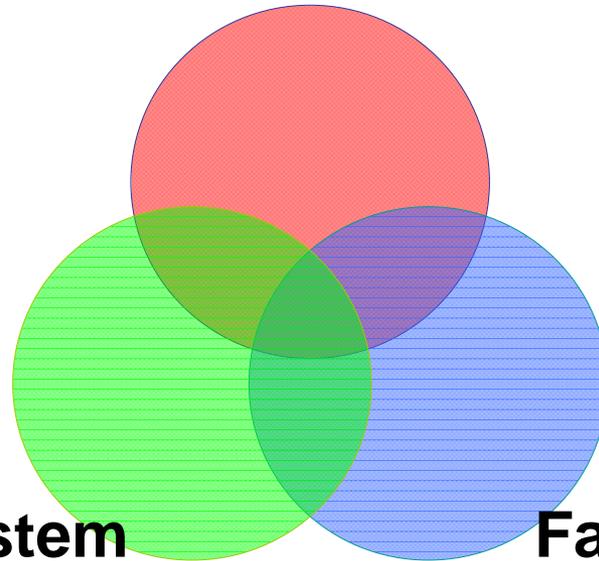
- **Raise Awareness**
- **“Survivorship Care Plan” following primary treatment**
- **Clinical practice guidelines**
- **Define quality care measures**
- **Delivery system**
- **Survivorship as public health concern**
- **Education and training of health care providers**
- **Employment-related concerns**
- **Health Insurance**
- **Research**

Total Care of the Cancer Survivor

- **Health care system**
 - **Accessibility**
 - **Coordinated**
 - **Knowledgeable**
 - **Holistic- Mind, Body and Spirit**
- **Self-care**
- **Caregiver/Family**

Total Care of the Cancer Survivor

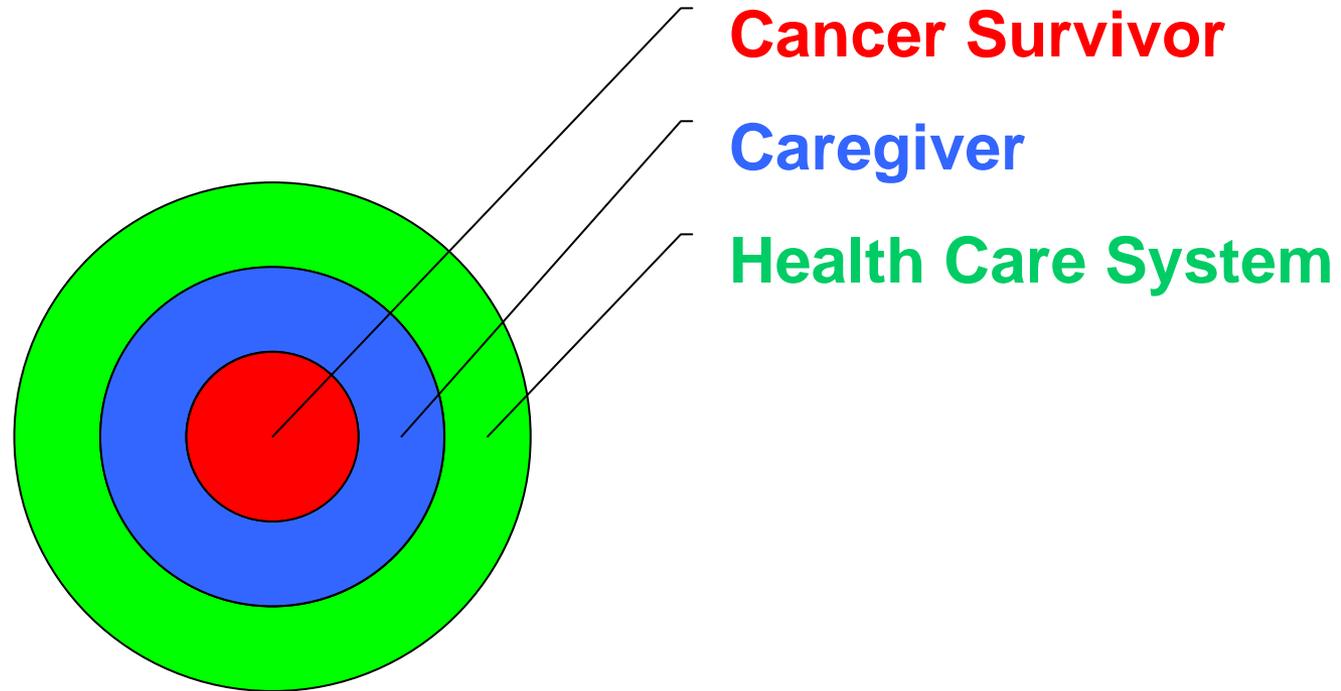
Survivor



Health Care System

Family/Caregiver

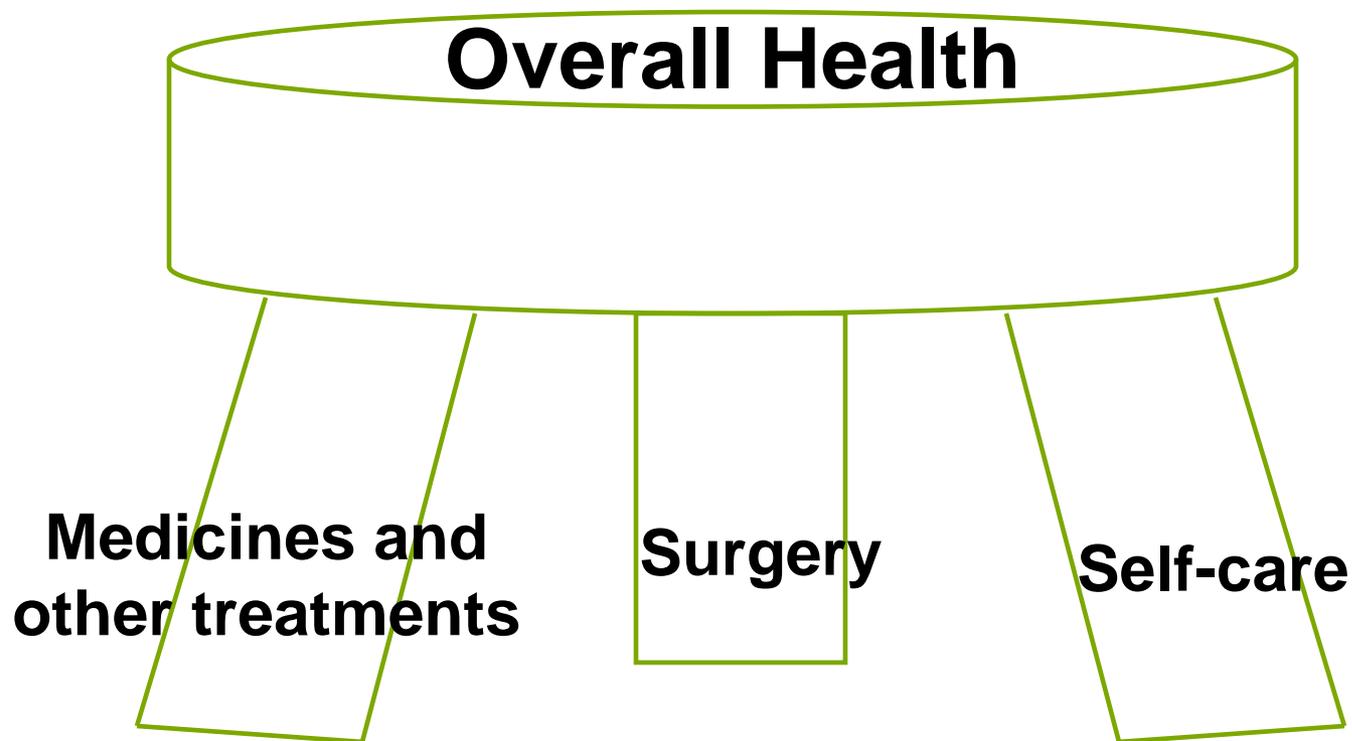
Total Care- Patient and Family Centered



Be Well



The Three-Legged Stool

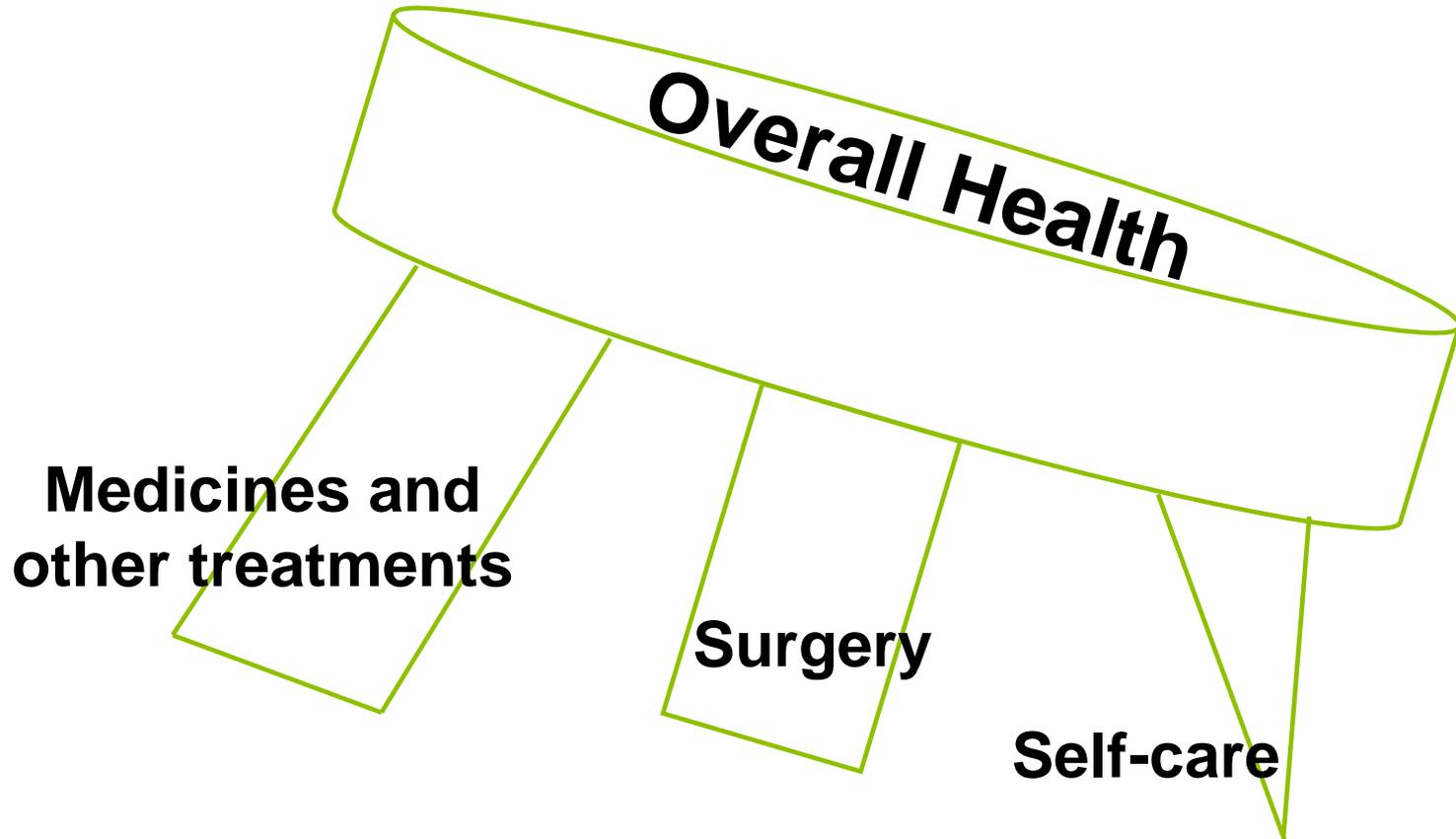


Be Well



Stay Healthy™

Unbalanced Three-Legged Stool



Fatigue After Cancer Treatment

- **Documented after breast cancer treatment – but applies to all**
- **Persistent severe fatigue affects 30% to 40% of breast cancer survivors.**
- **Many contributing factors-**
 - **Stress**
 - **Pain**
 - **Sleep disturbance**
 - **Depression**
 - **Decreased physical activity**

Improving Persistent Fatigue in Breast Cancer Survivors Using a Holistic Group-Based Mind-Body Intervention

Sponsor: Susan G. Komen for the Cure

Being Well



Staying Healthy

THE TEAM

**Kathy Helzlsouer
Susan Appling
Susan Scarvalone
Maureen McBeth
Bindu Kalesan
Lisa Gallicchio
Neal Fedarko
Kritka Jainsinghani**

Background- Persistent Fatigue

- Persistent severe fatigue following treatment affects 30% to 40% of breast cancer survivors.**
- Many contributing factors- stress, pain, sleep disturbance, depression, decreased physical activity and menopausal symptoms.**
- Little research on persistent fatigue**



Purpose

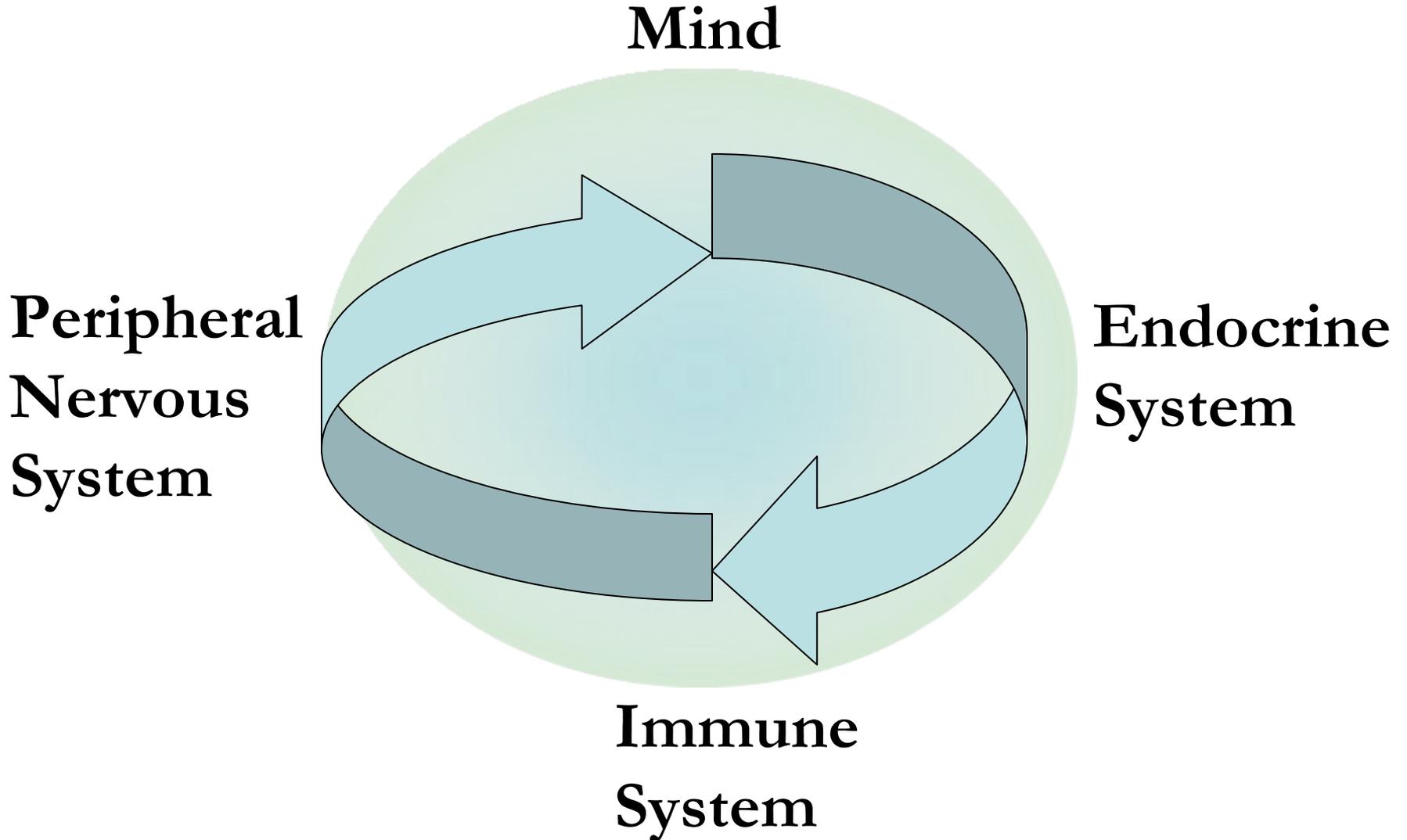
To test the effectiveness of a ten-week holistic, group-based mind-body medicine intervention to treat persistent fatigue among breast cancer survivors



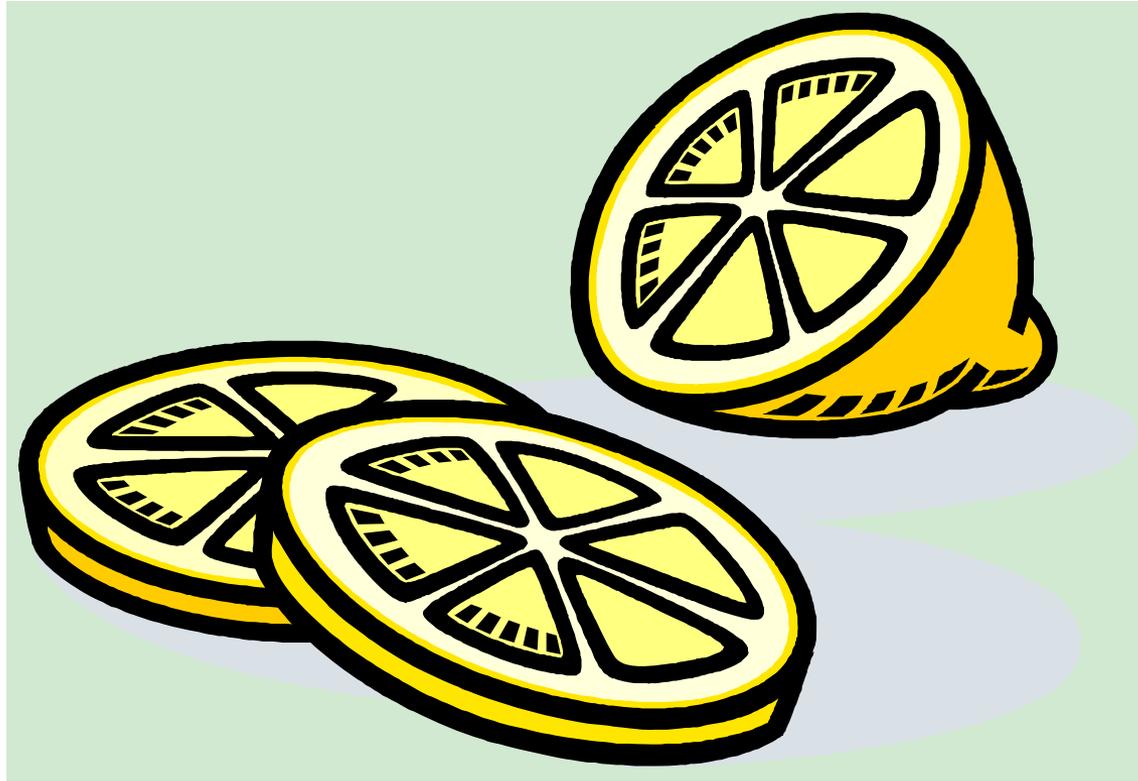
The Program

- **Broad-based – focusing on self-care**
- **Cognitive behavioral approaches with an emphasis on positive psychology**
 - Address stress and anxiety
 - Teach the relaxation-response
 - Increase physical activity
 - Improve nutrition
 - Develop a more positive framework

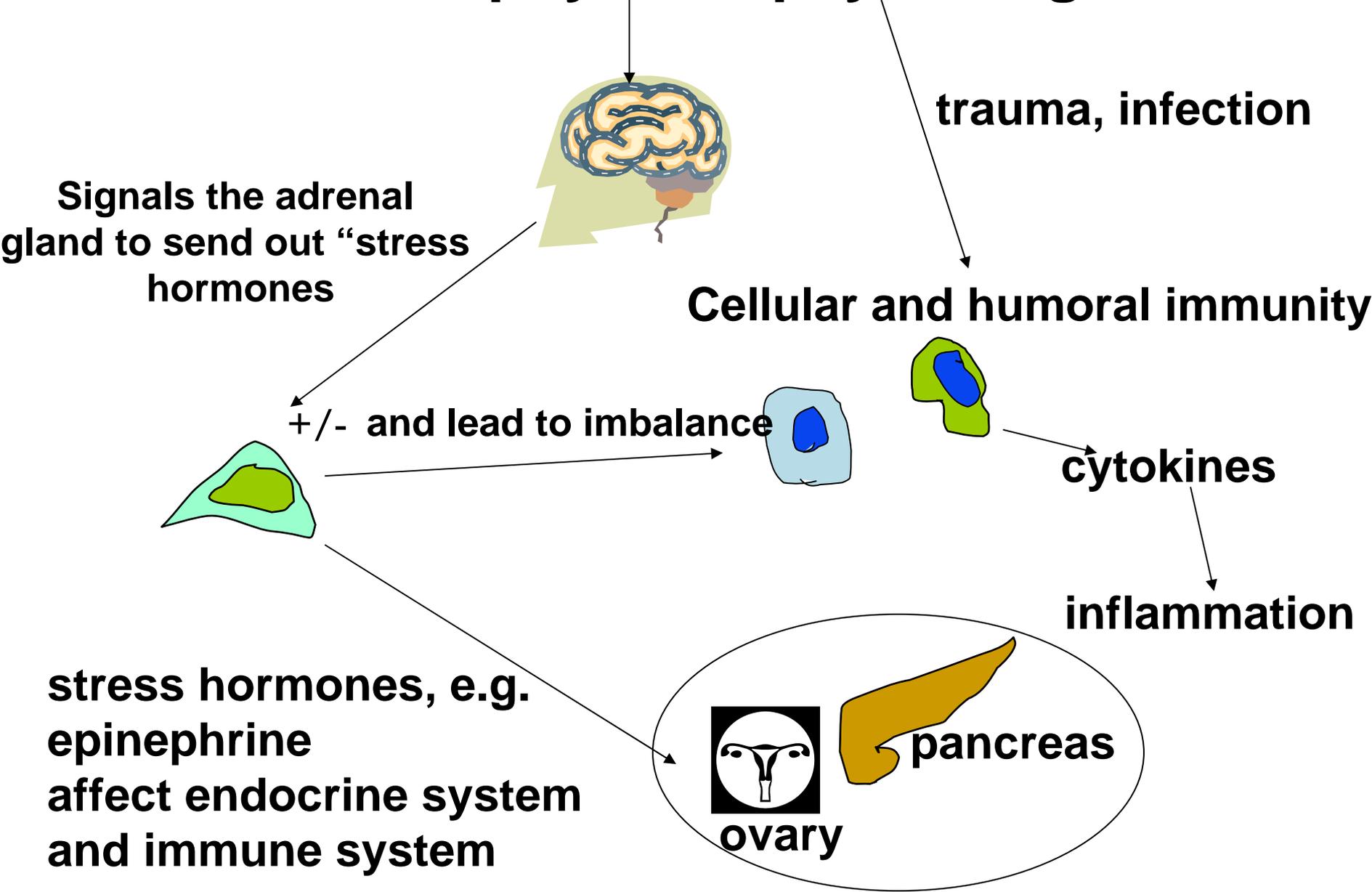
COMMUNICATION



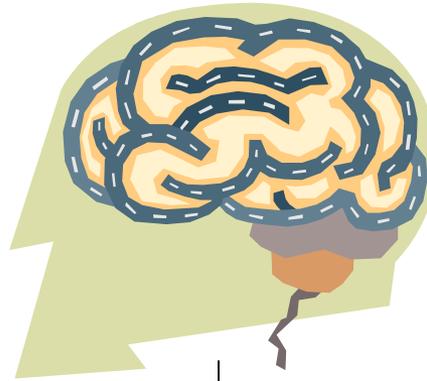
The Mind Body Connection



Stress: physical, psychological



Stress: physical, psychological



Endocrine
Diabetes
Ovary

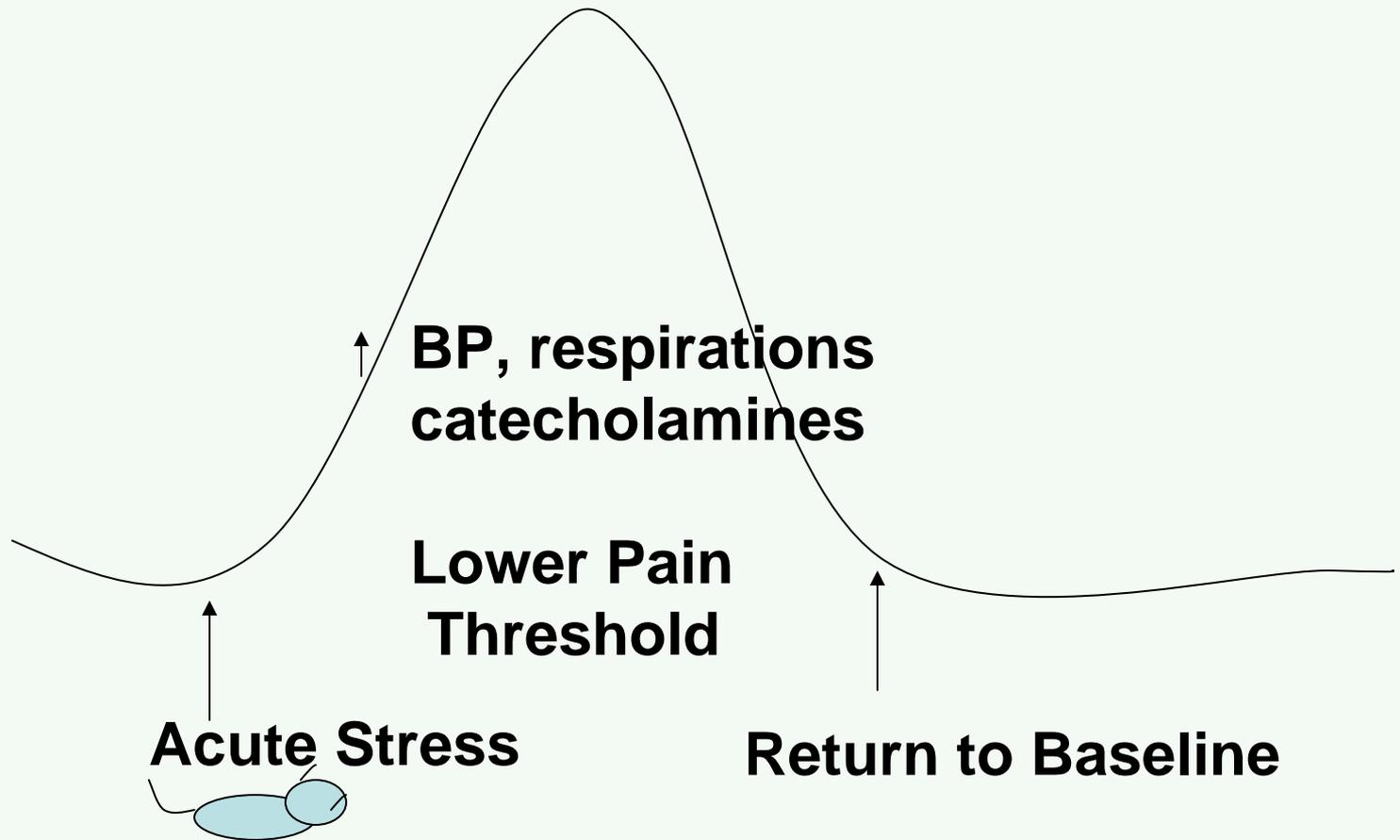
Heart

Immune
System

Acute Stress

Fight or Flight Response

Acute Stress

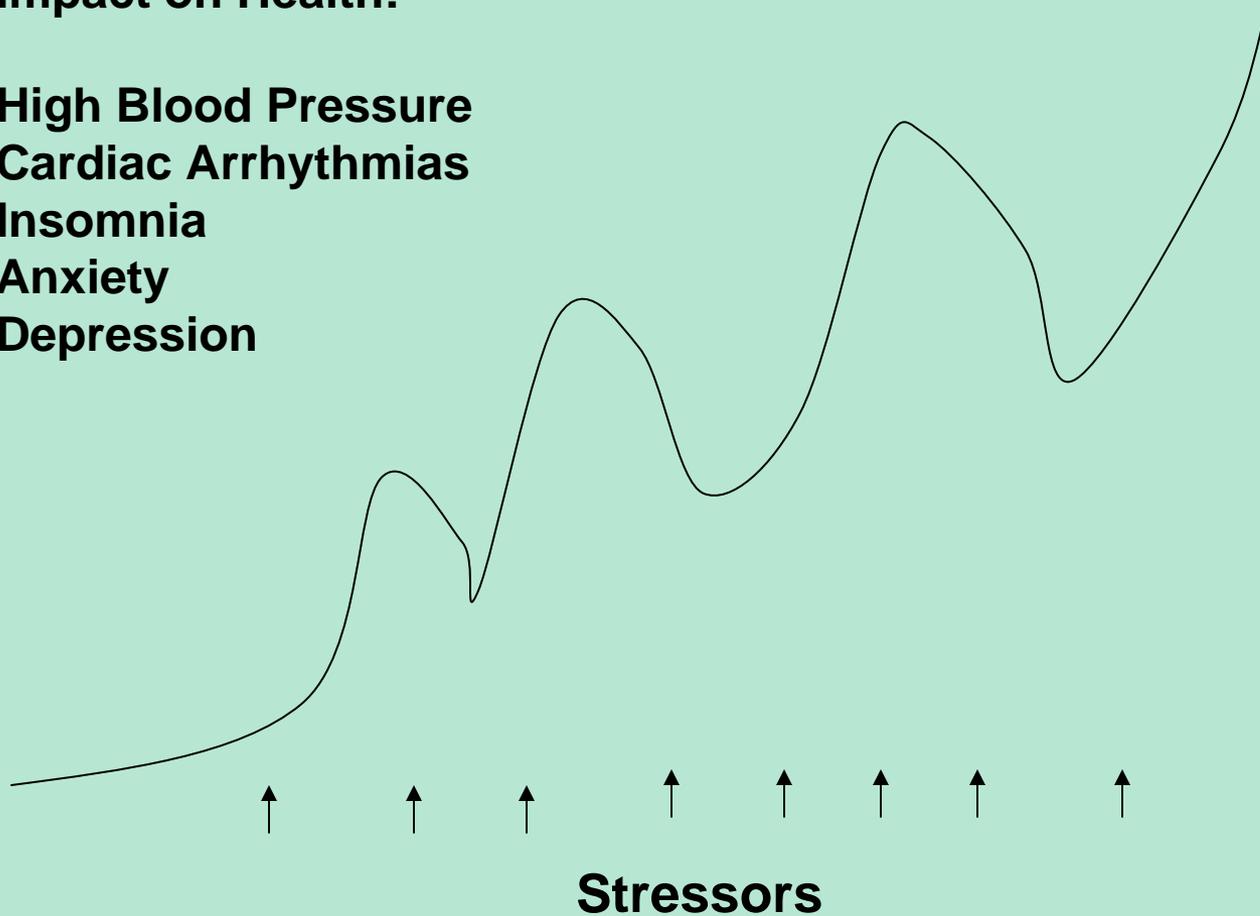


Chronic Stress

Chronic Stress- Allostatic Load

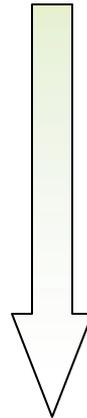
Impact on Health:

High Blood Pressure
Cardiac Arrhythmias
Insomnia
Anxiety
Depression



STRESS

IT'S EXHAUSTING!



FATIGUE

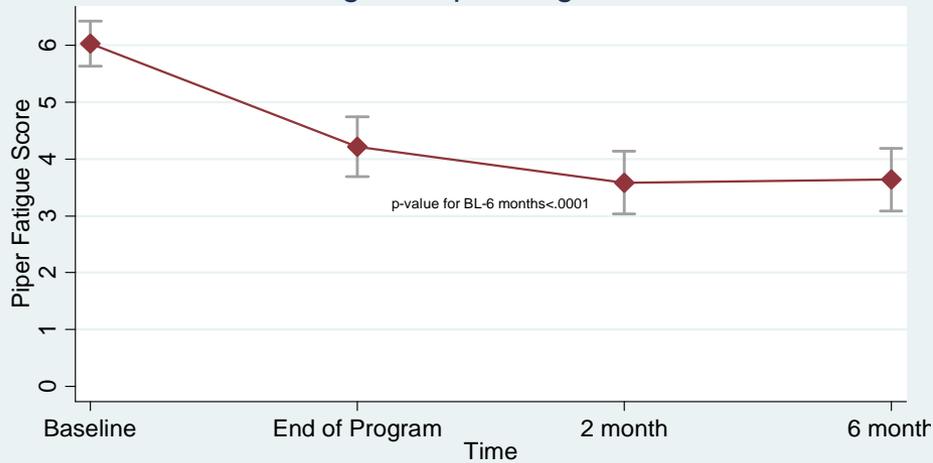
Self Care

- ▶ **Relaxation – Meditation – Mindfulness**
- ▶ **Physical Activity**
- ▶ **Nutrition**
- ▶ **Attitudes and beliefs**



Change in fatigue and vitality up to 6 months after program completion

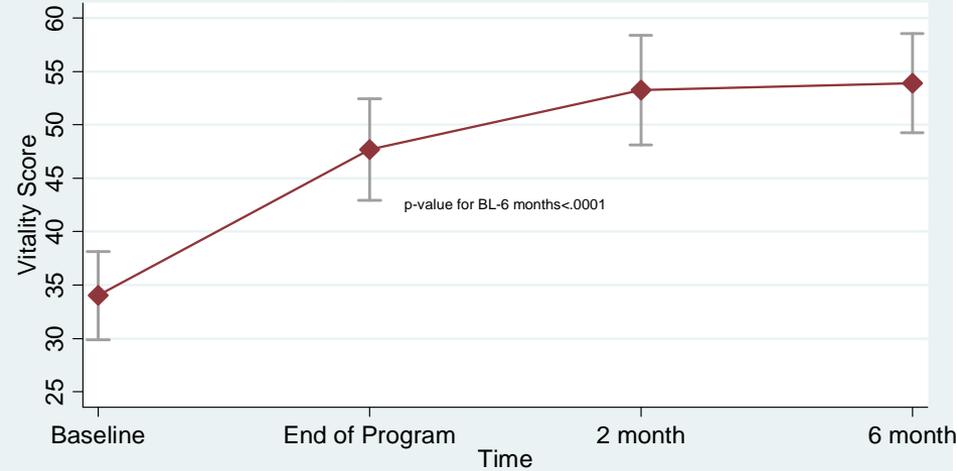
Change in Piper fatigue scores



—◆— Mean Score |—| 95%CI

p-value for EOP-6 months=0.0735
 p-value for EOP-6months (BL-adjusted)=0.3109
 high score= high fatigue

Change in Vitality Scores of SF-36



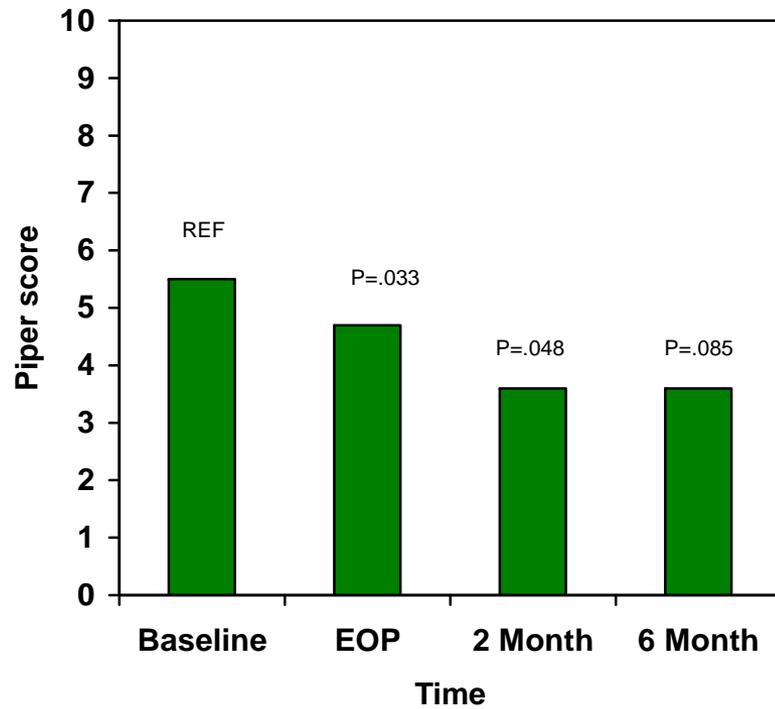
—◆— Mean Score |—| 95%CI

p-value for EOP-6 months=0.0362
 p-value for EOP-6months (BL-adjusted)=0.7104
 high score= high vitality

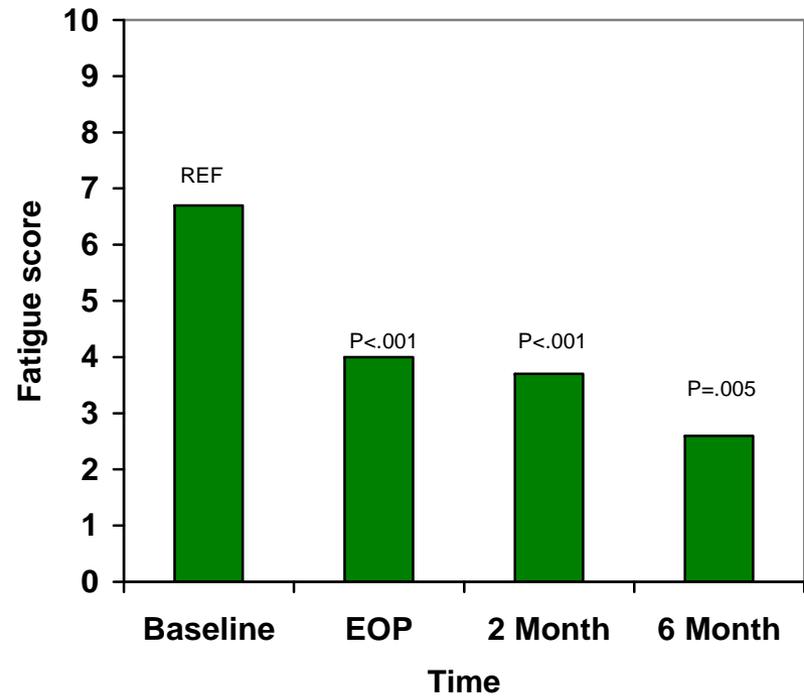


Be Well, Stay Healthy Program

PIPER FATIGUE SCALE (0-10)



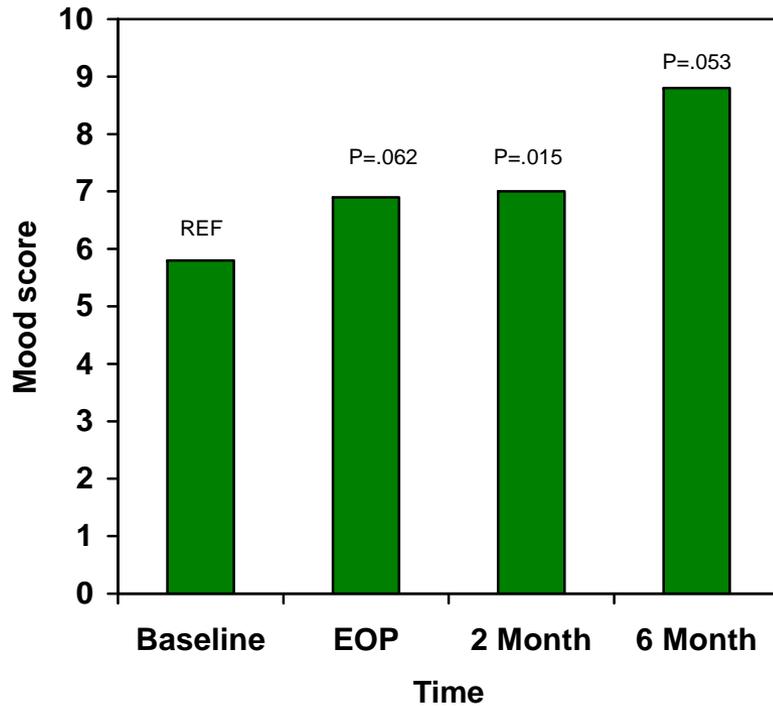
FATIGUE VISUAL ANALOG SCALE (0-10)



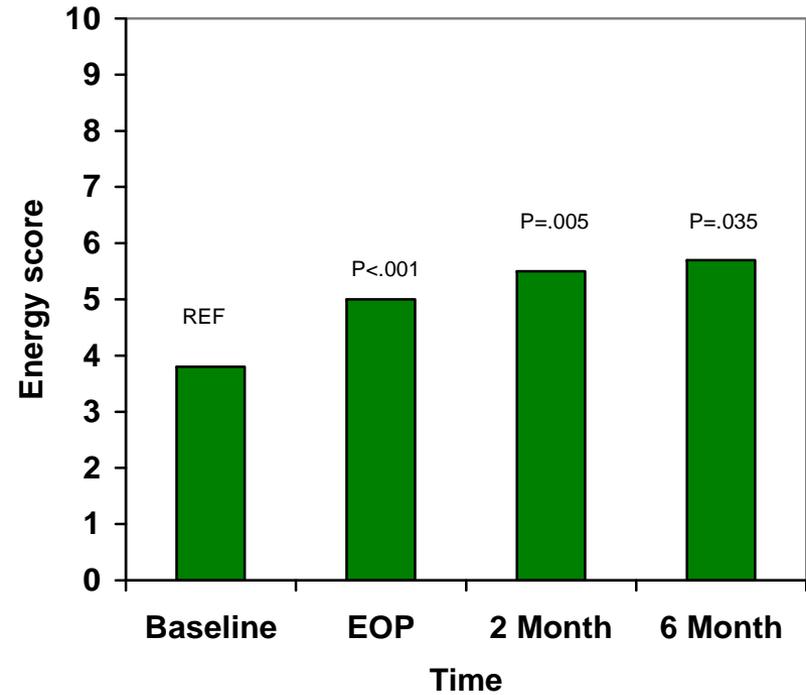


Be Well, Stay Healthy Program

MOOD VISUAL ANALOG SCALE (0-10)



ENERGY VISUAL ANALOG SCALE (0-10)



Total Care of the Cancer Survivor

- **Patient centered**
- **Family centered**
- **Mind, Body and Spirit**
- **Coordinated**
- **Accessible**
- **Knowledgable**