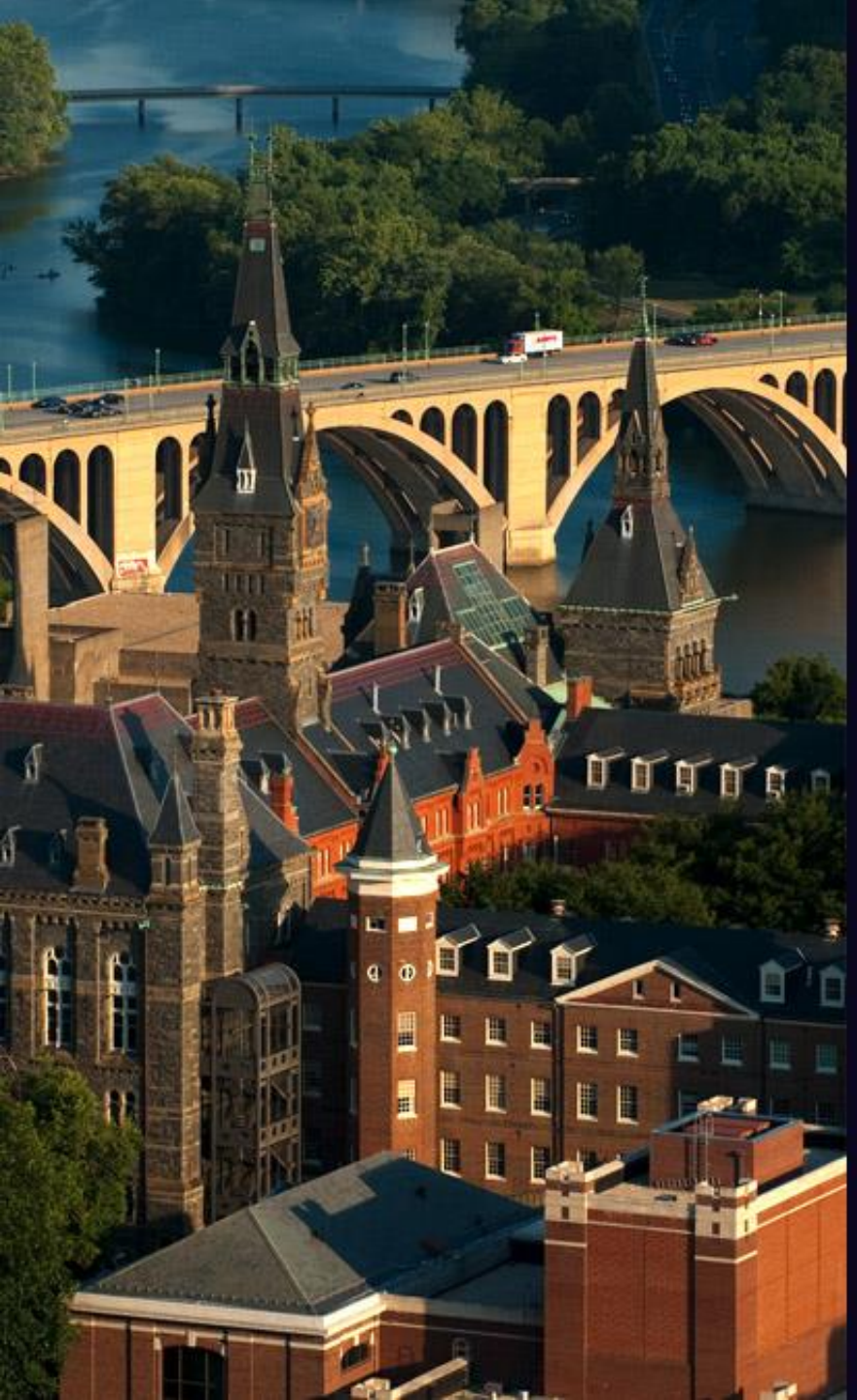


Georgetown | Lombardi
COMPREHENSIVE CANCER CENTER

Cancer and Mental Health: From Screening for Distress to Improving Quality of Life

November 18, 2020

Kristi D. Graves, PhD

NCI CCC® A Comprehensive Cancer Center Designated by the National Cancer Institute

NO FORMAL DISCLOSURES

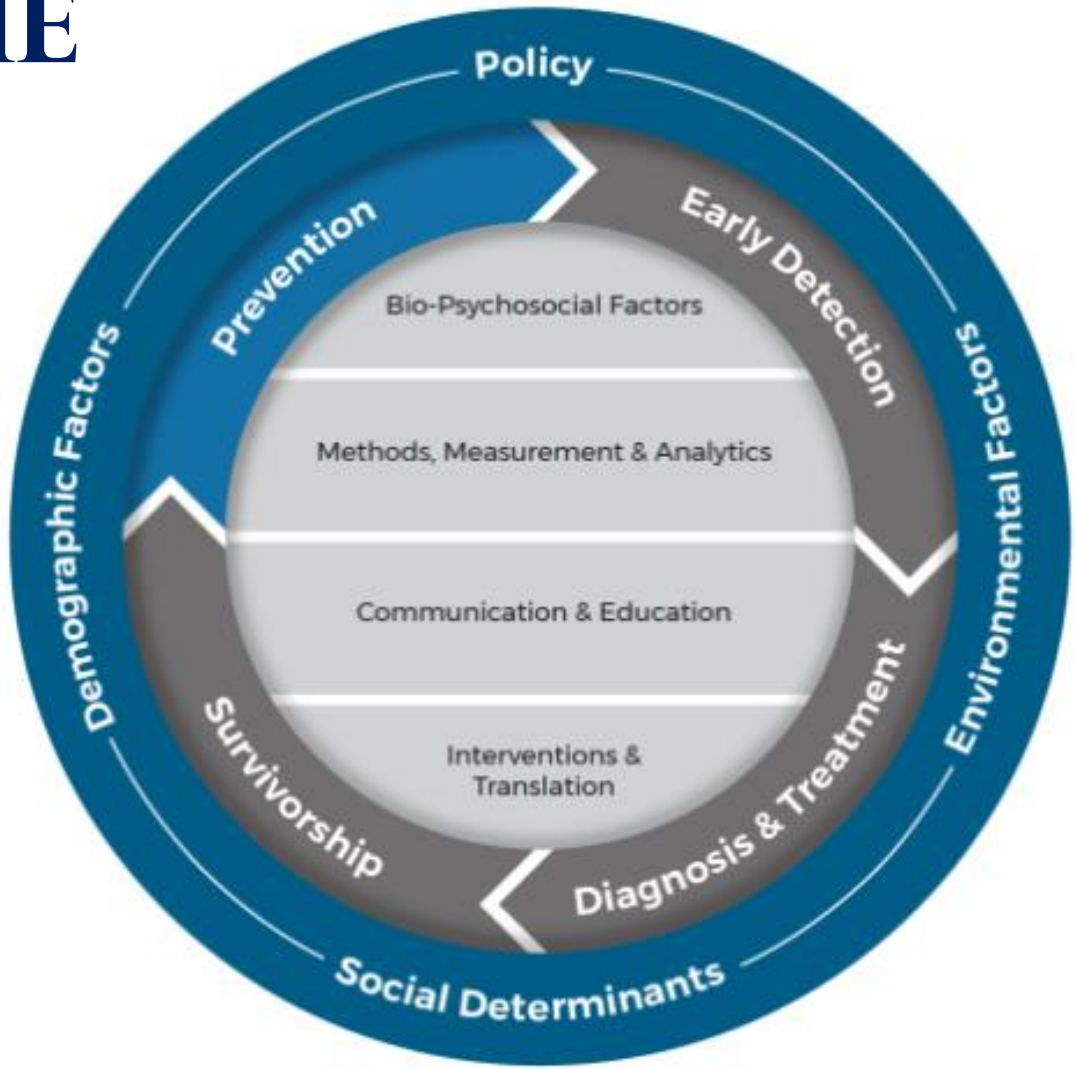
Learning objectives:

- Identify barriers and facilitators to screening for distress in patients diagnosed with cancer.

- Describe current evidence-based efforts to improve quality of life among individuals diagnosed with cancer.

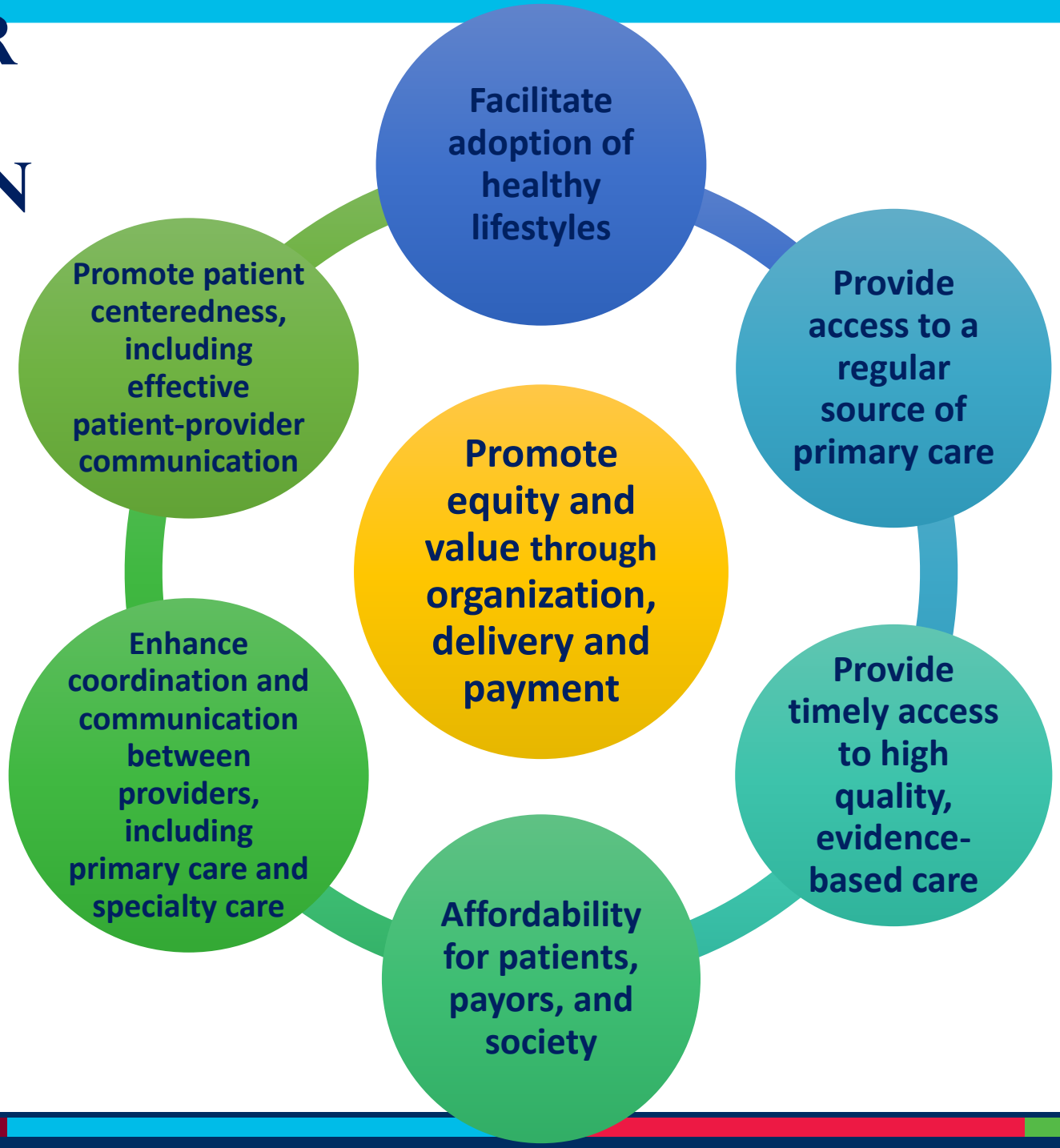
SETTING THE STAGE

Behavioral Research in Cancer Prevention and Control Framework



SOURCES: National Cancer Institute Behavioral Research Program: https://cancercontrol.cancer.gov/brp/about.html

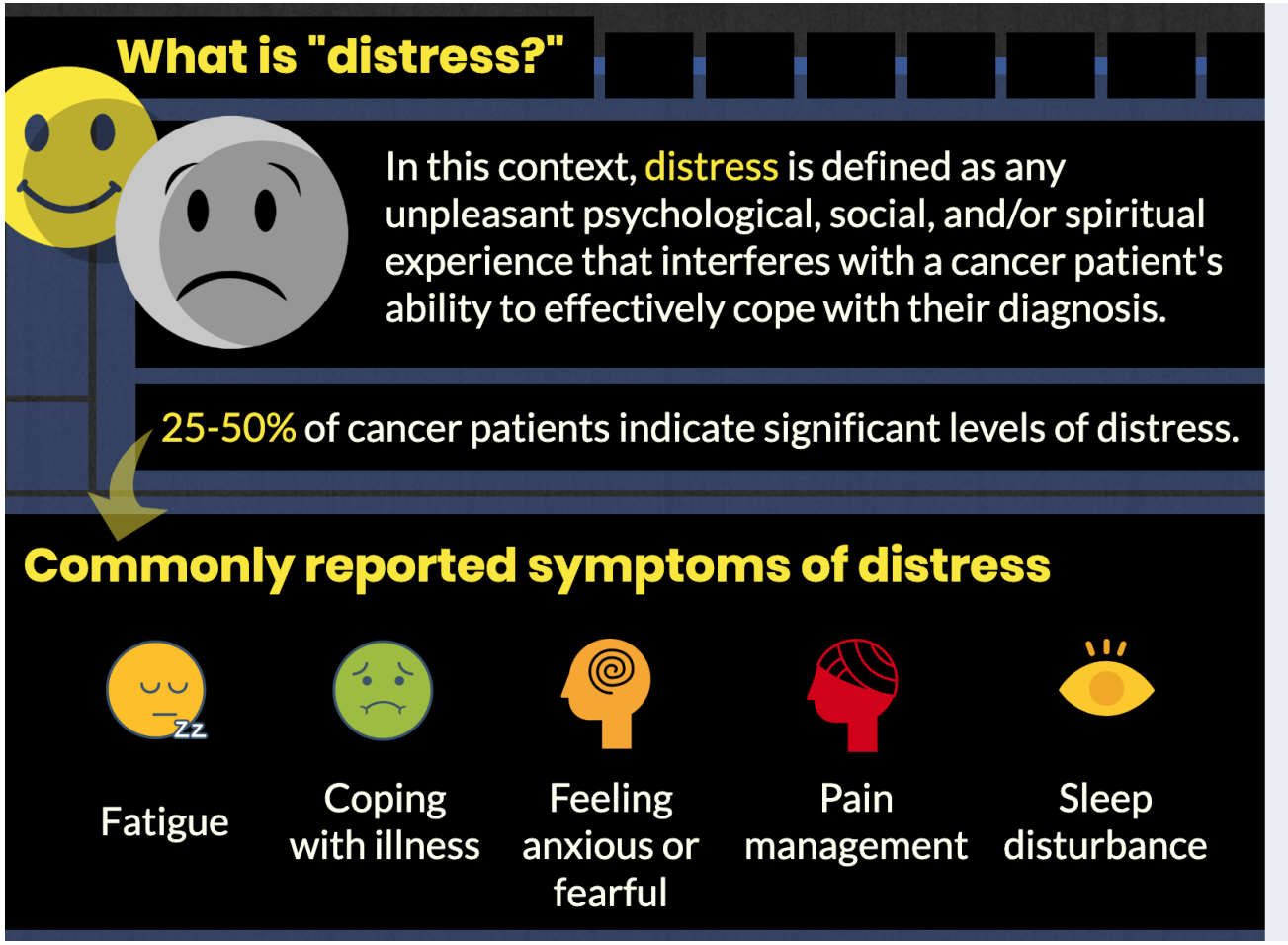
GOALS FOR A HIGH PERFORMING HEALTH CARE SYSTEM



Goals for a High Performing Health Care System;
Yabroff et al., 2019, *Cancer*

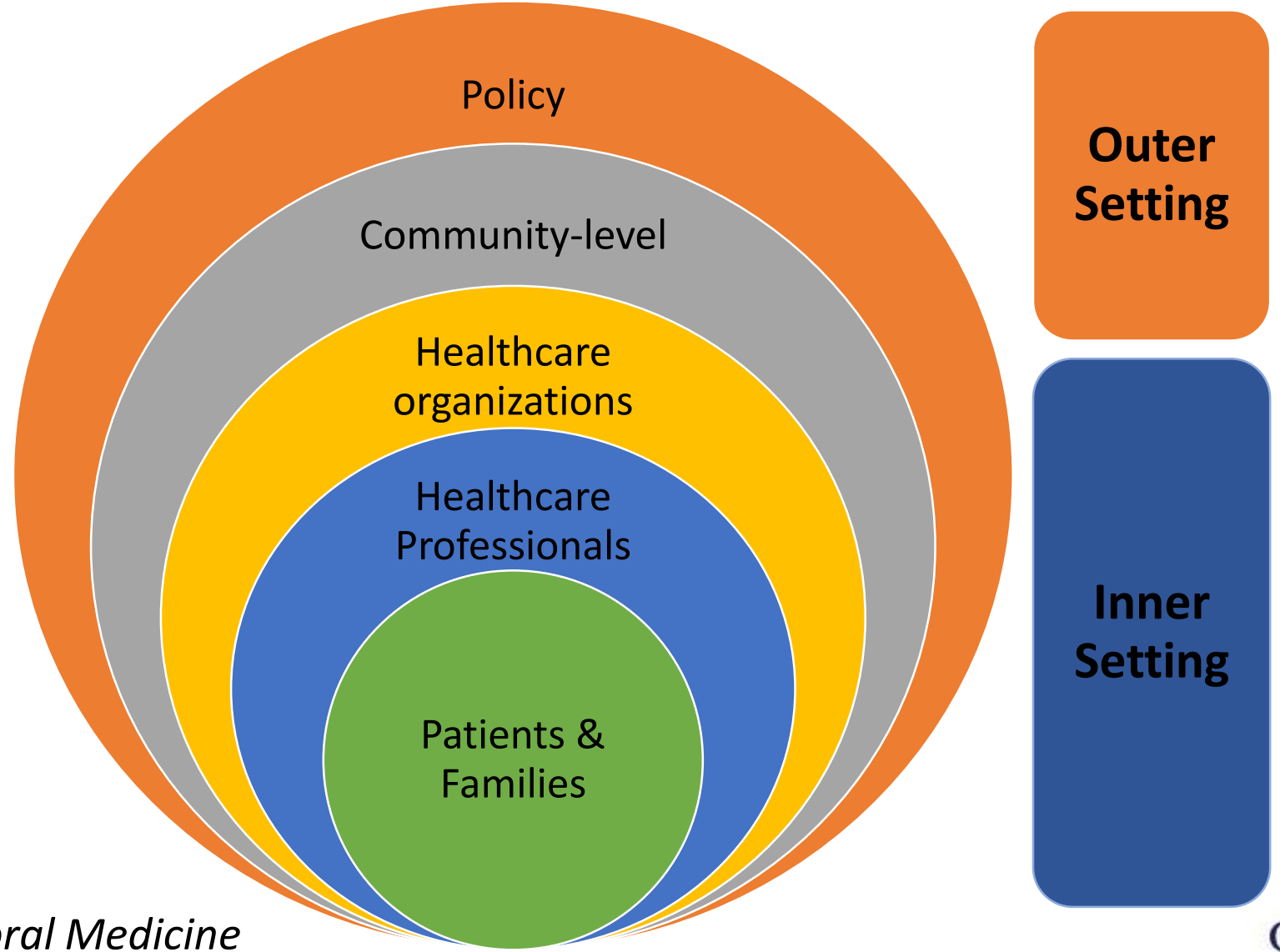
Cancer Distress: Overview

- Distress is a multidimensional construct
- Considered 'more acceptable' and less stigmatizing than other terms
- Some refer to terms such as depression and anxiety (Andersen et al., 2014)



Source: SBM: https://create.piktochart.com/output/37777492-cancer-is-distressing

Multi-Level Considerations for Distress Screening



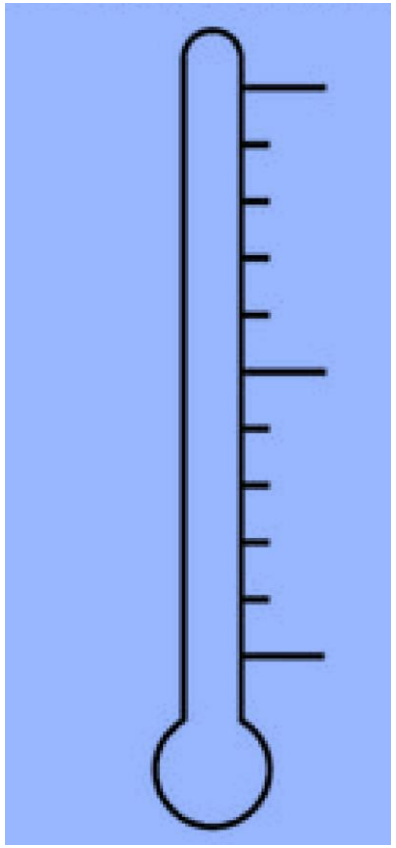
Ehlers et al., 2019
Translational Behavioral Medicine

BARRIERS TO DISTRESS SCREEN

- IDENTIFICATION OF SCREENING TOOL(S)
  - NCCN DISTRESS THERMOMETER; ASSOCIATED PROB
  - BRIEF 1-ITEM SCREENERS (E.G., HOSPITAL ANXIETY AND DEPRESSION SCALE (HADS)
- EMERGING EVIDENCE ABOUT PREDICTIVE VALUE OF SCREENING
  - RECENT STUDY: 55 INSTITUTIONS; ADHERENCE TO DISTRESS SCREENING PROTOCOLS; LOWER ER VISITS AND HOSPITALIZATIONS
  - ANOTHER SINGLE-SITE STUDY DID NOT SEE IMP OUTCOMES
- WORKFORCE / SYSTEM-LEVEL CHALLENGES
  - TOO FEW MENTAL HEALTH PROFESSIONALS
  - CONSTRAINED FINANCIAL RESOURCES

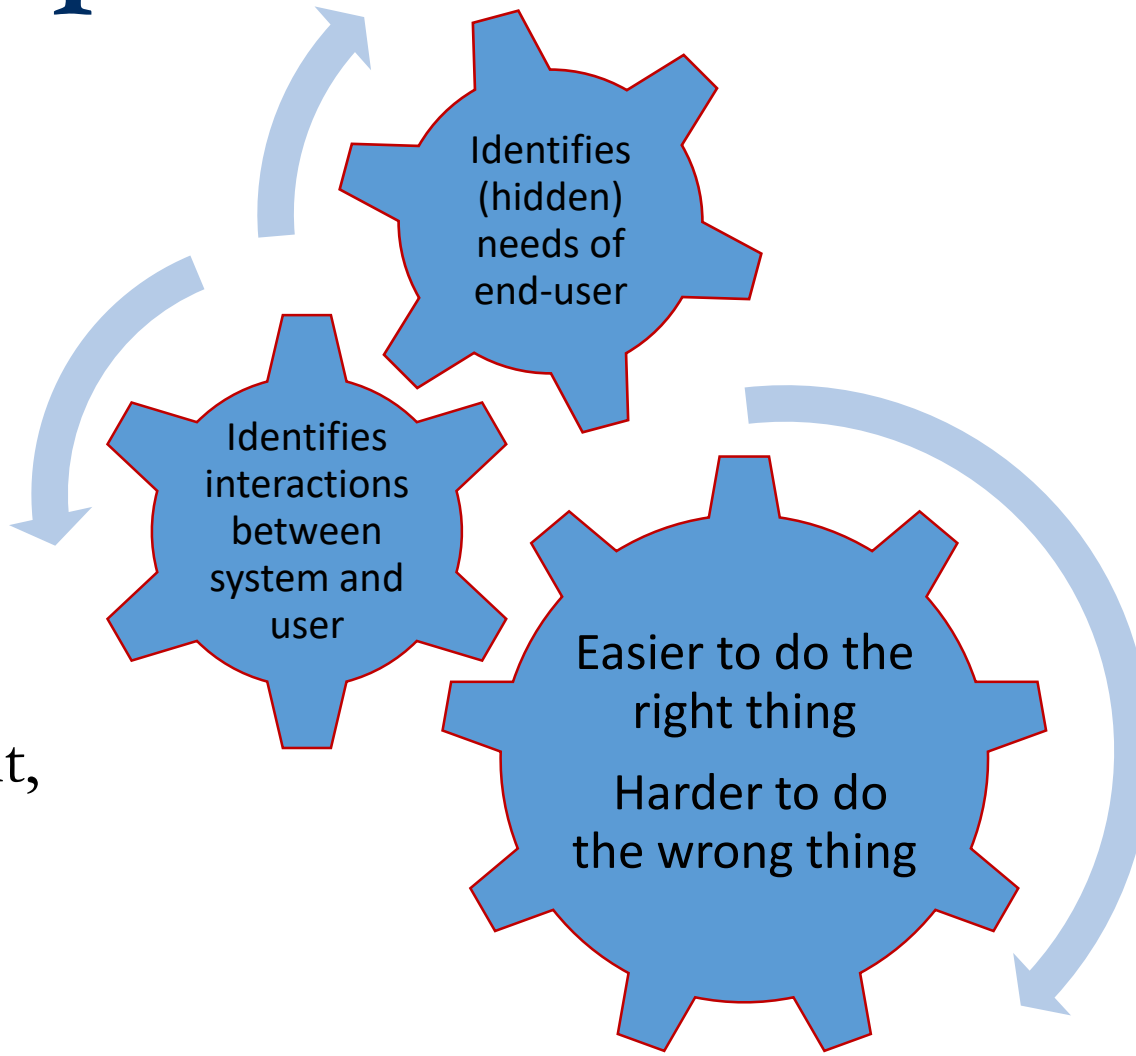
Dissemination and Implementation

- Initiating Screening:
  - Identification of target construct
    - Distress, depression, anxiety, resilience
  - Selection of appropriate measure(s)
    - Brief screeners (e.g., NCCN Distress Thermometer; depression screeners)
    - Clinical assessments
    - Consideration of time, ease, workflow and referral procedures
  - Determination of who, what, how, when



Dissemination and Implementation

- Improving Screening
  - Interdisciplinary teams
  - Distress 'champion'
  - Human factors engineering elements
    - Designing systems, tools, software to fit human capacities and limitations
    - Deliberate design to enhance safe, efficient, effective and timely clinical care
- Protocol for referrals; follow up

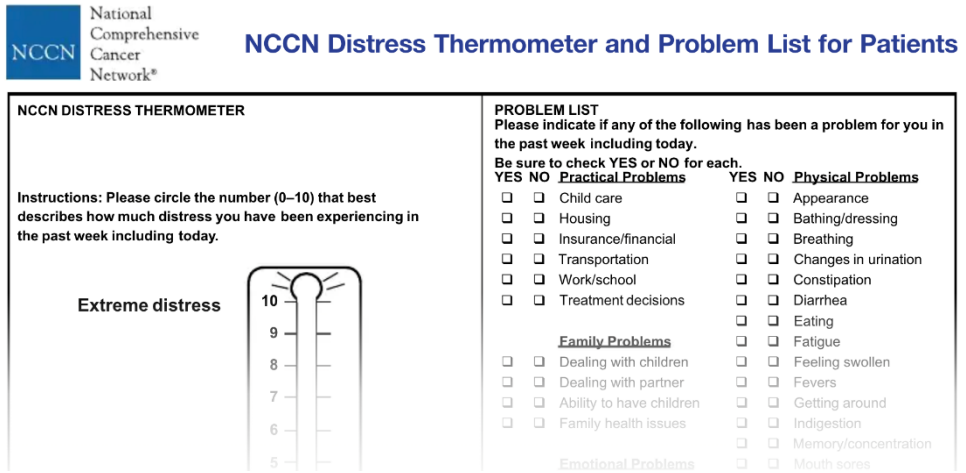


Dissemination and Implementation

- Maintaining Screening
  - Evaluation of 'upstream' or 'downstream' burden
    - Longer screening measures with lower false positive rates
    - Shorter screening measures with high false positive rates
  - Reducing time, obtaining institutional leadership buy-in
  - Provider burden, training, resources and costs
  - Use of efficient and effective electronic systems

Case Study

- Georgetown Lombardi
  - –1,286 patients (1/18 to 4/19)
  - –Distress screening included:
    - NCCN Distress Thermometer (DT), Problem Checklist
    - PROMIS® short-form (4-item) measures: Anxiety and Depression
    - Screening on tablets at time of diagnosis
  - –Focus on "Problems Communicating with Medical Team"



National Comprehensive Cancer Network®

NCCN Distress Thermometer and Problem List for Patients

NCCN DISTRESS THERMOMETER

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week including today.

Extreme distress

10
9
8
7
6
5

PROBLEM LIST

Please indicate if any of the following has been a problem for you in the past week including today.

Be sure to check YES or NO for each.

YES	NO	Practical Problems
❑	❑	Child care
❑	❑	Housing
❑	❑	Insurance/financial
❑	❑	Transportation
❑	❑	Work/school
❑	❑	Treatment decisions

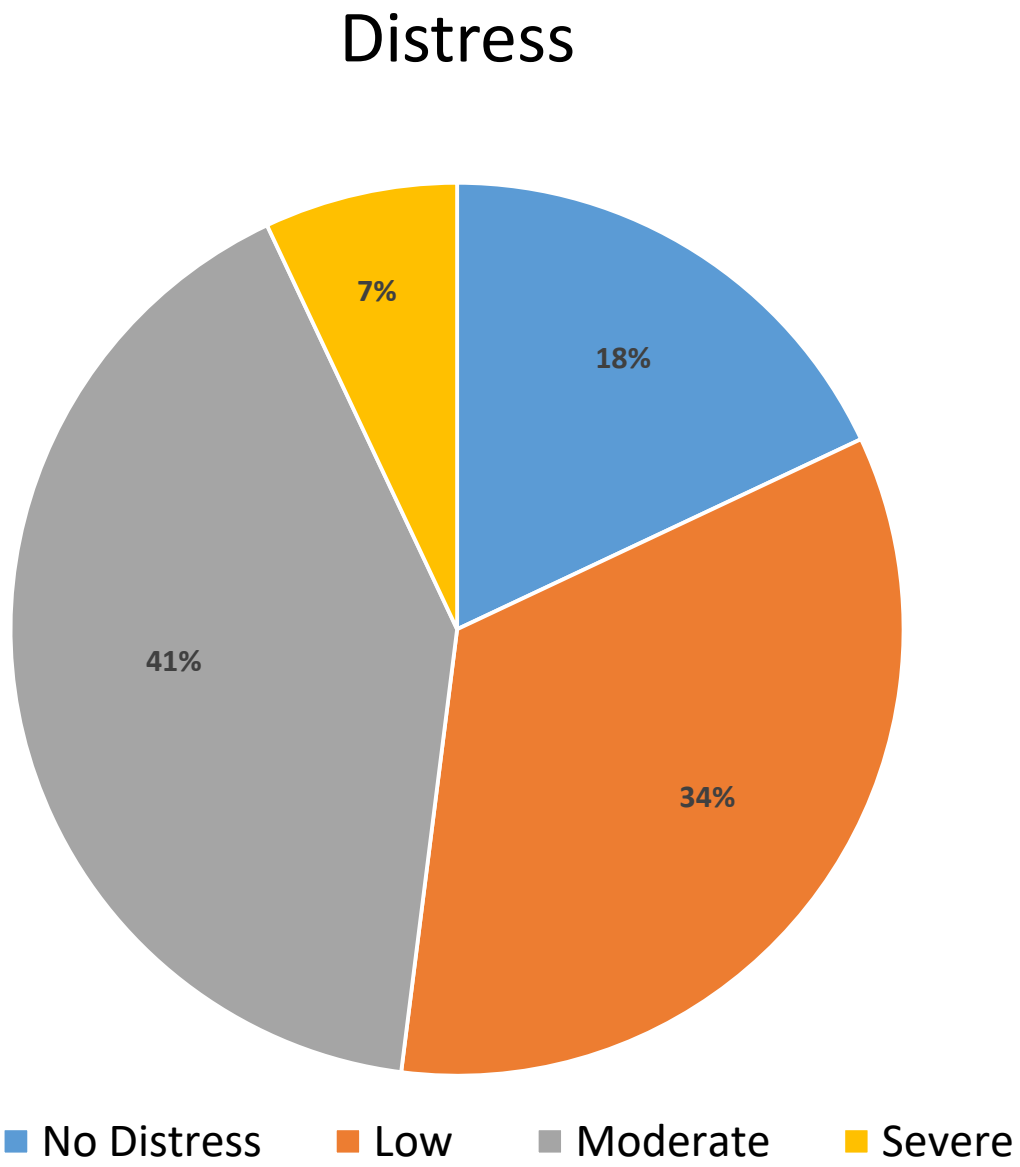
YES	NO	Physical Problems
❑	❑	Appearance
❑	❑	Bathing/dressing
❑	❑	Breathing
❑	❑	Changes in urination
❑	❑	Constipation
❑	❑	Diarrhea
❑	❑	Eating
❑	❑	Fatigue
❑	❑	Feeling swollen
❑	❑	Fevers
❑	❑	Getting around
❑	❑	Indigestion
❑	❑	Memory/concentration
❑	❑	Mouth sores

Family Problems

❑	❑	Dealing with children
❑	❑	Dealing with partner
❑	❑	Ability to have children
❑	❑	Family health issues

Emotional Problems

Demographic Characteristics (N=1,286)	
Age (M, SD)	59.9 years (14.70 years)
Gender	42.2% Male; 57.7% Female
Race	27.4% Black
	63.6% White
	8.1% Asian
	0.9% Other Race
Ethnicity	4.7% Hispanic
Education	8.7% < High School
	12.0% High School
	12.8% Some College
	66.5% College or more

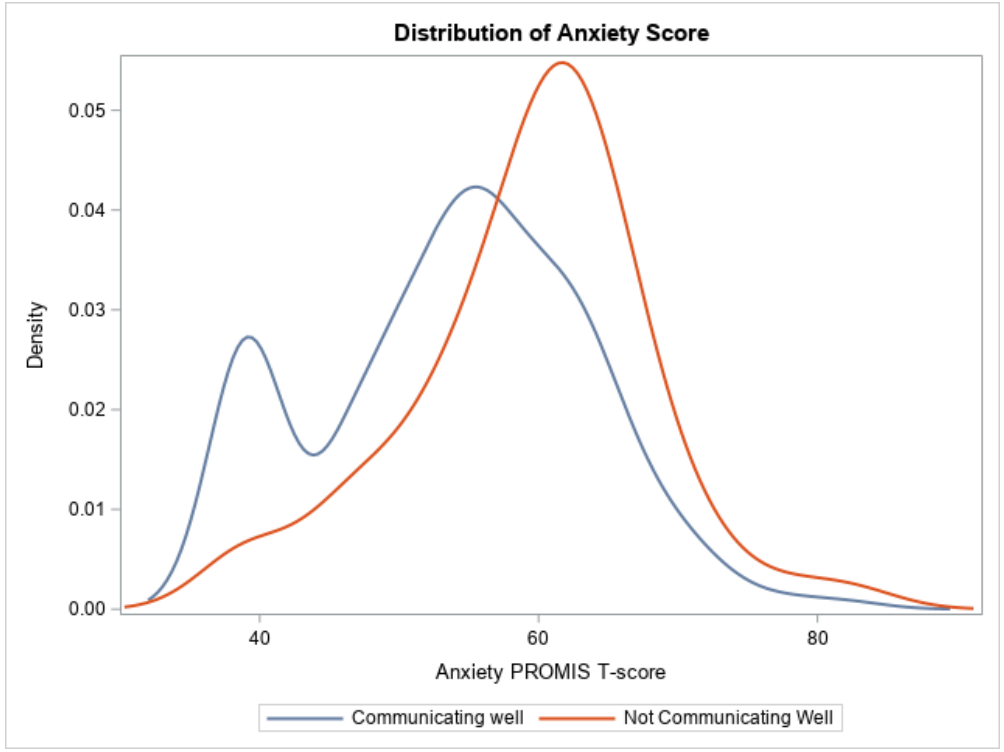


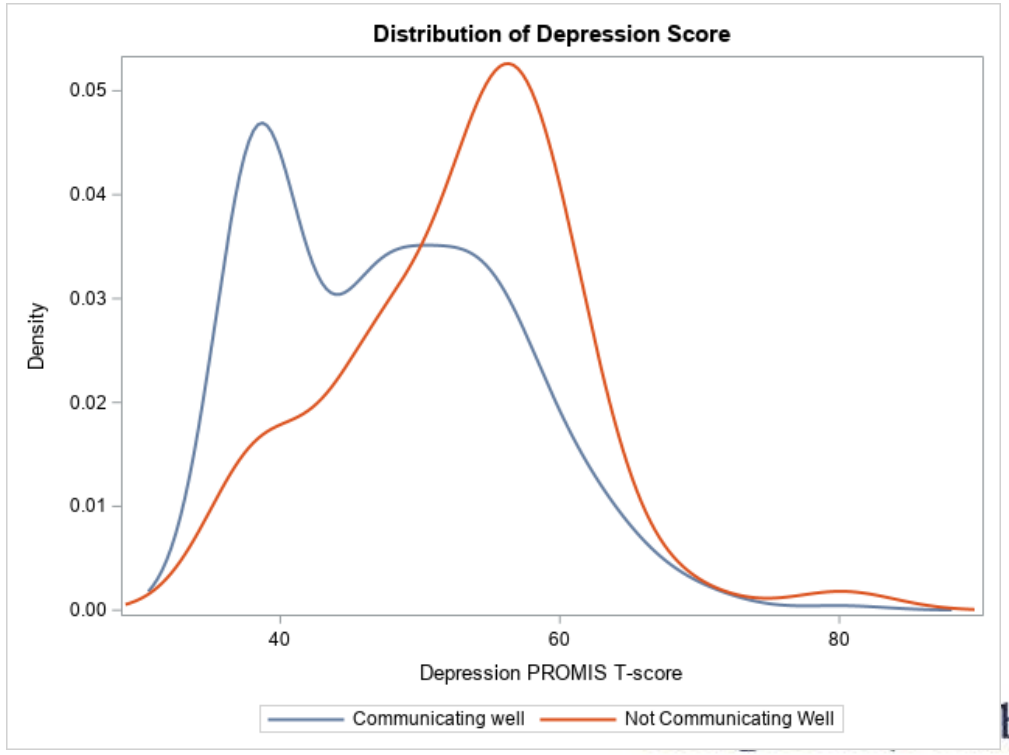
Results

- 'Problems communicating with the medical team' from Problem Checklist:
  - 4.7% of individuals (n=60) = Yes
  - Problems communicating not associated with: gender, race, ethnicity, age
  - Association with Distress (75%, n=45/60):
    - 53.3% (n=32 of 60) had moderate distress scores
    - 13.3% (n=13 of 60) had severe distress

Results, continued

- Controlling for overall distress score, patient gender and education, problems communicating associated with:
  - anxiety (t=2.68, p=.007), depression (t=3.06, p=.002)

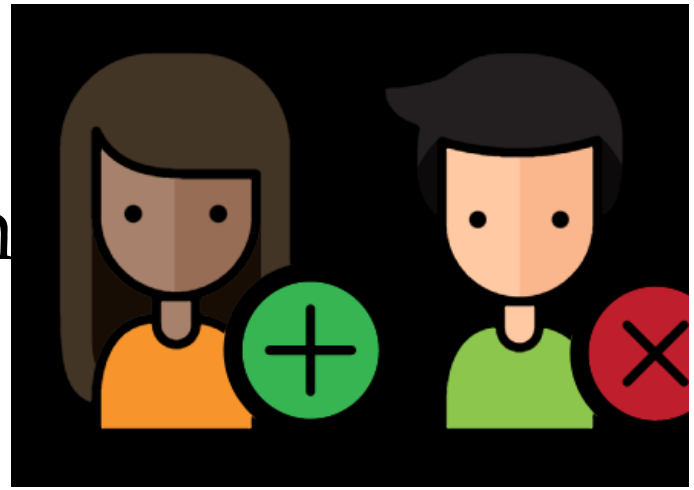




bardi

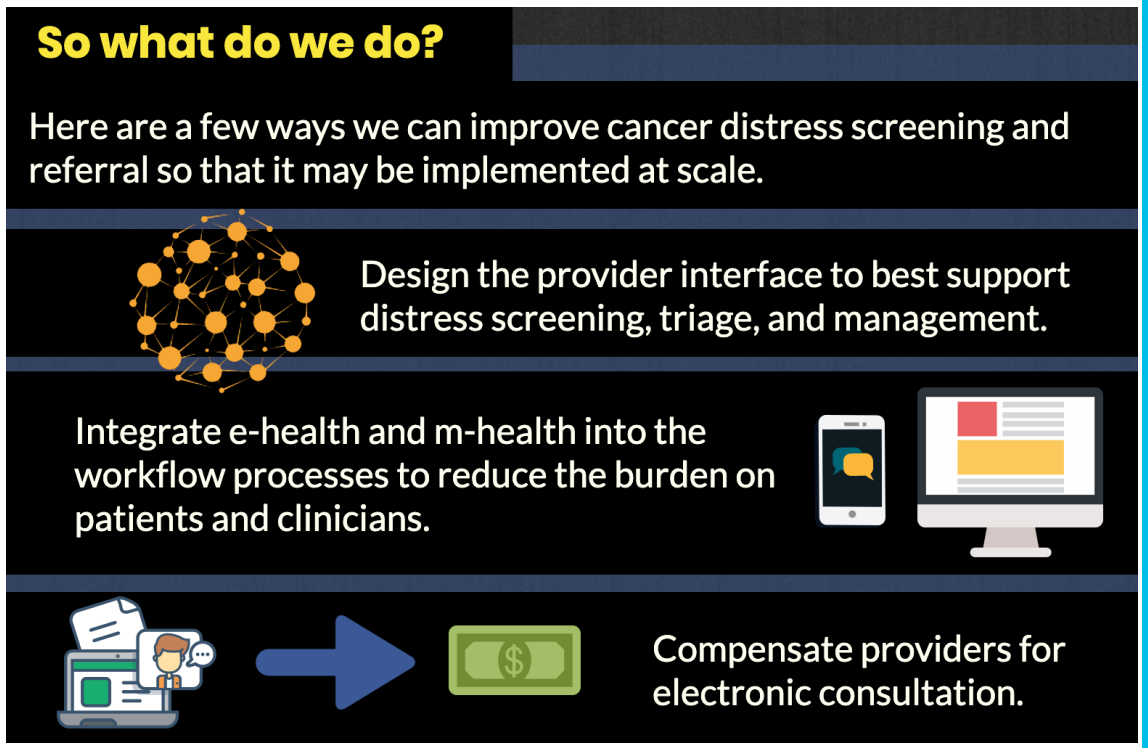
Implications

- Perceived problems communicating with the medical team associated with overall distress, anxiety and depression
- Elements of distress screening may suggest context for patient-centered interventions



Next Steps: Improving Screening & Referrals

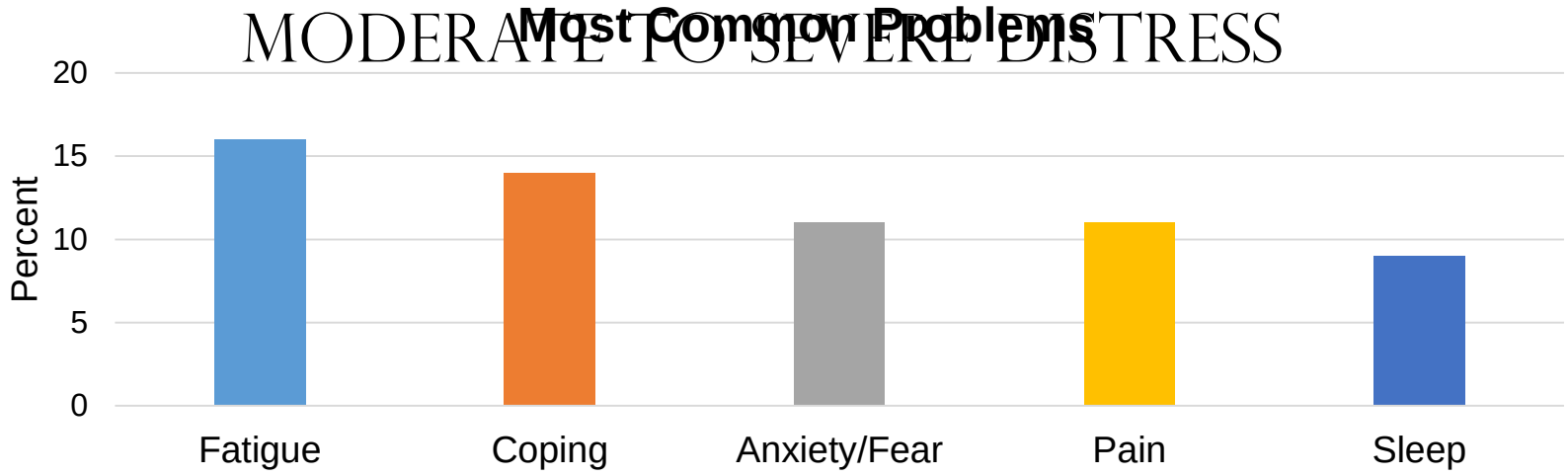
- Consider repeat screening
  - Toward end of treatment
    - Financial hardship
    - Short-term effects
- Capture uptake of referrals

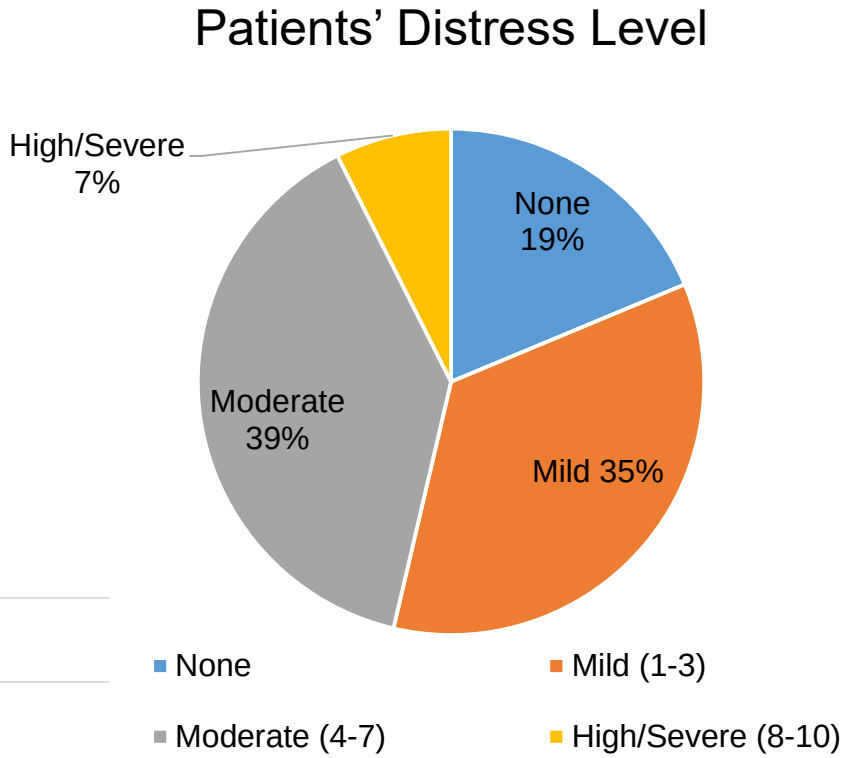


Source: SBM: https://create.piktochart.com/output/37777492-cancer-is-distressing

SURVIVORS' DISTRESS / UNMET NEEDS

- UNMET NEEDS OF CANCER SURVIVORS
  - NOW OVER 4,000 MEDSTAR PATIENTS HAVE COMPLETED DISTRESS SCREENING
  - ALMOST HALF (46%) REPORTED MODERATE TO SEVERE DISTRESS





Ehlers et al., 2018, *Translational Behavioral Medicine*

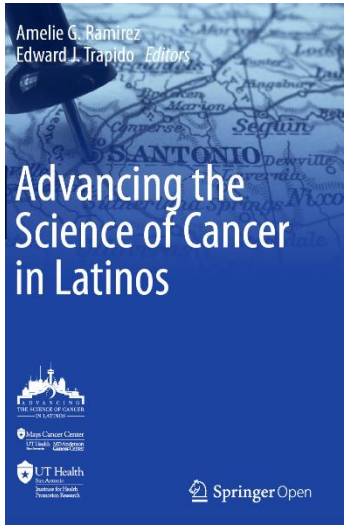
FINANCIAL DISTRESS AMONG LATINA BREAST CANCER SURVIVORS

PURPOSE: EXPLORE RELATIONSHIPS AMONG ACCULTURATION, FINANCIAL TOXICITY AND QUALITY OF LIFE AMONG LATINA BREAST CANCER SURVIVORS

DATA SOURCE: NUEVA VIDA INTERVENTION STUDY; SES OI

Chapter 16
Research Democracy in a Randomized Controlled Trial: Engaging Multiple Stakeholders in Patient-Centered Outcomes Research

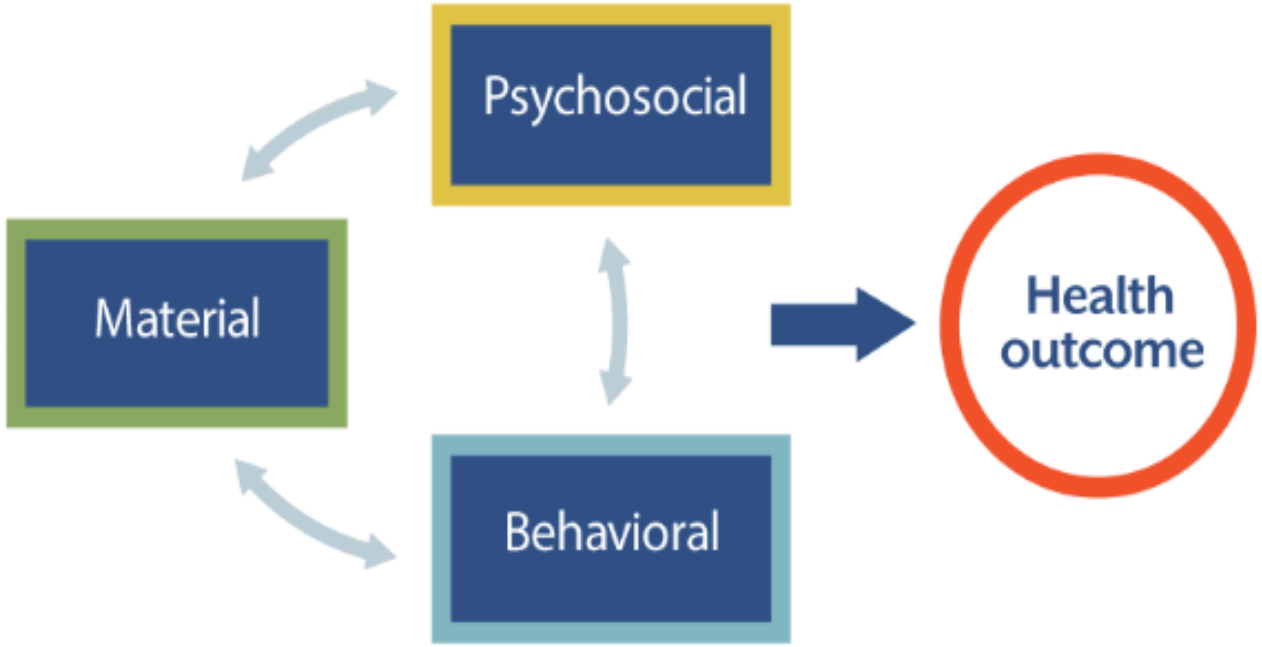
Charlene Kuo, Christina Rush, Abigail Montero, Claudia Campos, Gloria Elliott, Ivis Febus-Sampayo, Ysabel Duron, Migdalia Torres, Margaret Darling, and Kristi D. Graves



Rush et al. (2014). *Quality of Life Research*, 24(5), 1107-18.

FINANCIAL DISTRESS / FINANCIAL HARDSHIP BACKGROUND

- DISTRESS OR BURDEN DUE TO FINANCIAL CONCERNS
- MULTI-FACTORIAL
- EXAMPLE -- SURVIVORS REPORT CUTTING DOWN ON FOOD SPENDING:
  - 21.5% NHW PATIENTS
  - 22.5% ASIAN PATIENTS
  - 45.2% BLACK PATIENTS
  - 35.8% LATINA PATIENTS
    - JAGSI ET AL., 2018, *CANCER*



Reginald Tucker-Seeley's Conceptual Model of Financial Toxicity
http://tuckerseeley.org/measures

NUEVA VIDA STUDY OVERVIEW

- COMMUNITY-ACADEMIC PARTNERSHIP: NUEVA VIDA AND GEORGETOWN
  - NUEVA VIDA, INC. IS A COMMUNITY-BASED ORGANIZATION SERVING DC, MD AND VA
  - PARENT STUDY: EVALUATION OF AN INTERVENTION TO IMPROVE QUALITY OF LIFE AMONG LATINA BREAST CANCER SURVIVORS AND THEIR CAREGI
  - COLLABORATIONS WITH 3 OTHER COMMUNITY ORGANIZATIONS:
    - GILDA'S CLUB NEW YORK CITY (NY
    - LATINAS CONTRA CANCER (CA)
    - SHARE (NY, NY)

NUEVA VIDA STUDY PARTICIPANT CHARACTERISTICS

PARTICIPANT CHARACTERISTICS

N = 135 DYADS

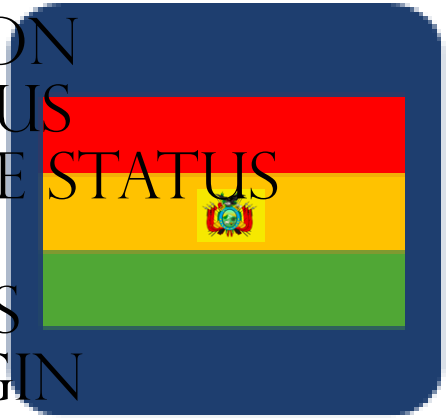
	Latina Survivors (n = 135)	Caregivers (n = 135) 55 males – 41% 80 females – 59%
% Spanish Survey	93%	82%
% Employed Full-Time at BL	15%	50%
% Less than HS Degree	43%	31%

Countries of Origin

Latina Survivors		Caregivers	
Bolivia	5.8%	Bolivia	3.6%
Colombia	4.4%	Colombia	5.5%
Chile	2.9%	Chile	3.6%
Ecuador	1.5%	Ecuador	3.6%
El Salvador	7.3%	El Salvador	7.3%
Guatemala	7.3%	Guatemala	7.3%
Mexico	23.2%	Mexico	20.0%
Peru	10.1%	Peru	11.0%
Puerto Rico	4.5%	Puerto Rico	3.6%
Dominican Republic	14.5%	Dominican Republic	11.0%
United States	7.3%	United States	18.2%
Other	10.1%	Other	5.5%

SECONDARY ANALYSES STUDY MEASURES

- SOCIODEMOGRAPHIC VARIABLES
  - AGE; AGE AT DIAGNOSIS
  - LEVEL OF EDUCATION
  - EMPLOYMENT STATUS
  - HEALTH INSURANCE STATUS
  - SURVEY LANGUAGE
  - IMMIGRANT STATUS
  - COUNTRY OF ORIGIN
  - YEARS IN US
- FINANCIAL DISTRESS



- CLINICAL VARIABLES:
  - TREATMENT HISTORY
    - SURGERY
    - CHEMOTHERAPY
    - RADIATION
    - HORMONAL THERAPY
  - DISEASE STAGE
  - COMORBIDITIES
- ACCULTURATION:
  - SHORT ACCULTURATION SCALE-HISPANICS, 12-ITEMS (MARIN ET AL., 1987)

FINANCIAL DISTRESS ITEMS

1. WHAT DO YOU FEEL THE LEVEL OF YOUR FINANCIAL STRESS IS TODAY? (1 TO 10 SCALE)
2. HOW OFTEN DO YOU WORRY ABOUT BEING ABLE TO MEET NORMAL MONTHLY LIVING EXPENSES? (1 TO 10 SCALE)
3. HOW OFTEN DOES THIS HAPPEN TO YOU? YOU WANT TO GO OUT TO EAT, GO TO A MOVIE OR DO SOMETHING ELSE AND BECAUSE YOU CAN'T AFFORD TO? (1 TO 10 SCALE)

CRONBACH'S ALPHA = .93

FROM THE "MY-HEALTH STUDY" (POTOSKY & MONTROSE, MPIS; PRAWITZ ET AL., 2006)

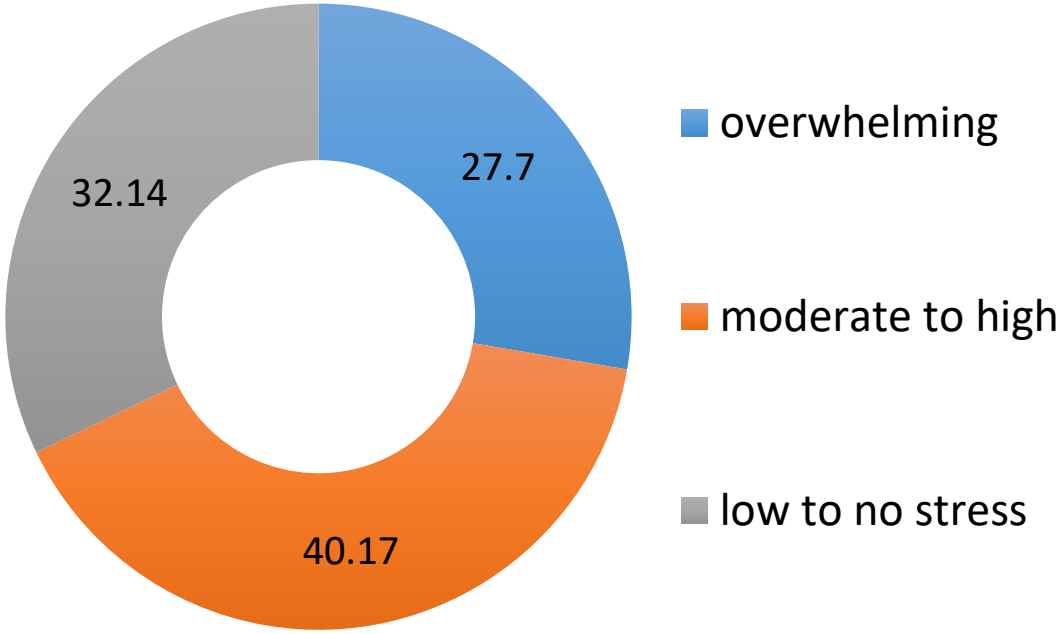
OUTCOMES: DOMAINS OF QUALITY OF LIFE

- PATIENT REPORTED OUTCOMES MEASUREMENT INFORMATION SYSTEM (PROMIS®)
  - PHYSICAL FUNCTIONING
  - SOCIAL FUNCTIONING
  - DEPRESSION
  - ANXIETY
  - FATIGUE

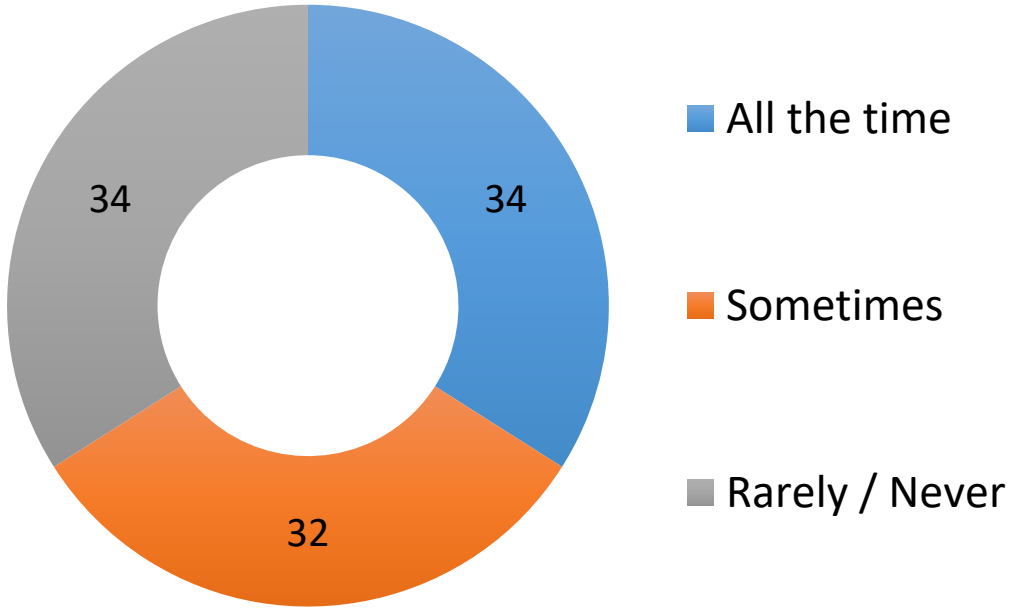
Jensen et al., 2017, Journal of Clinical Oncology

RESULTS AMONG SURVIVORS: FINANCIAL CONCERNS

Level of Financial Stress:



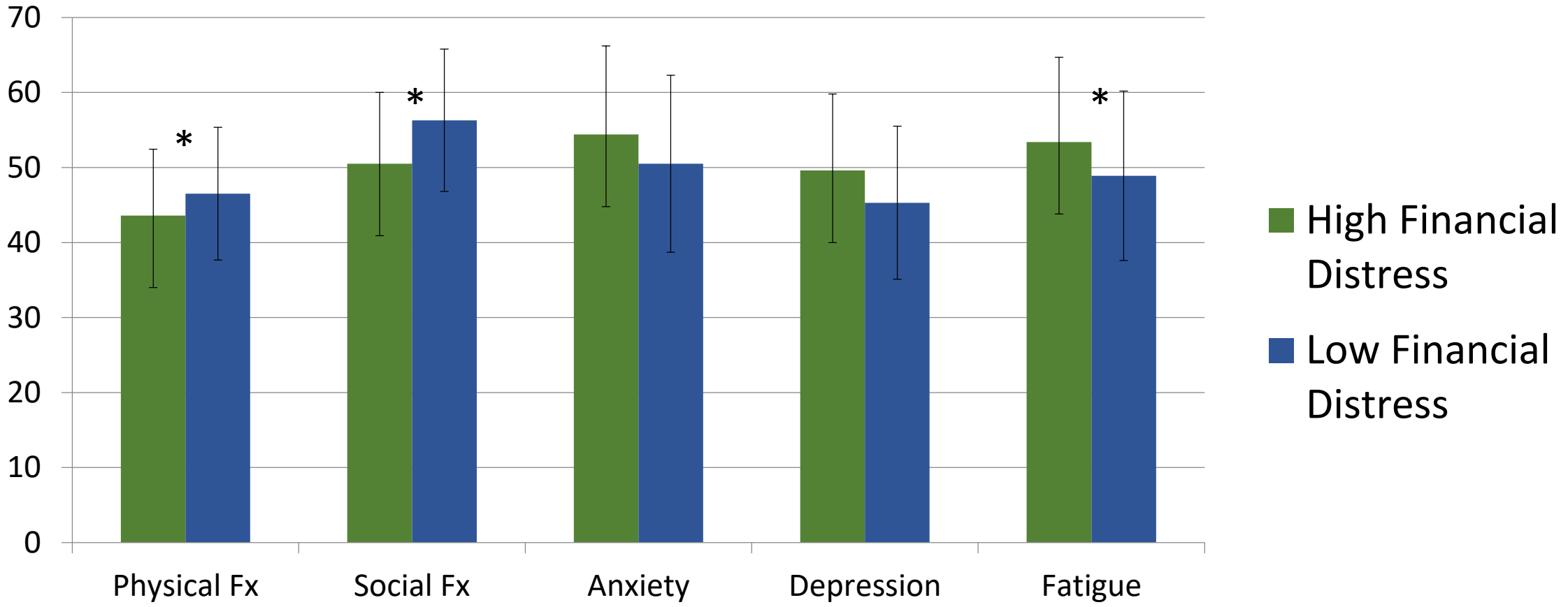
Worry about Normal Monthly Expenses:



RESULTS OVERVIEW

- ACCULTURATION ASSOCIATED WITH FINANCIAL DISTRESS, BUT RELATIONSHIPS BECAME NON-SIGNIFICANT ONCE CONTROLLING FOR OTHER CLINICAL AND DEMOGRAPHIC FACTORS
- FINANCIAL DISTRESS ASSOCIATED WITH SOME QUALITY OF LIFE DOMAINS: PHYSICAL, SOCIAL, FATIGUE
  - CONTROLLING FOR AGE, ACCULTURATION, CLINICAL VARIABLES, EDUCATION, EMPLOYMENT, BA OF LIFE AND RANDOMIZATION GROUP
  - UNRELATED TO ANXIETY AND DEPRESSION

FINANCIAL DISTRESS & QOL DOMAINS



* p < .05

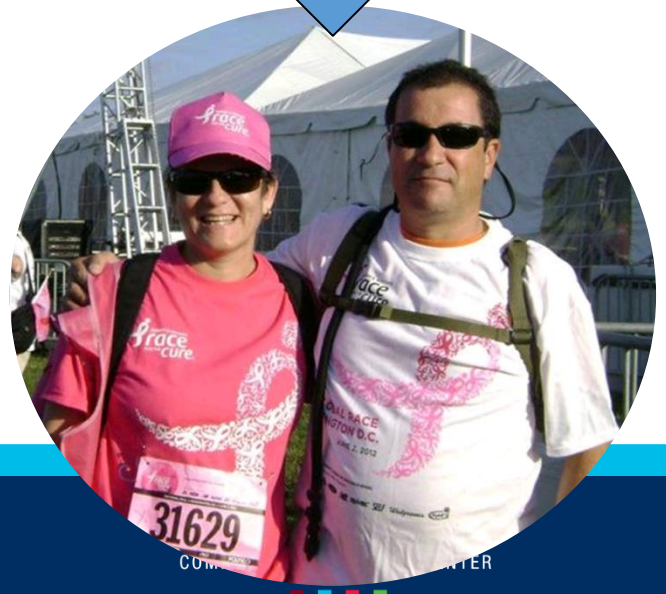
HOW MIGHT WE REDUCE DISTRESS?

NUEVA VIDA INTERVENTION

NUEVA VIDA INTERVENTION

Survivor Group

Caregiver Group



Gather together / Discuss topics

NUEVA VIDA INTERVENTION

- 8 *"TALLERES"* (WORKSHOPS)
  - 2 PER MONTH
  - 5 CORE TOPICS
  - 3 TOPICS: "RESEARCH DEMOCRACY"
- SURVIVORS AND CAREGIVERS MEET IN SEPARATE ROOMS
- ALL GATHER TOGETHER AT END TO DISCUSS
- GROUPS SHARE A MEAL

Impact of Cancer on Family (Introduction)*

Stress Management*

Improving Communication*

Spirituality and Cancer*

Balancing Physical and Emotional Needs*

Anger Management

Intimacy after cancer

Trauma and Cancer

Role Changes

Understanding Distress

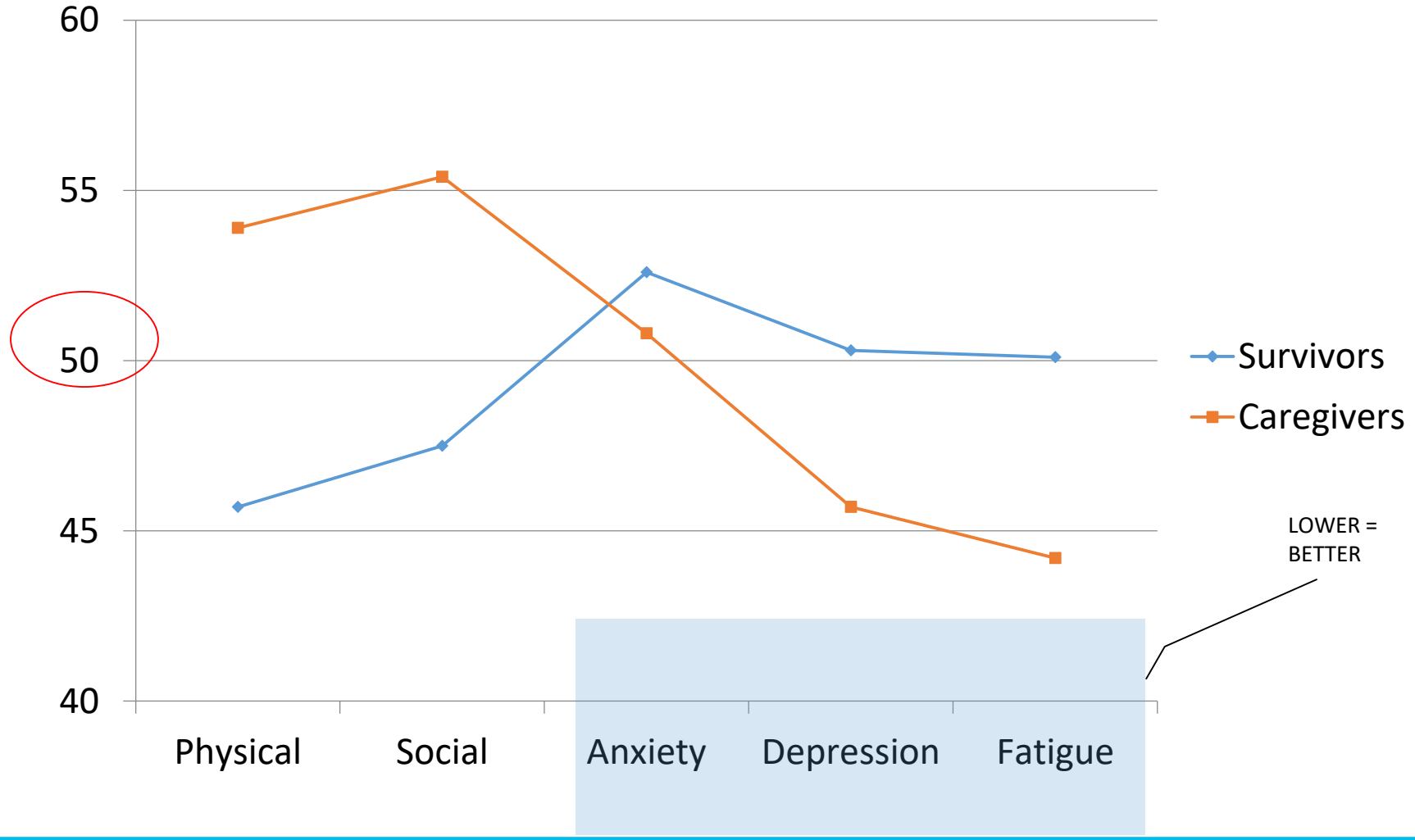
Myths and Cancer

Including Others in Helping Caregivers

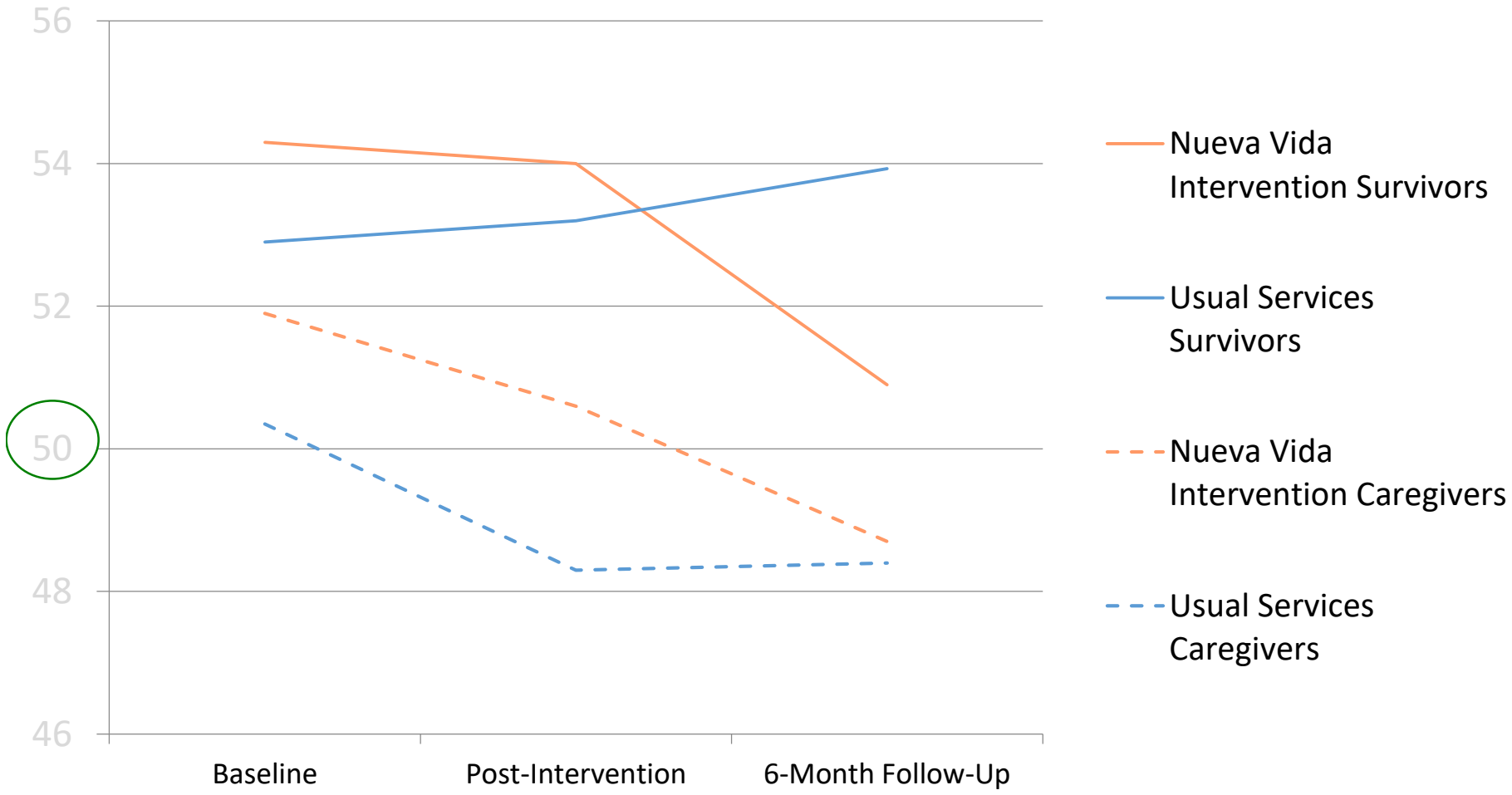
Putting Our Lives in Order

RESULTS: PROMIS OUTCOMES

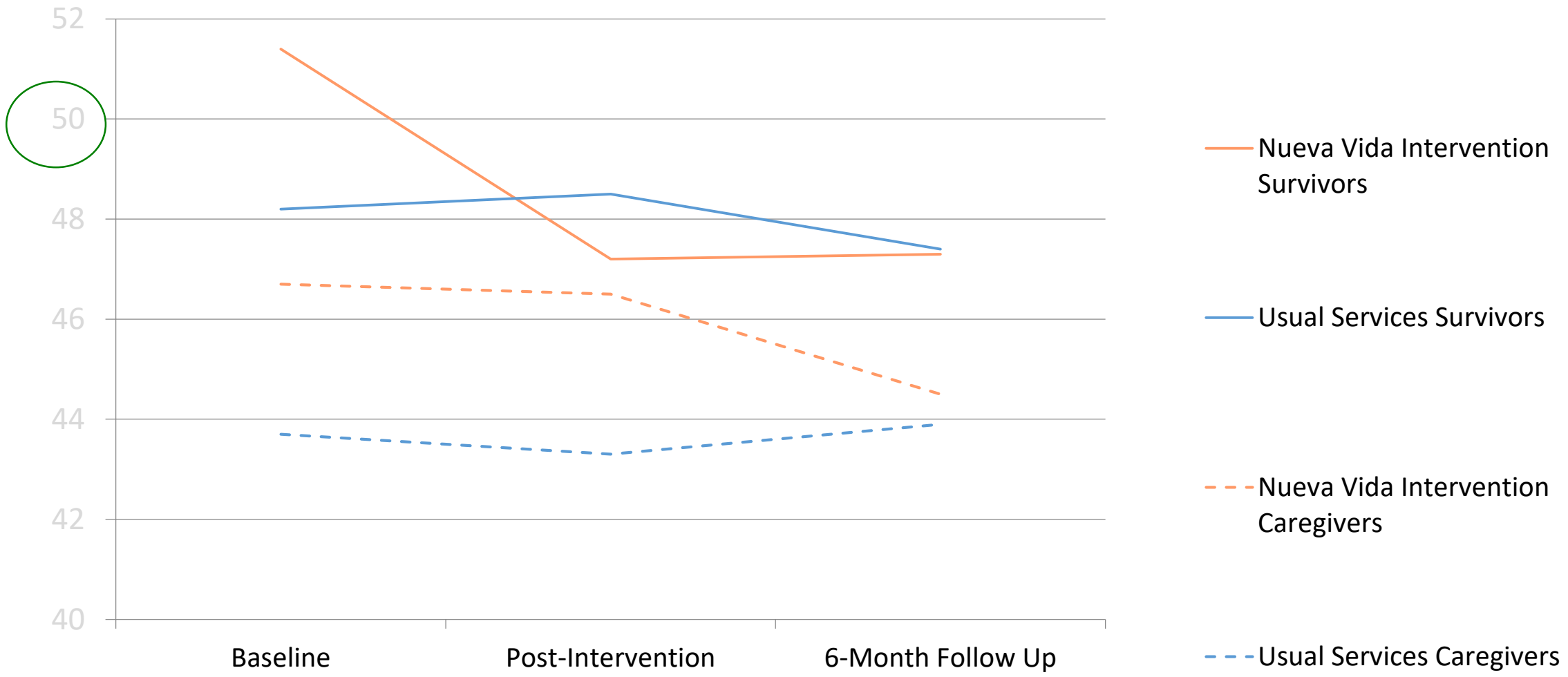
BASELINE PROMIS SCORES



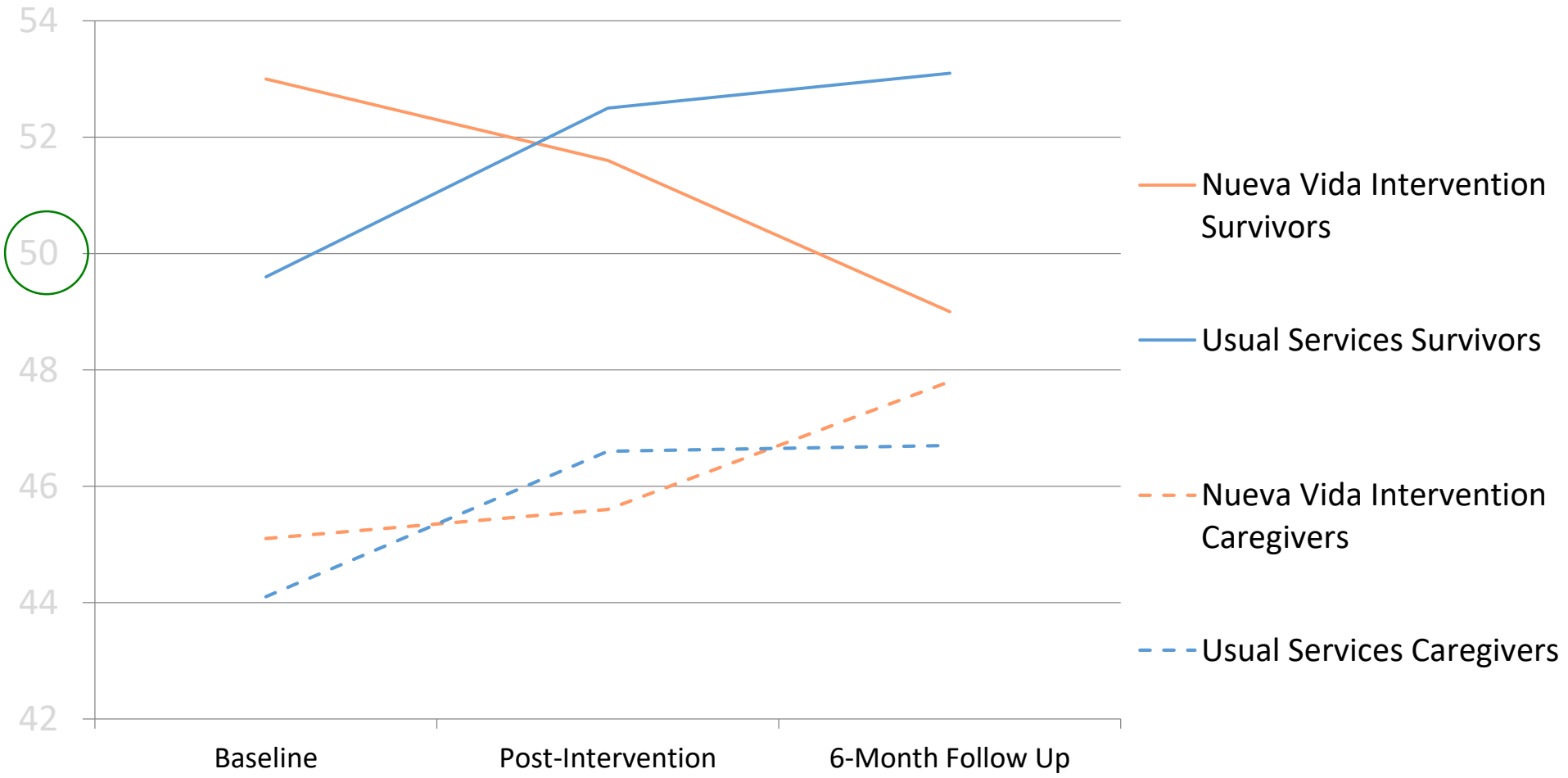
RESULTS: ANXIETY



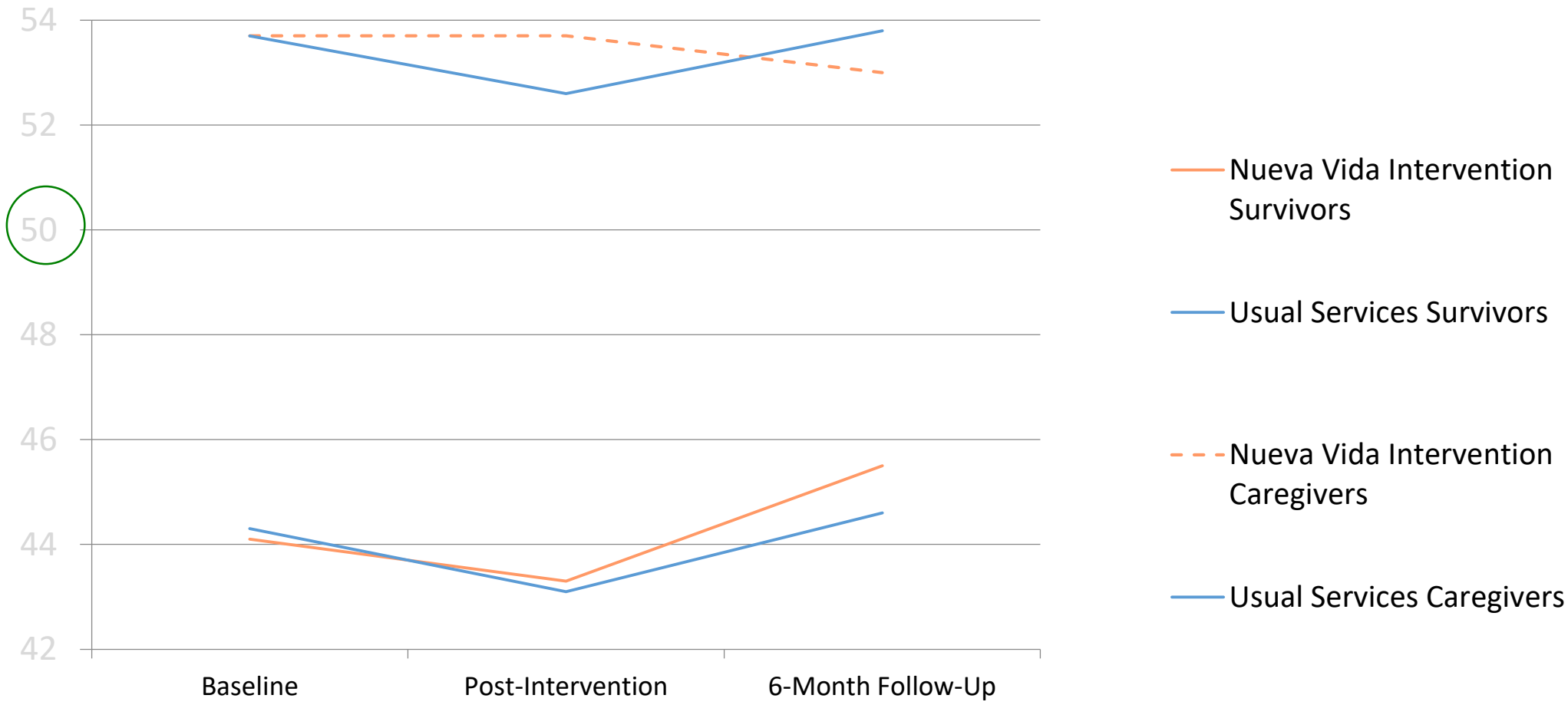
RESULTS: DEPRESSION



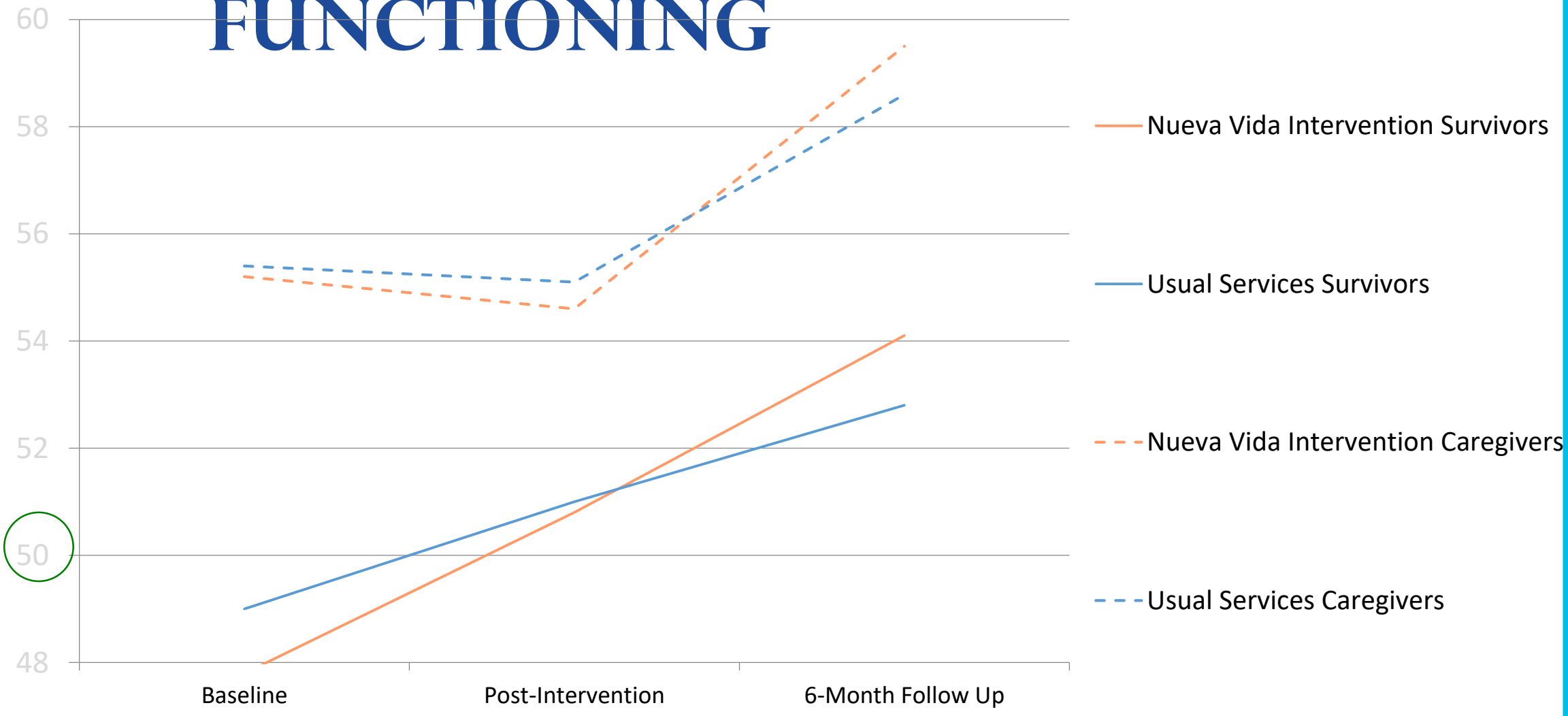
RESULTS: FATIGUE



RESULTS: PHYSICAL FUNCTIONING



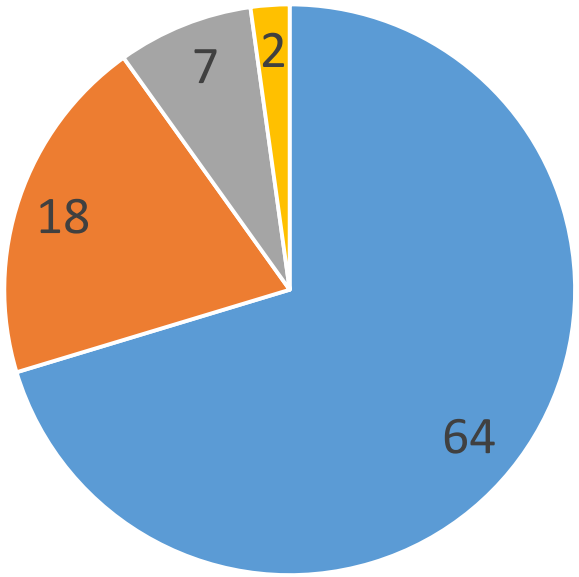
RESULTS: SOCIAL FUNCTIONING



WHAT IS THE IMPACT OF COVID-19 ON SURVIVORS?

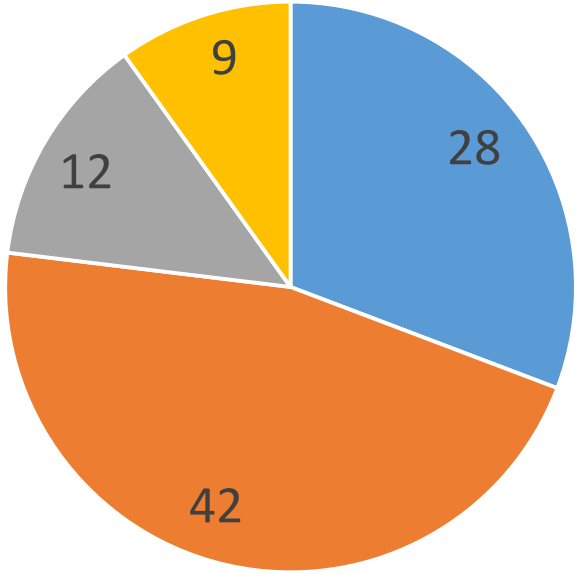
CANCER SURVIVORS DURING COVID-19: MENTAL HEALTH

Depression 29.7%



None Mild Moderate Severe

Anxiety 69.2%

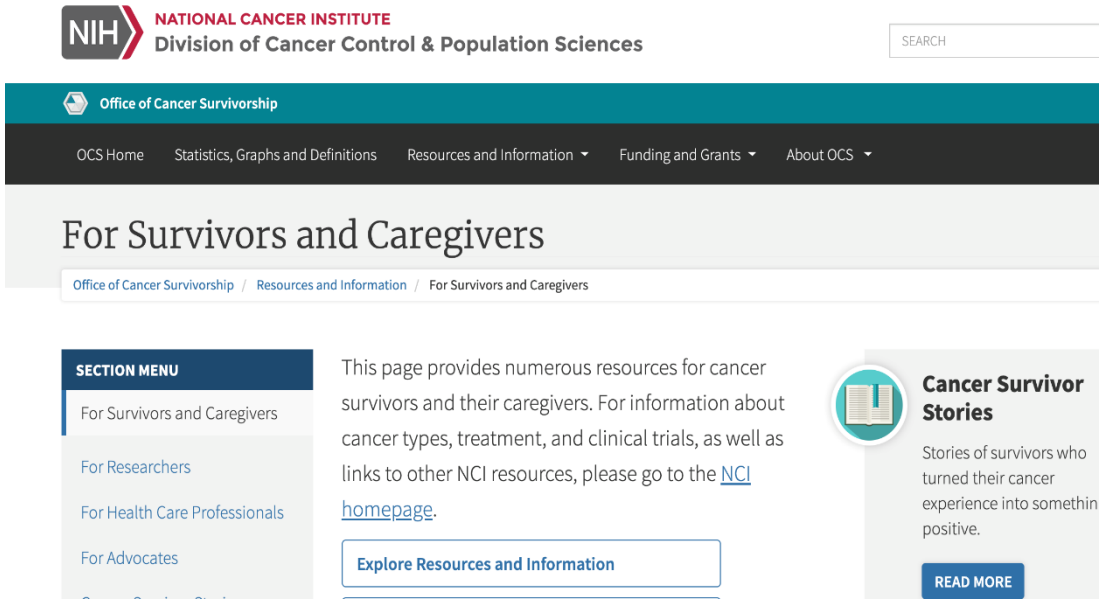


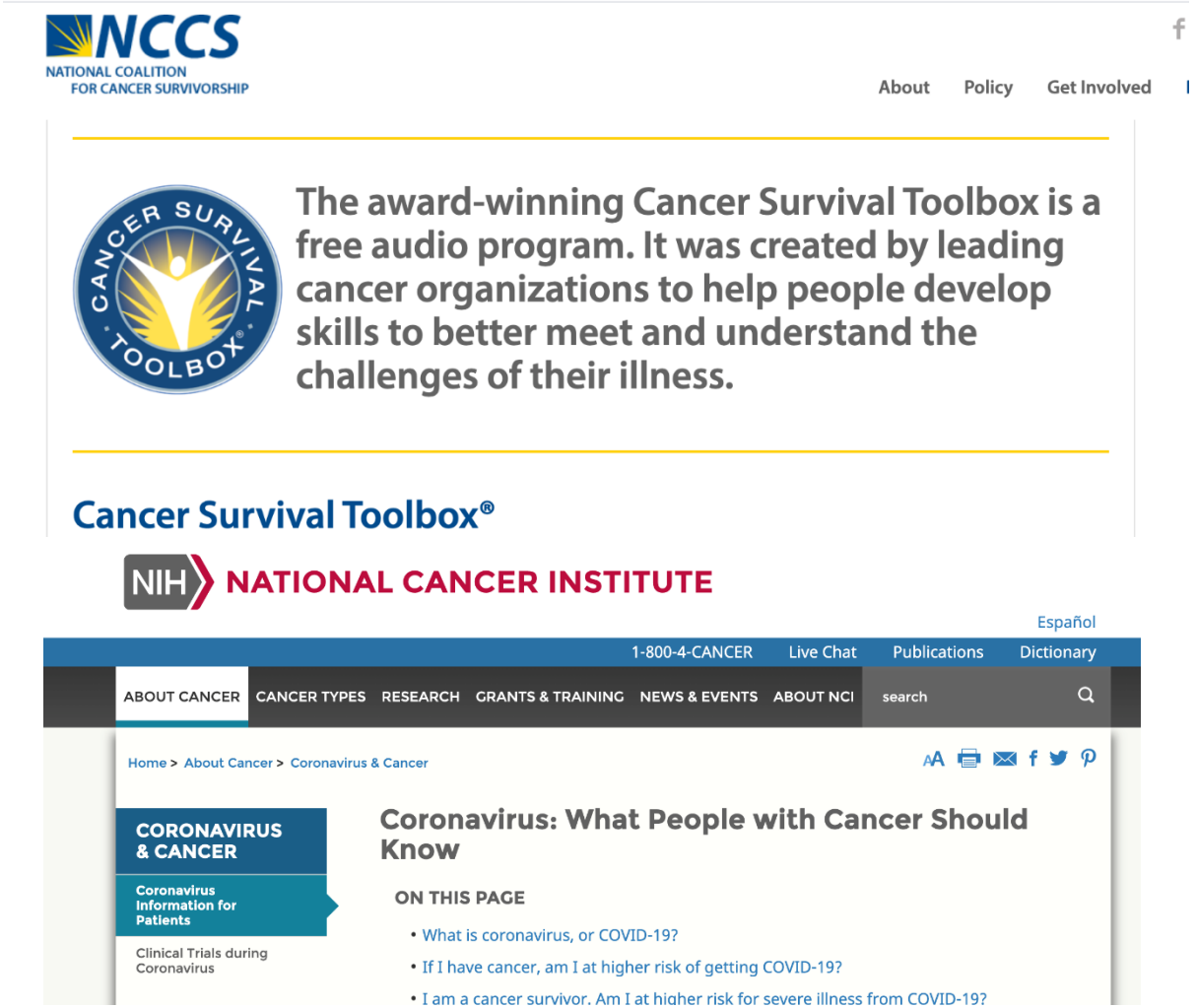
None Mild Moderate Severe

Higher family support associated with lower anxiety

Letaief-Ksontini et al., 2020, Ann Oncol. 2020 Sep;31:S957–8. PMCID: PMC7506327.

SOURCES OF INFORMATION & PATIENT RESOURCES





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