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# Caregivership Research and Practice: Quality of Life of Couples Dealing with Cancer

Youngmee Kim, PhD



*Facilitating Adjustment to Medical Illness in Your Family*

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# **Quality of Life among Cancer Caregivers**

# Faces of Cancer Caregivers

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- 7% of 43.5 million adult caregivers
- Females (60%); Mid-aged (55 years old); Spouse (66%)
- Provide complex care at home:  
Around dx and tx: In between: End-of-life
- Cancer in the family comes as a surprise - unprepared
- Greater emotional distress, poorer mental and physical health

# Caregivership Model

## Caregivership Phases (Five Seasons)

Early----- Mid-term ----- Long-term -----  
----- End-of-life ----- Bereavement -----  
----- Prevention -----

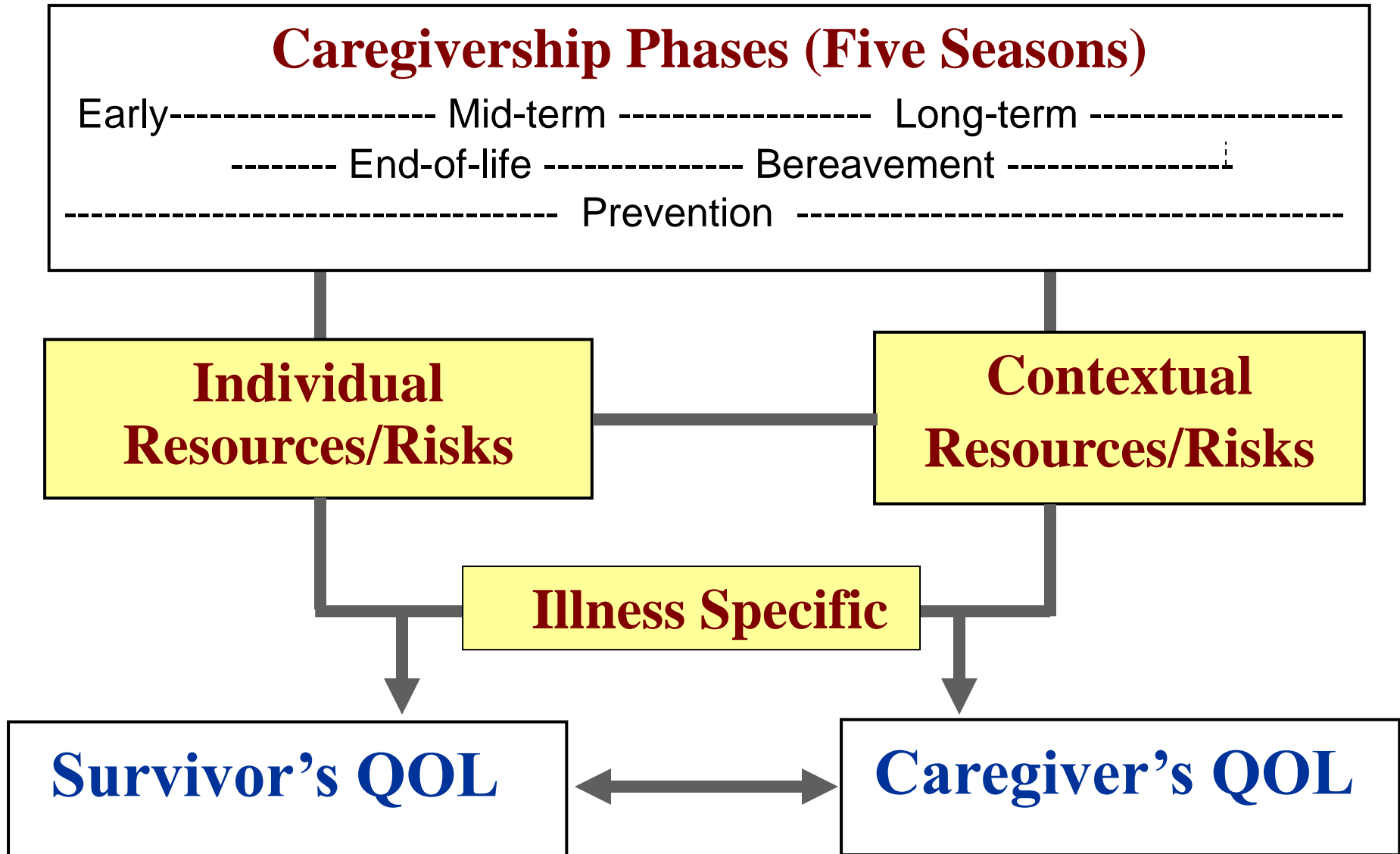
**Individual  
Resources/Risks**

**Contextual  
Resources/Risks**

**Illness Specific**

**Survivor's QOL**

**Caregiver's QOL**



Psychosocial  
Functioning



Spiritual  
Adjustment



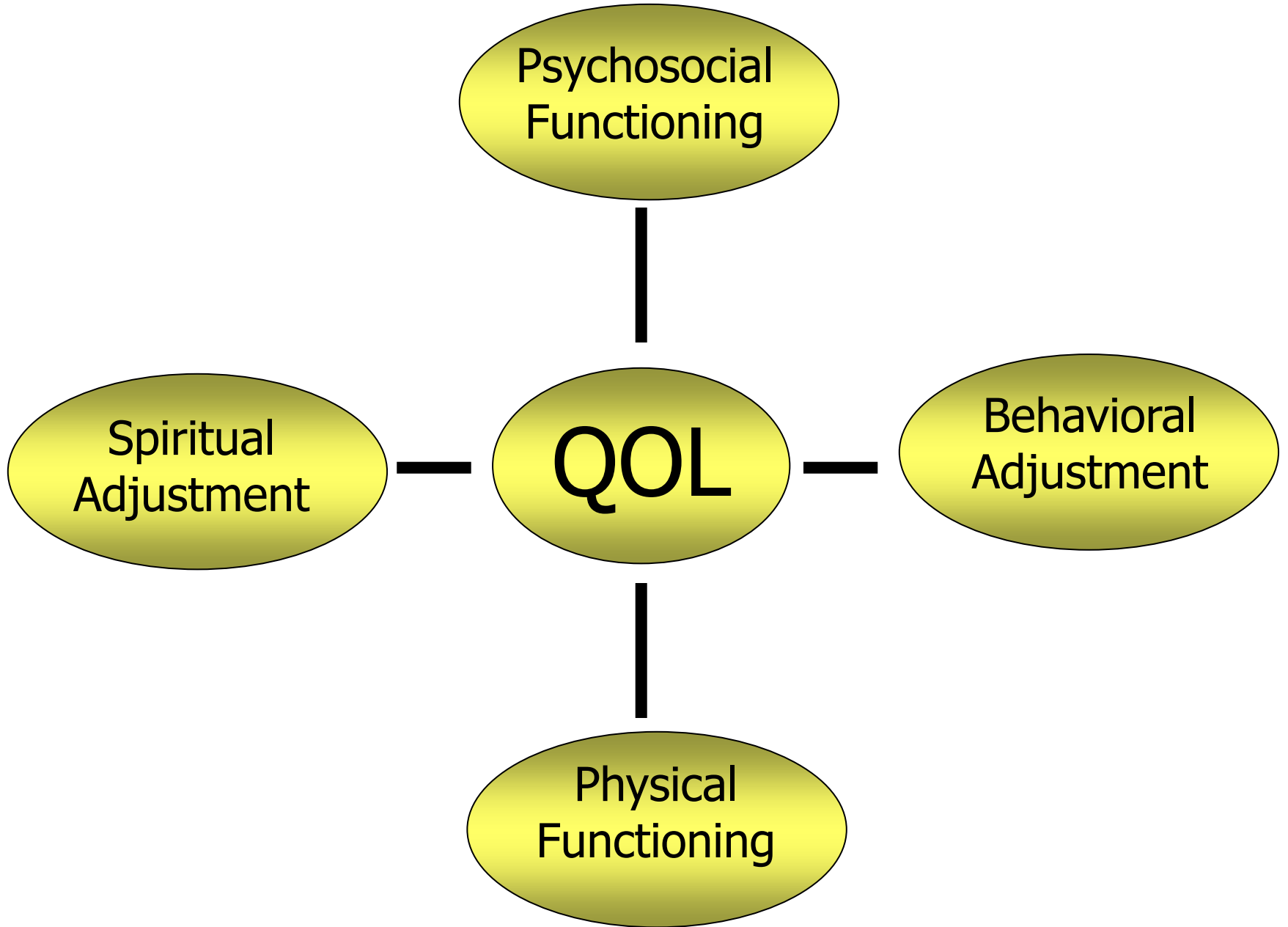
QOL



Behavioral  
Adjustment



Physical  
Functioning



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# **Psychosocial Predictors of Caregivers' QOL**

# Predictors of Caregivers' QOL

## Caregivership Phases (Five Seasons)

### ❖ Individual Factors: Demographics

----- End-of-life ----- Bereavement -----  
----- Prevention -----

#### • Factors studied: Age

#### Individual Resources/Risks

Gender  
Education  
Income  
Spouse

#### Contextual Resources/Risks

- Younger **age** related to poorer psychological and spiritual adjustment, and poorer mental health
- Older age related to poorer physical health

# Predictors of Caregivers' QOL

## Caregivership Phases (Five Seasons)

Early-----

----- End-of

Prevention -----

### ❖ Contextual Socio-Cultural Factors

- Factors studied: Ethnicity  
Employed  
Social Support

### Contextual Resources/Risks

- Social support related to better psychological and spiritual adjustment, and greater mental health
- Employment related to greater physical health



# Predictors of Caregivers' QOL

## ❖ Illness-Specific Factors

- **Factors studied:**
  - Caregiving hours
  - Perceived caregiving stress
  - Caregiver esteem
  - Patients' mental & physical functioning

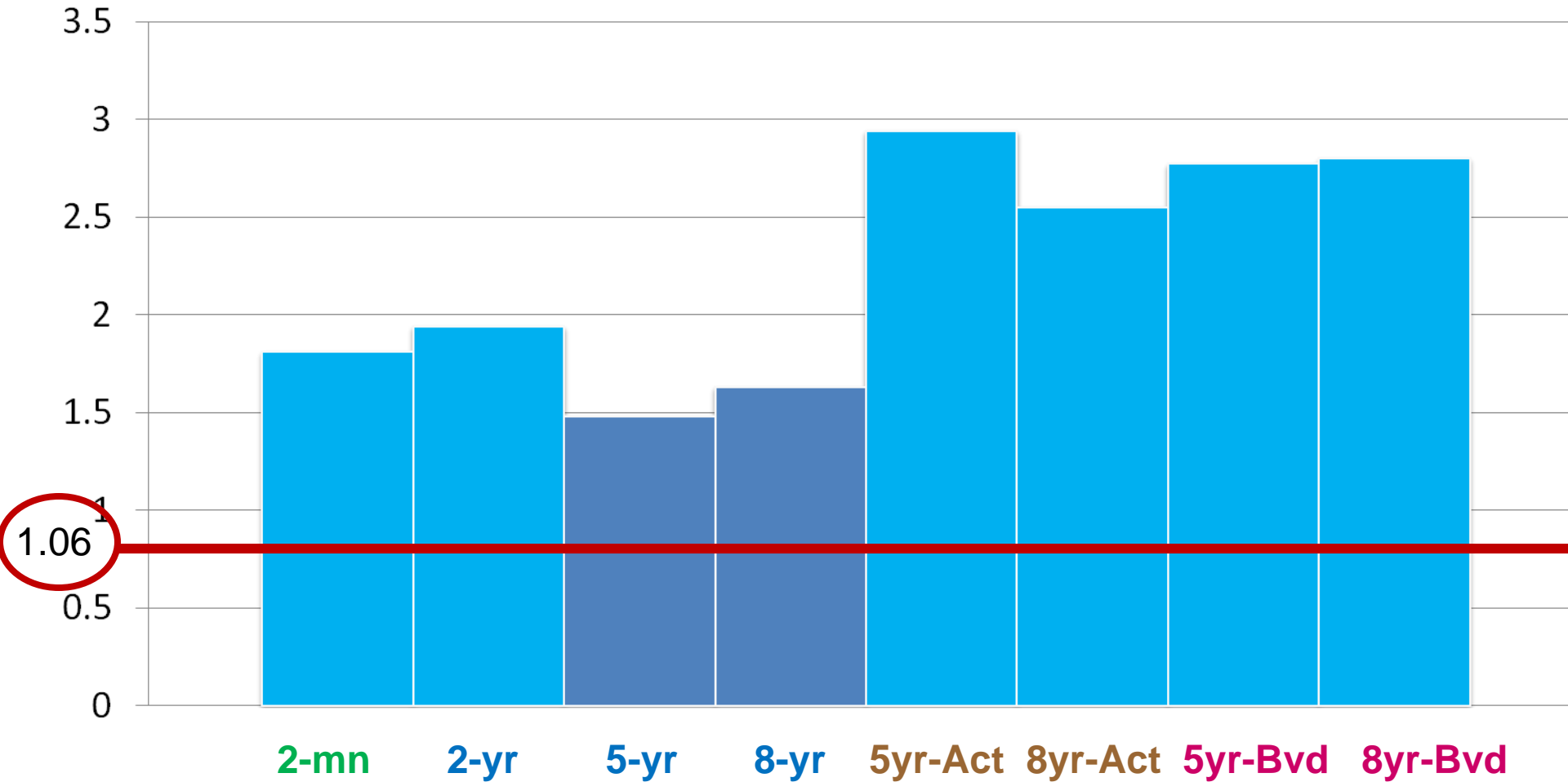
## Illness Specific

- Perceived/Subjective caregiving stress related to poorer psychological and spiritual adjustment, and poorer mental and physical health

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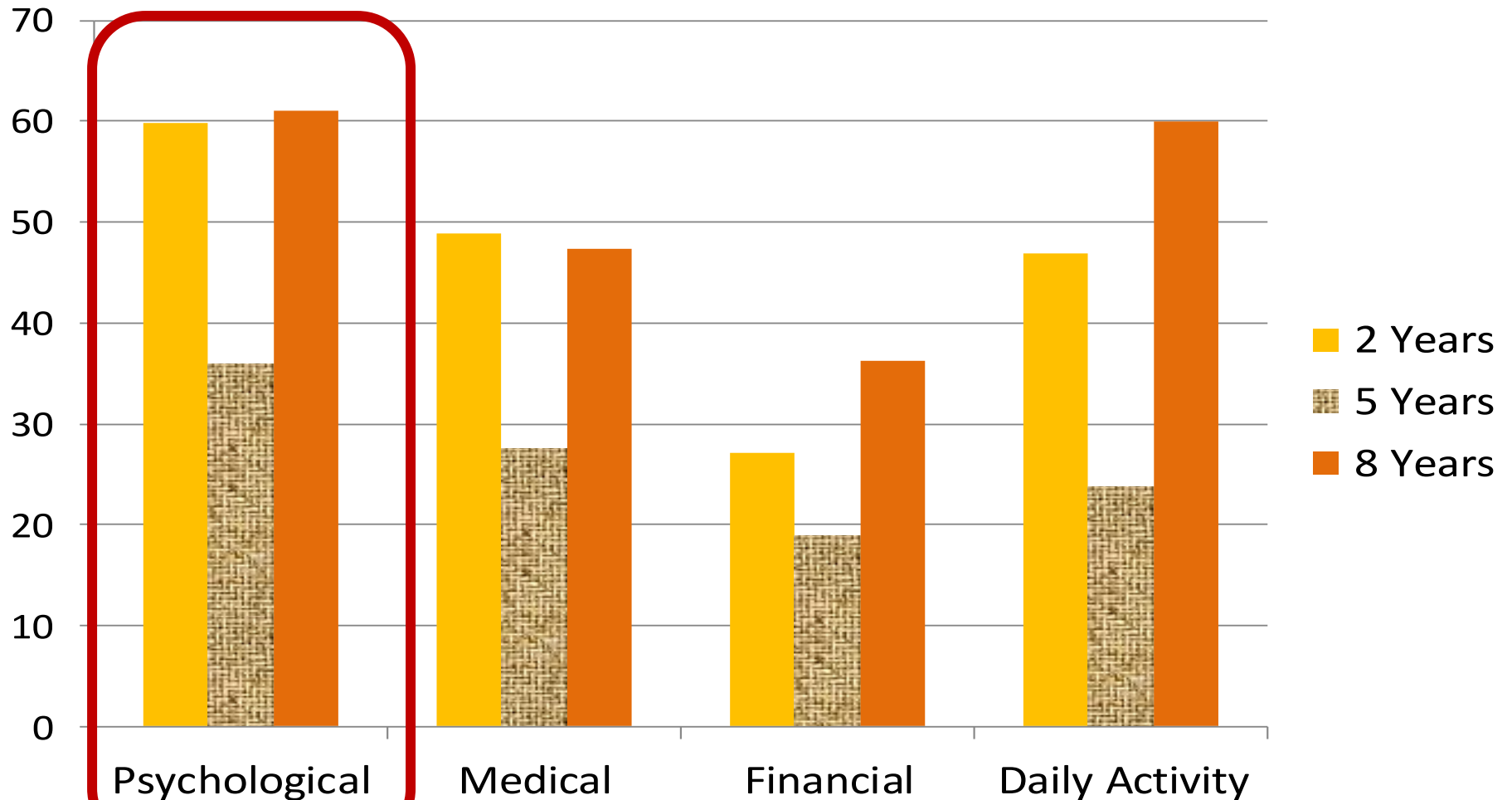
# **Additive & Synergistic Effects of Psychosocial Predictors**

# Caregiver Psychological Distress (POMS-SF)



Reference score: McNair & Neuchert (2005).

# % Reported Unmet Needs of Caregivers



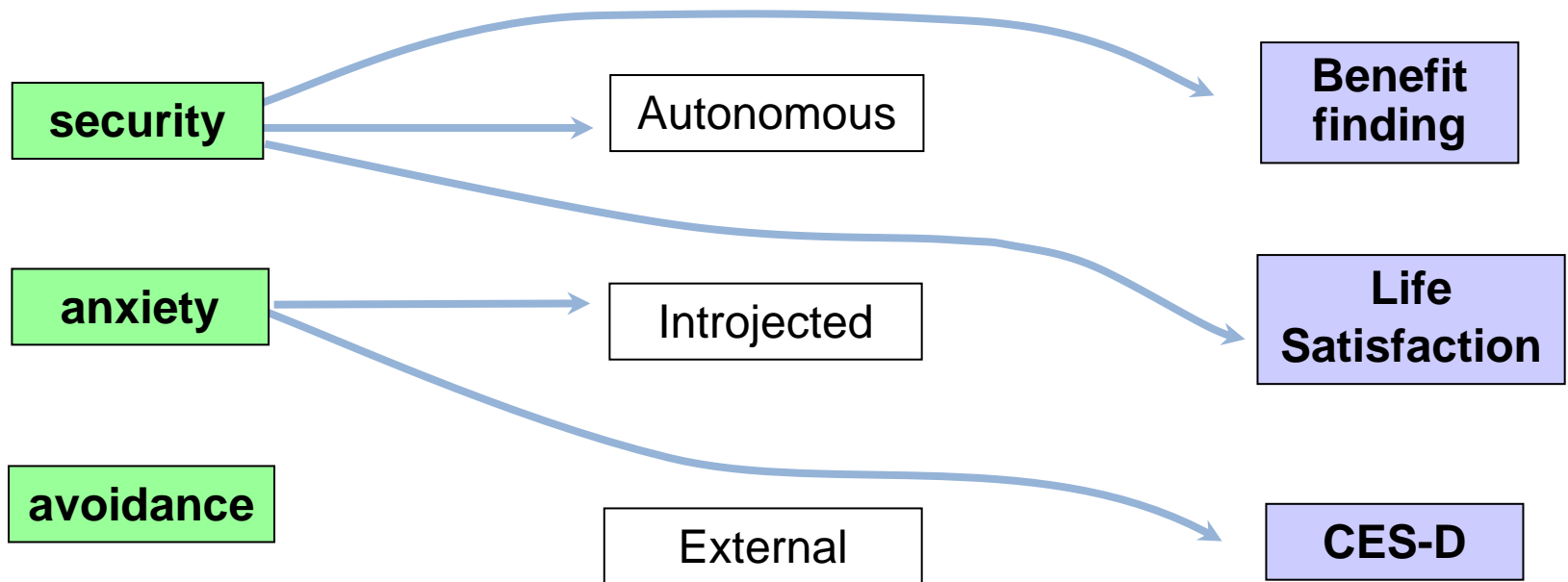
# Prevalence of Clinical Levels of Depressive Symptoms

		Former CG		Current CG		Bereaved	
		5 years post-dx					
		Depsd	Nondepsd	Depsd	Nondepsd	Depsd	Nondepsd
2 years post-dx: non-bereaved	Depressed	10.9%	10.0%	17.6%	12.2%	32.7%	17.3%
	Nondepsd	7.8%	71.3%	22.1%	52.9%	17.3%	32.7%

FCR = Former Caregivers-Remission (*N* = 230); CC = Current Caregivers (*N* = 68);  
FCB = Former Caregivers-Bereaved (*N* = 52)

Kim, Carver, Shaffer, & Cannady (2014).

# Attachment & Self-Determination Theories

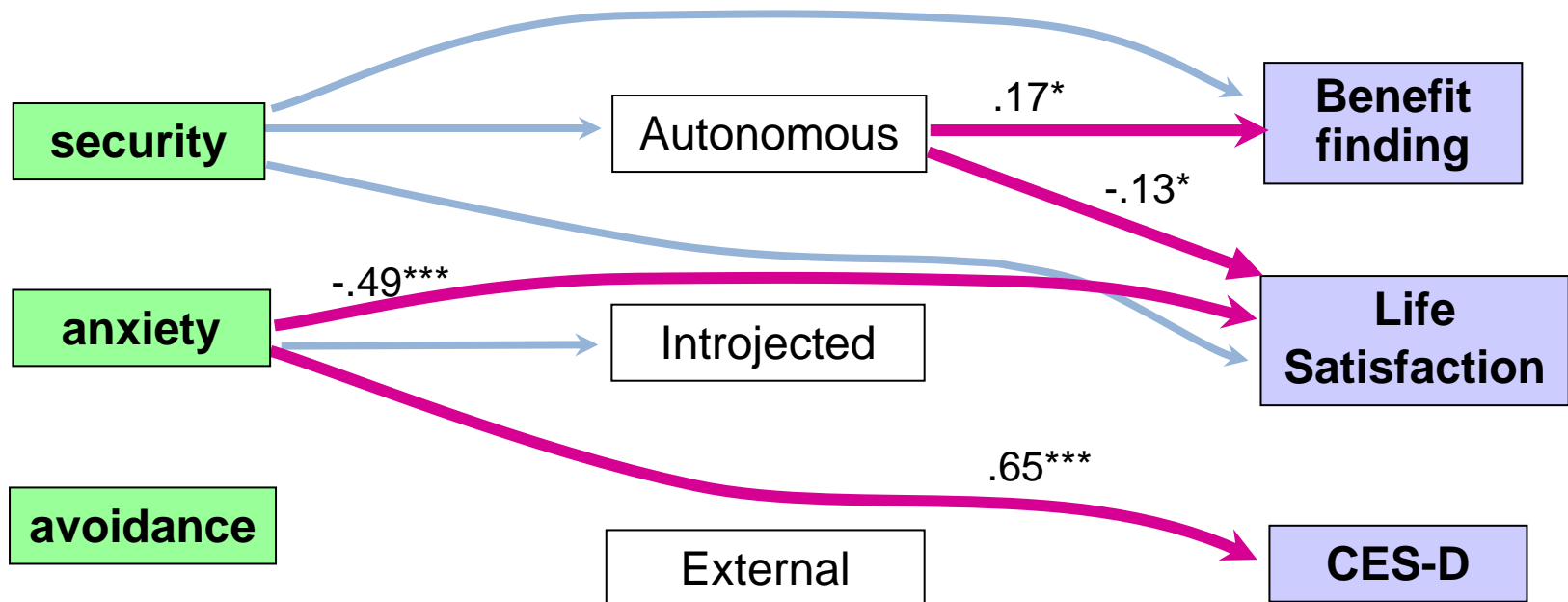


# Wives

Attachment qualities

Caregiving motives

Adjustment

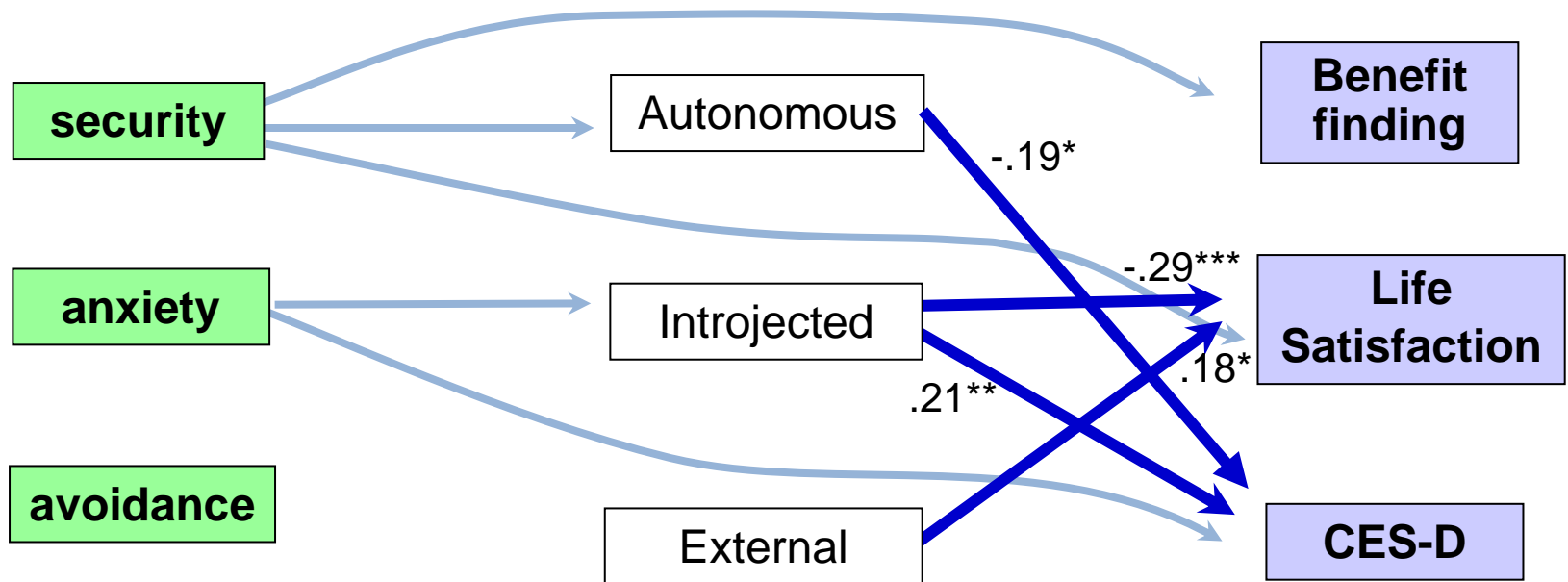


# Husbands

Attachment qualities

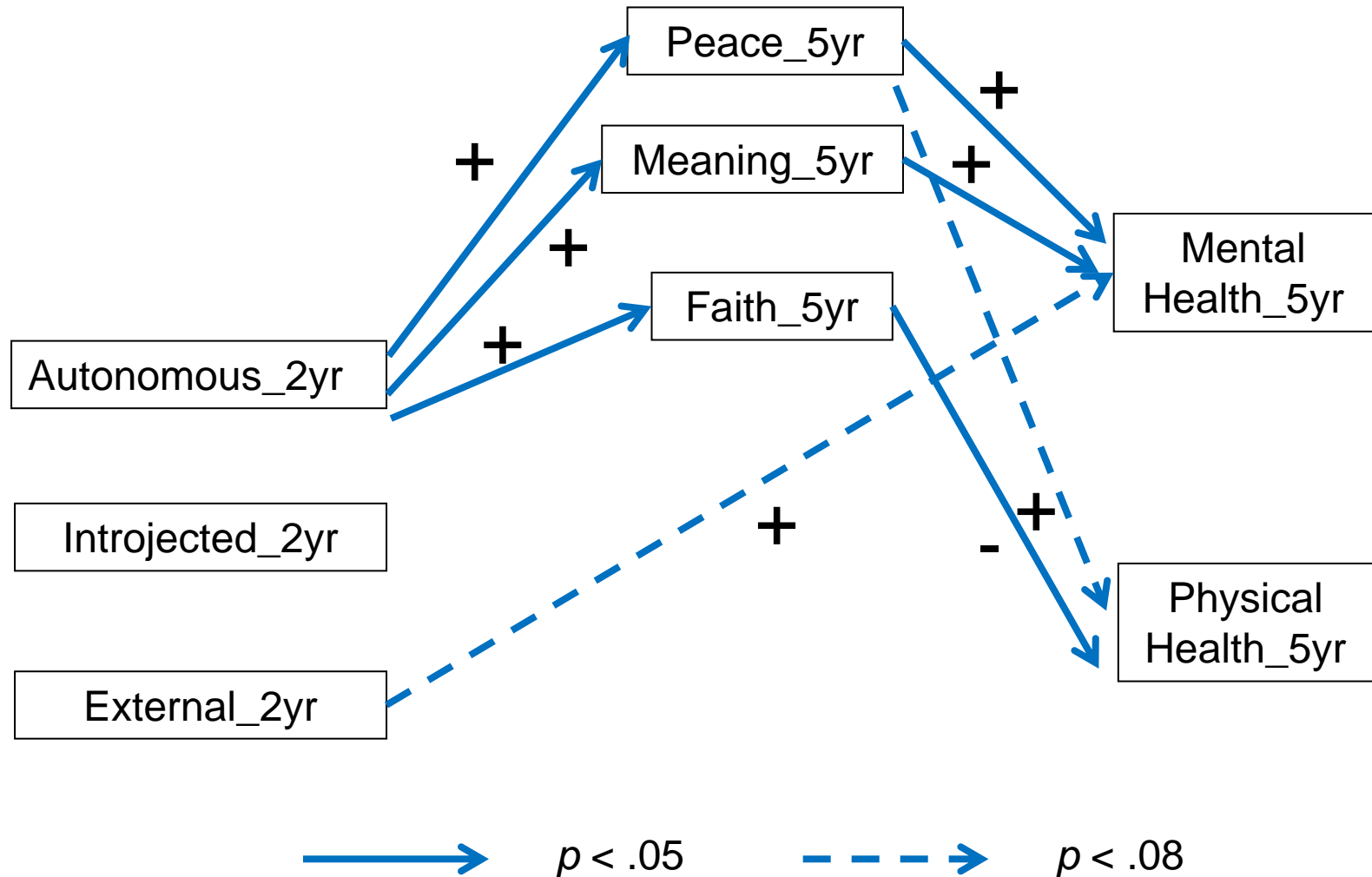
Caregiving motives

Adjustment





# Male Caregivers QOL at 5 years Post-Dx





# **Gender in Psycho-Oncology**

**YOUNGMEE KIM  
MATTHEW J. LOSCALZO**

**OXFORD**

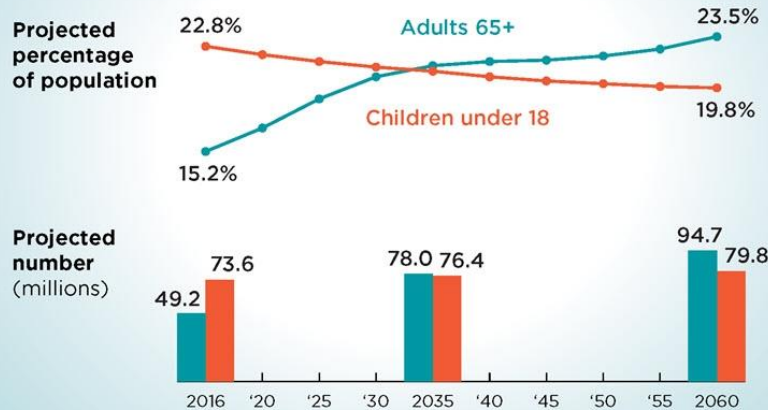
# An Aging Globe



## An Aging Nation

Projected Number of Children  
and Older Adults

For the First Time in U.S. History Older Adults Are  
Projected to Outnumber Children by 2035



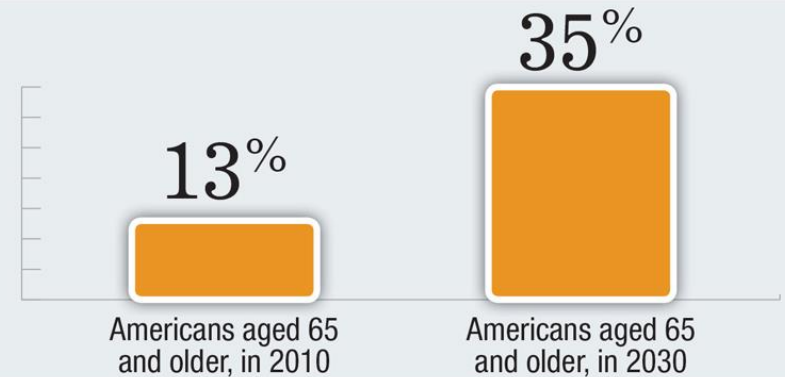
Note: 2016 data are estimates not projections.

United States<sup>™</sup>  
**Census**  
Bureau

U.S. Department of Commerce  
Economics and Statistics Administration  
U.S. CENSUS BUREAU  
[census.gov](https://www.census.gov)

Source: National Population  
Projections, 2017  
[www.census.gov/programs-surveys/popproj.html](https://www.census.gov/programs-surveys/popproj.html)

## Older Population Expected to Double by 2050



World population, aged  
65 and older, in 2011



546  
million

World population, aged  
65 and older, in 2050

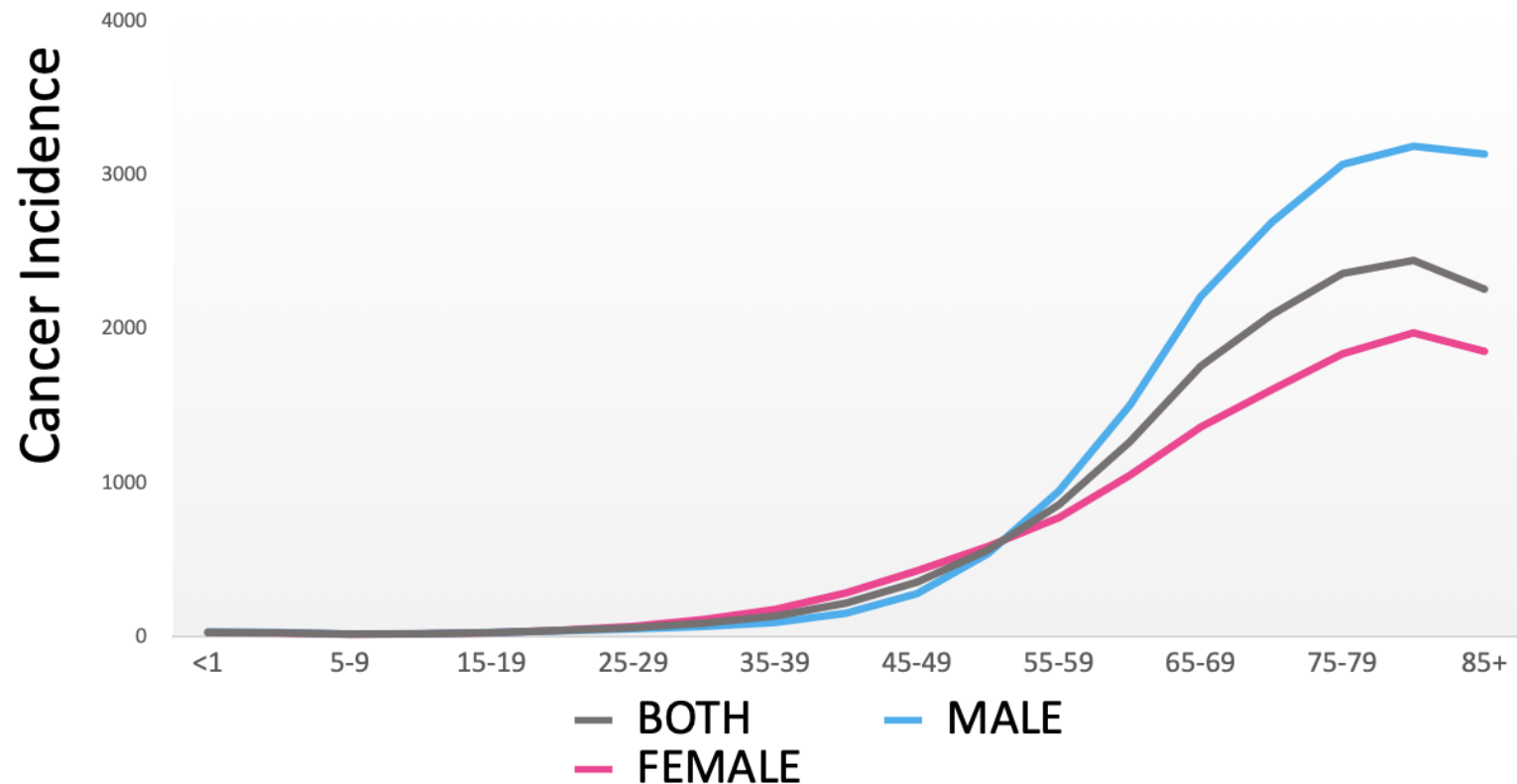


1.56  
billion

Source: U.S. Census Bureau

# Cancer Risk & Aging

Cancer Risk by Age Groups  
2004-2008 NCI-SEER data



# Physical Health of Caregivers

- ❖ Compared with non-caregivers, dementia caregivers had
  - ✓ 9% greater risk of health problems
  - ✓ 23% higher level of stress hormones
  - ✓ 15% poorer antibody production
  - ✓ 63% higher mortality
- ❖ Spouses of cancer patients increase the risks of coronary heart disease (CHD) and stroke by 13 to 29% up to 20 years after their spouse's cancer diagnosis, compared with a matched control



Pinquart & Sörensen, 2003; Vitaliano et al. (2003).

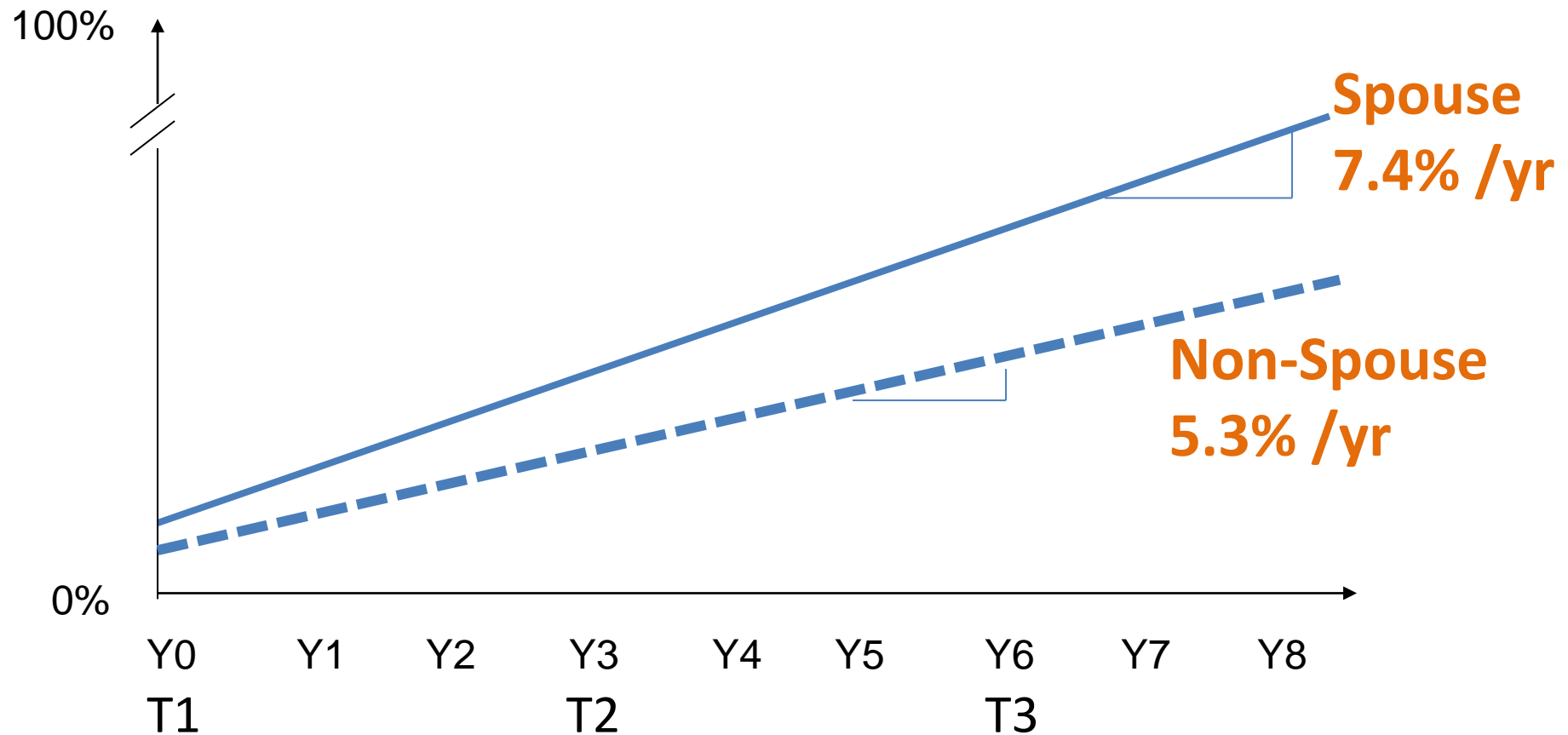
Ji, Zöller, Sundquist, & Sunquist (2012); Schneiderman, Kim, & Shaffer (2012)

# Predictors of Disability Markers

	Arthritis		Chronic Back Pain		Heart Diseases	
	Exp(B)	<i>p</i> <	Exp(B)	<i>p</i> <	Exp(B)	<i>p</i> <
Age	1.05	.0001	1.02	.004	1.05	.0001
Female Gender	1.41	.01	0.88	.47	0.71	.01
Education	1.03	.83	0.65	.01	0.80	.14
Income	0.68	.003	0.68	.02	1.11	.45
Spouse	0.84	.22	0.86	.39	0.75	.05
Obj Cg Stress	1.27	.39	0.89	.72	0.61	.06
Sub Cg Stress	1.31	.006	1.59	.0001	1.23	.05

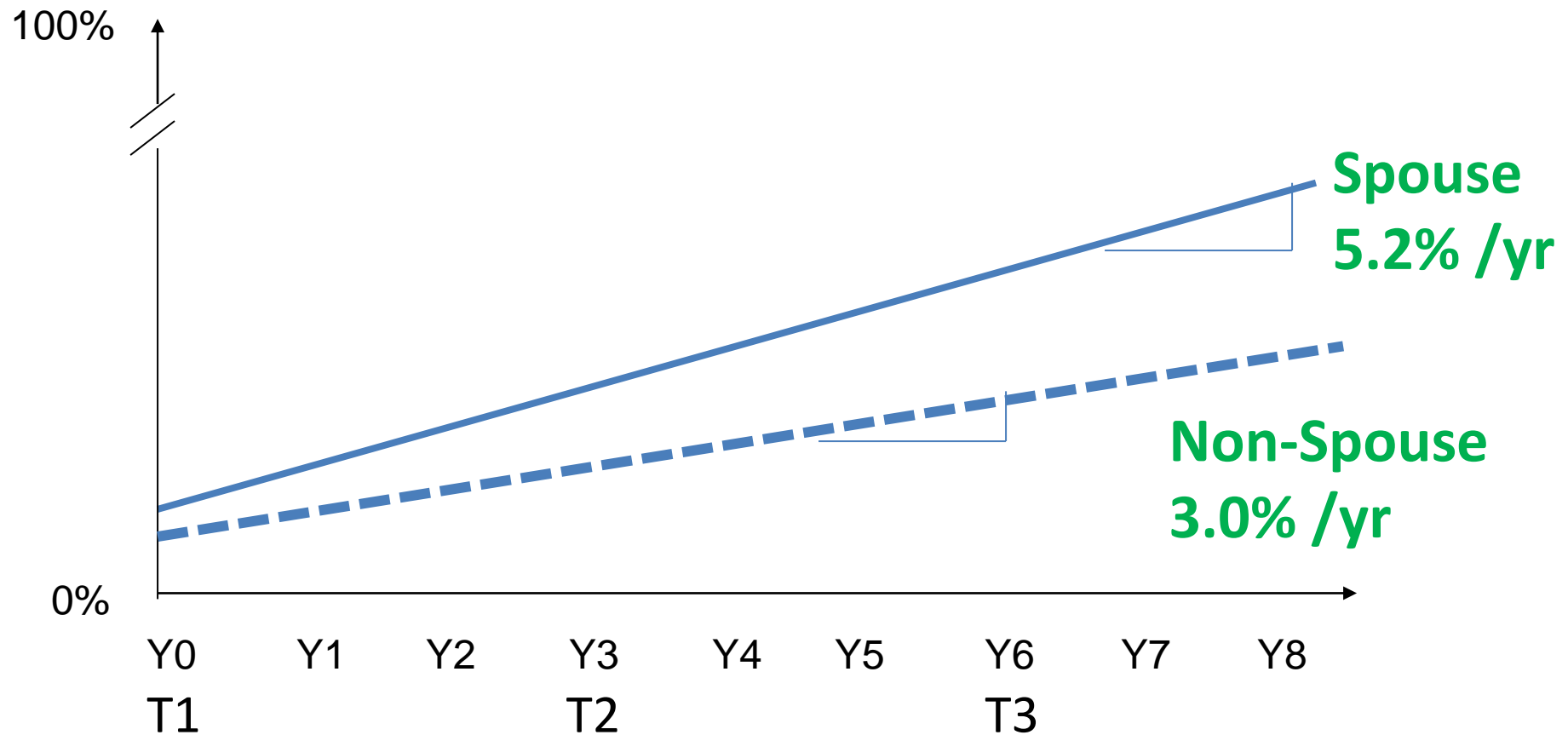
# Predictors of Disability Markers: Person x Time

**Spousal** Caregivers x Time Effect on Development of Arthritis



# Predictors of Disability Markers: Person x Time

**Spousal** Caregivers x Time Effect on Development of Back Pain

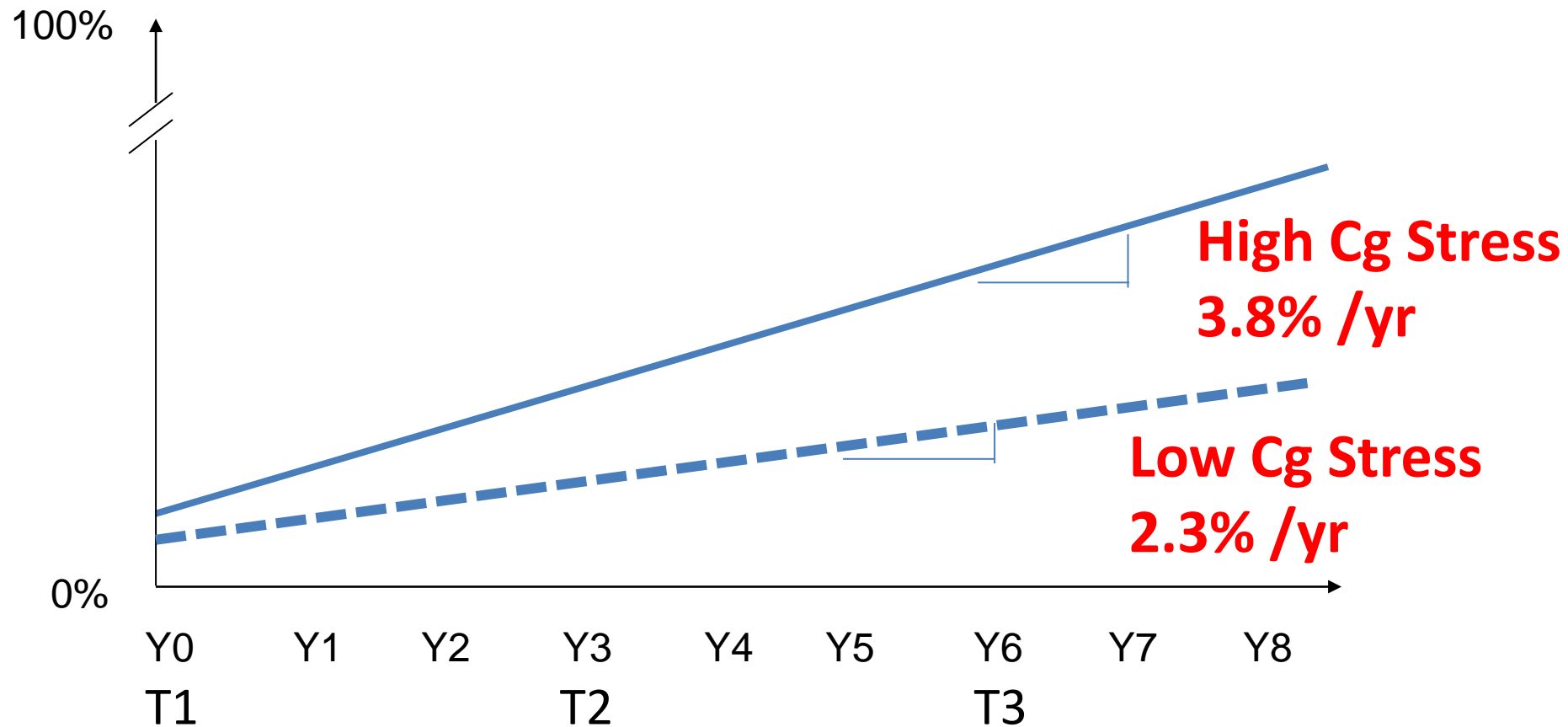


Kim, Carver, Shaffer, Gansler, & Cannady (2015)

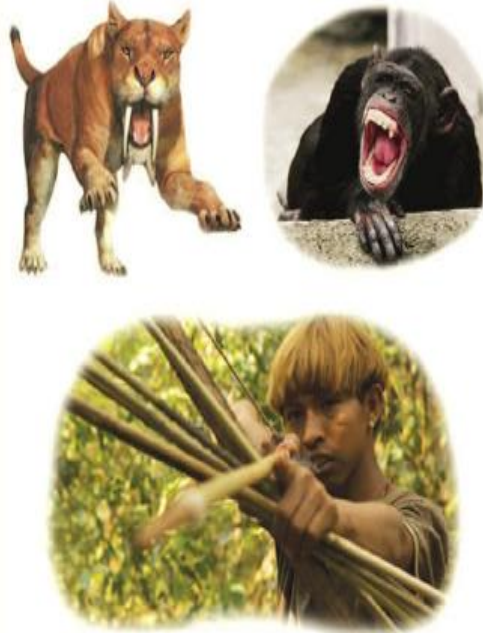


# Predictors of Disability Markers: Person x Time

Sub. Cg Stress x Time Effect on Development of Heart Diseases



## Historical Physical Threats



## Contemporary Social Threats



# Cancer Caregiving

## Conserved Transcriptional Response to Adversity (CTRA)



### Short-Term Benefits (Responding to Actual Physical Threat)

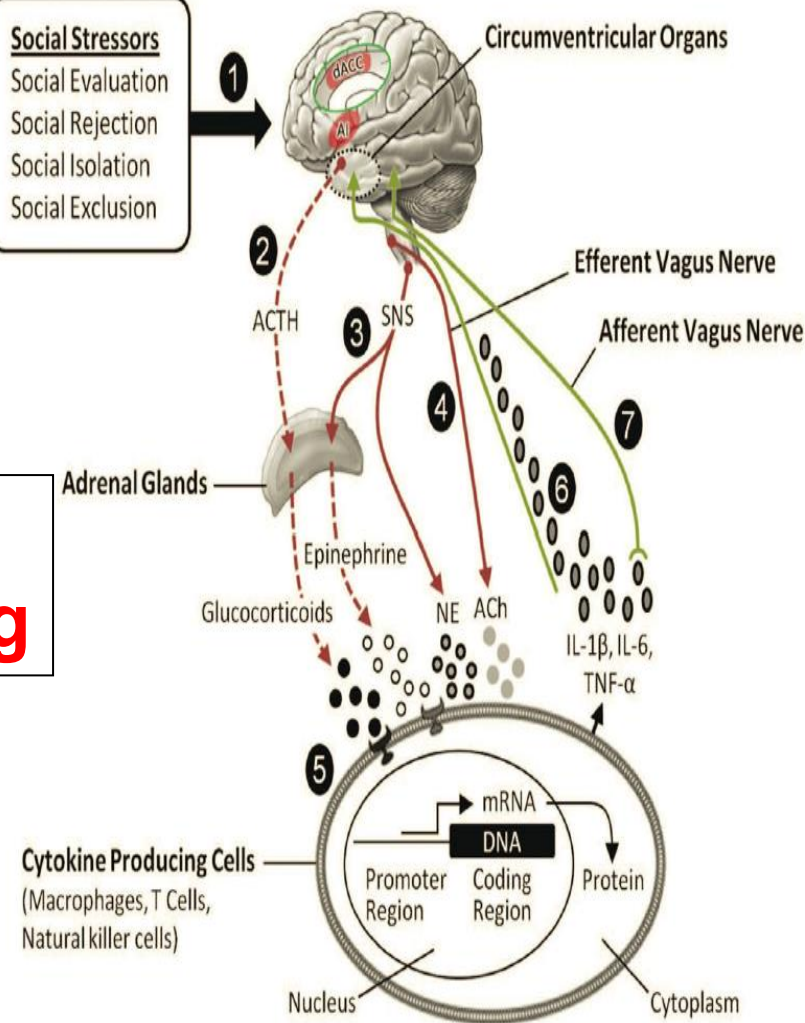
Enhanced Wound Healing  
Improved Physical Recovery  
Greater Likelihood of Survival

### Long-Term Costs (Responding to Perceived Social Threat)

Greater Inflammation-Related Disease Risk  
Increased Vulnerability for Viral Infection  
Lower Likelihood of Survival

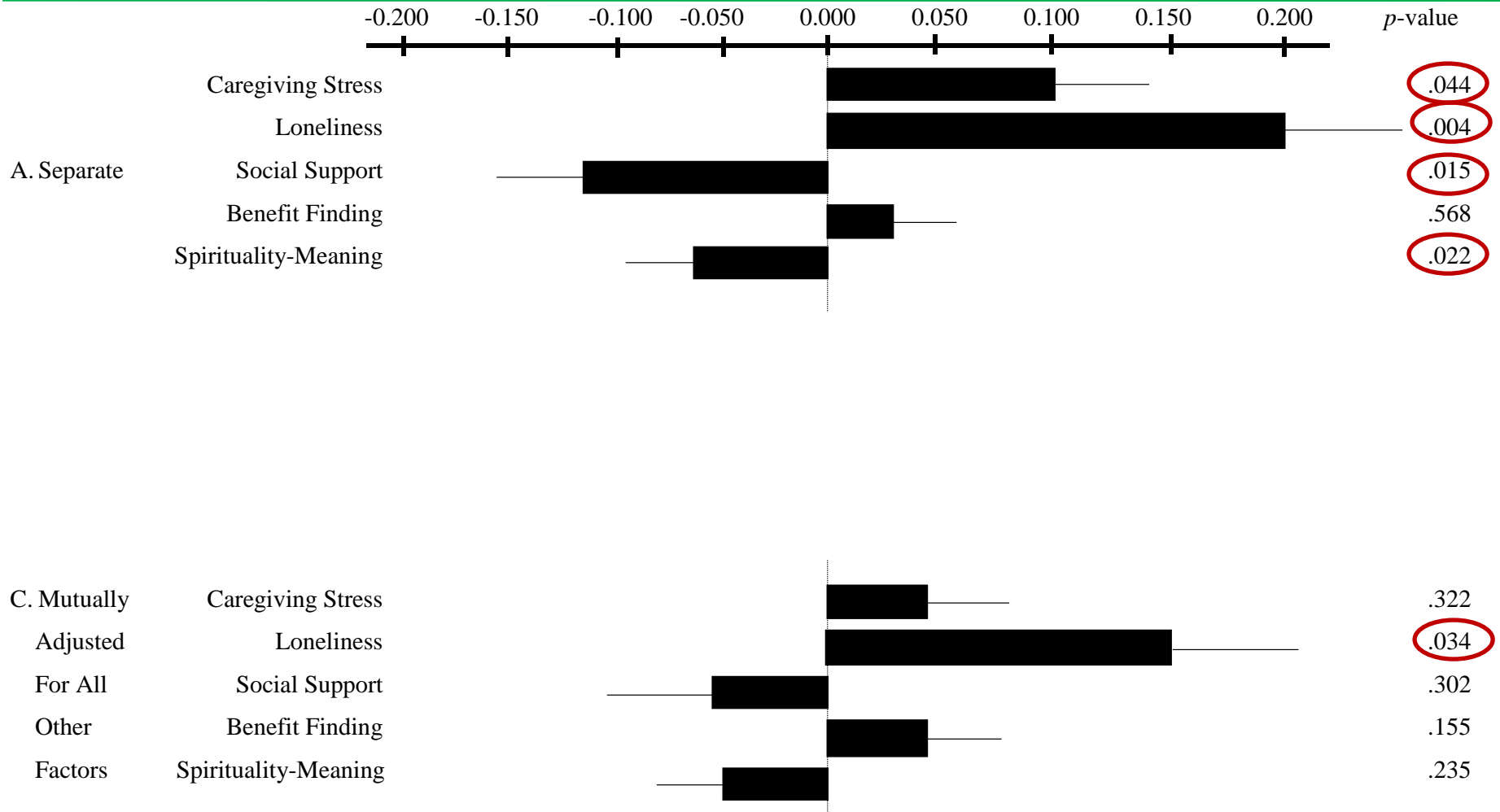
### Social Stressors

Social Evaluation  
Social Rejection  
Social Isolation  
Social Exclusion



Slavich & Irwin (2014, Psychol Bull)

# Caregiving & Gene Expression (CTRA)

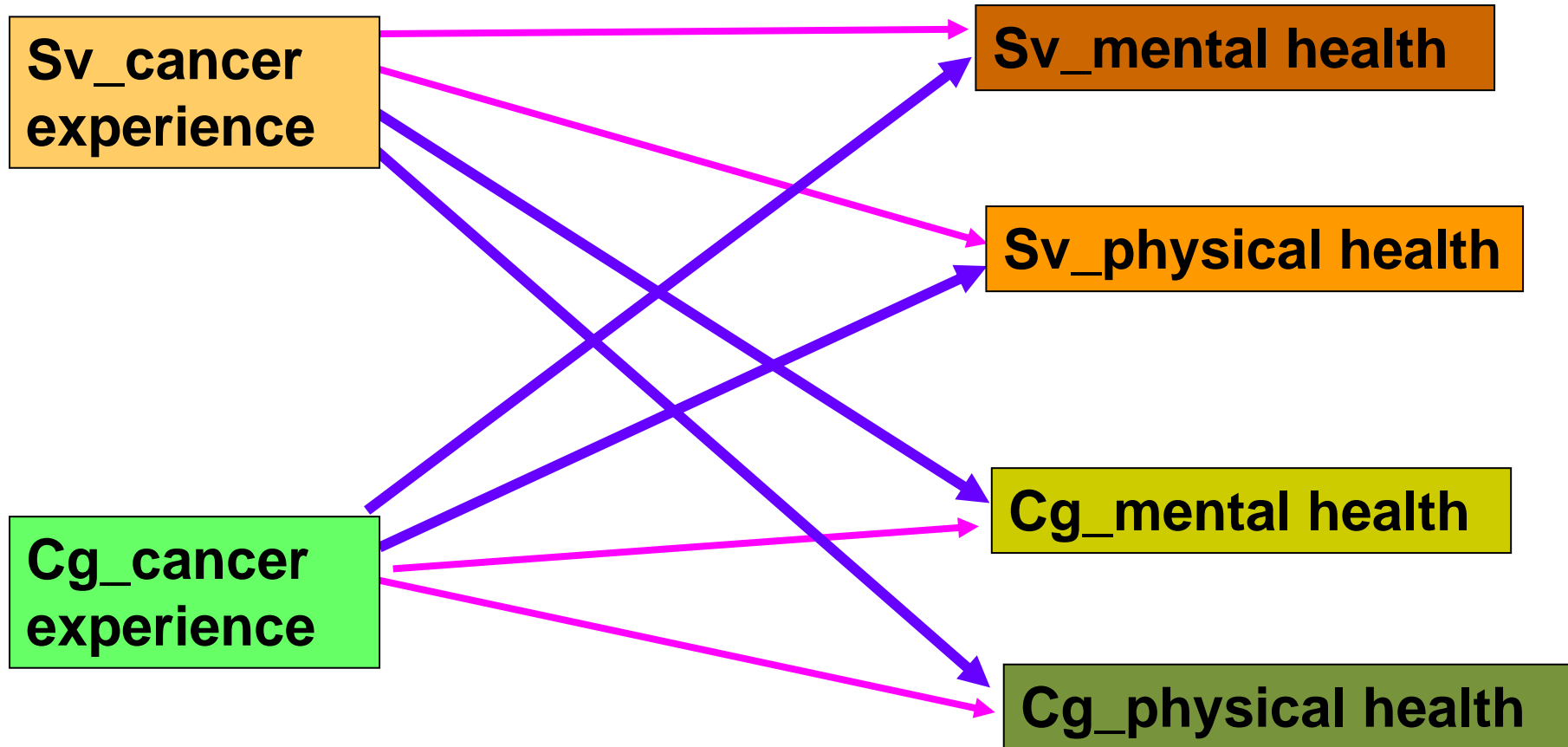


Note. Data represent strengths of associations ( $B \pm SE$ ) of indicated predictors with the 44-gene CTRA indicator contrast in (A) separate analyses of individual stress- and meaning-oriented psychological factors, (B) mutually adjusted analyses within stress- and meaning-oriented psychological factor groups, and (C) mutually adjusted analyses of all stress- and meaning-oriented psychological factors, in which each factor was adjusted for covariance with the other, controlling for covariates (assessment timepoint, age, gender, ethnicity, BMI, and patients' cancer stage).

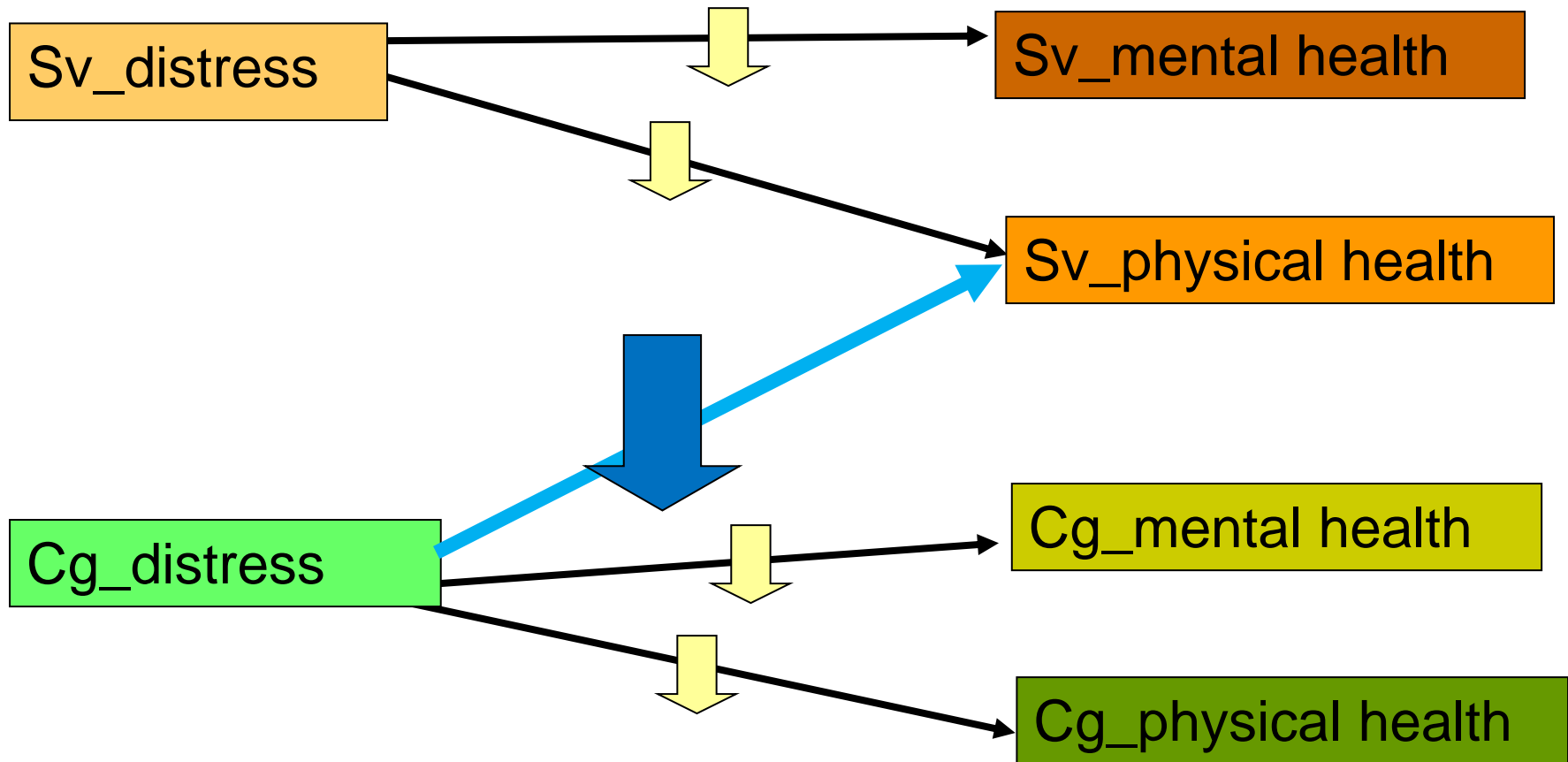
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# **Illness in the Relationship Context**

# Individual & Dyadic Effects



# Distress & QOL: Prostate Cancer



N = 168 dyads

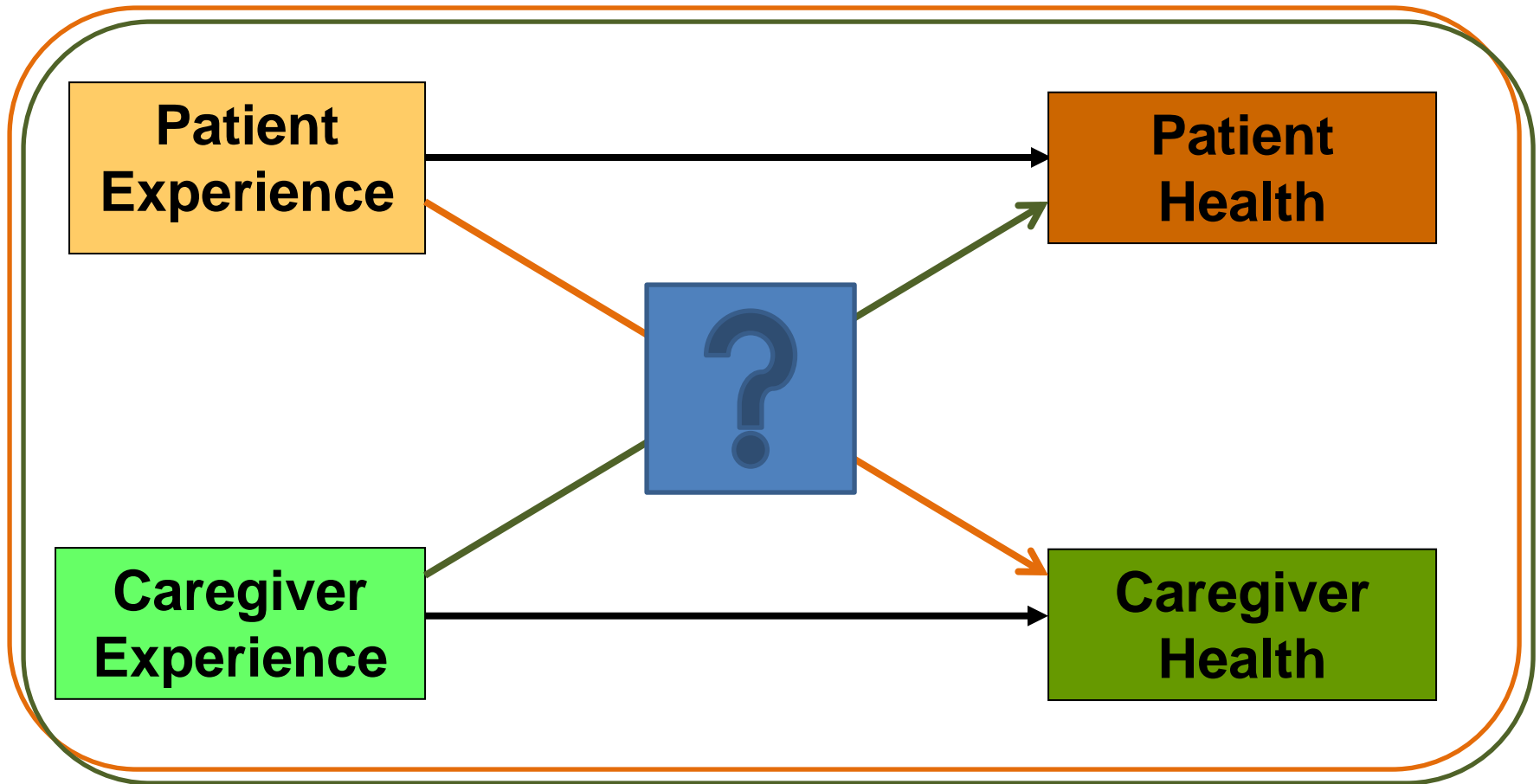
Kim, Kashy, Wellisch, et al. (2008)

# Individual & Dyadic Effects of Cancer

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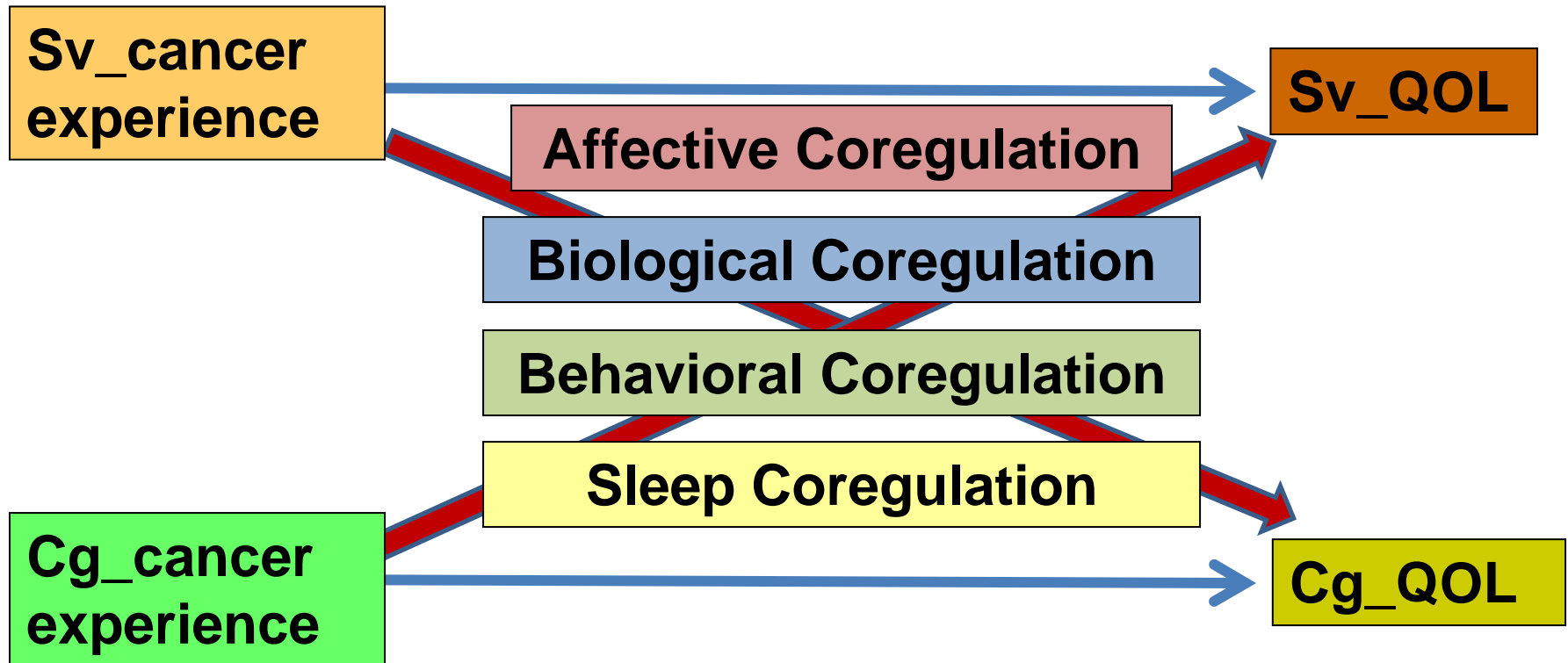
- ❖ Psychological distress on QOL: Spouses  
Mothers & Daughters
- ❖ Depression on QOL: Genders
- ❖ Depression on Biomarkers
- ❖ Fear of recurrence on QOL
- ❖ Spirituality on QOL
- ❖ Social support on QOL
- ❖ Health lifestyle behaviors on QOL
- ❖ Stress on Health lifestyle behaviors

# Individual & Dyadic Effects





# Mechanisms of Dyadic Effects



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# **How to Improve**

# Cancer Caregiver Interventions

- ✓ Meta-analysis and Systematic reviews of interventions with cancer caregivers of adult patients (Northouse et al., 2010; Applebaum & Breitbart, 2013; Waldron, Janke et al., 2013; Griffin et al., 2014; Li & Loke, 2014; Kaltenbaugh et al., 2015; Ferrell & Wittenberg, 2017; Ugalde et al., 2019)
- Various Types (Applebaum & Breitbart, 2012)

Psychoeducation	Problem-solving/skill building
Supportive therapy	Family/couple therapy
Cognitive-behavioral therapy	Interpersonal therapy
Complementary and alternative medicine	Existential therapy
- Effect Sizes
  - ➔ Small but maybe beneficial

# Dyadic Interventions

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- ✓ **Meta-analysis** (Hu et al., 2019)
  - 23 RCTs of dyadic intervention effects on patients' outcomes
  - Improved overall QOL; spirituality; emotional, mental and social adjustment; relatedness, marital functioning.
  - At 3-6 month follow-up, improved social adjustment and depression.
  - No effects on functional and physical aspects, hopelessness, pain, fatigue, and survival.

# Dyadic Interventions

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- ✓ Web-based/eHealth dyadic intervention review (Luo et al., 2020; Shaffer et al., 2020; Chen et al., 2022)
  - 17, 52, and 13 interventions, respectively
  - Information support, communication, psychoeducation, self-management skills, social support
  - Small to large effects on psychological, physical, and overall QOL, and relationship
  - Few studies evaluating unique effects of dyadic, as opposed to individual interventions, none for older adult dyads, few target/report caregiver outcomes
- ✓ State of the science statement (Badr et al., 2019)
  - Dyadic approach may improve various aspects of QOL
  - Unknown how, why, and for whom to be effective