
# Faculty Disclosure

| | |
|---|---|
| X | No, nothing to disclose |
| | Yes, please specify: |

| *Company Name* | *Honoraria/ Expenses* | *Consulting/ Advisory Board* | *Funded Research* | *Royalties/ Patent* | *Stock Options* | *Ownership/ Equity Position* | *Employee* | *Other (please specify)* |
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# Challenging Communication in Oncology: What about Carers?

Youngmee Kim

University of Miami

UNIVERSITY OF MIAMI
DEPARTMENT of PSYCHOLOGY

FAMILY

*Facilitating Adjustment to Medical Illness in Your Family*

# WHO:

# Cancer Caregivers

# Family Cancer Caregivers

- ✓ Who they are:
  - 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: End-of-life
  - Greater emotional distress, poorer mental and physical health

Kent et al. (2016); Kim & Schulz (2008); Kim & Spillers (2010); National Alliance for Caregiving (2015)

# WHAT:

# Quality of Life

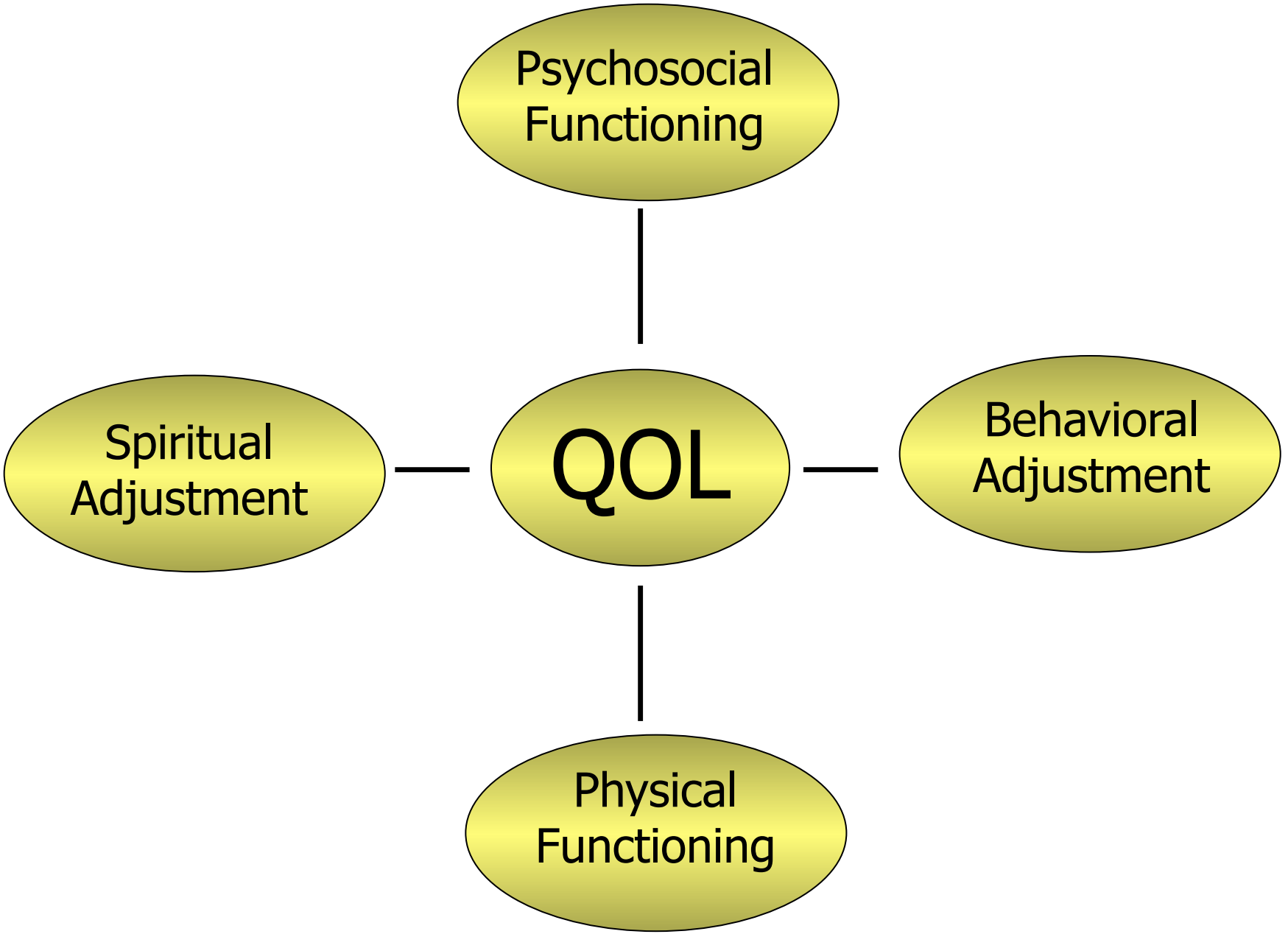
# among Cancer Caregivers

# Caregivership Phases (Five Seasons)

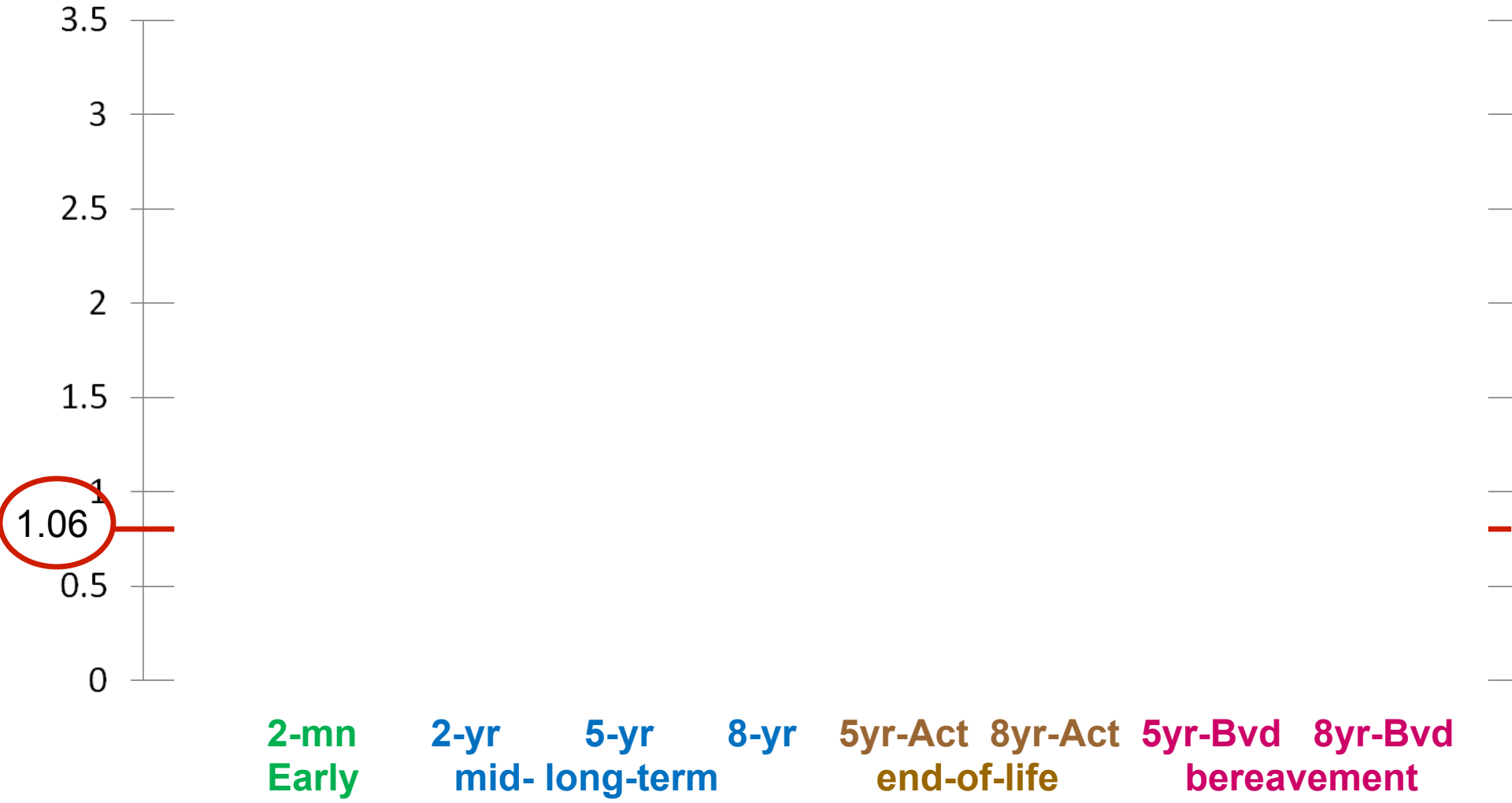
Early---------- Mid-term ---------- Long-term ----------

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

---------- Prevention ----------


Psychosocial Functioning
Spiritual Adjustment
QOL
Behavioral Adjustment
Physical Functioning

# Caregiver Psychological Distress (POMS-SF)




Reference score: McNair & Neuchert (2005).

# Depression and Anxiety

- ✓ Depression and Anxiety in Long-term Cancer Survivors

  (43 studies: Mitchell et al., 2013)

  - Compared with Healthy Controls:

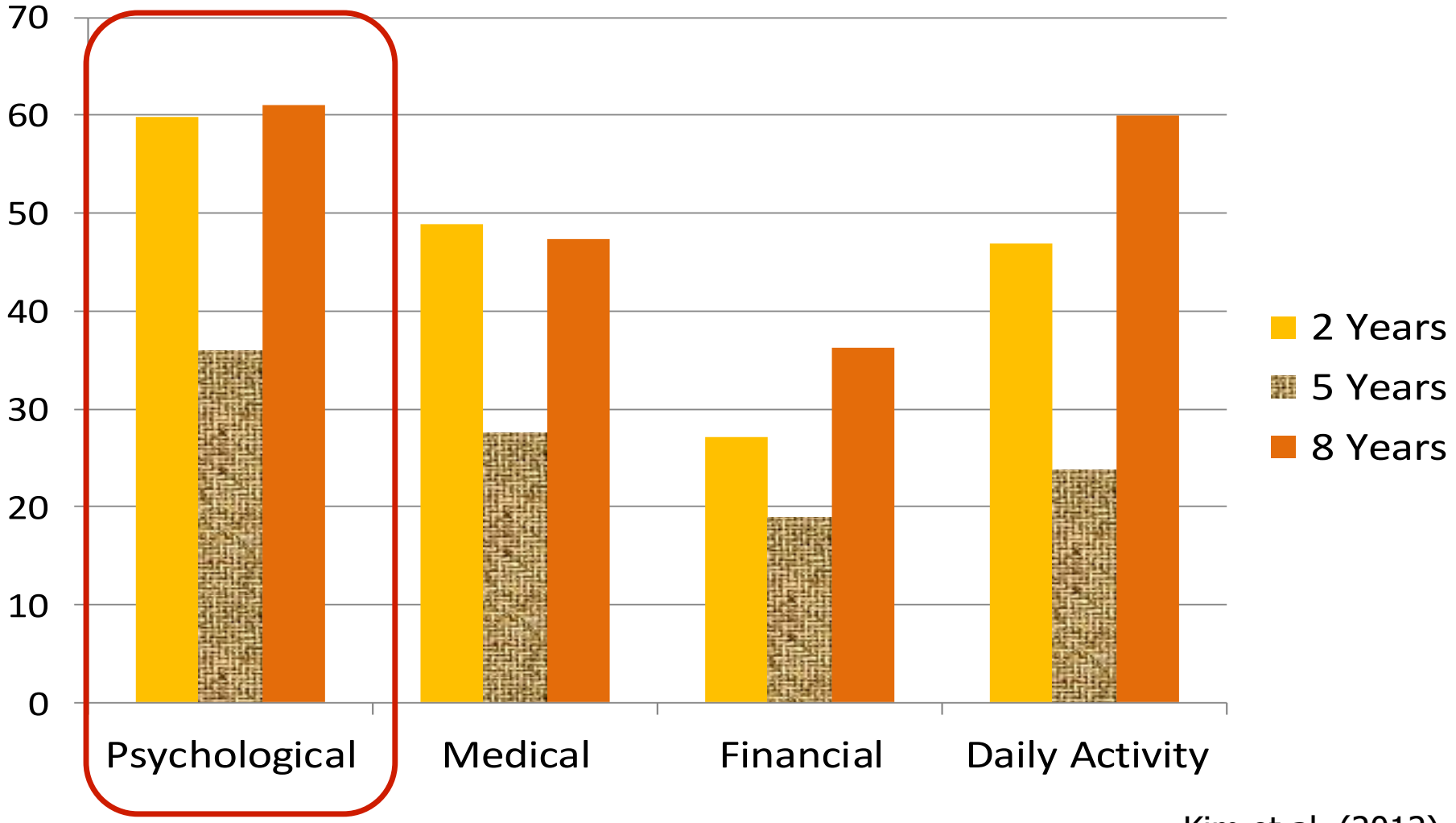
    -- prevalence of depression 111% higher

    -- prevalence of anxiety 139% higher

  - Compared with their Spouses:

    -- prevalence of depression & anxiety did not differ

# % Reported Unmet Needs of Caregivers

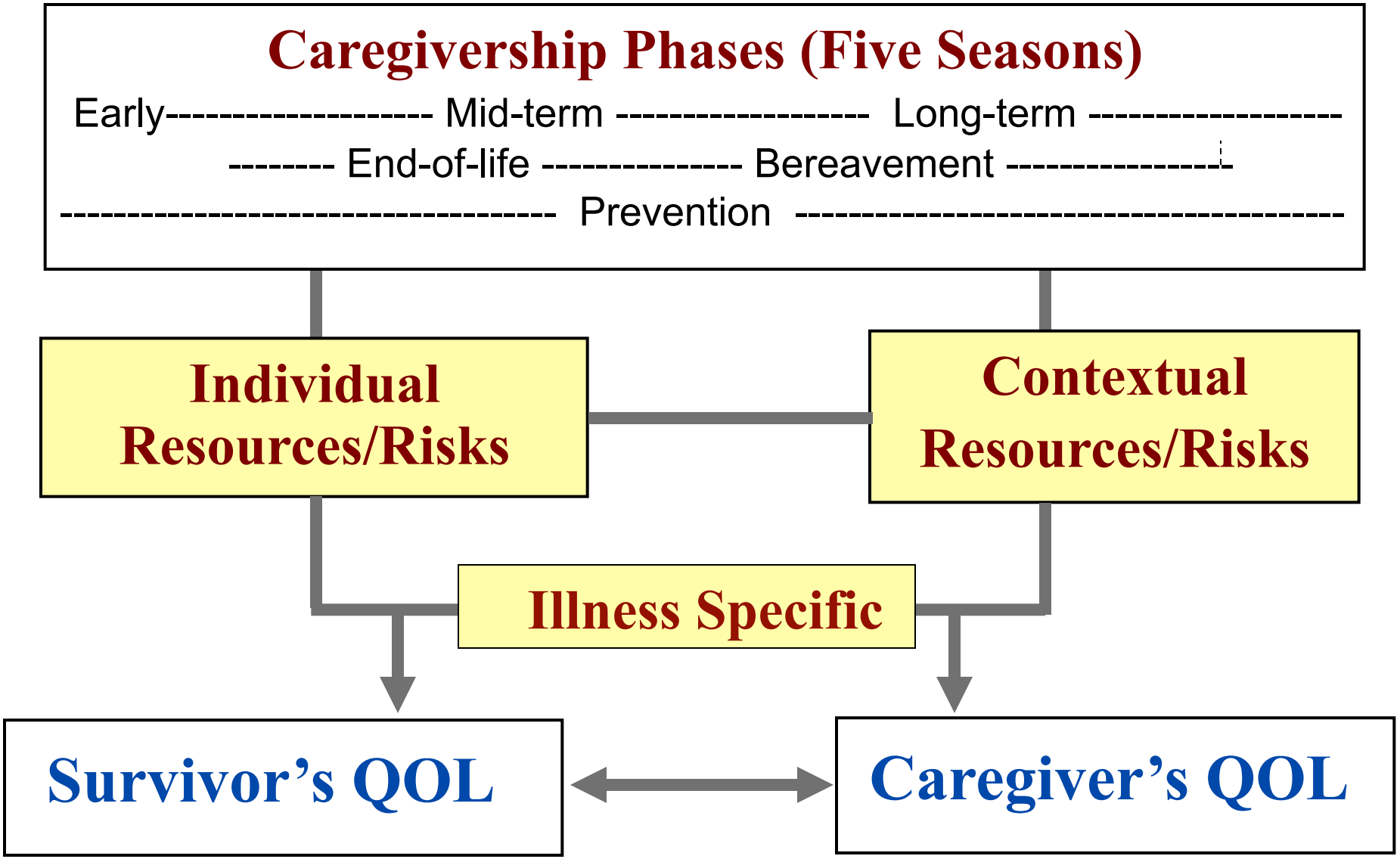



Kim et al. (2012)

# HOW:

# Psychosocial Predictors of Caregivers' QOL

# Caregivership Model



# Predictors of Caregivers' QOL

## ❖ Individual Factors: Demographics

- Factors studied: Age
  Gender
  Education
  Income
  Spouse

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

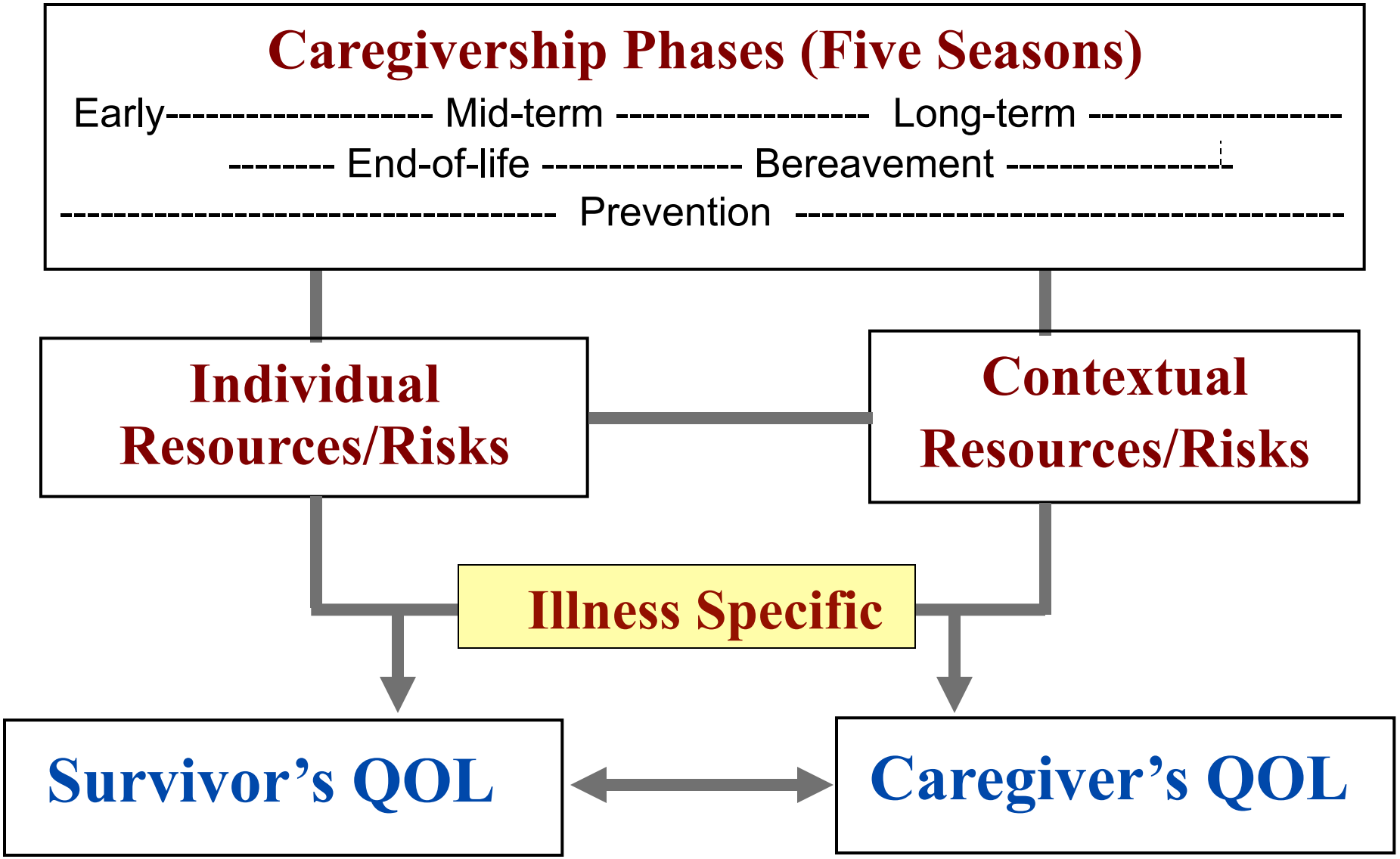
# Predictors of Caregivers' QOL

## ❖ Contextual Socio-Cultural Factors

- Factors studied: Ethnicity
  Employed
  Social Support

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

# Caregivership Model



# Predictors of Caregivers' QOL

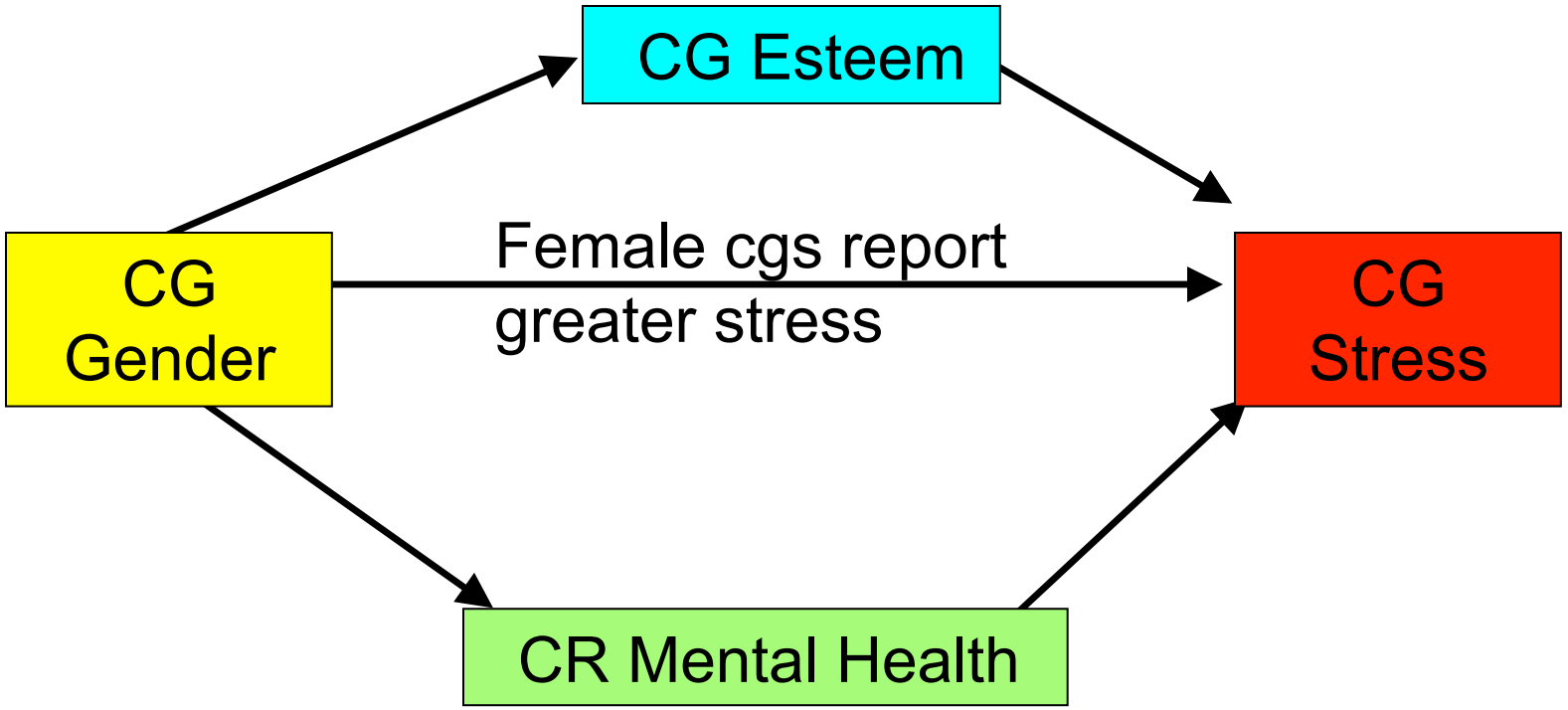
## ❖ Illness-Specific Factors

- Factors studied: Caregiving hours, Perceived caregiving stress, Caregiver esteem, Patients' mental & physical functioning
- Perceived/Subjective **caregiving stress** related to poorer psychological and spiritual adjustment, and poorer mental and physical health

# HOW:

# Additive & Synergistic Effects of Psychosocial Predictors

(Fe)Male cgs report
(lower)greater cg esteem –> (greater)less stress



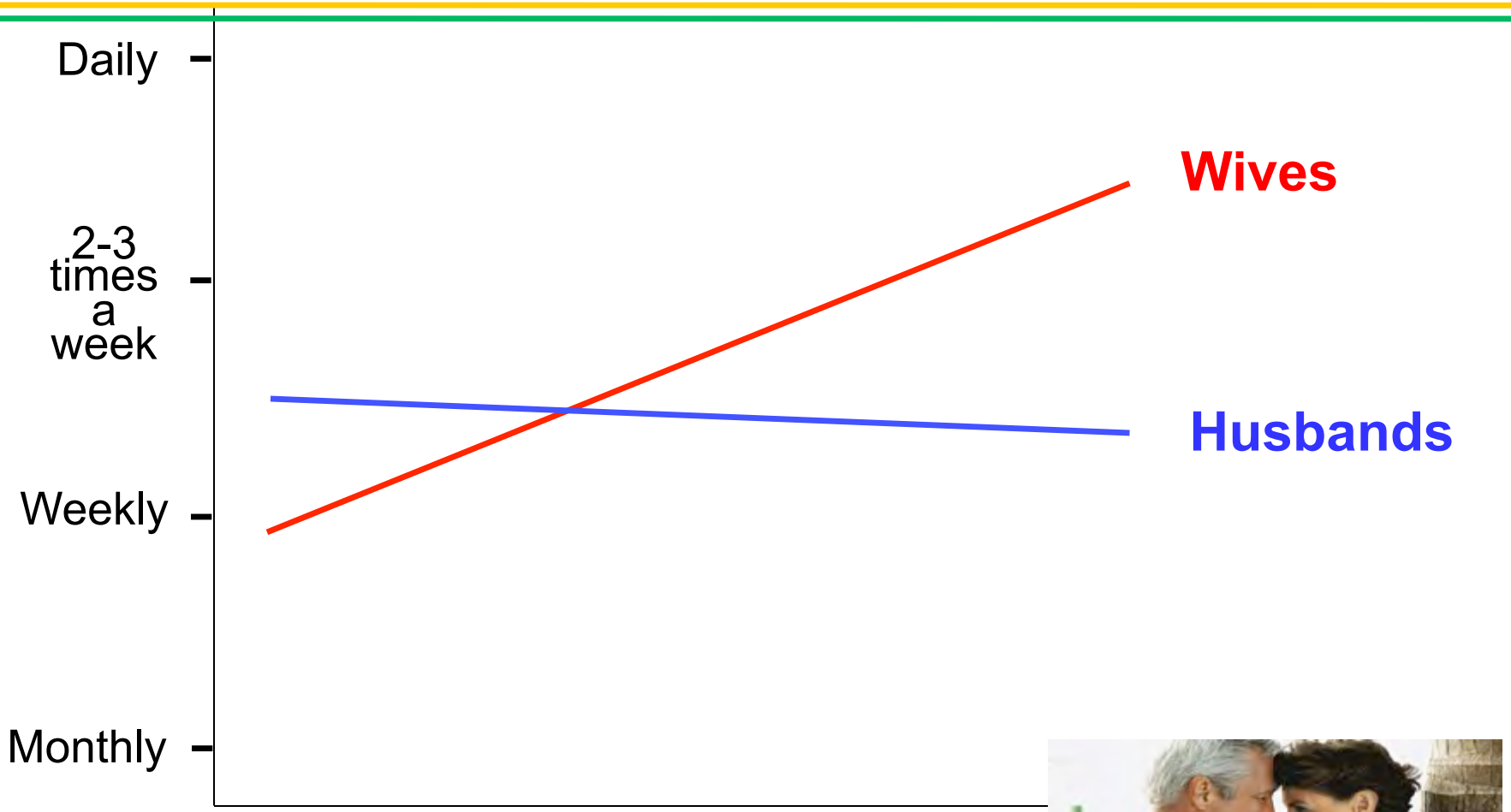

When male cgs manage female pt's emotional distress -> greater stress

CG = Caregiver
CR = Care-Recipient

N = 429

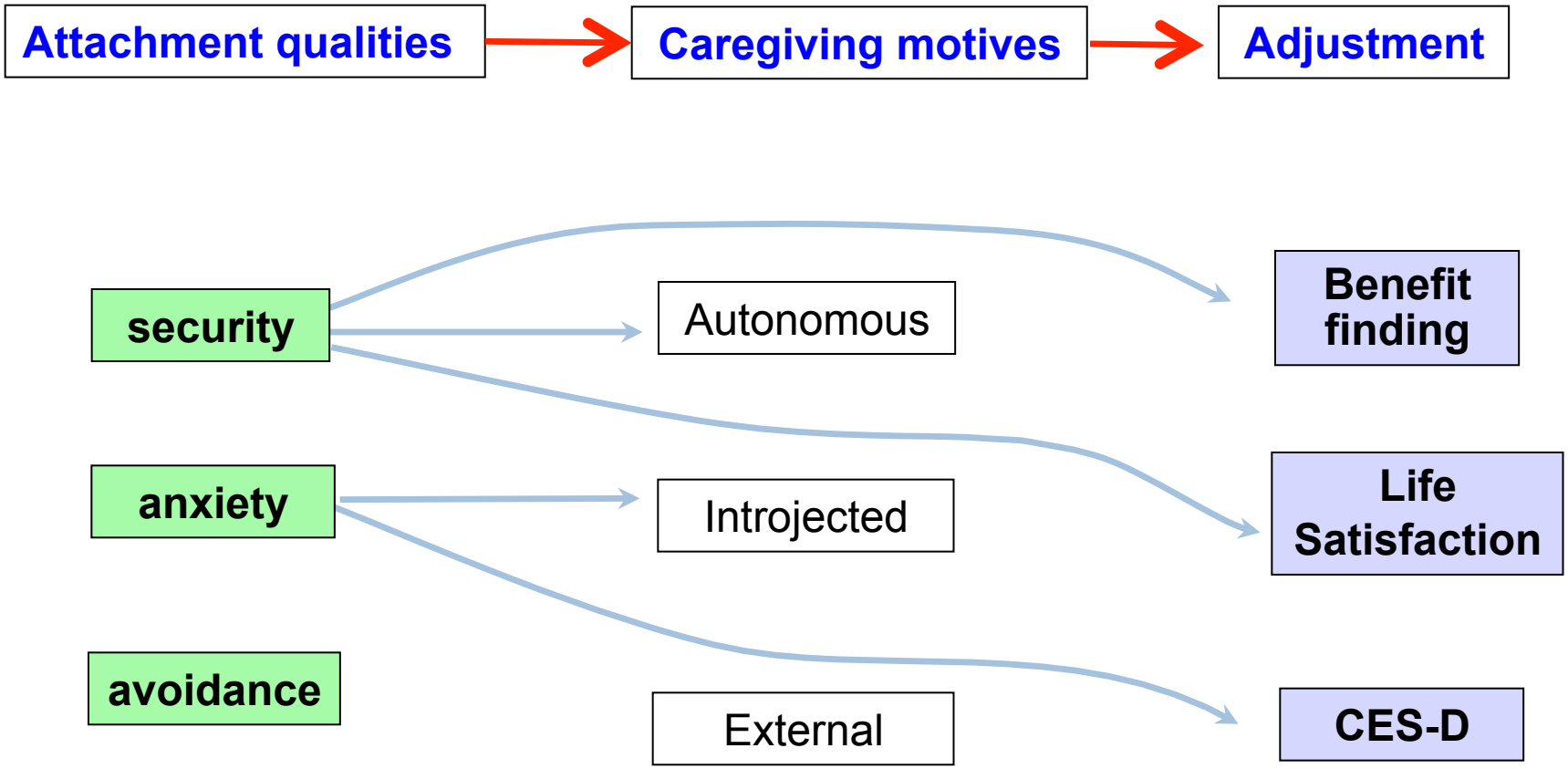
Kim, Loscalzo, Wellisch, & Spillers (2006).

# Frequency in Providing Emotional Care



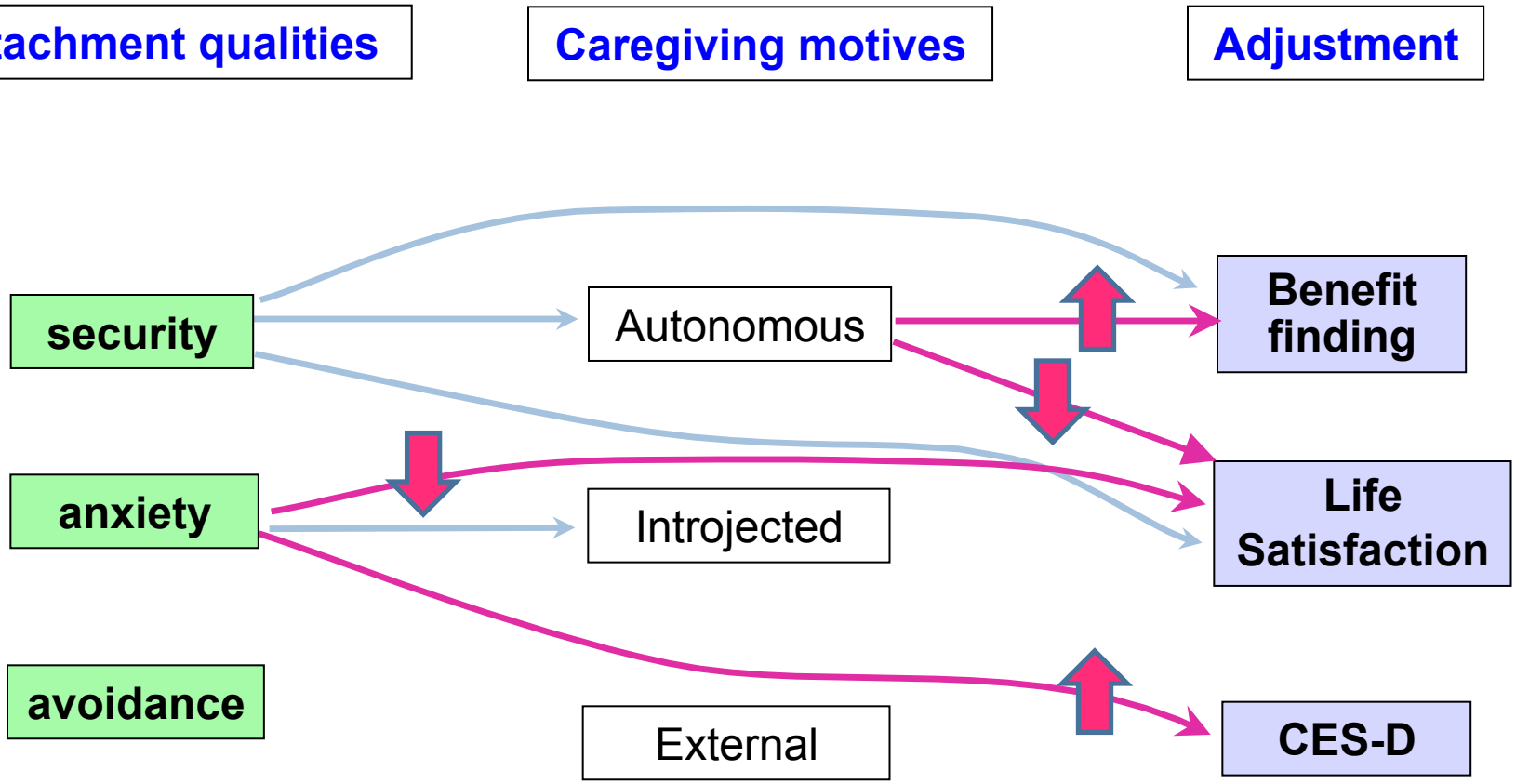

Kim & Carver (2007).

# Attachment & Caregiving Motives



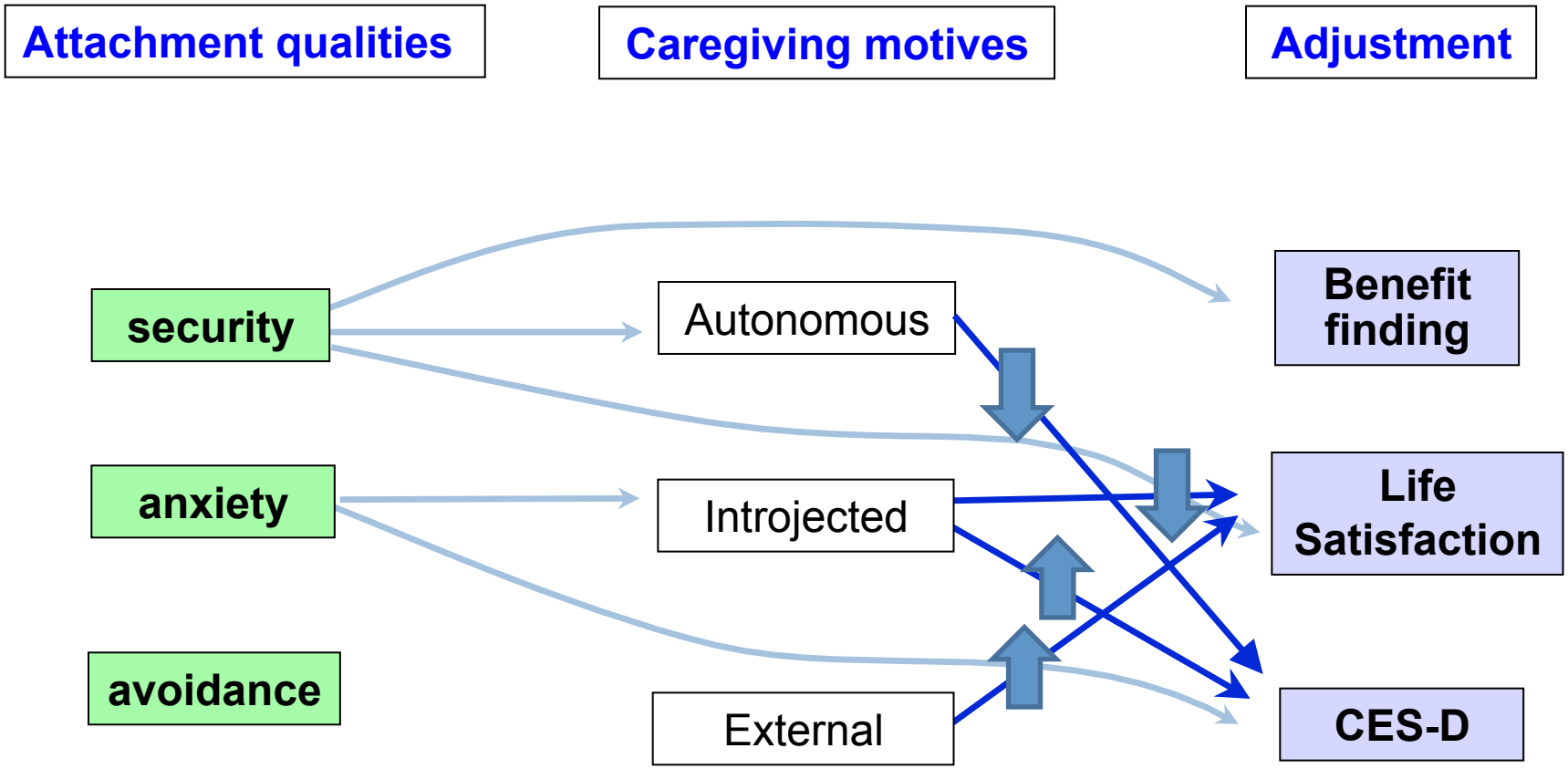

Kim, Carver, Deci, & Kasser (2008).

# Wives



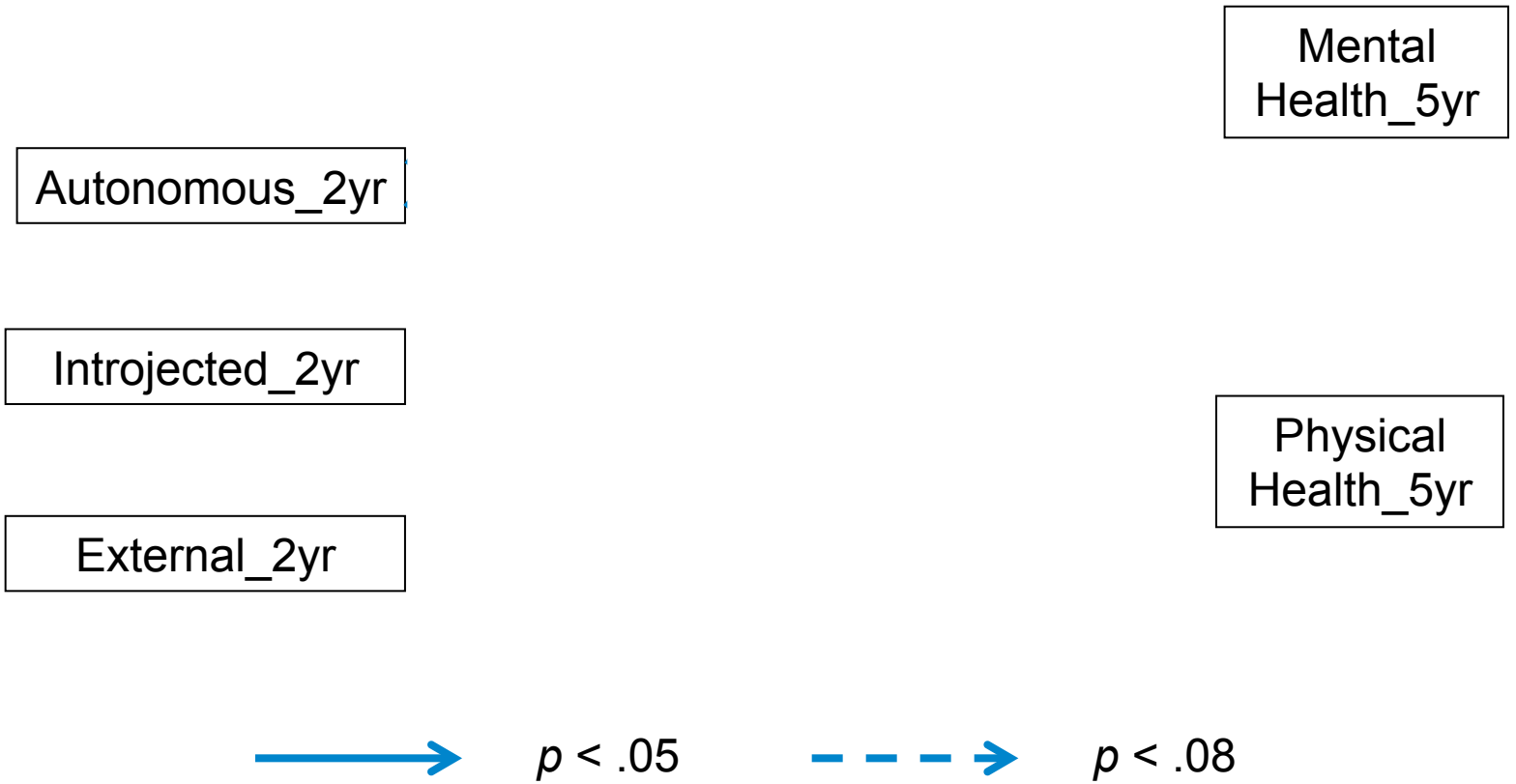

Kim, Carver, Deci, & Kasser (2008).

# Husbands

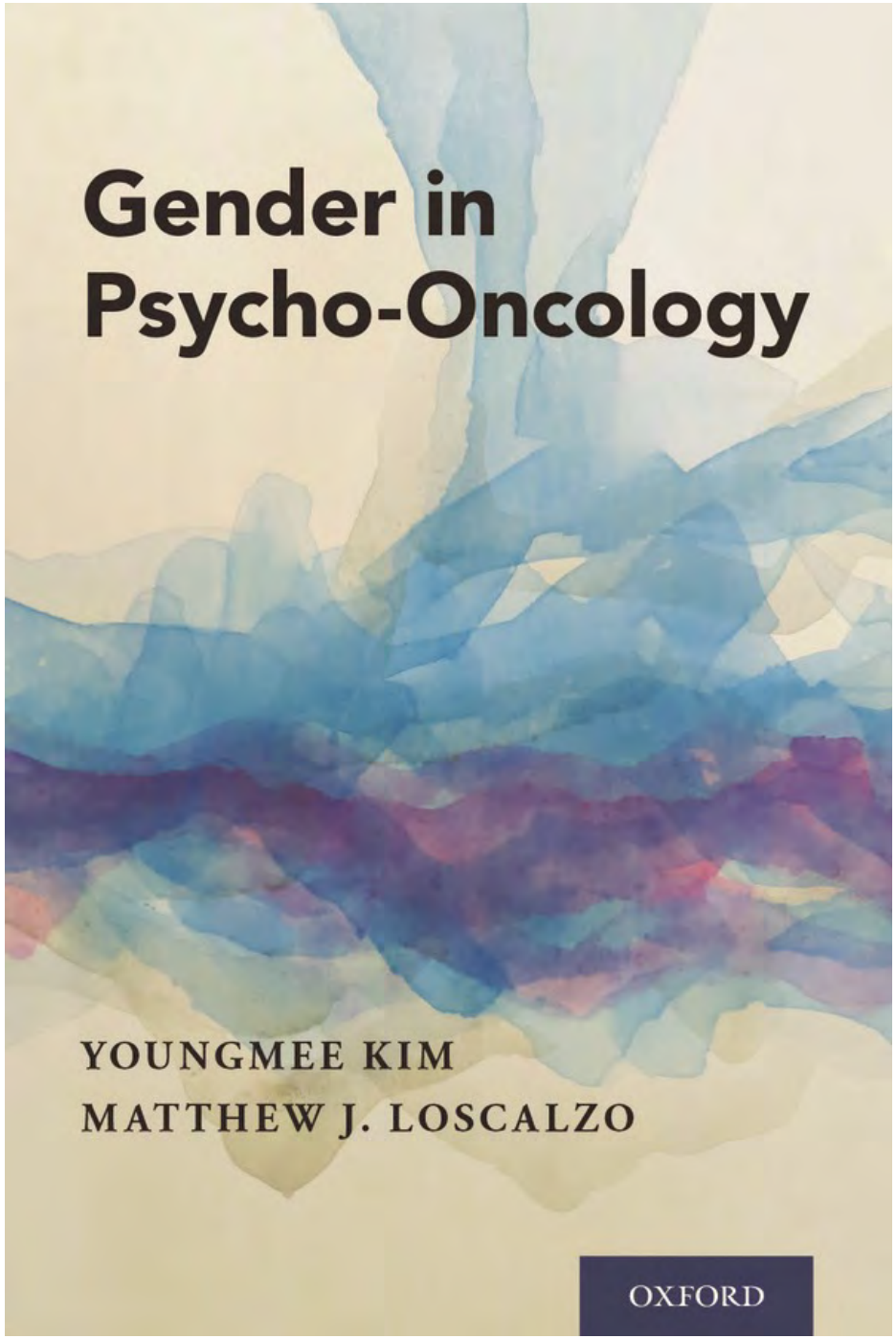



Kim, Carver, Deci, & Kasser (2008).

# Male Caregivers at 5 years Post-Dx




Kim, Carver, & Cannady (2013; 2015).


Gender in
Psycho-Oncology
YOUNGMEE KIM
MATTHEW J. LOSCALZO
OXFORD

# Clinical Levels of Depressive Symptoms: Prevalence

| | |
|---|---|
| 2 years post-dx: no one was bereaved | Depressed |
| | Nondepsd |

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

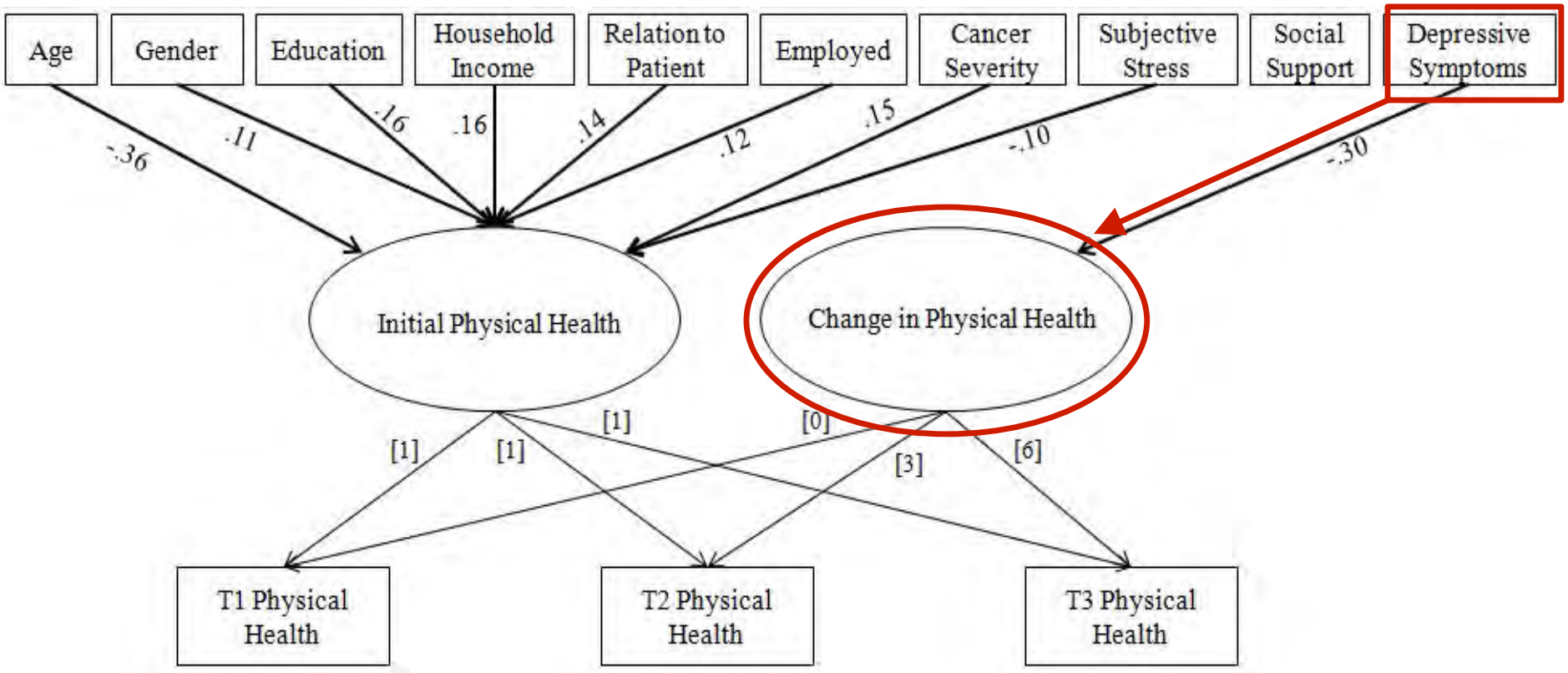
# Clinical Levels of Depressive Symptoms: Prevalence

| | | 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)

# Predicting Changes in Physical Health




Shaffer, Kim, Carver, & Cannady (2017a: Cancer, 2017b: Health Psychology)

# Long-term Bereavement Outcomes

| | 3 yrs | Case | 5 yrs | Case |
|---|---|---|---|---|
| Prolonged Complicated Grief (ICG) | 17.09 | 24.1% | 16.74 | 18.2% |
| Intense Emotional Reaction (TRIG) | 40.20 | 61.3% | 38.32 | 47.7% |
| Depression (CES-D) | 13.85 | 36.5% | 7.85* | 44.3% |
| Life Satisfaction | 4.44 | 1 ~ 7 | 4.43 | 1 ~ 7 |

N for 3-year = 137; N for 5-year = 88
Caseness for ICG > 25; for TRIG > 37; 20-item CES-D ≥ 16; 10-item CES-D ≥ 8
* 10-item CES-D (0 ~ 30)

Kim, Carver, Spiegel, Mitchell, & Cannady (2017).

# Long-term Bereavement Outcomes: Predictors

- **Prospectively at 8-year** post-diagnosis

  Preparedness at 5-year related to

  lower ICG and TRIG at 8-year

  * Medical, cognitive, affective preparedness

    (Hebert et al., 2009)

Kim, Carver, Spiegel, Mitchell, & Cannady (2017).

# Benefit Finding

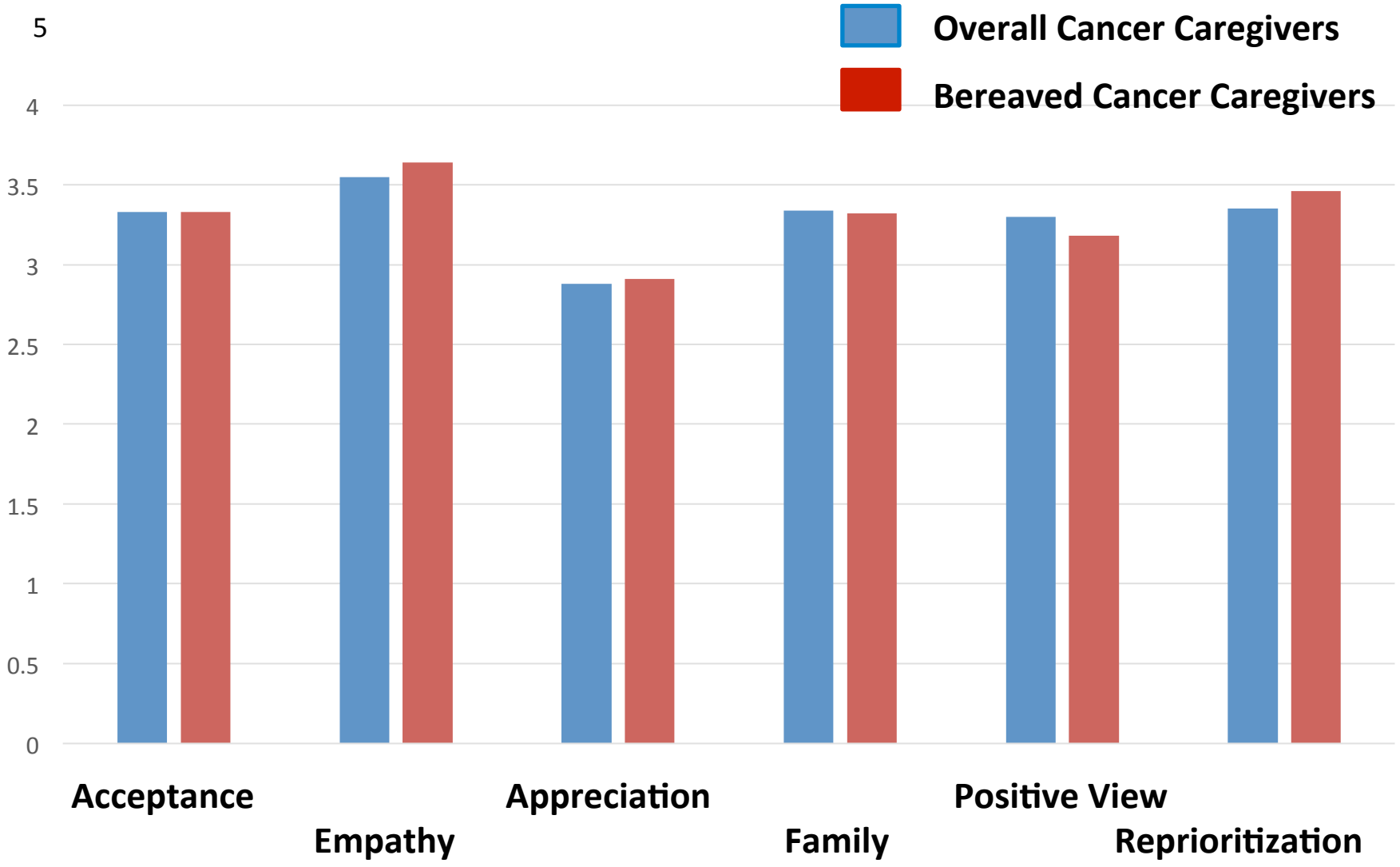
| | Life Satisfaction | Depression |
|---|---|---|
| Overall | 0.10** | 0.05 |
| Acceptance | 0.14** | -0.14** |
| Empathy | -0.09 | 0.16** |
| Appreciation | 0.11* | -0.01 |
| Family | 0.03 | 0.01 |
| Positive Self-View | 0.11 | -0.12* |
| Reprioritization | -0.16** | 0.17*** |

Controlling for age, gender, education, income, spousal status, perceived caregiving stress, sv's mental and physical functioning, religious coping, social support

N = 896

Kim, Schulz, & Carver (2007).

# Benefit Finding in Bereavement



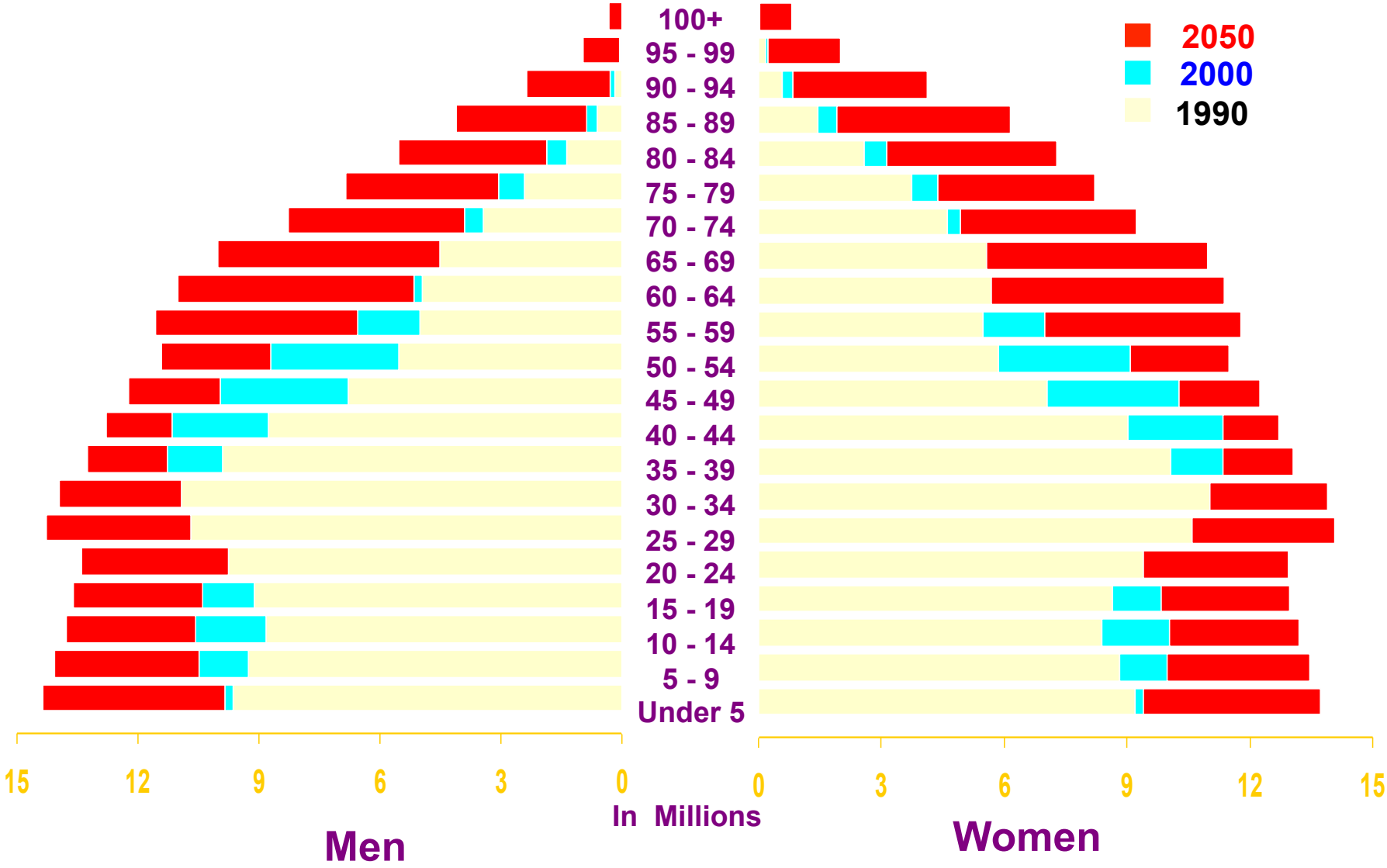

Kim, Schulz, & Carver (2007); Kim, Carver, Schulz, Lucette, & Cannady (2013).

# WHAT & HOW

# on Physical Health:

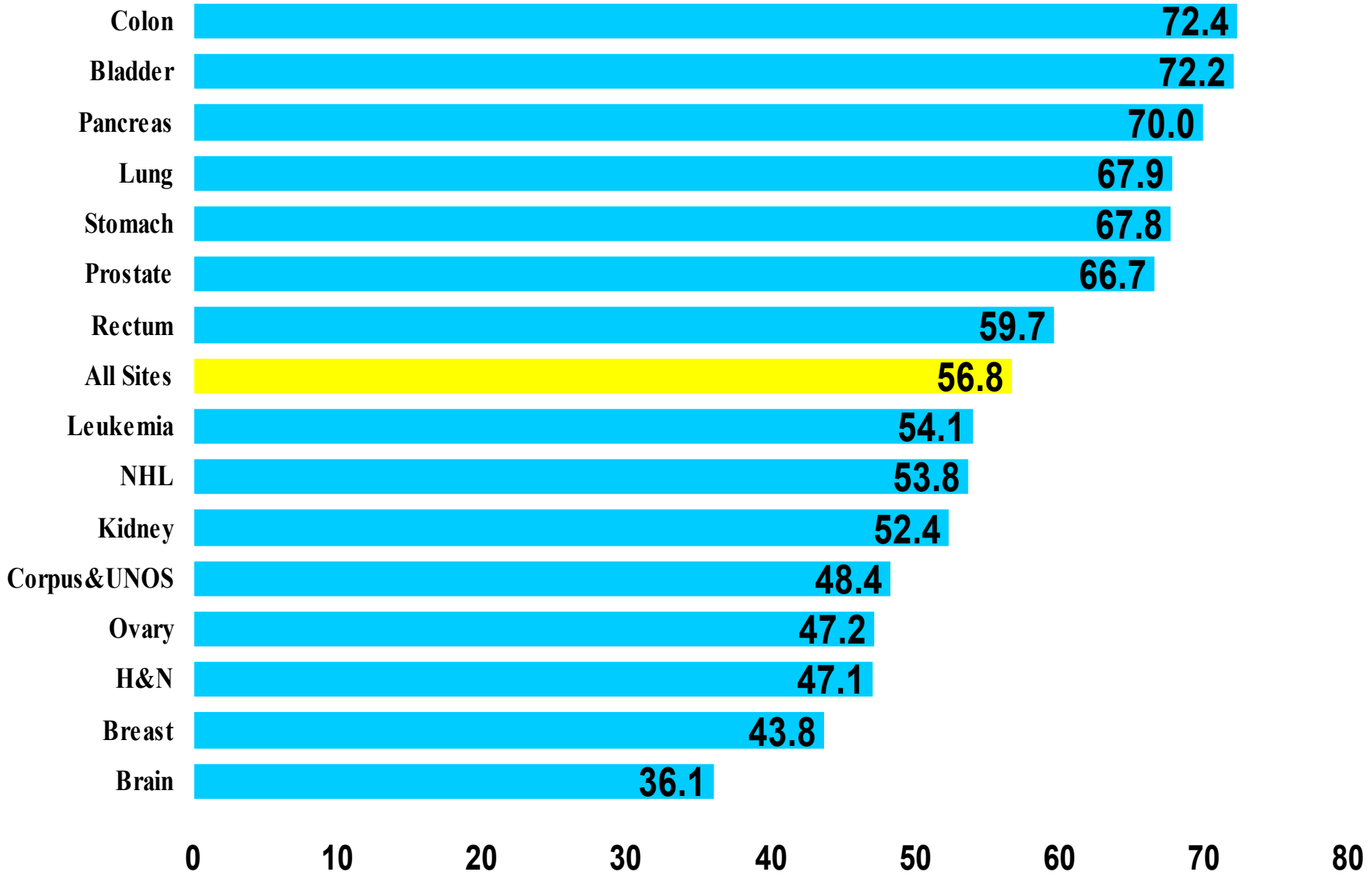
# Aging, Cancer, and Caregiving

# Expanding U.S. Aging Population




Total US Resident Population Projections from: U.S. Census Bureau, (1) 1990 Census and (2) U.S. Interim Projections by Age, Sex, Race, and Hispanic Origin, http://www.census.gov/ipc/www/usinterimproj/, accessed on 09/15/2004.

# Incidence (%) of Cancer in Patients ≥ 65*




*All Race/sex groups. Source: NCI SEER Program Data, 1997-2001.

# 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 & Sorensen, 2003; Vitaliano et al. (2003).
Ji, Zöller, Sundquist, & Sunquist (2012); Schneiderman, Kim, & Shaffer (2012)

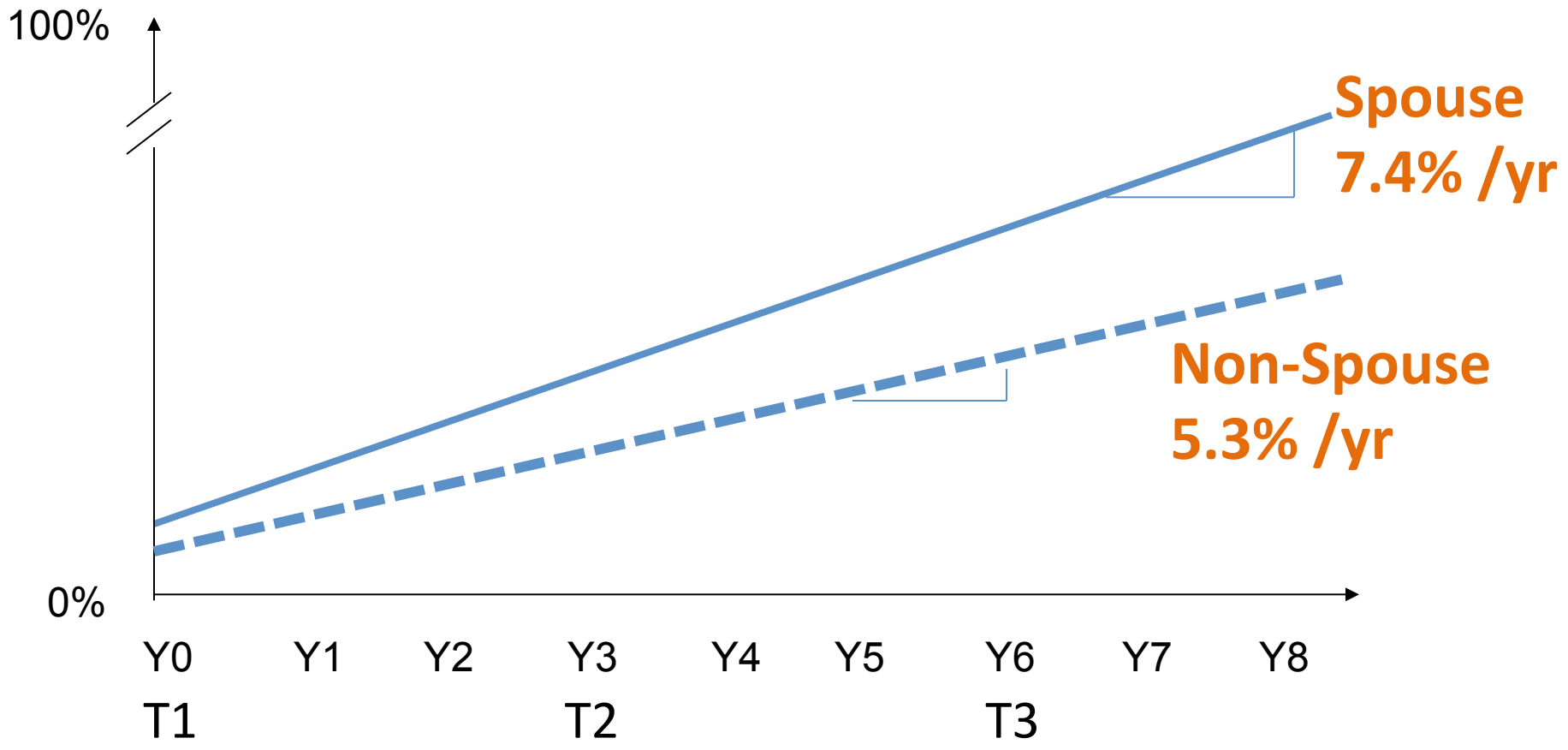
# Predictors of Disability Markers:

| | Arthritis | Chronic Back Pain | Heart Diseases |
|---|---|---|---|

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

# Predictors of Disability Markers: Person x Time

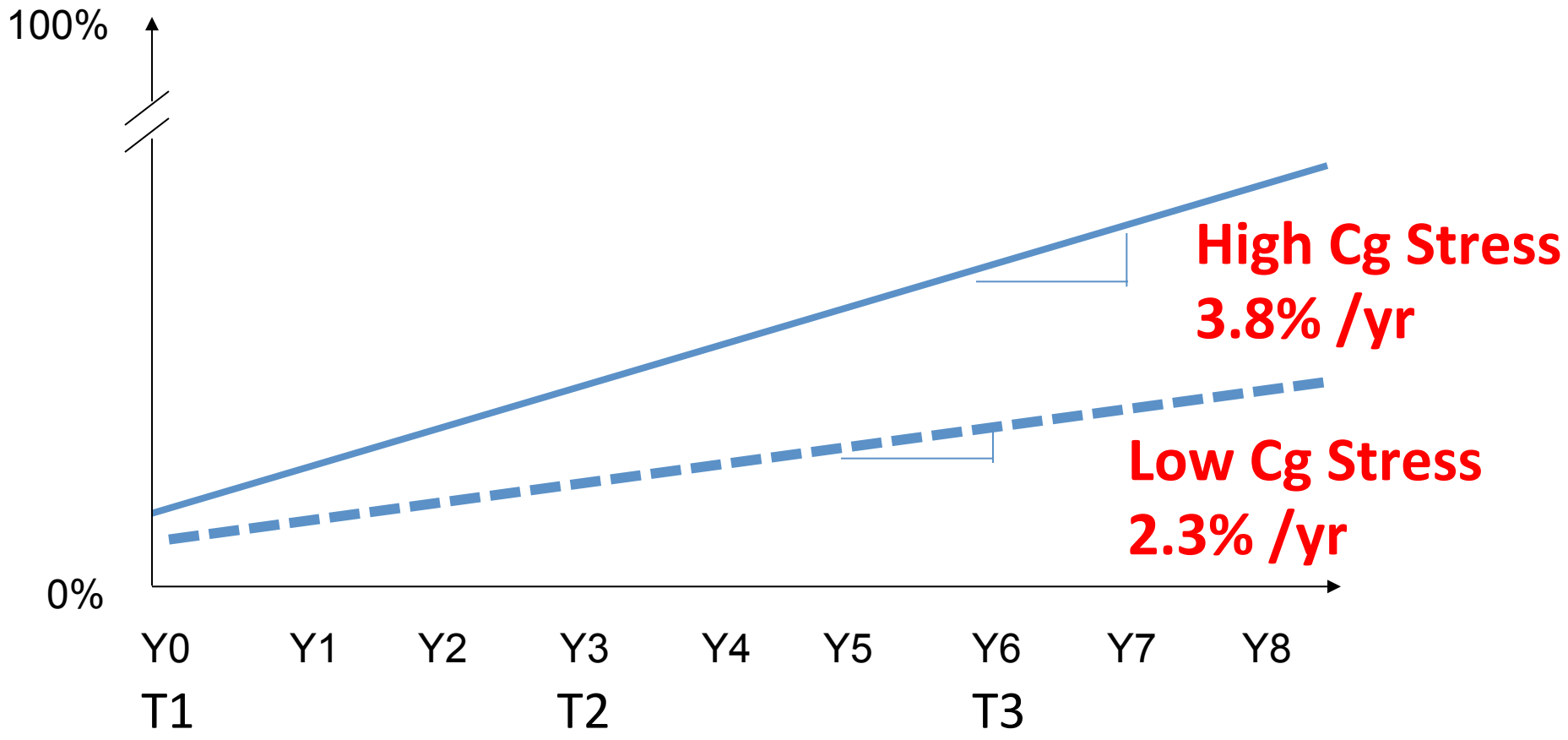
## Spousal Caregivers x Time Effect on Development of Arthritis




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

# Predictors of Disability Markers: Person x Time

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

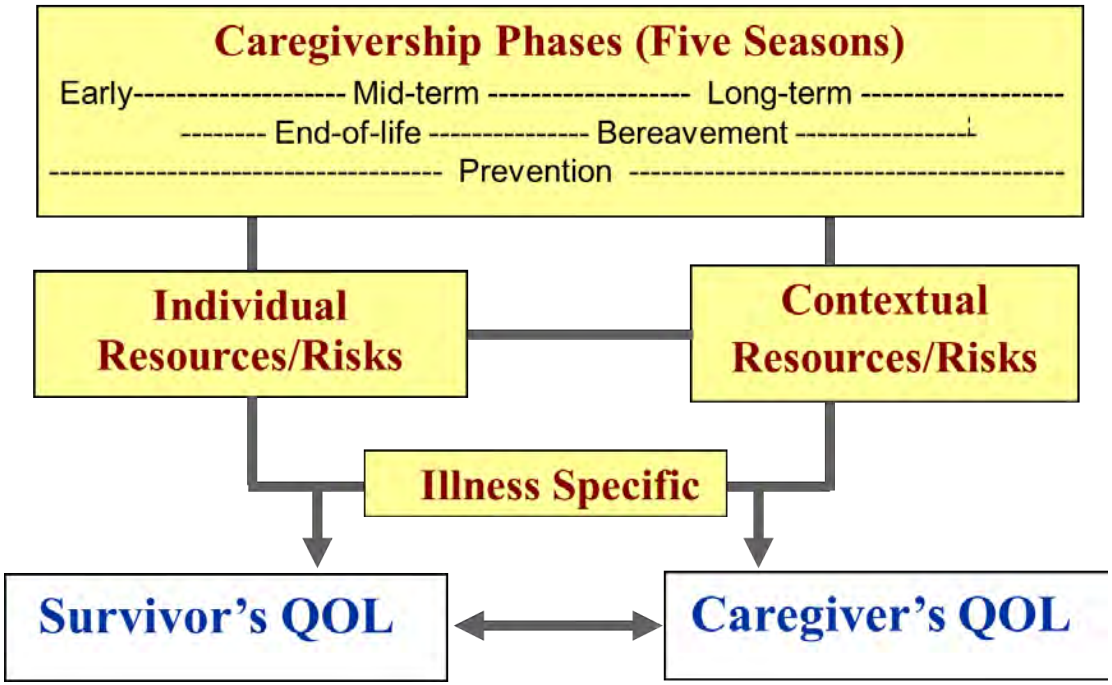



Kim, Carver, Shaffer, Gansler, & Cannady (2015)

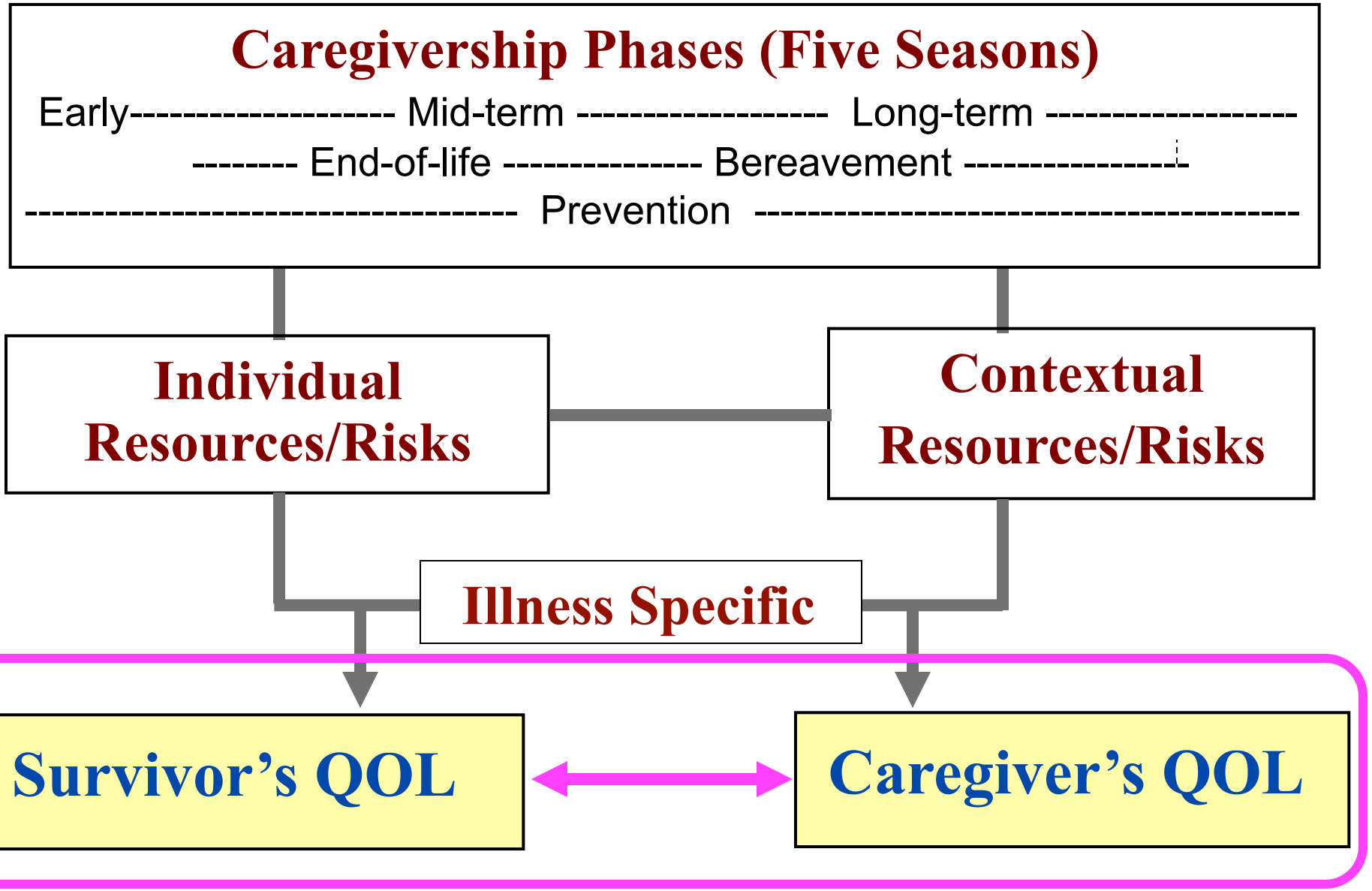
# WHAT: Predictors of Caregivers QOL

## ❖ Additive and Synergistic Effects of Multiple Factors

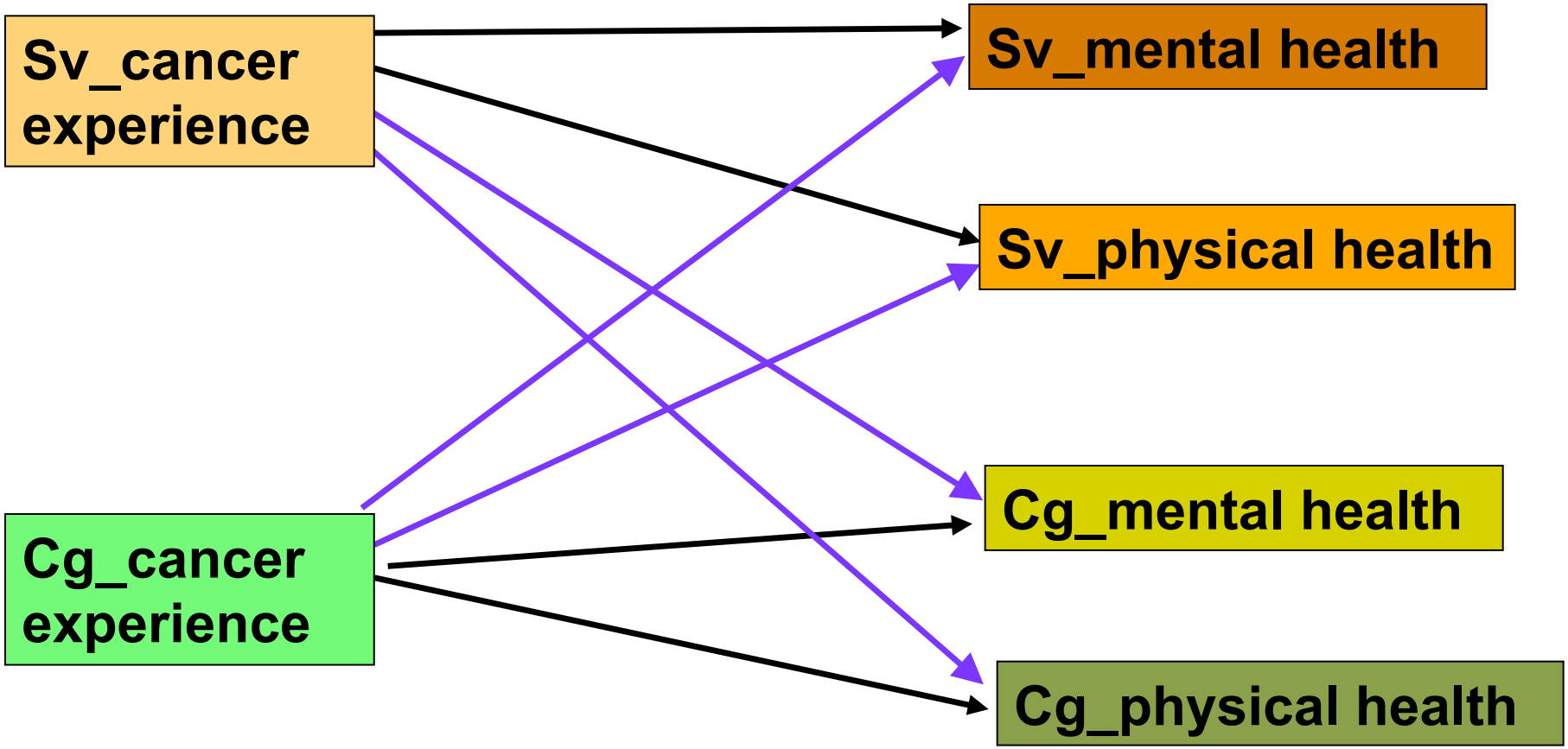
- Stress with Seasons
- Depression with Seasons
- Relationship quality with Gender
- Motivation for caregiving with Gender
- Stress with Ethnicity
- Social support with Ethnicity



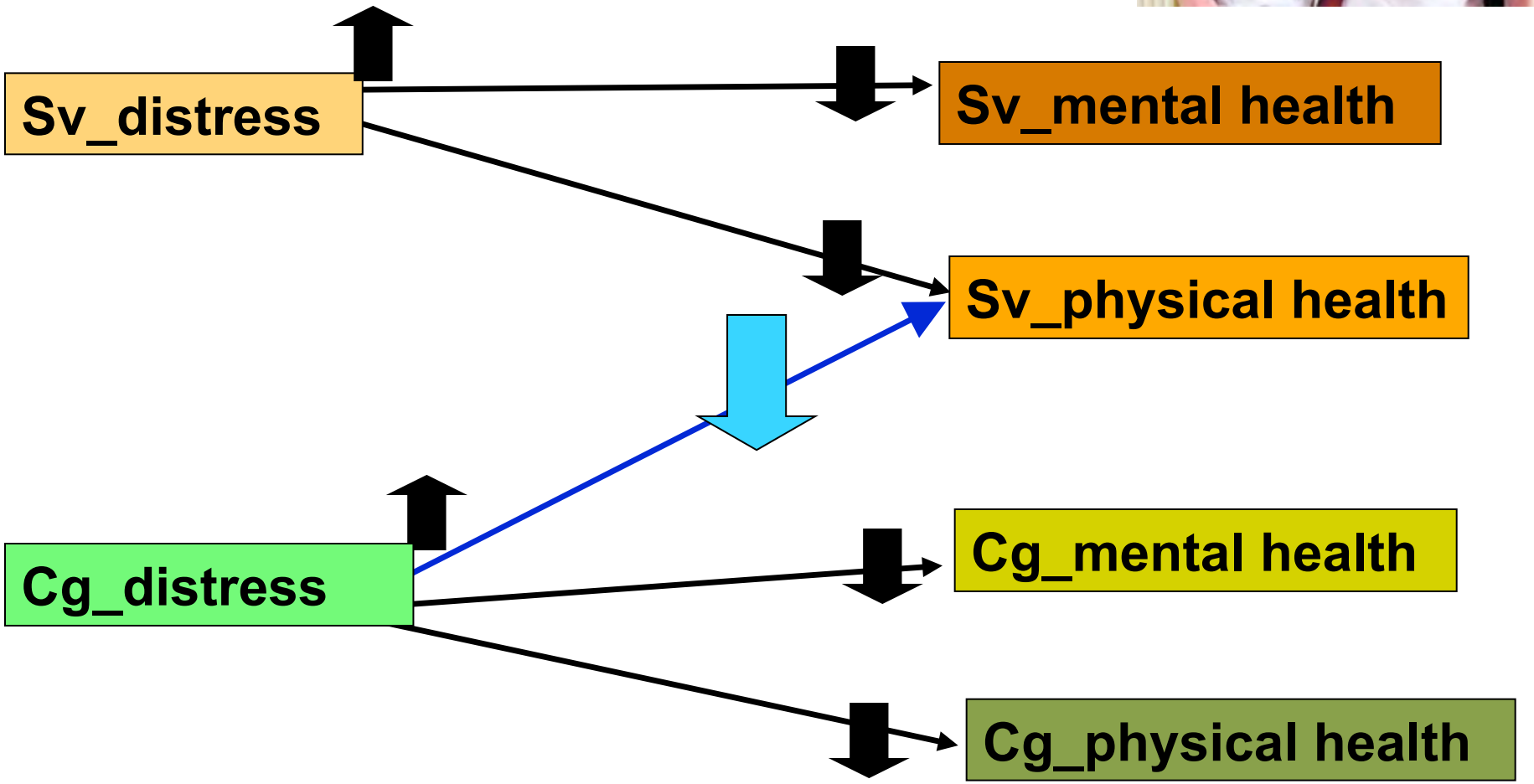
# Caregivership Model



# Individual & Dyadic Effects



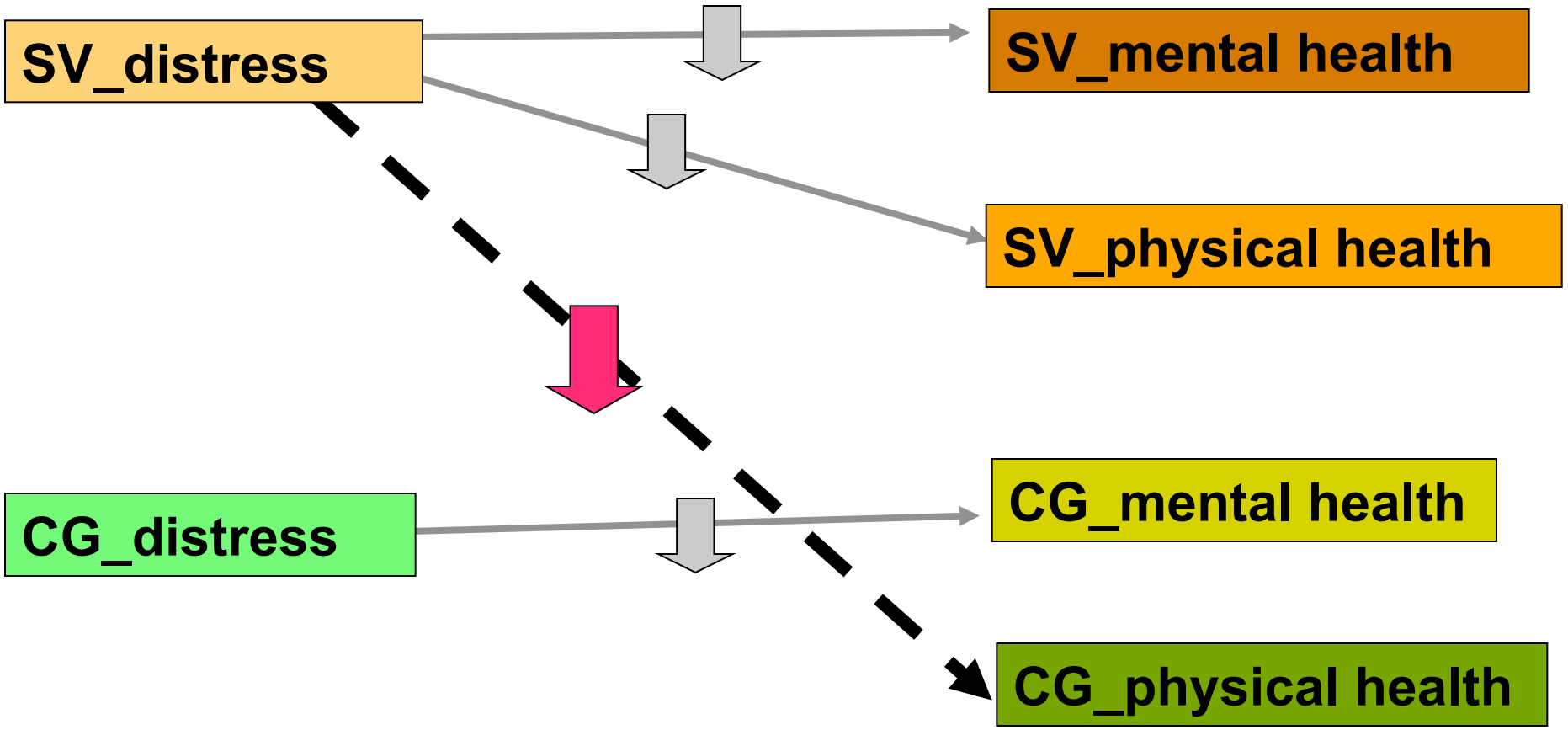
# Prostate Cancer Survivors & Spousal Caregivers




N = 168 dyads

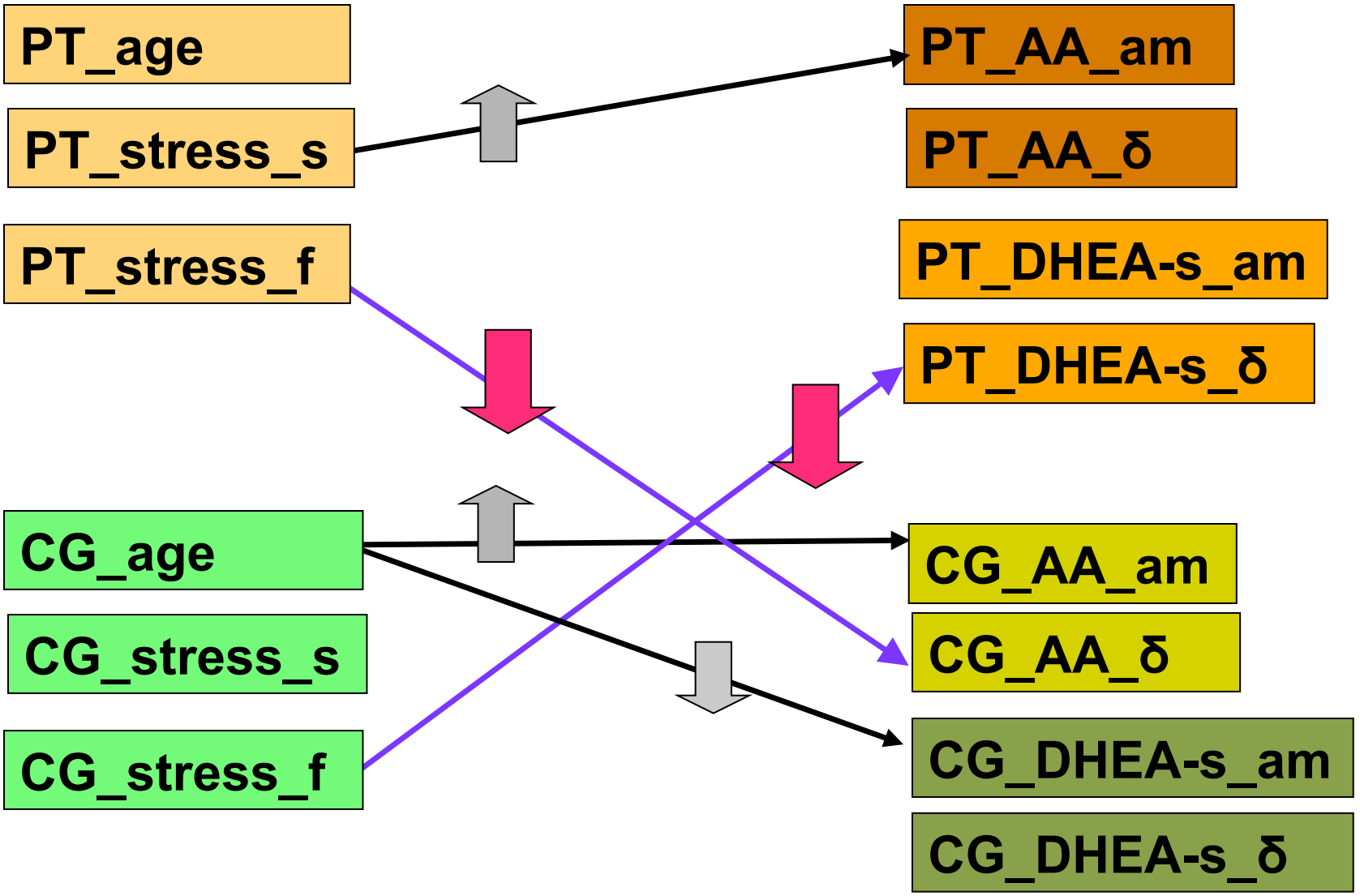
Kim, Kashy, Wellisch, et al. (2008).

# Mothers with Cancer & Their Caregiving Daughters



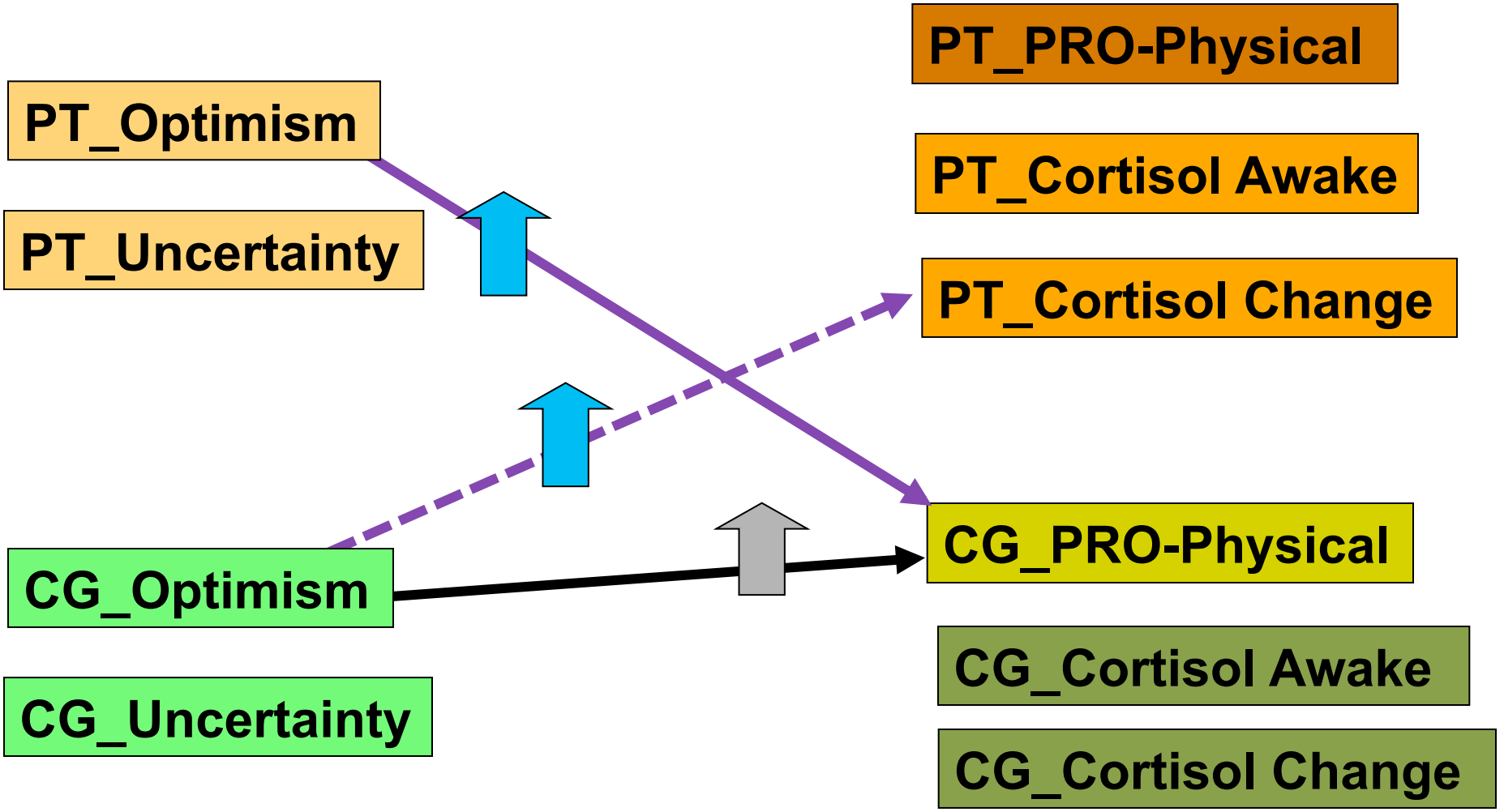

Kim, Wellisch, & Spillers. (2008).

# Perceived Stress & Biomarkers



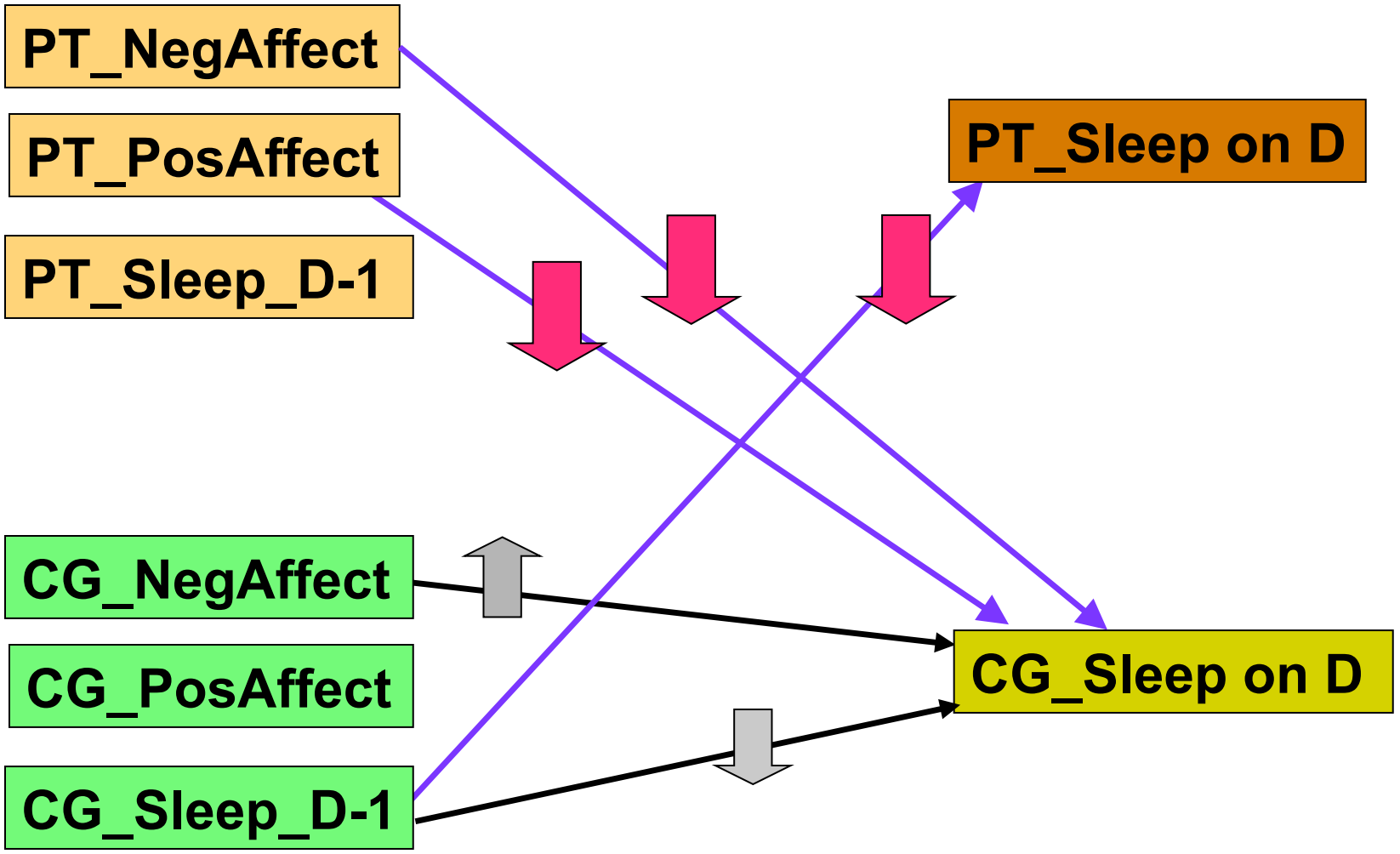

Kim et al. (2016b).

# Personality & Biomarkers




Kim et al. (2017).

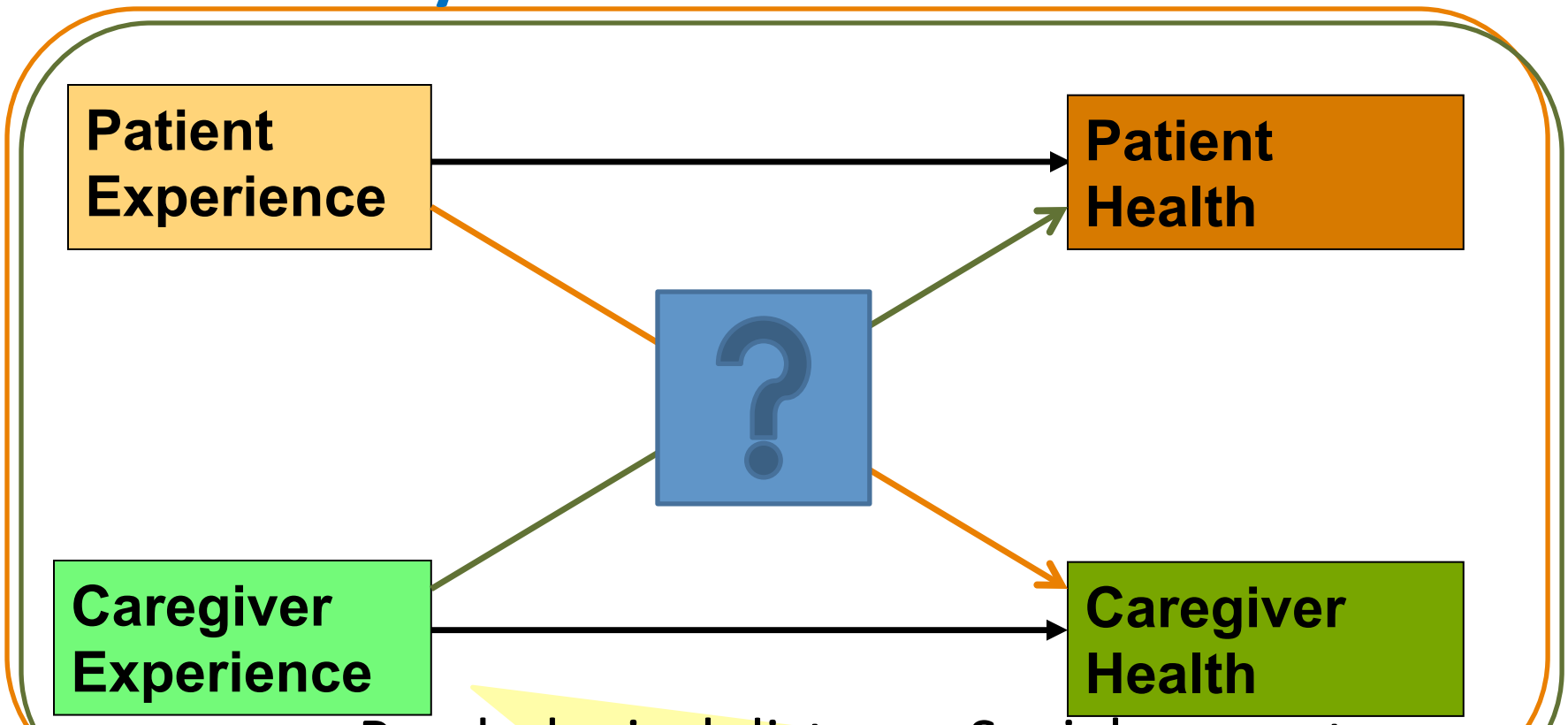
# Affect & Sleep




Ting et al. (2018).

# Illness in Relationships Context

## Individual & Dyadic Effects



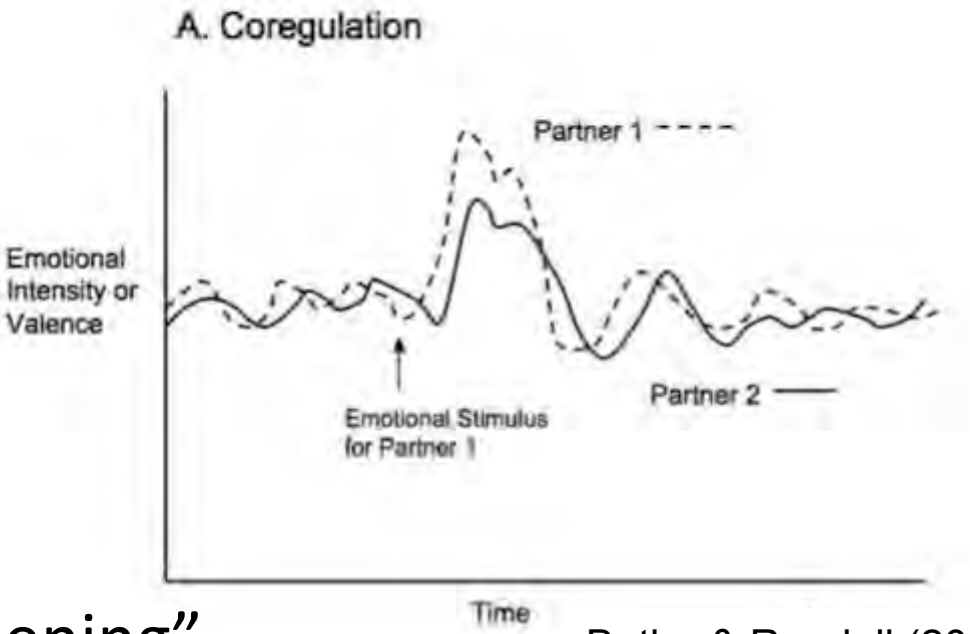

Psychological distress; Social support; Spirituality; Health Behaviors; Biomarkers

# Coregulation in Relationships & Health

Coregulation:

- ✓ Partner is a one's regulator
- ✓ "bidirectional linkage" & "oscillating processes"

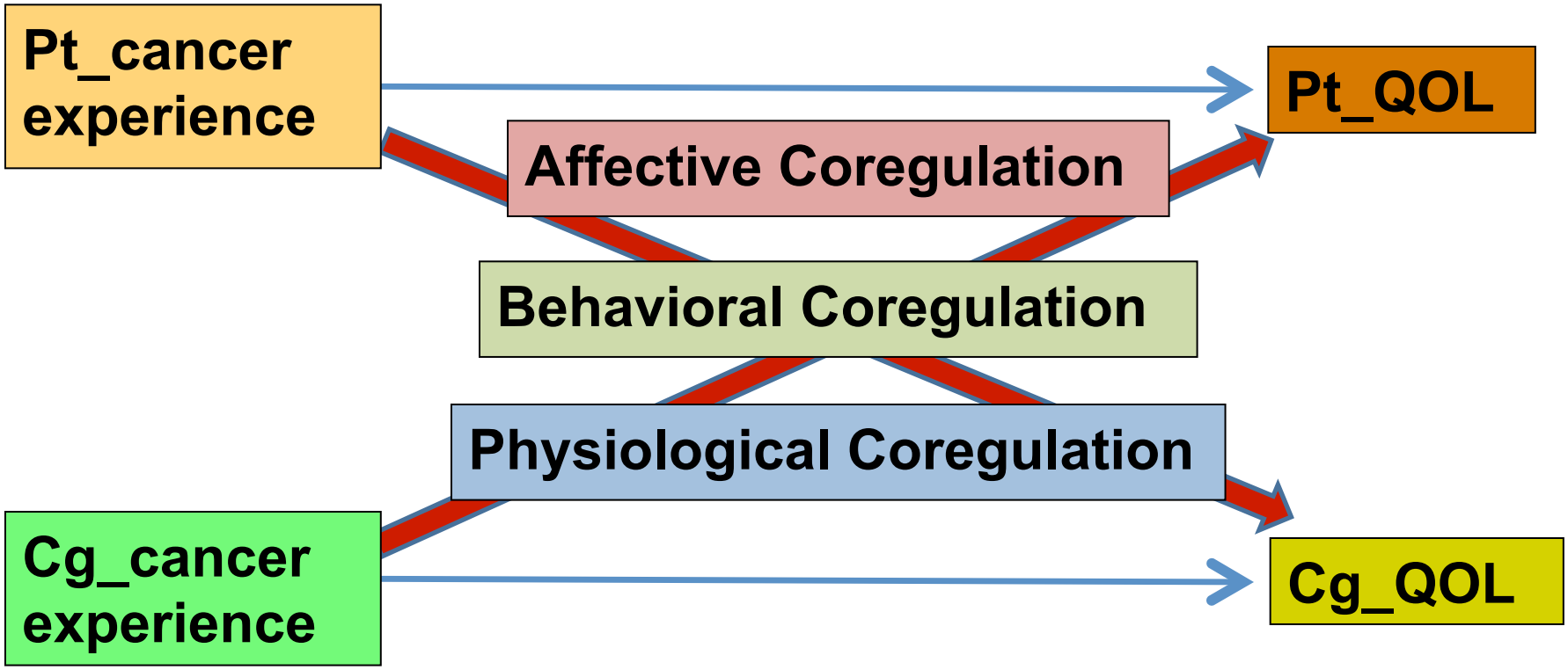
(Butler & Randall, 2013; Sbarra & Hazan, 2008)




Butler & Randall (2013)

- ➢ "Reciprocity" & "Dampening"
- ✓ may be a mechanism how close relationship partner plays a role in one's psychological well-being and physical health (Robles, Statcher, Trombello, & McGinn, 2013)

# Mechanisms of Dyadic Effects



# Cardiovascular Coregulation

- Young adults in a heterosexual romantic relationship (*n* = 23 dyads)
- Stress Induction Tool for Close Relationships and Health (STITCH)

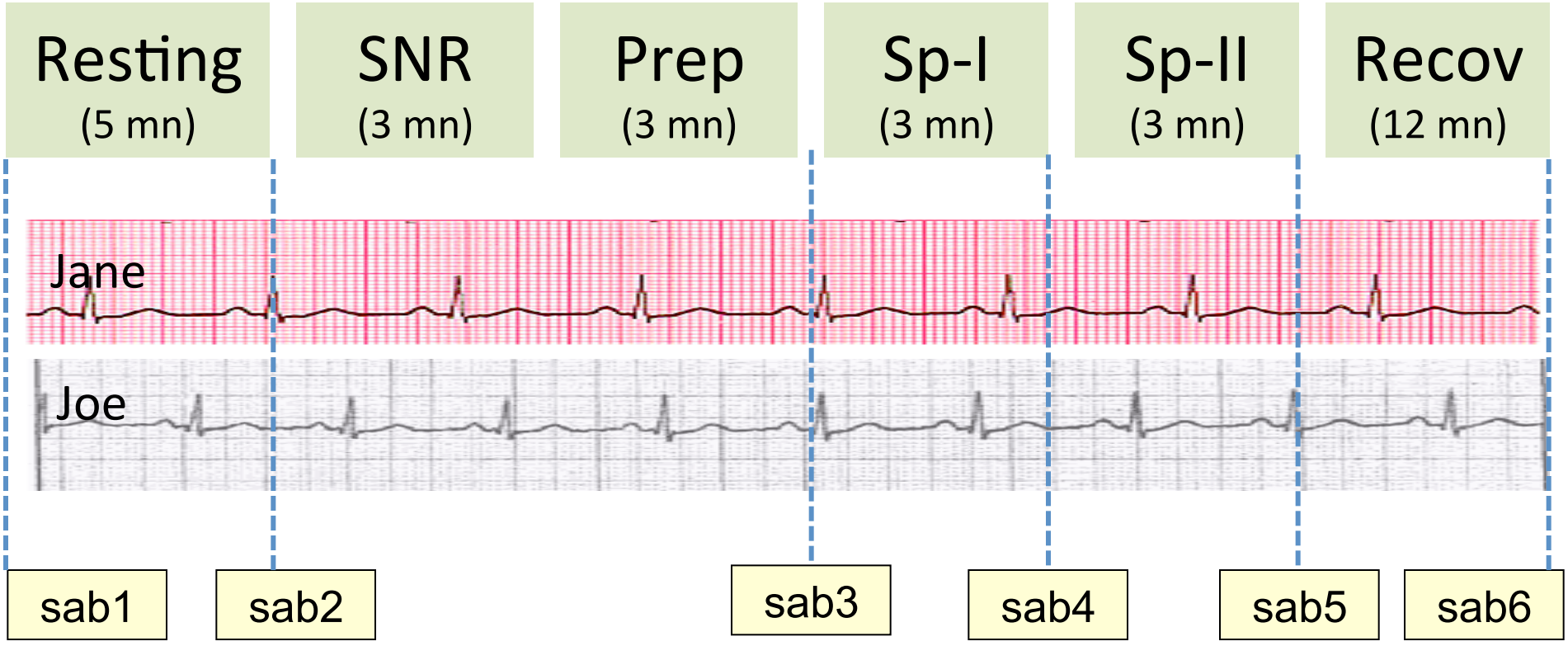
| Baseline | Preparation | Stress Task | Recovery |
|---|---|---|---|

Jane

Joe

# STITCH

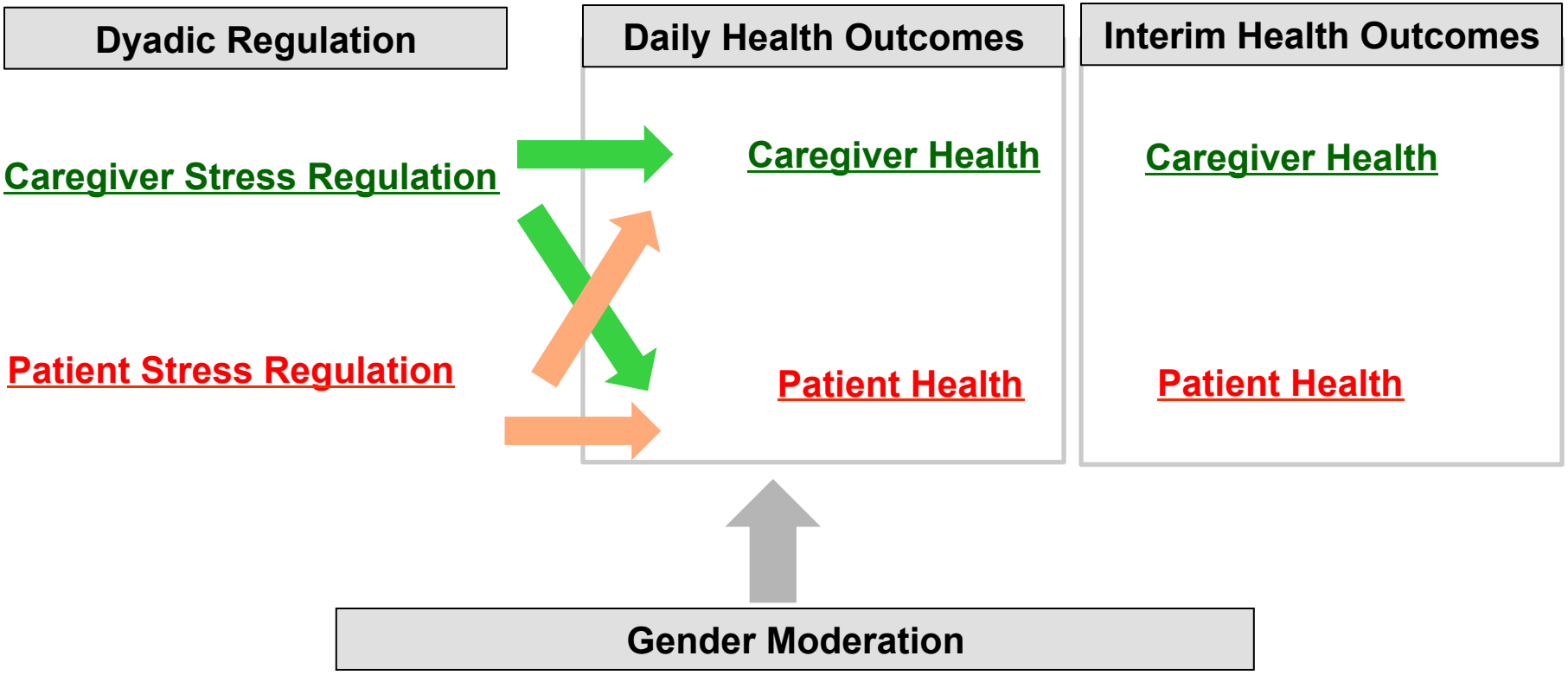
- Pilot tested with colorectal cancer survivors and their spouses




s = saliva;
a = affect (self-report);
b = blood pressure

sab7
30 mn after sab6

# BiPs:
# Biological & PsychoSocial Mechanisms




**Post-doc Opportunity through Diversity Supplement**

1R01NR016838

# HOW to Help:

# Interventions

# Cancer Caregiver Interventions

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

  - 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

# Cancer Caregiver Interventions

- Effect Sizes
  - small to medium effects – 29 RTC (Northouse et al., 2010)
  - nil to small effects (.05 to .27) – 6 RCT on cg QOL (Waldron et al., 2013)
  - small effects on patients' outcomes – 27 RCT (Griffin et al., 2014)

- Couple-based similar effect sizes to patient-only or caregiver-only (*d*=.35 - .45) – (Regan et al. 2012)
- Couple-based effect size for patients, .25-.31; for caregiver, .21-.24 – 17, 23 articles (Li & Loke, 2014; Badr & Krebs, 2013)

➔ Small but maybe beneficial

# Cancer Caregiver Interventions

- Weaknesses & Future Directions
  - Insufficient evidence
  - unclear theoretical framework
  - short (< 3 months) follow-up
  - delivery mode – lack of disseminability

    Web-based caregiver interventions as effective as traditional intervention, although quality of current web-based caregiver interventions is weak – 4 interventions (Kaltenbaugh et al., 2015)

  - Uniqueness of cancer caregiving
    – compare and contrast with other caregiver research

  - lack of targeting and tailoring

    Gender, SES, Sociocultural Factors, Country and Culture

# IPOS Online Surveys

- Phase I with professionals
- To gauge current involvement in clinical services and research with cancer patients/survivors in various ages and their family caregivers
  - In collaboration with IPOS
  - Survey developed in 15 languages:
    Catalan, Chinese-simplified, Chinese-traditional, English, French, German, Hindi, Hungarian, Italian, Japanese, Korean, Portuguese, Romanian, Spanish, Turkish
  - Survey is in the field:

https://ipos-society.org/ipos-survivorship-online-survey/

- Next phases will directly engage with cancer patients/ survivors in various ages and their family caregivers

# Conclusions

- Illness affects not only the patients but also their family.
- Certain caregivers are more likely to develop greater psychological and physical morbid conditions.
- Identifying more refined psycho-social predictors and psychobiobehavioral mechanisms may help improving communication quality and protecting survivors and caregivers from prematurely declining health.
- Take seasons (illness trajectory) into consideration in designing programs and target transitions (to end of life, to bereavement) for effective communications with caregivers
- Evidence-based, socioculturally sensitive, interdisciplinary interventions to reduce the burden of cancer and improve the quality of life among persons touched by cancer

# Acknowledgement

*All the families who participated in these projects*

*FAMILY Lab*

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ykim@miami.edu

## University of Miami

Charles Carver, PhD
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Amanda Ting, BS

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Richard Schulz, PhD. U of Pittsburgh
David Spiegel, MD, Stanford University
David Wellisch, PhD, UCLA
Jamie Zeitzer, PhD, Stanford University