
Research and Practice for Informal Cancer Caregivers: Past, Present and Future

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Facilitating Adjustment to Medical Illness in Your Family

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International Conference on Cancer Nursing

2012> 2030

WORLDWIDE CANCER CASES
ARE PROJECTED TO INCREASE BY

 **50%**

FROM **14 million** TO **21 million**

WORLDWIDE CANCER DEATHS
ARE PROJECTED TO INCREASE BY

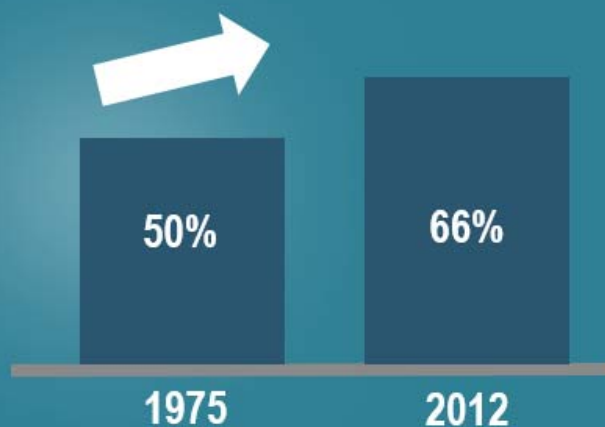
 **60%**

FROM **8 million** TO **13 million**

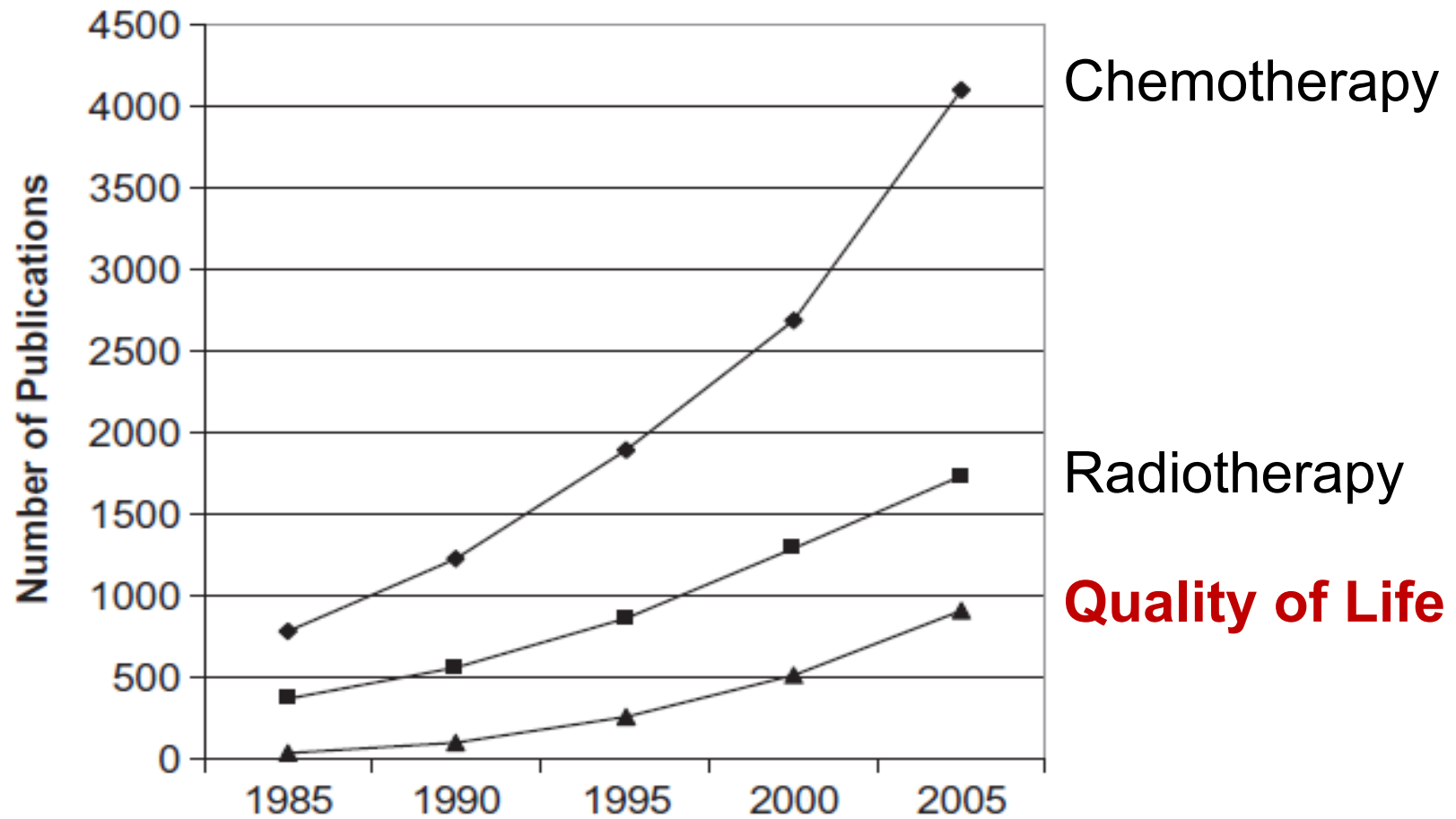
Source: American Cancer Society: Global Cancer Facts & Figures, Second Edition
cancer.gov



5-YEAR SURVIVAL FOR THE MOST COMMON TYPES OF CANCER COMBINED **INCREASED** FROM 1975 TO 2012



Cancer and “I”



Sanson-Fisher et al. (2010). European J of Cancer Care

Cancer and “I”

- ✓ Psychosocial Interventions for Adult Cancer Survivors
(meta-analysis with 16 RCTs: Stanton et al., 2013)
 - Alteration in cognition (expectancies, illness representation)
 - Self-efficacy for using coping strategies/skills targeted by the intervention
 - Psychological symptoms (mood disturbance)
 - Psychosocial resources (self-esteem)
 - Physical symptoms (pain)

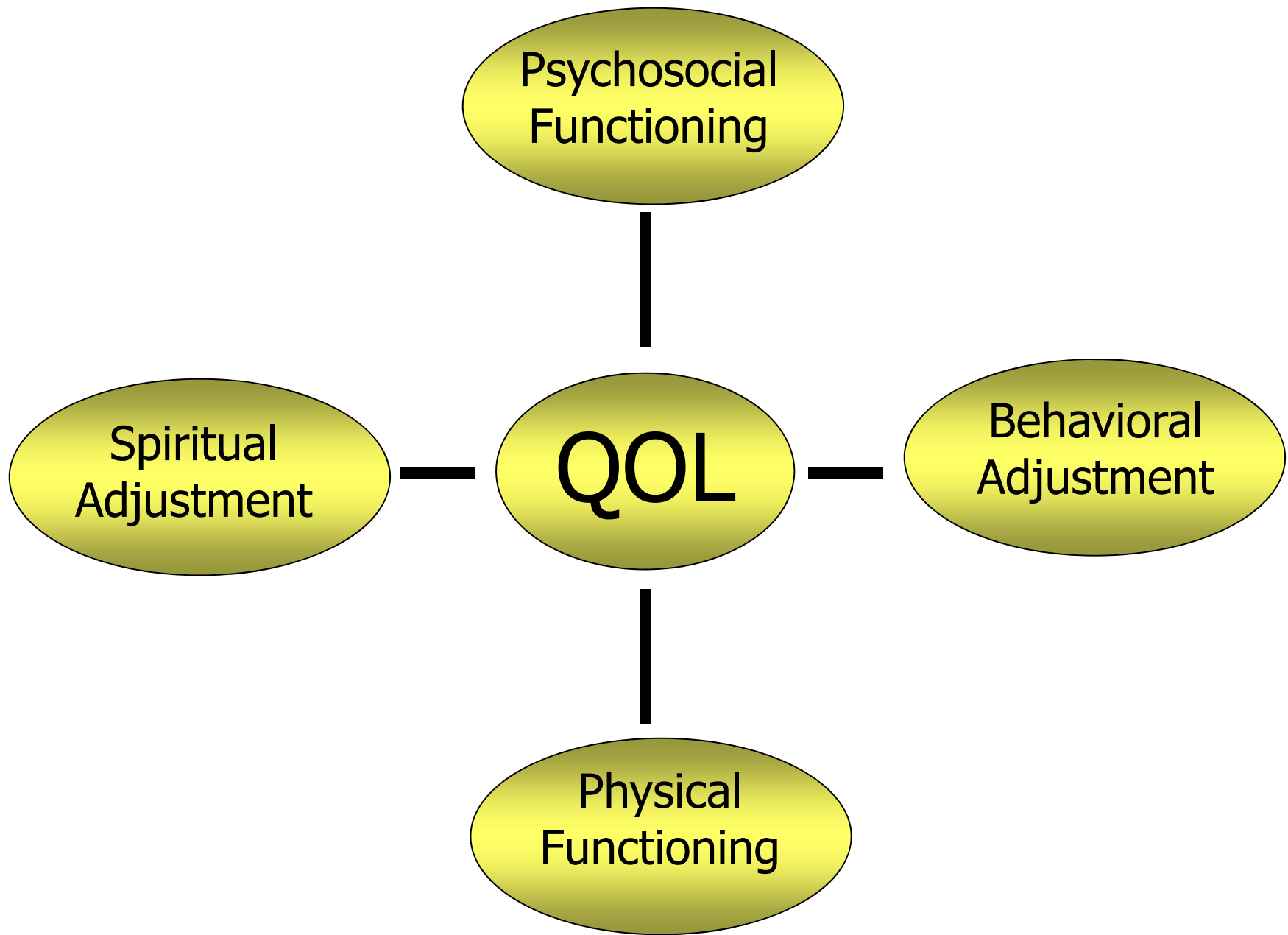
Cancer and Us

- ✓ 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

Cancer and Us

- ✓ Publications on cancer caregivers
 - # of publication: 2010 – 2014 Tripled of 2000 - 2004
 - One fourth dealt with one or more aspects of QOL
 - One in eight dealt with changes in QOL over time (either longitudinal or intervention studies)

Quality of Life among Cancer Caregivers



Caregivership Model

Caregivership Phases (Five Seasons)

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

**Individual
Resources/Risks**

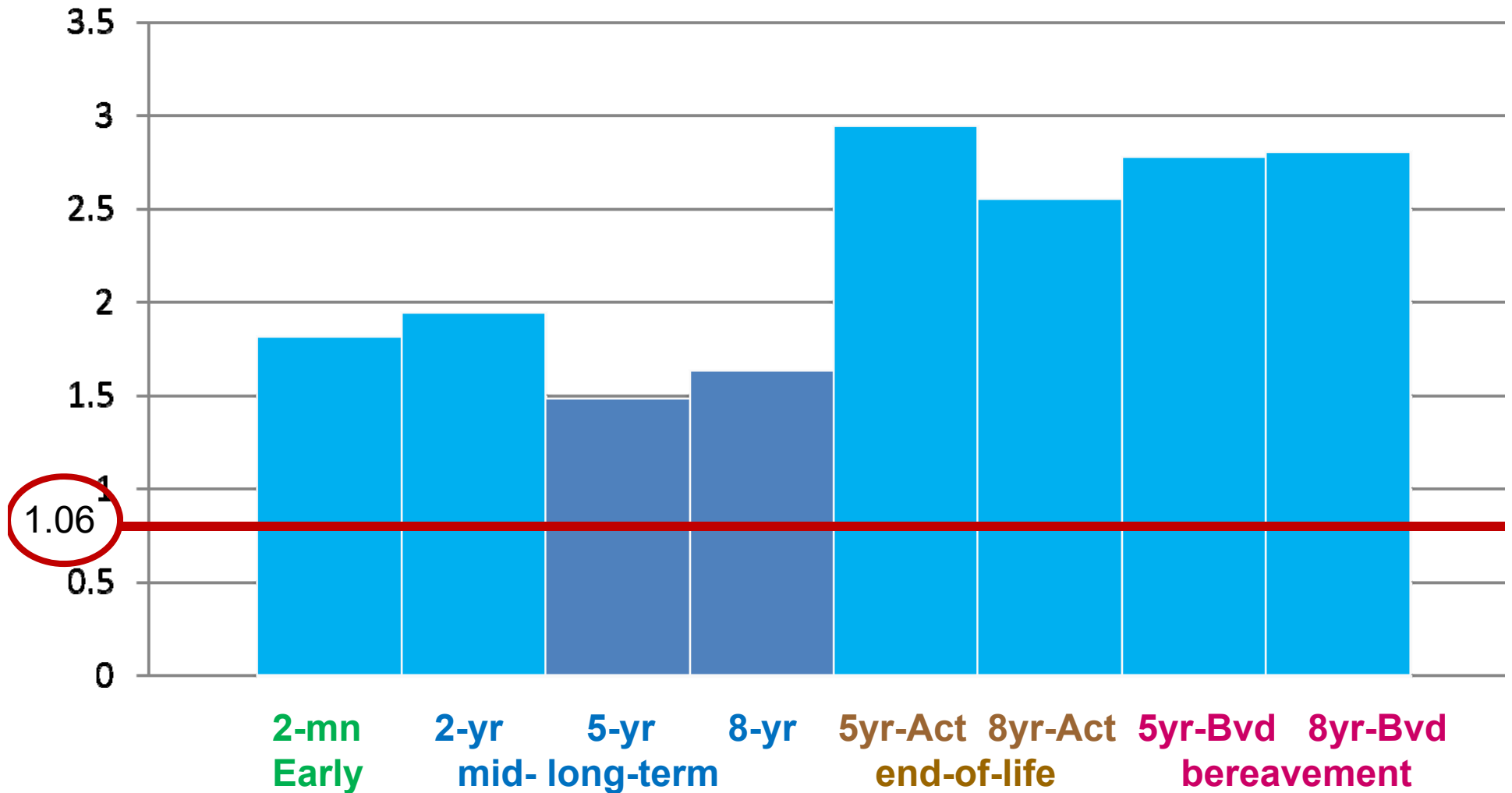
**Contextual
Resources/Risks**

Illness Specific

Survivor's QOL

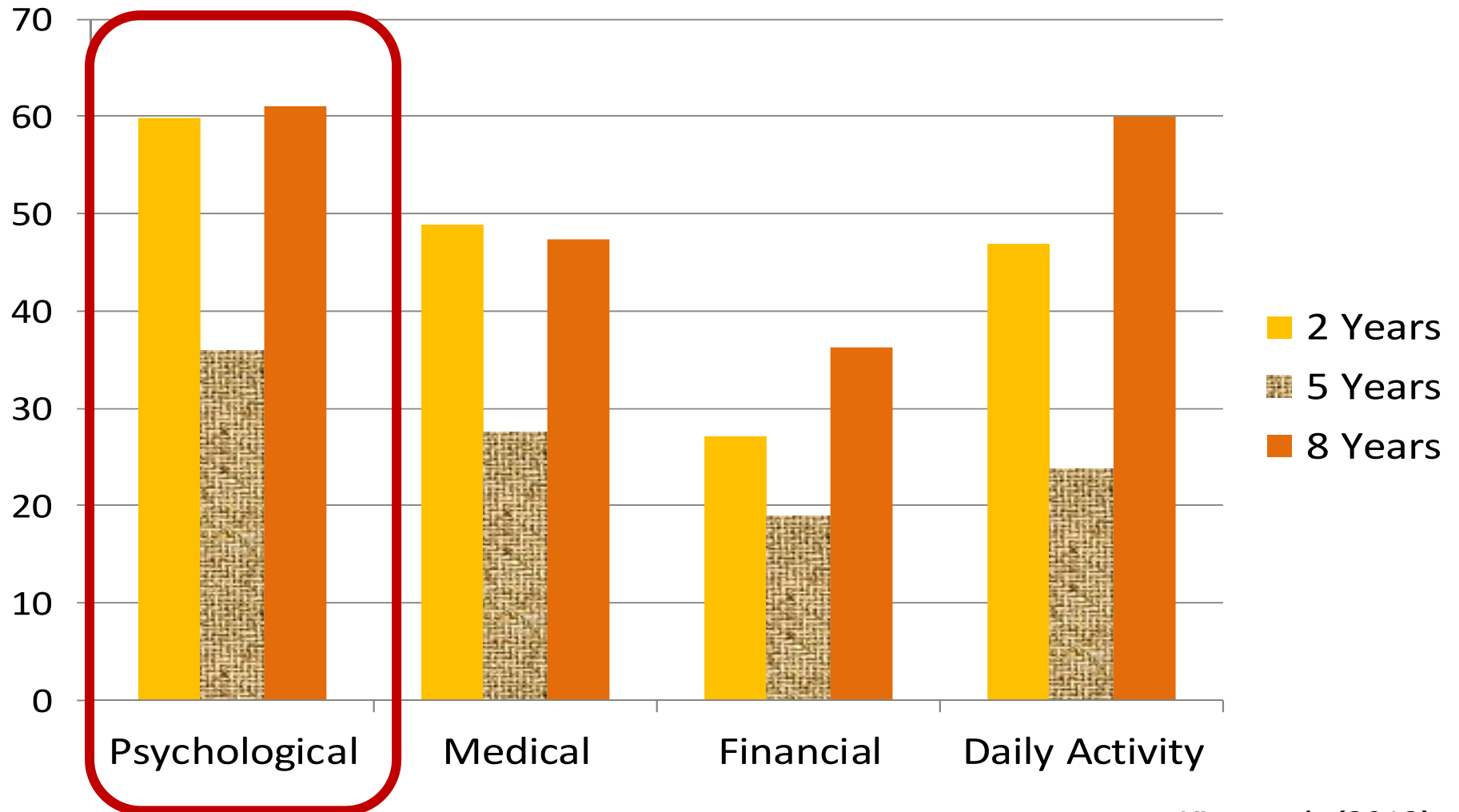
Caregiver's QOL

Caregiver Psychological Distress (POMS-SF)



Reference score: McNair & Neuchert (2005).

% Reported Unmet Needs of Caregivers



Kim et al. (2012)

Psychosocial Predictors of Caregivers' QOL

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

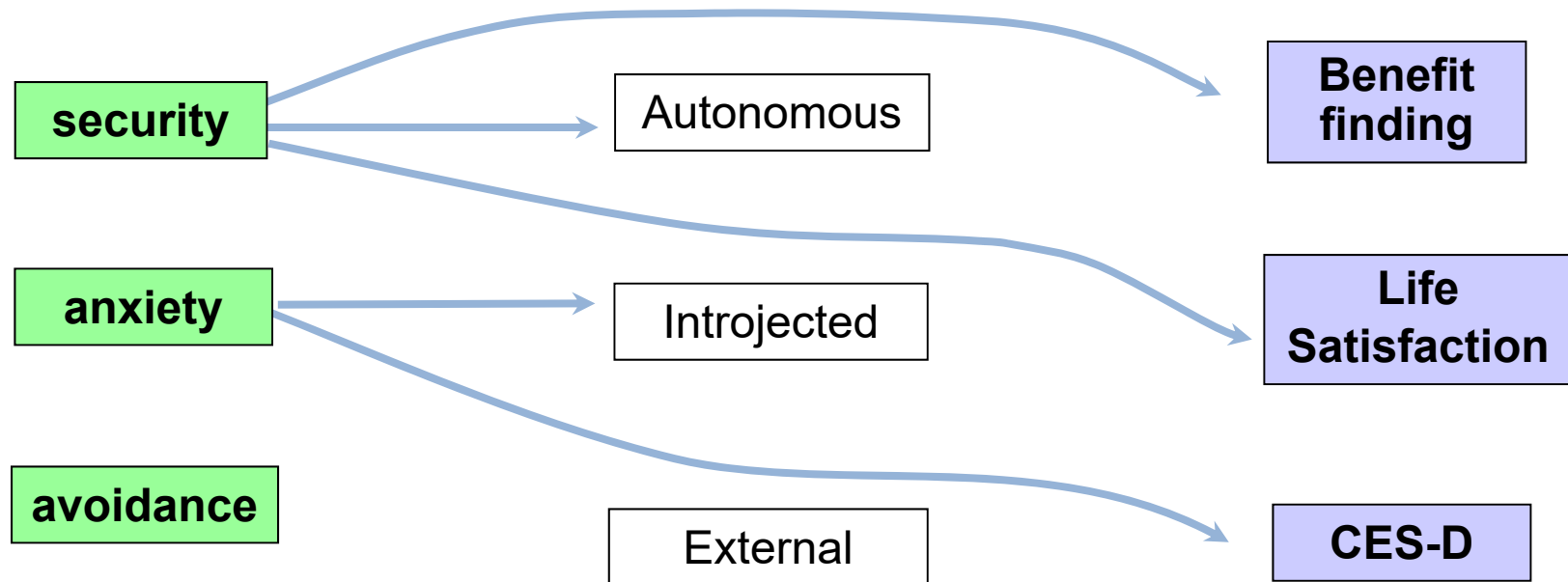
Predictors of Caregivers' QOL

❖ 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

**Interactions Among
Individual, Socio-Cultural,
Illness-Specific Factors,
and the Five Seasons**

Attachment & Caregiving Motives



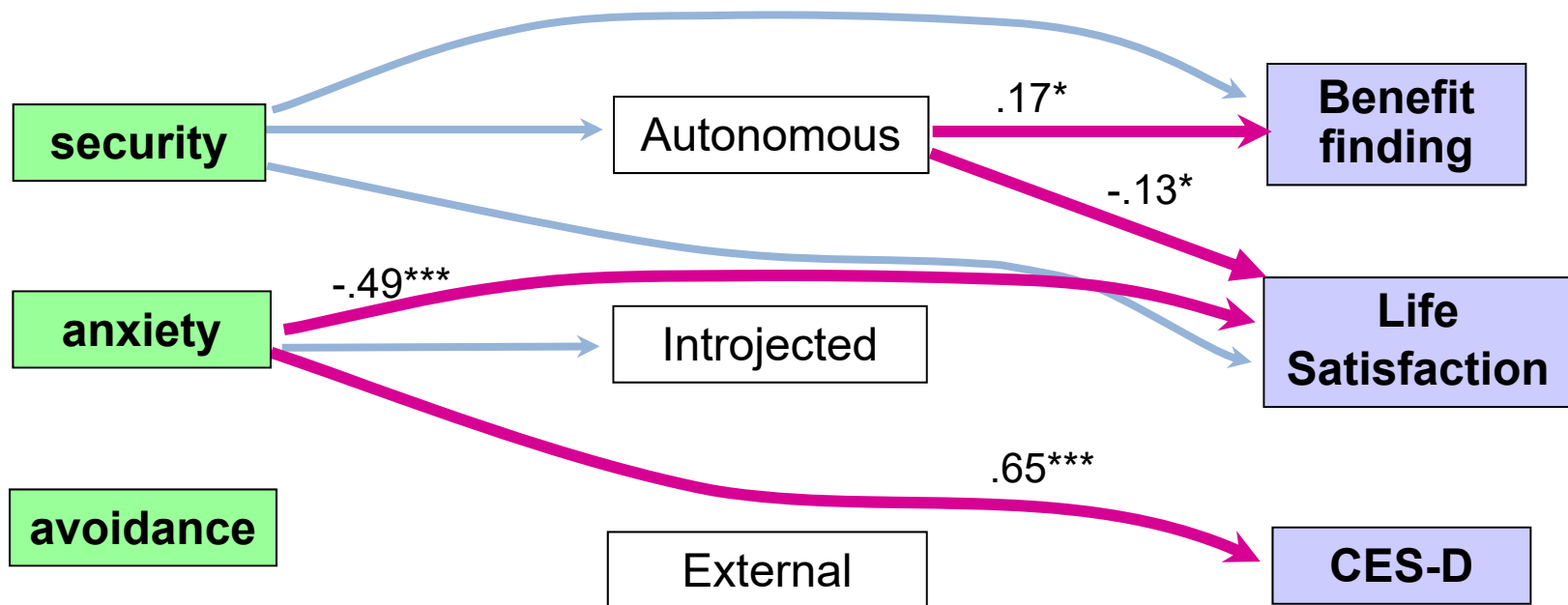
Kim, Carver, Deci, & Kasser (2008).

Wives

Attachment qualities

Caregiving motives

Adjustment



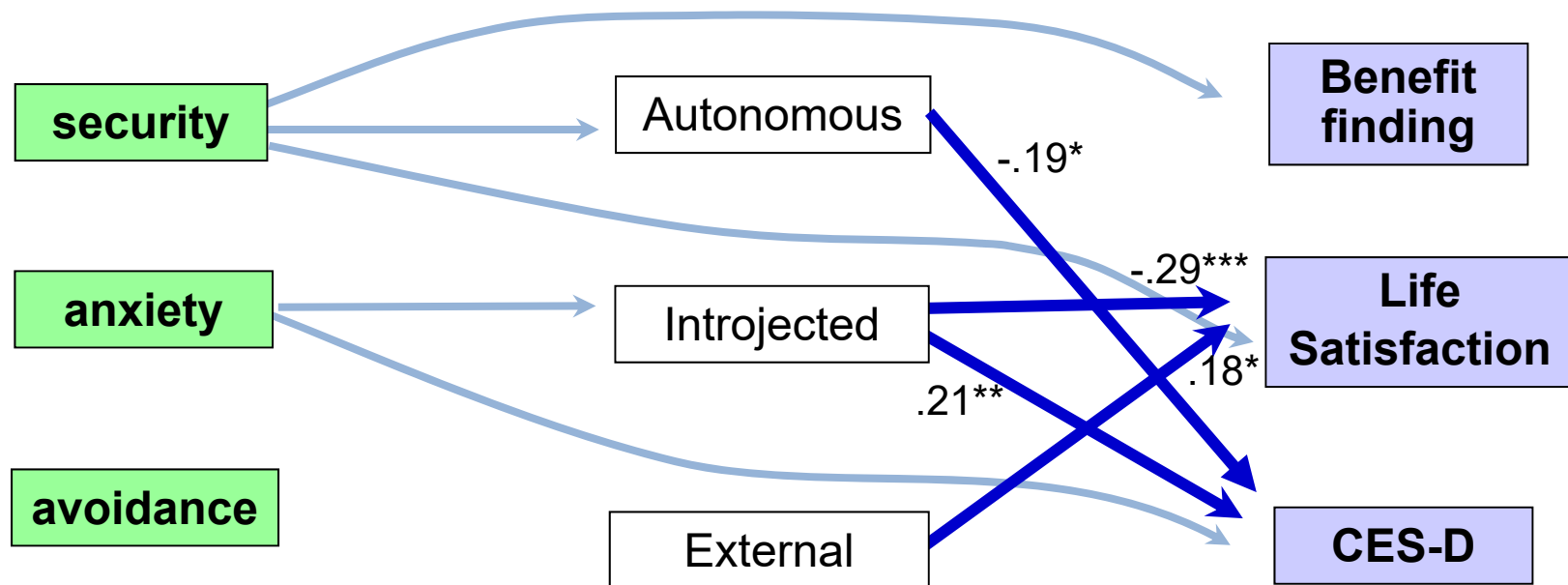
Kim, Carver, Deci, & Kasser (2008).

Husbands

Attachment qualities

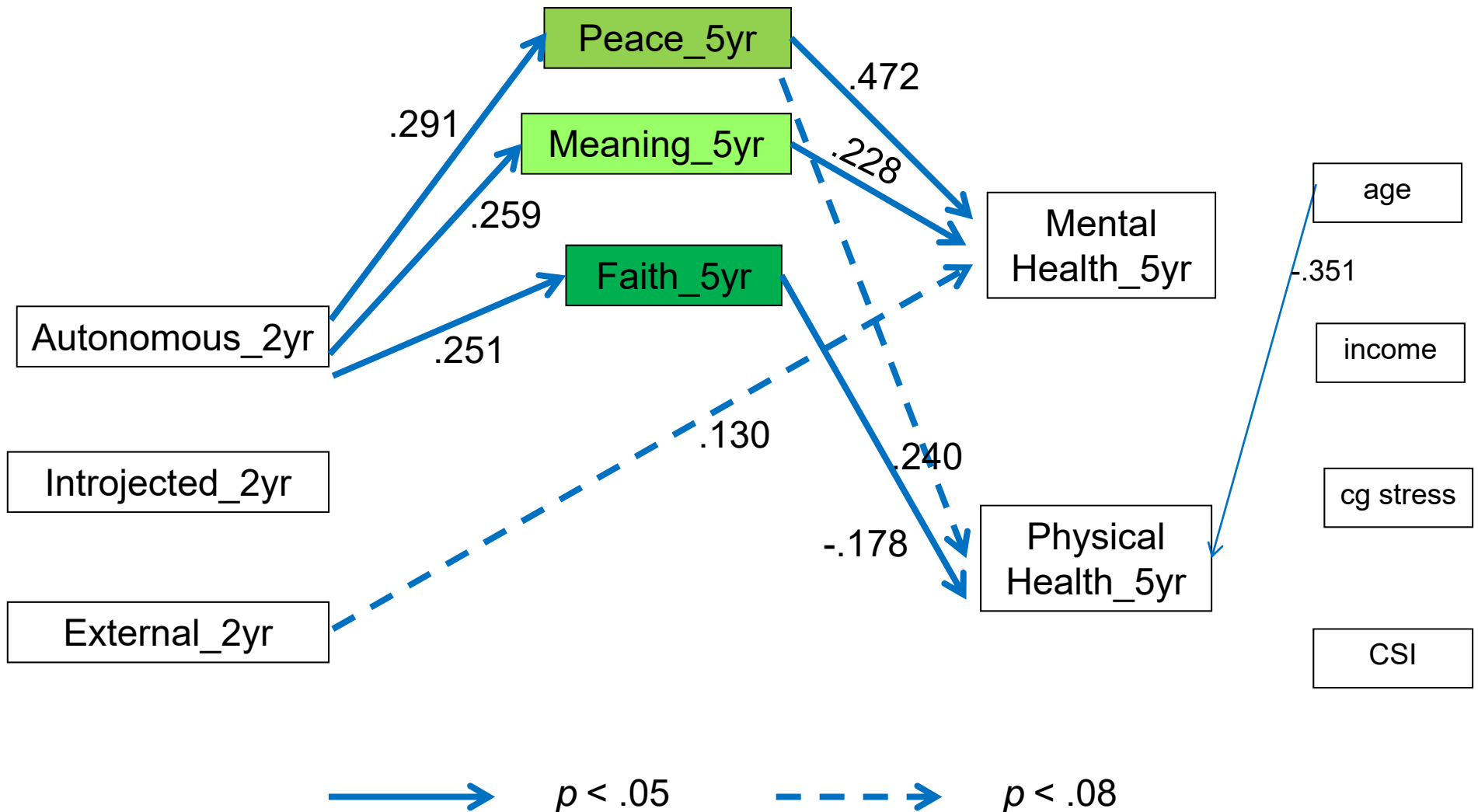
Caregiving motives

Adjustment



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

Male Caregivers at 5 years Post-Dx



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

Benefit Finding

Life Satisfaction

Depression

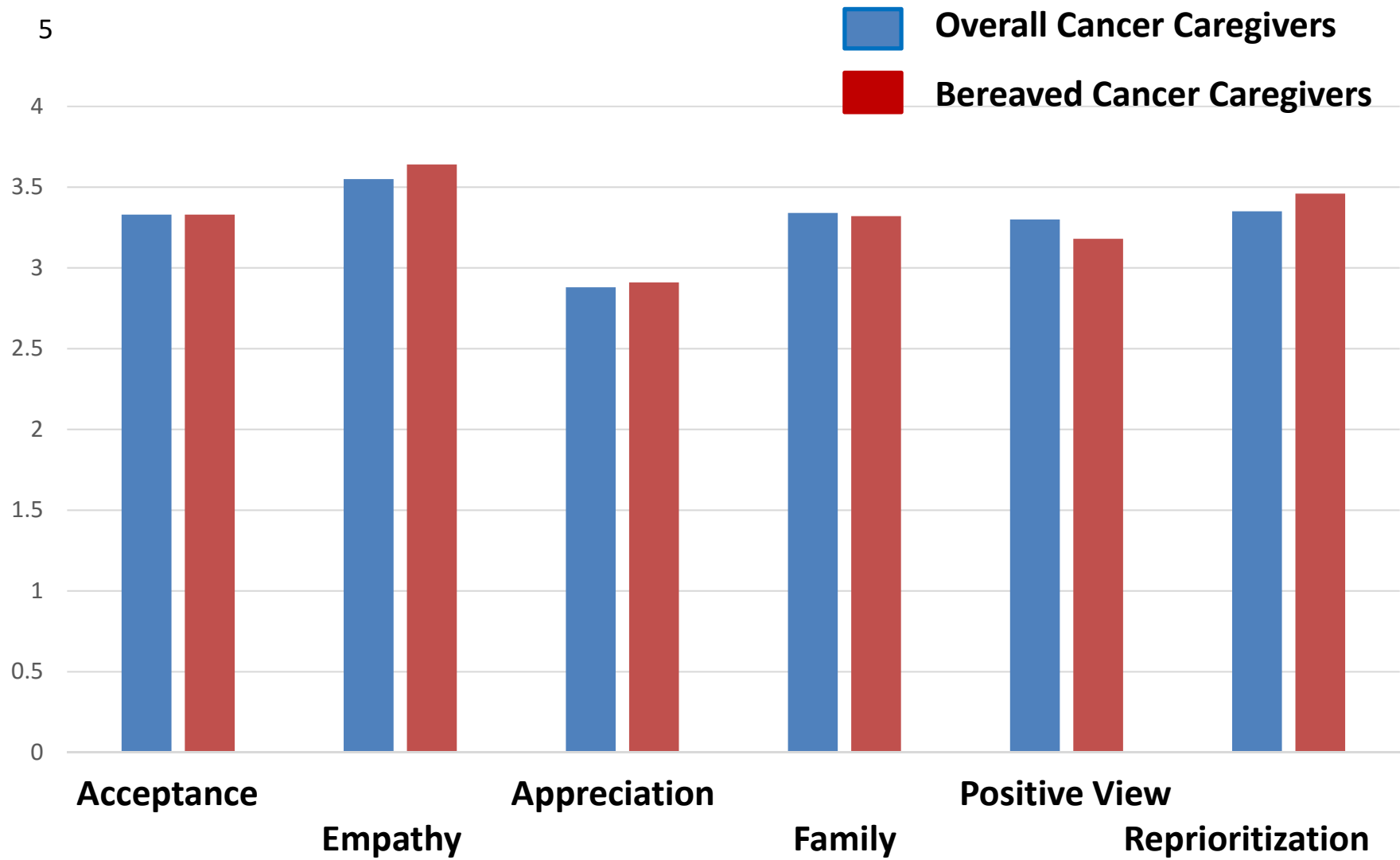
Overall	0.10**	0.05
Acceptance	0.14**	-0.14**
Empathy	-0.09	0.16**
Appreciation	0.11*	-0.01
Family	0.03	0.01
Positive Self-View	0.11	-0.12*
Reprioritization	-0.16**	0.17***

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).

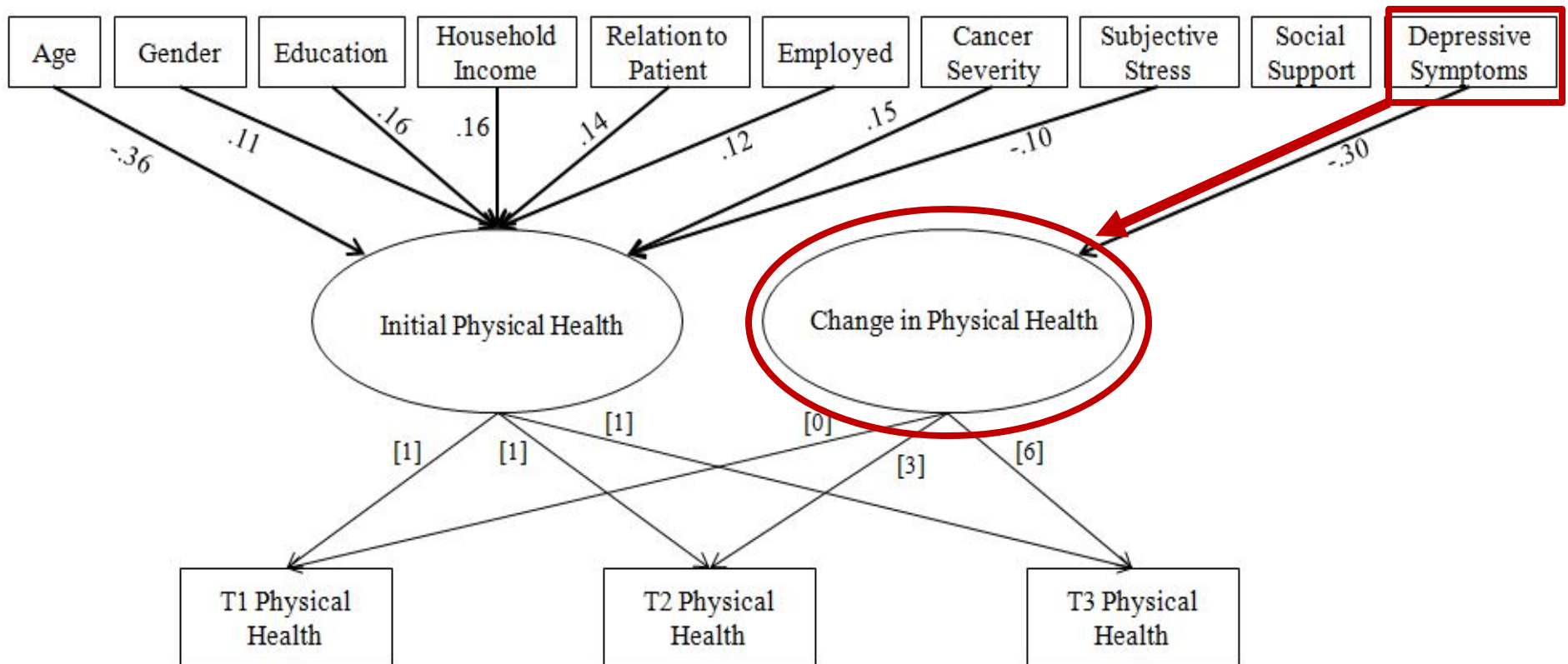
Clinical Levels of Depressive Symptoms: Prevalence

		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)

Long-term Bereavement Outcomes: Predictors

- ❖ **Cross-sectionally at 5-year post-diagnosis**
 - Younger age related to greater ICG, TRIG and lower SWLS
 - Distressed related to greater ICG, TRIG, CES-D; lower SWLS
 - High Spirituality related to lower ICG and greater SWLS
 - Severe cancer related to lower TRIG and greater SWLS
- Satisfaction with patient's physical ailment related to lower ICG and CES-D
- Preparedness related to lower ICG, TRIG, and CES-D

Long-term Bereavement Outcomes: Predictors

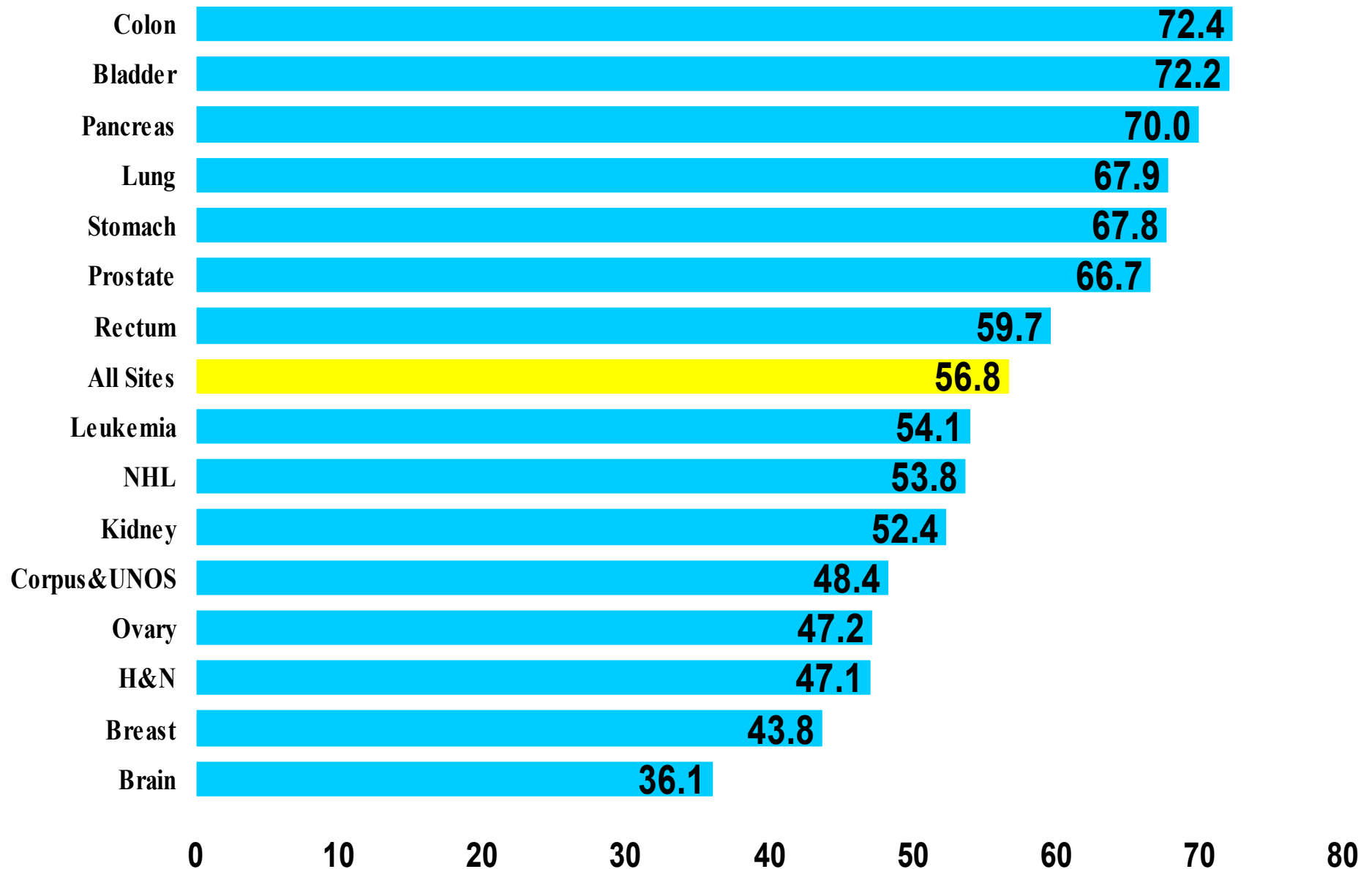
❖ **Prospectively at 8-year** post-diagnosis

Preparedness at 5-year related to

lower ICG and TRIG at 8-year

Aging, Cancer, and Caregiving

Incidence (%) of Cancer in Patients $\geq 65^*$



*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)

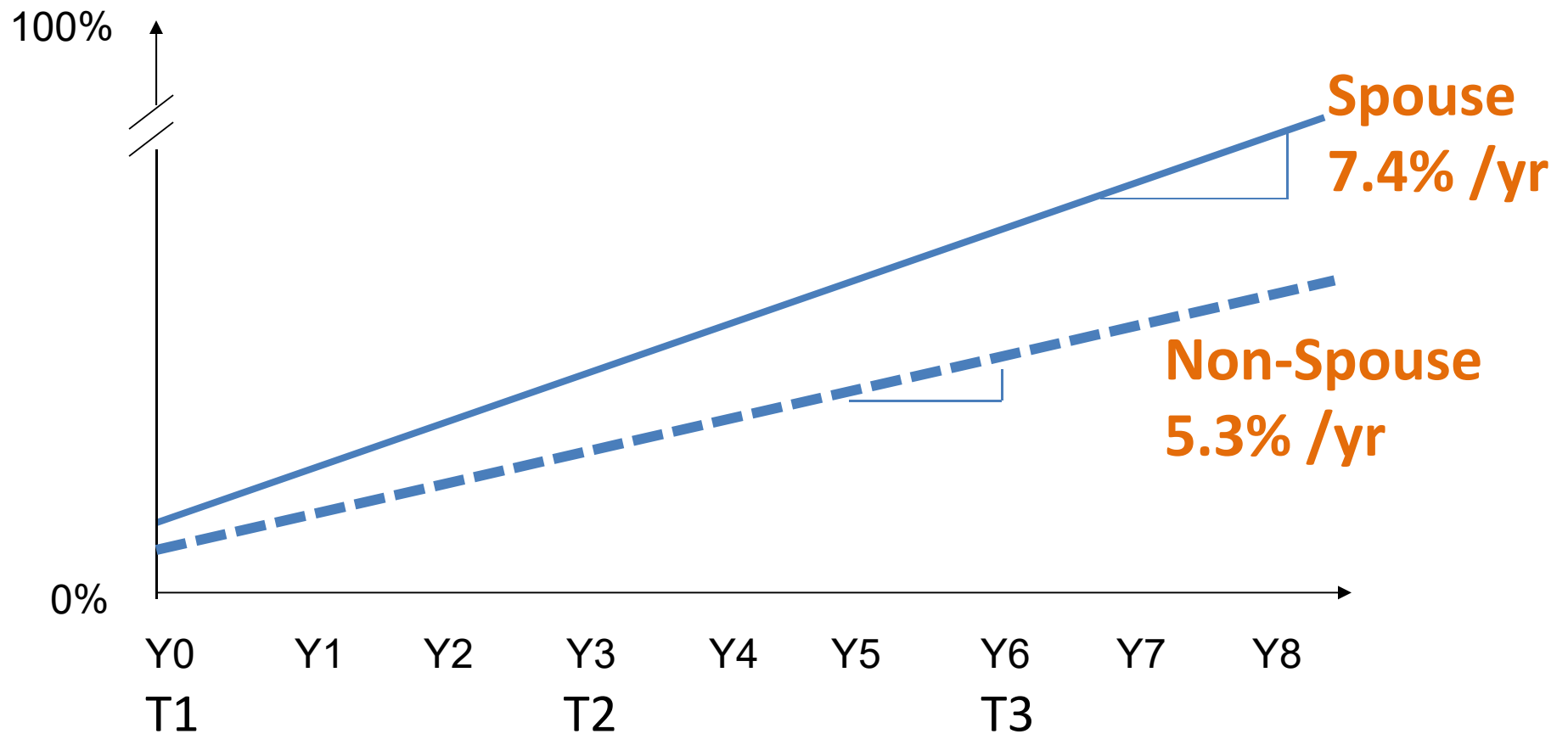
Predictors of Disability Markers:

	Arthritis		Chronic Back Pain		Heart Diseases	
	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
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

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

Predictors of Disability Markers: **Person x Time**

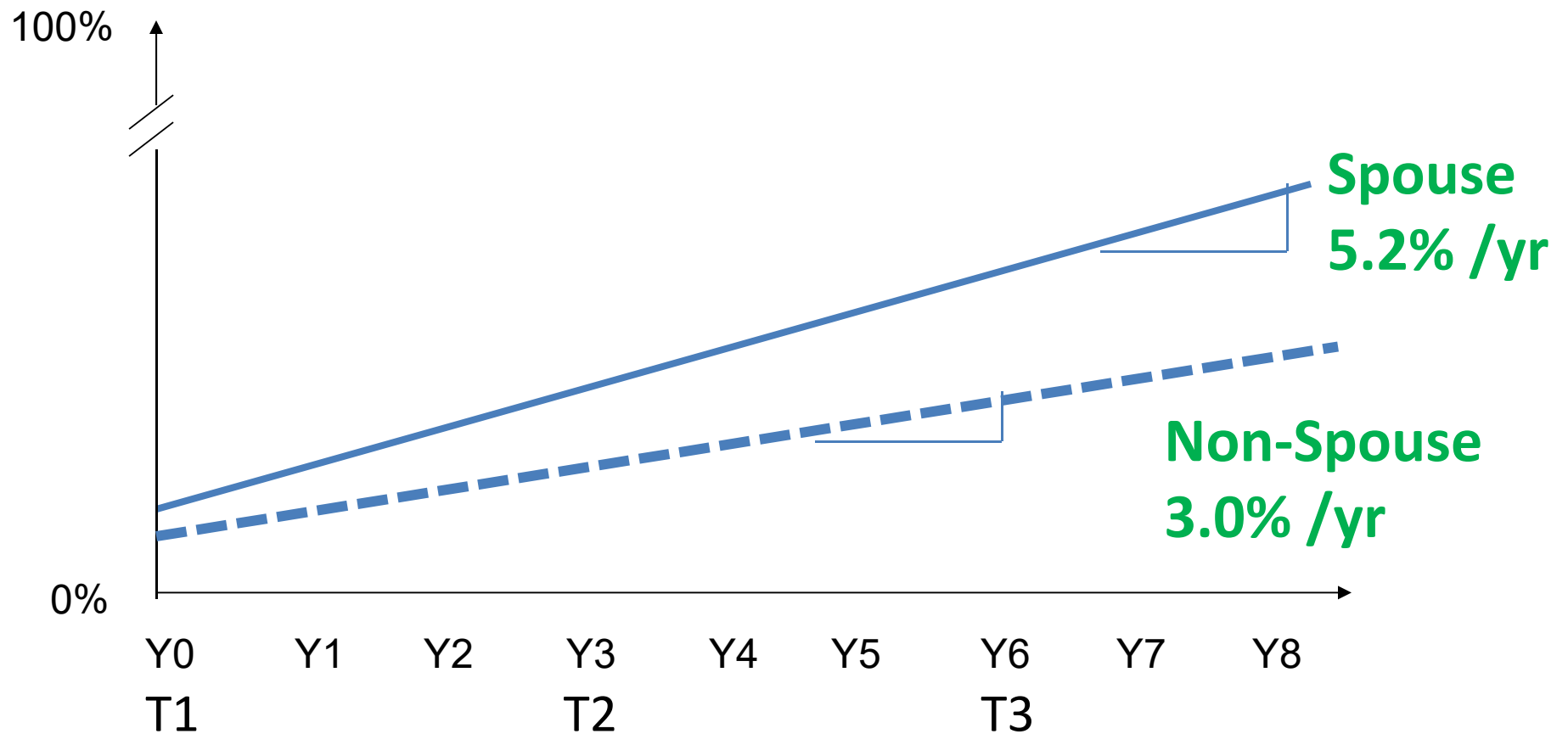
Spousal Caregivers x Time Effect on Development of Arthritis



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

Predictors of Disability Markers: Person x Time

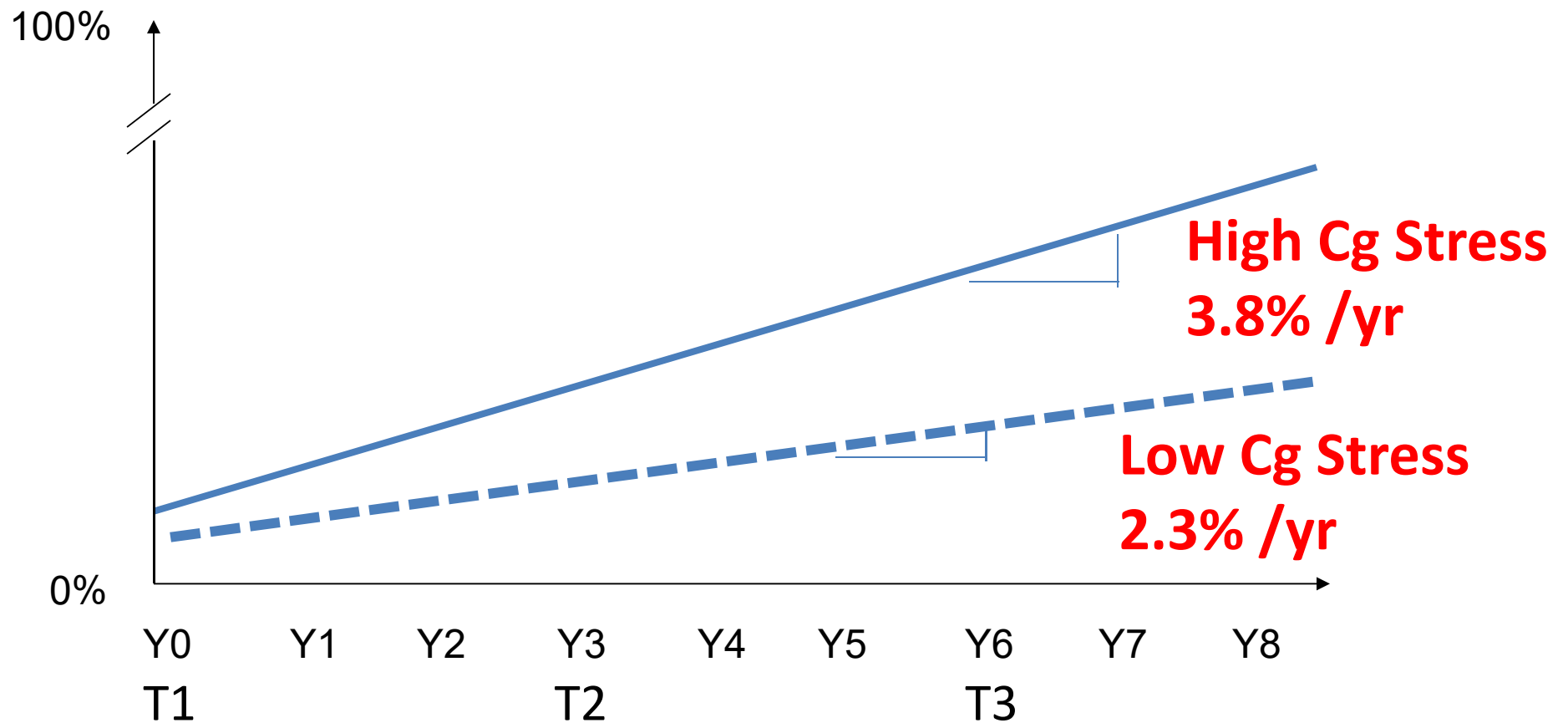
Spousal Caregivers x Time Effect on Development of Back Pain



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

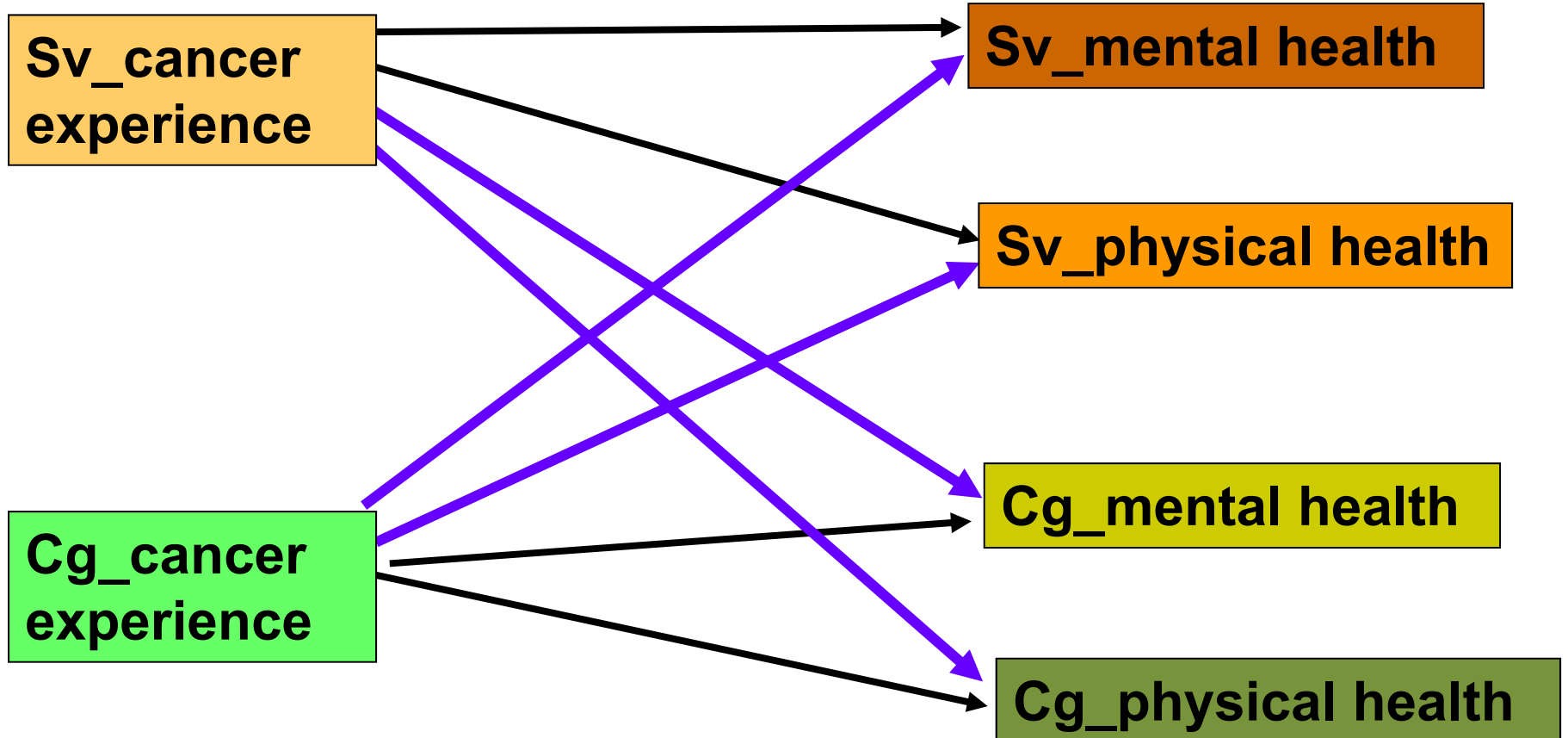
Predictors of Disability Markers: **Person x Time**

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

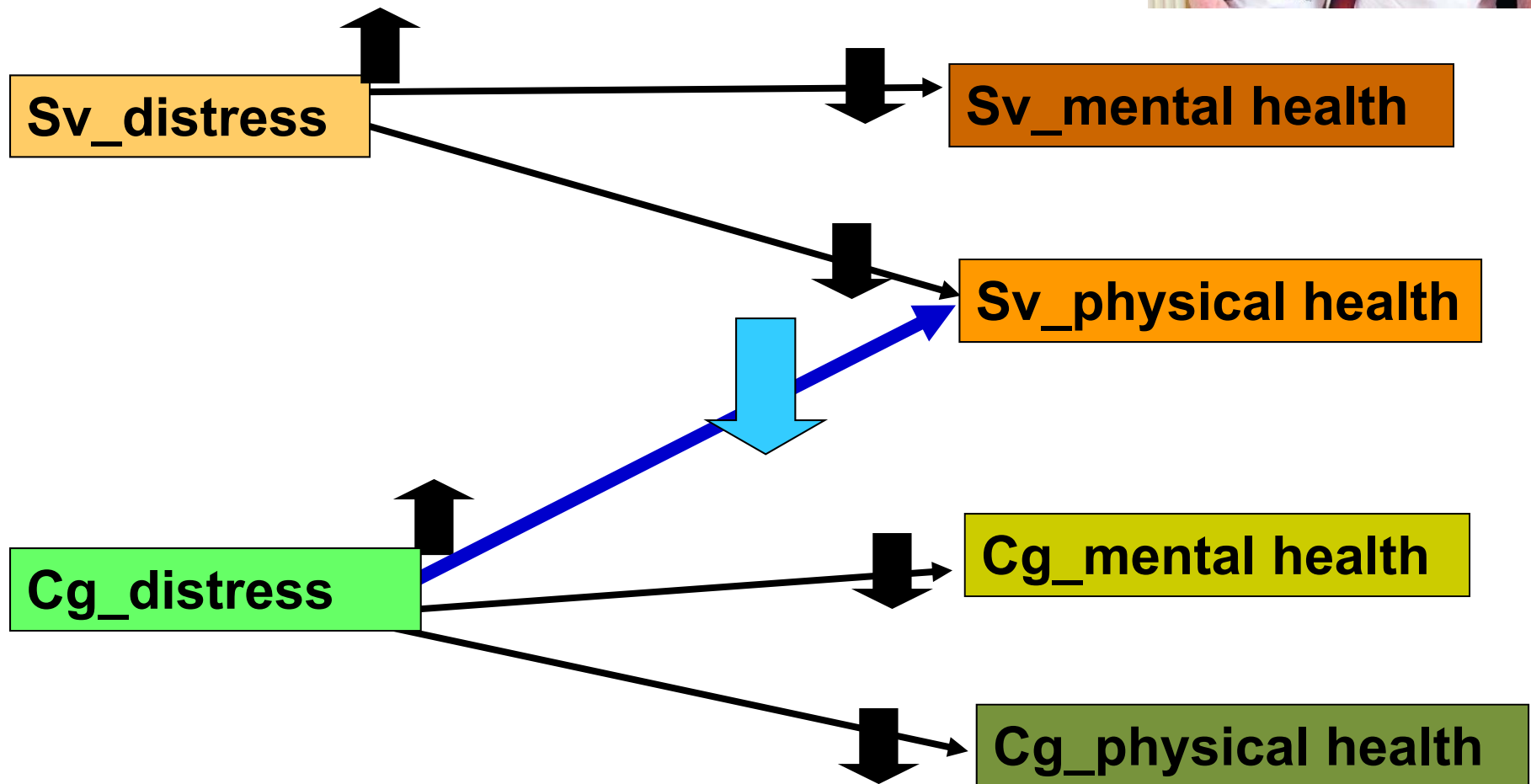


Kim, Carver, Shaffer, Gansler, & Cannady (2015)

Individual & Dyadic Effects



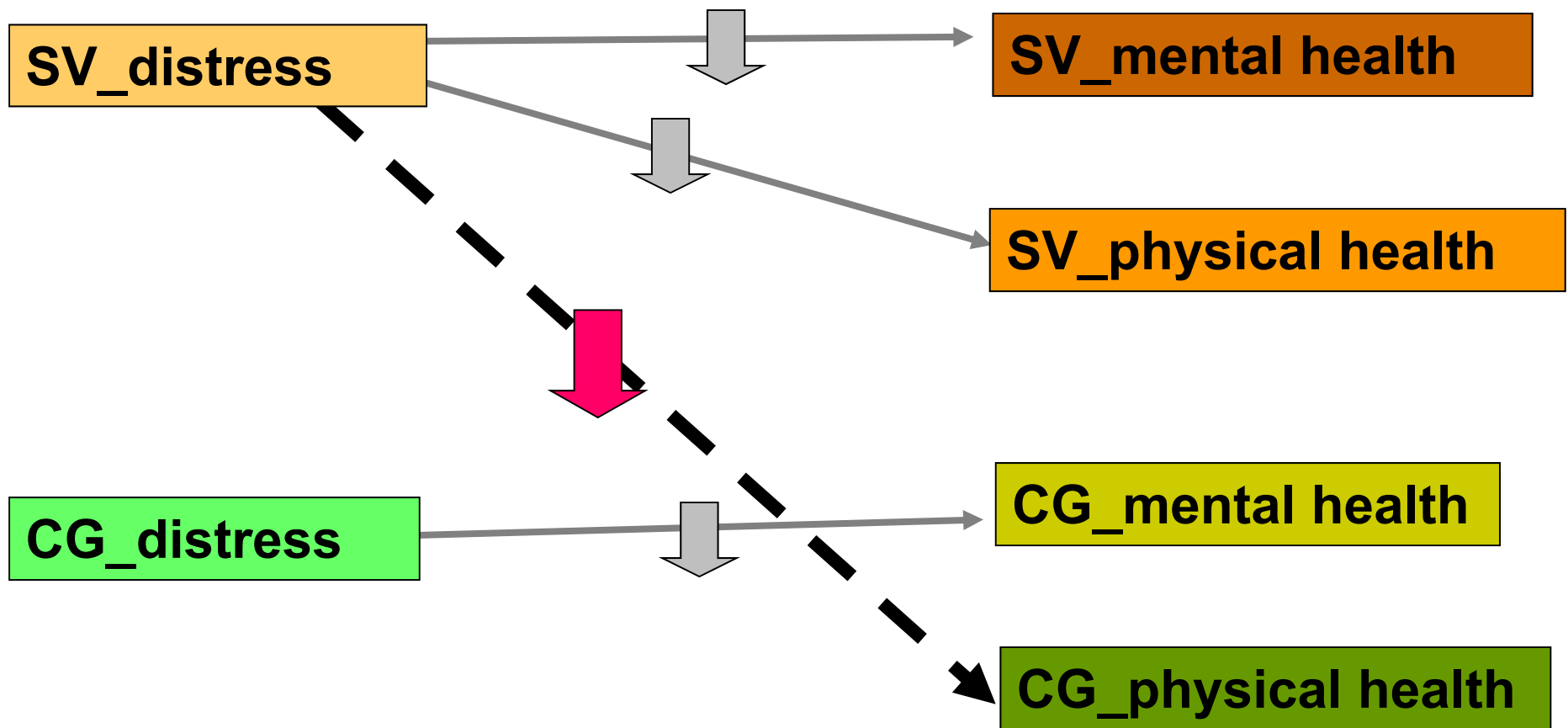
Prostate Cancer Survivors & Spousal Caregivers



N = 168 dyads

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

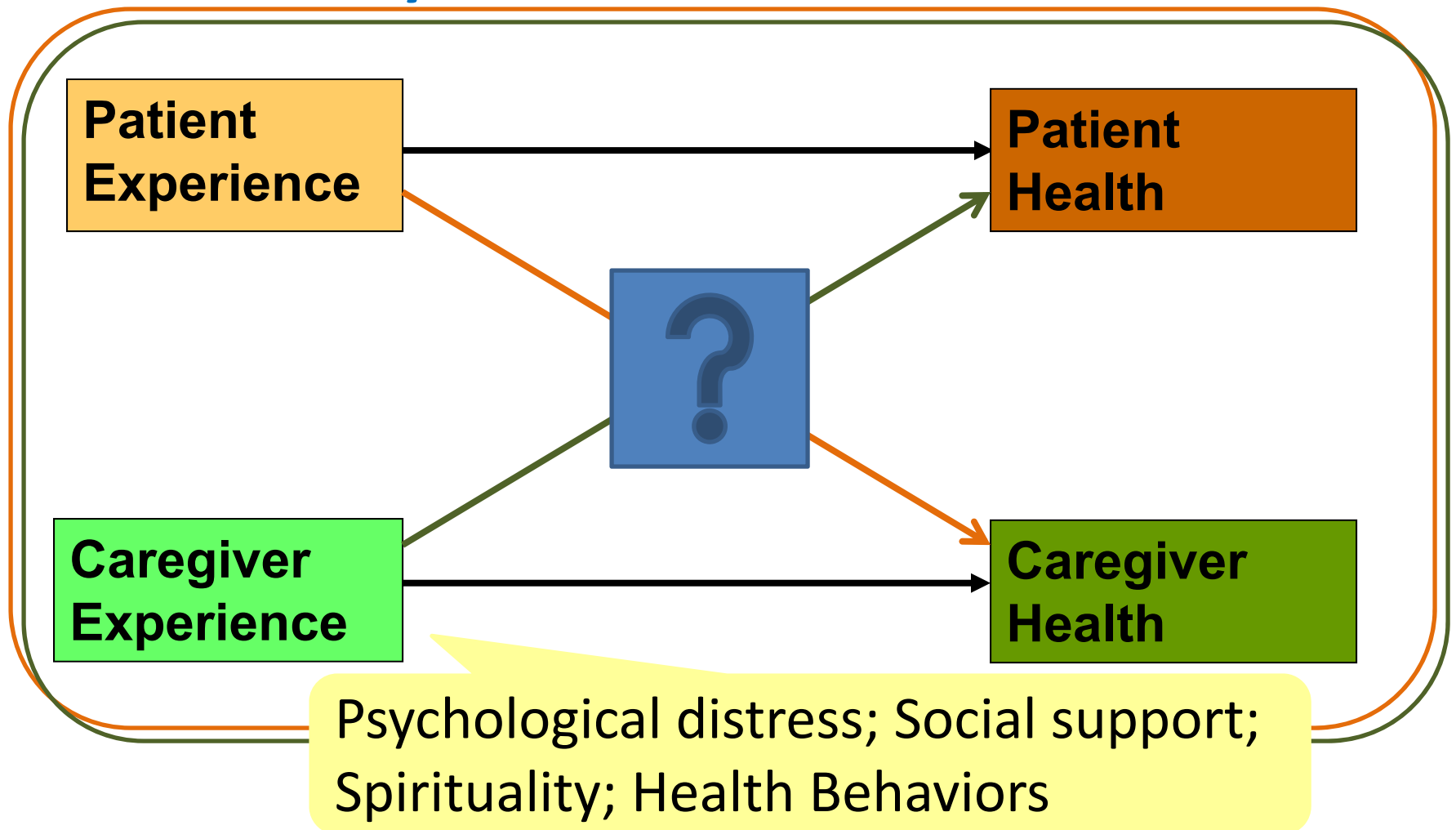
Mothers with Cancer & Their Caregiving Daughters



Kim, Wellisch, & Spillers. (2008).

Illness in Relationships Context

Individual & Dyadic Effects



Coregulation in Relationships & Health

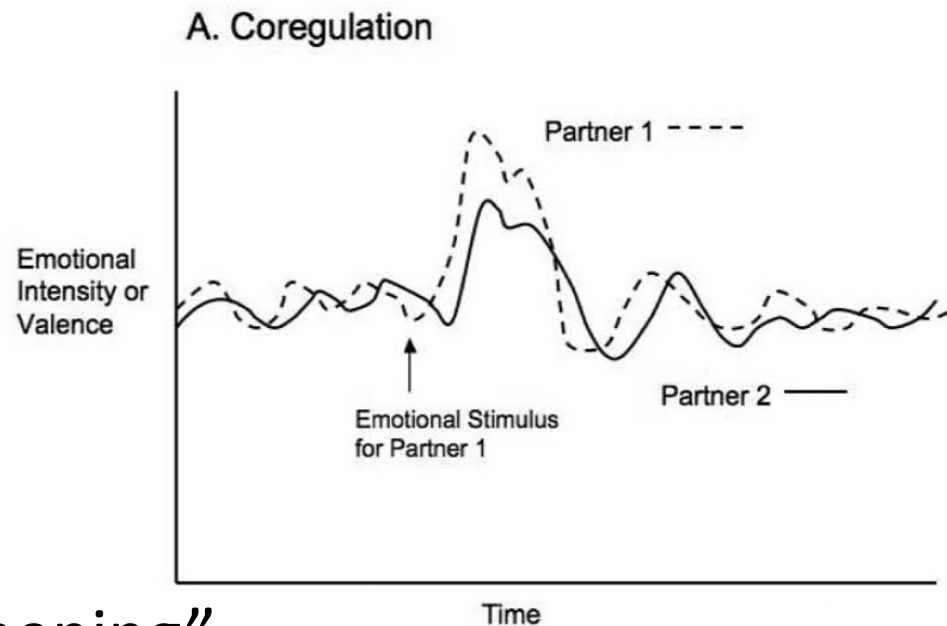
Coregulation:

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

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

➤ “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)



Butler & Randall (2013)

Cardiovascular Coregulation

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

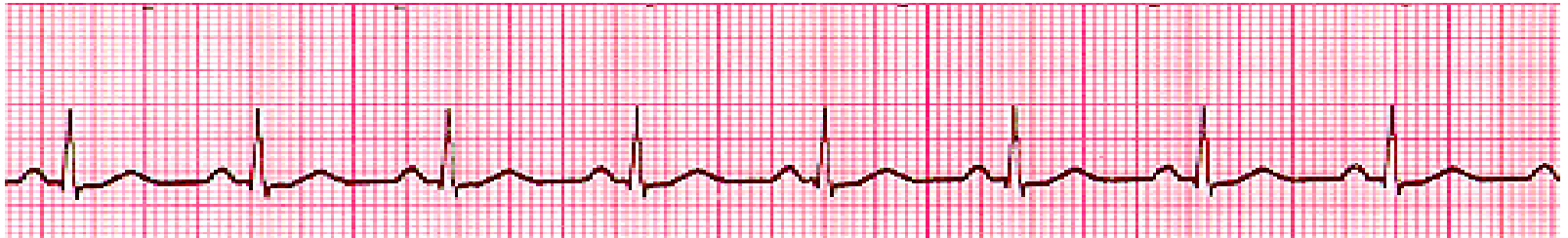
Baseline

Preparation

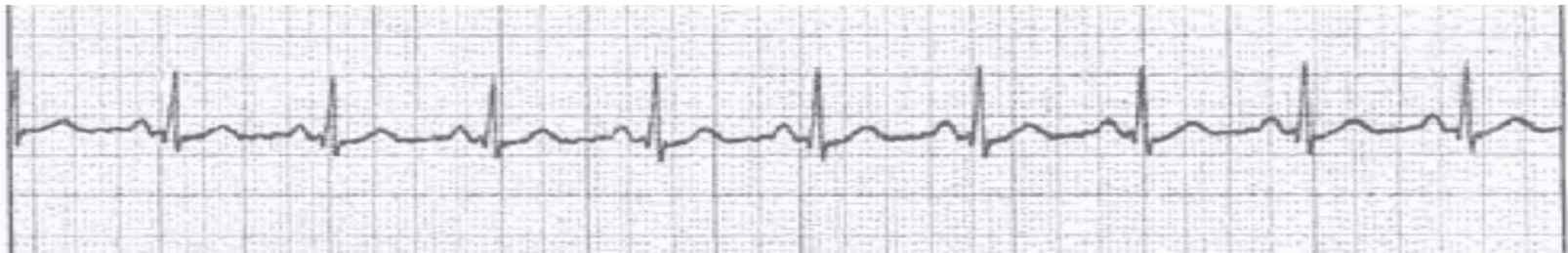
Stress Task

Recovery

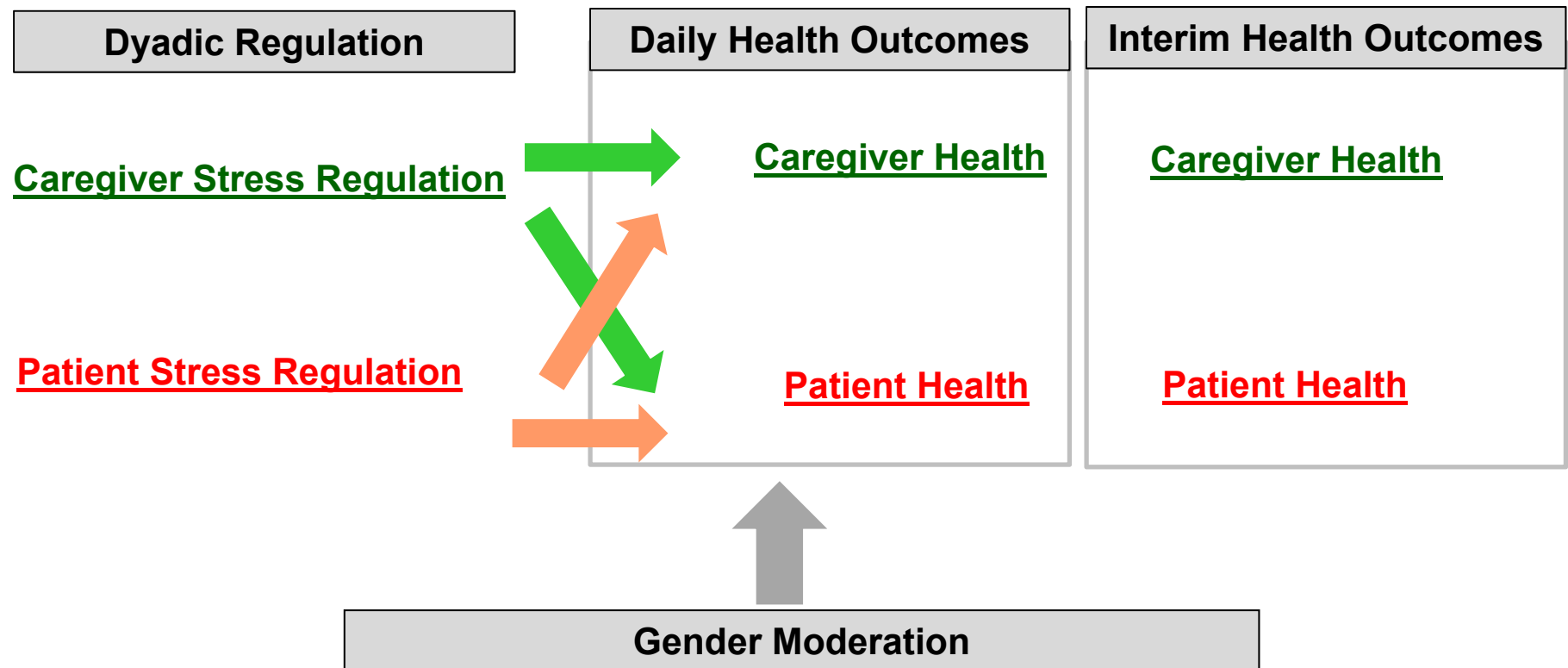
Jane



Joe



BiPs: Biological & PsychoSocial Mechanisms



Post-doc Opportunity through Diversity Supplement

1R01NR016838

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 12 languages:
Catalan, Chinese-simplified, Chinese-traditional, English, German, Hindi, Italian, Japanese, Korean, Portuguese, Spanish, Turkish
 - Surveys will be launched during the 2017 IPOS World Congress
- 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 protecting survivors and caregivers from prematurely declining health.
- ❖ Evidence-based, socioculturally sensitive, interdisciplinary interventions to reduce the burden of cancer and improve the quality of life among persons touched by cancer