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

Youngmee Kim, PhD

Facilitating Adjustment to Medical Illness in Your Family

5th Symposium on Cancer Survivorship for Clinicians, September 9-10, 2022
Quality of Life
among Cancer Caregivers
Faces of Cancer Caregivers

- 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

Kent et al. (2016); Kim et al., 2017; Kim & Schulz (2008); Kim & Spillers (2010); National Alliance for Caregiving (2015)
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
QOL

Psychosocial Functioning

Behavioral Adjustment

Physical Functioning

Spiritual Adjustment
Psychosocial Predictors of Caregivers’ QOL
### Individual Factors: Demographics

<table>
<thead>
<tr>
<th>Factors studied:</th>
<th>Age</th>
<th>Gender</th>
<th>Education</th>
<th>Income</th>
<th>Spouse</th>
</tr>
</thead>
</table>

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

❖ Contextual Socio-Cultural Factors

- Factors studied: Ethnicity, Employed, Social Support

Contextual Resources/Risks

Illness Specific

- Social support related to better psychological and spiritual adjustment, and greater mental health
- Employment related to greater physical health
Predictors of Caregivers’ QOL

Caregiving Phase (Five Seasons)
- Early
- Mid-term
- Long-term
- End-of-life
- Bereavement

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
Additive & Synergistic Effects of Psychosocial Predictors
Caregiver Psychological Distress (POMS-SF)

% Reported Unmet Needs of Caregivers

Kim et al. (2012)
Prevalence of Clinical Levels of Depressive Symptoms

<table>
<thead>
<tr>
<th></th>
<th>Former CG</th>
<th>Current CG</th>
<th>Bereaved</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Depsd</td>
<td>Nondepsd</td>
<td>Depsd</td>
</tr>
<tr>
<td>5 years post-dx</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depressed</td>
<td>10.9%</td>
<td>10.0%</td>
<td>17.6%</td>
</tr>
<tr>
<td>Nondepressed</td>
<td>7.8%</td>
<td>71.3%</td>
<td>22.1%</td>
</tr>
</tbody>
</table>

2 years post-dx: non-bereaved

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

Attachment qualities → Caregiving motives → Adjustment

- security
- anxiety
- avoidance

Autonomous
Introjected
External

Benefit finding
Life Satisfaction
CES-D

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

Attachment qualities
- security
- anxiety
- avoidance

Caregiving motives
- Autonomous
- Introjected
- External

Adjustment
- Benefit finding
- Life Satisfaction
- CES-D

Kim, Carver, Deci, & Kasser (2008).
Male Caregivers QOL at 5 years Post-Dx

Peace_5yr

Mental Health_5yr

Faith_5yr

Meaning_5yr

Autonomous_2yr

Introjected_2yr

External_2yr

Physical Health_5yr

$p < .05$

$p < .08$

Gender in Psycho-Oncology

YOUNGMEE KIM
MATTHEW J. LOSCALZO

OXFORD
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

Projected percentage of population

- 22.8% Adults 65+
- 19.8% Children under 18

Projected number (millions)

- 49.2 in 2016
- 73.6 in 2025
- 78.0 in 2030
- 76.4 in 2035
- 94.7 in 2040
- 79.8 in 2050

Note: 2016 data are estimates not projections.

Older Population Expected to Double by 2050

- 13% Americans aged 65 and older, in 2010
- 35% Americans aged 65 and older, in 2030

- 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

Source: National Population Projections, 2017
www.census.gov/programs-surveys/popestproj.html
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

<table>
<thead>
<tr>
<th></th>
<th>Arthritis</th>
<th>Chronic Back Pain</th>
<th>Heart Diseases</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Exp(B)</td>
<td>p &lt;</td>
<td>Exp(B)</td>
</tr>
<tr>
<td>Age</td>
<td>1.05</td>
<td>.0001</td>
<td>1.02</td>
</tr>
<tr>
<td>Female Gender</td>
<td>1.41</td>
<td>.01</td>
<td>0.88</td>
</tr>
<tr>
<td>Education</td>
<td>1.03</td>
<td>.83</td>
<td>0.65</td>
</tr>
<tr>
<td>Income</td>
<td>0.68</td>
<td>.003</td>
<td>0.68</td>
</tr>
<tr>
<td>Spouse</td>
<td>0.84</td>
<td>.22</td>
<td>0.86</td>
</tr>
<tr>
<td>Obj Cg Stress</td>
<td>1.27</td>
<td>.39</td>
<td>0.89</td>
</tr>
<tr>
<td>Sub Cg Stress</td>
<td>1.31</td>
<td>.006</td>
<td>1.59</td>
</tr>
</tbody>
</table>

Kim, Carver, Shaffer, Gansler, & Cannady (2015)
Predictors of Disability Markers: Person x Time

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

- Spouse: 7.4% /yr
- Non-Spouse: 5.3% /yr

Kim, Carver, Shaffer, Gansler, & Cannady (2015)
Predictors of Disability Markers: Person x Time

Spousal Caregivers x Time Effect on Development of Back Pain

Spouse 5.2% /yr
Non-Spouse 3.0% /yr

Kim, Carver, Shaffer, Gansler, & Cannady (2015)
Predictors of Disability Markers: Person x Time

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

![Graph showing the effect of Cg Stress on the development of heart diseases over time.]

- **High Cg Stress:** 3.8% /yr
- **Low Cg Stress:** 2.3% /yr

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

Slavich & Irwin (2014, Psychol Bull)
Figure 1. Associations of Stress- and Meaning-oriented Psychological Factors with CTRA Gene Expression

Log2 CTRA RNA / predictor SD

-0.200 -0.150 -0.100 -0.050 0.000 0.050 0.100 0.150 0.200

Caregiving Stress
Loneliness
A. Separate
Social Support
Benefit Finding
Spirituality-Meaning

B. Mutually
Loneliness
Adjusted Social Support
Benefit Finding
Spirituality-Meaning

C. Mutually
Caregiving Stress
Adjusted Loneliness
For All Social Support
Other Benefit Finding
Spirituality-Meaning

Note. Data represent strengths of associations (B±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).

Kim, Cole, Carver, Antoni, & Penedo (2021)
Illness in the Relationship Context
Distress & QOL: Prostate Cancer

N = 168 dyads

Kim, Kashy, Wellisch, et al. (2008)
Individual & Dyadic Effects of Cancer

- 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

- Patient Experience
- Caregiver Experience
- Patient Health
- Caregiver Health
Mechanisms of Dyadic Effects

Sv_cancer experience

Affective Coregulation

Biological Coregulation

Behavioral Coregulation

Sleep Coregulation

Sv_QOL

Cg_cancer experience

Cg_QOL
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
✓ 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.
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