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

Youngmee Kim
University of Miami

Facilitating Adjustment to Medical Illness in Your Family

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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

1975: 50%
2012: 66%

seer.cancer.gov
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)
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)

Kim, Shaffer, Carver, & Cannady (2016)
Quality of Life among Cancer Caregivers
Quality of Life (QOL) includes:
- Psychosocial Functioning
- Behavioral Adjustment
- Physical Functioning
- Spiritual Adjustment
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)

% Reported Unmet Needs of Caregivers

Kim et al. (2012)
Psychosocial Predictors of Caregivers’ QOL
Predictors of Caregivers’ QOL

الفactors: 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

Attachment qualities → Caregiving motives → Adjustment

- Security
- Anxiety
- Avoidance

Autonomous → Introjected → External

Benefit finding → Life Satisfaction → CES-D

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

Attachment qualities  Caregiving motives  Adjustment

security  Autonomous  Benefit finding

anxiety  Introjected  Life Satisfaction

avoidance  External  CES-D

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

## Benefit Finding

<table>
<thead>
<tr>
<th></th>
<th>Life Satisfaction</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>0.10**</td>
<td>0.05</td>
</tr>
<tr>
<td>Acceptance</td>
<td>0.14**</td>
<td>-0.14**</td>
</tr>
<tr>
<td>Empathy</td>
<td>-0.09</td>
<td>0.16**</td>
</tr>
<tr>
<td>Appreciation</td>
<td>0.11*</td>
<td>-0.01</td>
</tr>
<tr>
<td>Family</td>
<td>0.03</td>
<td>0.01</td>
</tr>
<tr>
<td>Positive Self-View</td>
<td>0.11</td>
<td>-0.12*</td>
</tr>
<tr>
<td>Reprioritization</td>
<td>-0.16**</td>
<td>0.17***</td>
</tr>
</tbody>
</table>

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

### Clinical Levels of Depressive Symptoms: Prevalence

<table>
<thead>
<tr>
<th></th>
<th>Former CG</th>
<th>Current CG</th>
<th>Bereaved</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>5 years post-dx</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Depsd</td>
<td>Nondepsd</td>
<td>Depsd</td>
</tr>
<tr>
<td>2 years post-dx: non-bereaved</td>
<td>10.9%</td>
<td>10.0%</td>
<td>17.6%</td>
</tr>
<tr>
<td></td>
<td>Nondepsd</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>7.8%</td>
<td>71.3%</td>
<td>22.1%</td>
</tr>
</tbody>
</table>

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

## Long-term Bereavement Outcomes

<table>
<thead>
<tr>
<th></th>
<th>3 yrs</th>
<th>Case</th>
<th>5 yrs</th>
<th>Case</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prolonged Complicated Grief (ICG)</td>
<td>17.09</td>
<td>24.1%</td>
<td>16.74</td>
<td>18.2%</td>
</tr>
<tr>
<td>Intense Emotional Reaction (TRIG)</td>
<td>40.20</td>
<td>61.3%</td>
<td>38.32</td>
<td>47.7%</td>
</tr>
<tr>
<td>Depression (CES-D)</td>
<td>13.85</td>
<td>36.5%</td>
<td>7.85*</td>
<td>44.3%</td>
</tr>
<tr>
<td>Life Satisfaction</td>
<td>4.44</td>
<td>1 ~ 7</td>
<td>4.43</td>
<td>1 ~ 7</td>
</tr>
</tbody>
</table>

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 ≥ 65*

<table>
<thead>
<tr>
<th>Tumor Type</th>
<th>Incidence (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Colon</td>
<td>72.4</td>
</tr>
<tr>
<td>Bladder</td>
<td>72.2</td>
</tr>
<tr>
<td>Pancreas</td>
<td>70.0</td>
</tr>
<tr>
<td>Lung</td>
<td>67.9</td>
</tr>
<tr>
<td>Stomach</td>
<td>67.8</td>
</tr>
<tr>
<td>Prostate</td>
<td>66.7</td>
</tr>
<tr>
<td>Rectum</td>
<td>59.7</td>
</tr>
<tr>
<td>All Sites</td>
<td>56.8</td>
</tr>
<tr>
<td>Leukemia</td>
<td>54.1</td>
</tr>
<tr>
<td>NHL</td>
<td>53.8</td>
</tr>
<tr>
<td>Kidney</td>
<td>52.4</td>
</tr>
<tr>
<td>Corpus &amp; UNOS</td>
<td>48.4</td>
</tr>
<tr>
<td>Ovary</td>
<td>47.2</td>
</tr>
<tr>
<td>H&amp;N</td>
<td>47.1</td>
</tr>
<tr>
<td>Breast</td>
<td>43.8</td>
</tr>
<tr>
<td>Brain</td>
<td>36.1</td>
</tr>
</tbody>
</table>

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:

<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>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**

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**

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

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Kim, Carver, Shaffer, Gansler, & Cannady (2015)
Individual & Dyadic Effects

Sv_cancer experience → Sv_mental health
Sv_cancer experience → Sv_physical health
Cg_cancer experience → Cg_mental health
Cg_cancer experience → Cg_physical health
Prostate Cancer Survivors & Spousal Caregivers

N = 168 dyads

Mothers with Cancer & Their Caregiving Daughters


SV_distress → SV_mental health → SV_physical health
CG_distress → CG_mental health → CG_physical health
Illness in Relationships Context

Individual & Dyadic Effects

- Patient Experience
- Patient Health
- Caregiver Experience
- Caregiver Health

Psychological distress; Social support; Spirituality; Health Behaviors
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)
Cardiovascular Coregulation

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

<table>
<thead>
<tr>
<th>Baseline</th>
<th>Preparation</th>
<th>Stress Task</th>
<th>Recovery</th>
</tr>
</thead>
</table>

Jane

Joe
BiPs: Biological & PsychoSocial Mechanisms

Dyadic Regulation

Caregiver Stress Regulation

Patient Stress Regulation

Gender Moderation

Caregiver Health

Patient Health

Daily Health Outcomes

Interim Health Outcomes

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