

## Stress on Family Caregiver of Terminally Ill Patient in Cancer: A Systematic Review of Literature

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**Objective:** This research refers previous study, Cancer family caregivers during the palliative, hospice, and bereavement phases: A review of the descriptive psychosocial literature, limited in recent decade, as template. The purpose of this review was to organize the literature as compared to the different result of previous study.

**Method:** As a systematic review, major databases were searched for non-intervention descriptive studies. Psychosocial variables of family caregivers to adults with cancer during the different phases would be included.

**Result:** The 23 studies reviewed were conducted in ten countries and varied considerably by samples, outcome measures, and results. Despite limiting to several conditions, results, such as age, gender, and relationship to the patient, were inconsistent. Across the 23 studies, 53 unique instruments were used; 13 of which were no psychometric testing. The family caregivers who were younger and faced level of daily life impairment tended to be burden, anxious, depress. To summarize the different factors influencing caregivers' status, complicated grief was consistent with their situation.

**Conclusion:** As compare with previous study, it demonstrated inconsistent results, which were spouse, gender and age, affecting family caregivers' status. However, regarding to measurement instruments using, it was much more rigorous than before. Also, it had been changed in the major study site and the number of studies. As a consequence of physical and psychosocial status of family caregivers, they were in high risk population.

*Keywords:* Cancer, Family Caregiver, Hospice, Palliative Care, Bereavement

## INTRODUCTION

### *Patients' issue*

“Patient Right to Autonomy Act”, published at January 6, 2016, was stipulated to respect patient autonomy in healthcare, to safeguard their rights to a good death, and to promote a harmonious physician-patient-relationship. A patient, who has made an advance decision, suffered from terminally ill, irreversible coma, permanent vegetative state and severe dementia, then the medical institution or physician may, in accordance with the advance decision, partially or fully terminate, withdraw, or withhold life-sustaining treatments, artificial nutrition and hydration (Ministry of Justice, ROC). End-of-life implicated that many kinds of aspects towards death and expectation in the society. Definitions of end-of-life was diverse in different culture and times; then it took a leap forward to adapt diversity in the final chapter. If there was a way to satisfy the expectation of patients and families, it can, in accord with clinical, cultural and ethical standards, eliminate the frustration and misfortune of patients, families, and caregivers. Thus, the end of life may be competed[1].

### *Family caregivers' issue[2]*

After all these years, topic issue was always focused on welfare of dementia and physical and mental disabilities, but it ignored the family caregiver, who was being in shadow and silence. While caring for patients, family caregivers took them as priority; there is no purpose on their life without patients. They pay no regret on their loved one. However, as long as patients passed away, because of physically and mentally exhausted, no savings and difficult to return to workplace, the family caregiver possibly became the poor population. In the face of aging population, it was gradually being followed with interest on family caregiver in the developed country. Family caregiver paid an important role on long term caring system, so it should render particularly on policy support; it implicated that caregiver can extend their duration of caring but also prevent their health status from stress or other illness because of caring. If family caregiver's health status had deteriorated, patient's quality of life decreased as well; on the other world, they would be forced to send to nursing home by necessary. Thus, it is a major issue to provide a supportive service for family caregiver in the purpose of reducing burden on caring. So, we shall create an amiable environment for patient and family caregiver at home place

### *Bereavement*

Bereavement was a slow process from birth to death and death to be alive, which made people experience different step on grief. People in bereaved would suddenly be anger, deniable, bargaining or even depress[3]. After psychological mechanism, their paralyzed thought would gradually fade away; It might take into healed and balance

instead of desperate feeling on significant loss. People undergone this situation possibly lasting less than few months or even being several years. Sadness and despair tool place repeating again and again; grief, fear, hopeless, imbalance, solitude and heartbroken feeling often strike quietly that makes people departed from normal life[4]. If grief hadn't been got appropriate catharsis, it might become eternal melancholy[5]. It was best to face positively and actively on bereavement; so long as we came in front of it, sorrowful experience would be disappeared. Treatment of trauma probably took one or two years; but if we accepted and honestly confront sorrowful feeling, pain shall be end[6]. In the process of being death to alive, people found their way continuously on life and attempt to stand at a point among many aspects of impact. Living and death definitely can form a profound but unique experience and feeling allowing particular training and gift for all of us.

We apply a previous research, Cancer family caregivers during the palliative, hospice, and bereavement phases: A review of the descriptive psychosocial literature[7], as reference. Because a caregiver's perceived burden and psychosocial concerns might be different at different phases of the patient's disease, it brought them physically and mentally exhausted. Usually, the psychological burden of the caregiver was underestimated as compared with the stress of the terminal ill patient. The precious review urgently suggested to develop research standards, especially regarding measurement instruments, so it could intervene objectively and support actively family caregiver. Thus, and so, this literature review tended to find out the research on the family caregivers of terminal ill patients in the last ten years. With different phase of challenge, it should figure out that the truth and contradiction by experience and research result.

## METHOD

At first, we modified review article[7] “Cancer family caregivers during the palliative, hospice, and bereavement phases: A review of the descriptive psychosocial literature” as referral formwork. The major database was searched in PubMed from 2008-2016. The terms “caregiver,” “caregiving,” “neoplasm,” “oncology,” and “cancer” were entered as keywords. In addition, circumscription of website program was set in "“caregiver' OR 'caregiving'" AND "“neoplasm' OR 'oncology' OR 'cancer' "

Results were limited to English language, non-intervention descriptive studies, and sample was included from psychosocial variables of family caregivers to adult patients. As for results by year were shown in figure 1502 articles were found; afterwards, it was selected artificially out in 23 articles. This study had finished looking for the research article at the beginning of 2017, so the research after the beginning of 2017 was excluded.

## RESULT

Despite limiting the articles reviewed to descriptive studies of cancer family caregivers in the palliative, hospice, or post-death bereavement phases, there remained considerable heterogeneity relative to caregiver characteristics, patient characteristics, measurement tools, and analytic methods. The 23 English language studies were conducted in 10 countries: Korea (7 studies), USA (7 studies), Taiwan (3 studies), Germany (1 studies), France (1 studies), Denmark (1 studies), Austria (1 studies), Canada (1 studies), Indonesia (1 studies), United Kingdom (1 studies). Study sample sizes ranged from 56 to 3560. Of the 23 studies, 13% (3 studies) had a sample size of <100 family caregivers.

Three studies of the 23 were longitudinal in design, and 14 of which were cross sectional study; however, two of the studies[8,9] used similar material and method. Those of two cross-sectional studies show several detriments influencing family caregiver's quality of life which burdensomeness, younger age, disruptiveness and low social support or income were associated with emotional distress. Most of the studies were of caregivers who attended to patients with a variety of cancers; only two studies focused on caregivers to individuals with a particular type of cancer: head and neck cancer[10] gastrointestinal cancer and lung cancer[11]. The two studies that looked at a particular type of cancer each had, respectively, a sample size of 56 and 275 participants. The small number samples made it difficult to interpret the influence of cancer type on the caregiver experience; relatively, enough quantity of sample made confidence in study research. The extant literature regularly ascribed the relationship of the caregiver to the care recipient (spouse/partner, adult child, friend and so on) as a major influence on the caregiving experience. Of the 23 studies reviewed, only 2 limited their sample to gender, exclusively. One study focused on age. Three studies did not report the caregiver's relationship to the care recipient, and the remaining 20 studies had caregiver samples that were composed of individuals with a variety of different relationships with the care recipient. (Table S1)

For particular type of the demographic predictor variables of connection to patient, which was age and gender, the inconstant results across studies might be corresponded to whether the investigators controlled for confounders such as financial status, employment status, ethnicity, health status and any other factor that might occupy caregiver's time and attention. While confounder was in control, differences by predictor variables were less likely to be identified.

Besides, 8 studies compared spouses versus non-spouses on psychosocial outcomes. Results were inconsistent. When comparing spouses versus non-spouses in the palliative/hospice phase, they[8,11,12] found no significant difference between groups. Paradoxically, studies[9,13] revealed worse psychosocial outcomes during hospice/palliative phase as compared to other researches[14,15] reported non-spouses that

had worse psychosocial outcomes. Two study[16,17] in the bereaved phase that compared spouses versus non-spouses found negative influence from the relationship . Age was a predicted variable for psychosocial outcomes and also provided inconsistent results frequently. Seven palliative studies examined age[8,11-13,15,18,19]. Three of the seven studies showed no influence from age[8,11,12], whereas three studies showed younger caregivers experiencing worse psychosocial outcomes than did older caregivers[13,15,18]. One bereavement phase study viewed at age as a intermediate variable, and found that older age were relevant to depressed mood and grief[19]. The effect of gender differences on psychosocial outcomes was reported with mediocre, with seven palliative/hospice phase studies[8,9,11,12,15,19,20] and one bereavement phase studies[19] examining the association. Most ordinarily, no significant influence from gender was found[8,11,12,15]. Two palliative/hospice phase studies[9,20] showed that female had worse psychosocial outcomes than male. One study also appointed out that female had worse psychosocial outcome during bereavement[19]. (Table 1)

Across the 23 studies examining family caregivers in the palliative, hospice, and bereavement phases, 53 unique instruments were used. There were several instruments being used; Medical Outcome Study Social Support Survey, Caregiver Reaction Assessment, Center for Epidemiological Studies-Depression scale, Hospital Anxiety and Depression Scale, Caregiver Quality of Life Index-Cancer scale appeared in nine times, six times, four times, four times and three times, respectively. Although some instruments reused frequently, the vast majority of instruments used were with rare confirmation of the findings with an objective measure. As compare to MOS Social Support Survey of Chinese version[21] (Reliability: all Alphas >0.93; Validity: 0.88~0.99, 2004), it made barely differences in the original version (Reliability: all Alphas >0.91; Validity: 0.69~0.82, 1991). So, we assumed that psychometric instrument would not be influenced by location, culture, language and time.

Coincidentally, it was worth to mention that caregiver got worst status before patient's death would positively be relevance to mechanisms active coping, feel burden, get level of daily life impairment; and negatively associated with strength of believe, social functioning, role emotional and mental health. After patient' s death, caregiver showed worst status on being staying mental health at baseline, mechanisms active coping, depressive symptom and quality of death assessed; and exacerbate in discrepancy between perceived and ideal levels of practical support, anxiety and depressive symptoms, role physical, general health, mental component summary, vitality, social functioning, role emotional and mental health. (Table 2)

At last but not least, there were 16 factors, which was being younger, social support, environmental, patients with functional deterioration , adapting poorly, at the beginning of home care, caregiver's perception of health, caring for a patient with poor ECOG, degree

of kinship(partner/other), geographic location, hospitalized patients, poor health, shorter length of stay, the spouse of the patient, unable to function normally and younger age and poorer self-rated global health, were correlated with caregiver's depression; 7 factors, also known as being younger, caregiver's educational level , emotional distress, having no previous experience of caring , hospitalized patients, not being the spouse, physical function, were associated with caregiver's quality of life; nine factors, which was being younger, social support, environmental, feeling burdened, prefer palliative care, symptoms of CMD, WHOQOL-BREF TOTAL, women, are relevant to caregiver's burden; 7 factors, also known as being younger, environmental, caregiver's perception of health, caring for a patient with poor ECOG, poorer self-rated global health, caregiver's perception of money, grief, were concerned with caregiver's anxiety. (Table 3)

## DISCUSSION

Descriptive systematic review of literature in family caregiver was difficult to handle and integrate, which research obstacle was as same as previous research[7]. The major of obstacle to aggregation was in poverty of research standard. Numerous unique measurement tools existed. All of studies were at high range of sample size and uses cross-sectional design thereby unable to provide information on the development of continuity and couldn't show individual differences in development.

The definition of emotional express was staggering. Emotion, generally speaking, was a series of subjective experiences that produced a combination of feelings, thought and behavior[22]. However, in regard to mental illness, researchers applied reliable measurement tool to illustrate potential sufferers' status; it might be helpful for subjects to prevent their deterioration. Although original definition of emotion was divergent, result of reaction from caregivers during bereavement were with two theories, which was the relief model and the complicated grief model[23]. Relief model[24] suggested that caregivers who suffered increasing strain would experience relief after the death of the care recipient. As the caregiving role ended, it was assumed that the caregiving strain vanishes at the same time. Furthermore, complicated grief model proposed that increasing caregiver role strain predicted poorer bereavement adjustment. It argued that caregiver stress escalated over time, leaving the individual with weaker coping resources to adjust to the bereavement experience. According to Table 1, it might be sorted out a possible outcome. If strength of belief and coping mechanism substance abuse were worthwhile, then family caregiver can make better quality of life. While taking care of patients, caregiver faced level of daily life impairment so that brought them burden. No matter what caregiver status before or after patient's death, they were poor in mental health, social functioning and role emotional. Discrepancy between perceived and ideal levels of practical support and low score of mental component summary, it caused anxiety and depressive symptoms easily. Anxiety, depression and stress were influence by being younger, environment and low level of life quality; and low level of life quality was influenced by emotional distress and stress. It was mutually affected then lead family caregiver to worst situation. If quality of death assessed by carer did not achieve their satisfaction, while mental health was under baseline, depressive symptoms occur. After patient passed away, caregivers' role physical and viability declined, which also meant deterioration of their general health. However, a subject of emotional reaction was worth to be viewed as personal difference, but it showed that the complicated grief model was suitable to our findings.

Many of variance, composed by personal status, hospitalized service and environmental factor, were highly frequently appeared in burden, quality of life, anxiety and depression. Comparatively, those variances were difficult to be exited independently;

as a result, it was imperative to clarify their relationship also known as cause and effect. At the same time, 23 studies showed no culture difference in their attitude toward their loved one.

As compared to previous research[7], it showed same result on following, which cross section study design was more than longitude study design; sample in various cancer type was more than in specific type; spouses, gender, and age have no consistent influence on family caregivers; and number of studies on relationship between age and caregiver barely changed.

As previous research demonstrated that main study site was in the US, but, after time elapsed, Korea (n=7) was keeping pace with the US (n=7). However, we discovered that researcher used same material dividing into two pieces for studying; this phenomenon might derive from focusing on the number of papers and anxiously creating study research in short term. The influence of caregiver by spouses showed inconsistent result, but number of studies had been increased from three to nine. Unlike almost two decades ago, spouses were narrowly defined as relationship of bisexuality; it was assumed that people stood for their right, despite being mute, in the society. In contrast to previous study which reported 89 unique instruments including almost half of (n=41) instrument showing no psychometric testing; it was worthwhile to mention that there were 54 unique instruments containing less than a quarter (n=13) no psychometric study reported. As for instrument testing, MOS social support survey[21], for example, started from definition of perception; hereafter, the selection of the pool of items was instructed by a strong a priori conceptual framework. Nineteen variables, selected from 50 items, were conducted in progress by multitrait and factor analyses in order to test their validity and reliability. The specificity and stability of psychometric instrument all went through rigorous study design, so that made results of the study being much more persuasive. As for the concerns in previous review, it had been changed, after suggestion, better than before.

### *Limitation*

Although it restricted from English, it might exclude other relevant research in different language. The major database was used in PubMed, but it used to be categorized as medicine and health, which, on the other words, humanities and social science would be out of option. Because the research after beginning of 2017 was excluded, the latest study may show different result which may led our inference indecisive.

### *Suggestion*

Although family caregivers paid their attention for their loved one with no regret, deterioration of health and financial crisis confronted against caregivers after time elapsed. It was a major issue to set them back in appropriate employment when they were out of

society. Either opportunity of development or self-identity was precarious and in jeopardy, which exploited family caregiver's psychosocial and physical wellbeing. Despite of non-intervention study, if questionnaire can react the current status to cases, it was able to help them understanding their situation. The none-intervention study should belong to no intervene in the study; and researcher acted positively on supporting cases after questionnaire completed. While looking after of their loved one, family caregivers took patient as priority; in the meanwhile, erosion of carers' self-identity had been virtually on the remaining life time of patient. With respect to regard caregiving as ethical responsibility, it was urgently considered caregiving, whether carer or cared one, as fundamental human rights; thus, caregiving should be a choice instead of obligation. Family caregivers were necessary to treat themselves well, seek for help, own their life, refuse being guilty, accept positive feedback and complete their career plan in the future.

## CONCLUSION

By integrating the descriptive study dedicates to carer during different phase, this literature review shoulders previous research. We showed same doubt as previous study. There was inconsistent result in spouse, gender, and age. However, it was much rigorous than before while using instrument, and also made changes on main study site and research on spouses. Afterwards, we inferred that the complicated grief was suitable to status of family caregiver after patient's death. The physical and psychological issue of family caregiver in the palliative, hospice, and bereavement phases shall not be ignored; mostly, they are high-risk population.

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**Conflicts of interest:** Author declare no conflicts of interest.

**Table 1.** Hierarchical induction of caregiver with worse psychosocial outcomes

Spouse			
Phase of disease	Spouse	No difference	non-spouse
Palliative/ Hospice	Young Sun Rhee[9] Debra Parker Oliver[13]	Tanguy Leroy[12] Jamie M. Jacobs[11] Yong Joo Lee[8]	Mette Kjaergaard Nielsen[14] Christantie Effendy[15]
Bereavement	H. Go^tze[16] Sing-Fang Ling[17]	No studies	No studies
Age			
Phase of disease	Older	No difference	Younger
Palliative/ Hospice	No studies	Tanguy Leroy[12] Jamie M. Jacobs[11] Yong Joo Lee[8]	Debra Parker Oliver[13] Youn Seon Choi[18] Christantie Effendy[15]
Bereavement	Linda E. Francis[19]	No studies	No studies
Gender			
Phase of disease	Female	No difference	Male
Palliative/ Hospice	Young Sun Rhee[9] Beate Schrank[20]	Tanguy Leroy[12] Jamie M. Jacobs[11] Christantie Effendy[15] Yong Joo Lee[8]	No studies
Bereavement	Linda E. Francis[19]		No studies

No studies = no studies demonstrated the outcome.

**Table 2.** Caregiver status before/after patient's death

	Caregiver worst status Before patient's death	Caregiver worst status after patient's death
Carer mental health at baseline	NR	P
Coping mechanisms active coping	P	P
Quality of death assessed by carer	NR	N
Depressive symptoms	NR	P
Religion (strength of believe)	N	NR
Coping mechanism substance abuse	N	NR
Level of daily life impairment	P	NR
QOL	N	NR
Burden	P	NR
Discrepancy between perceived and ideal levels of practical support	NR	N
Anxiety and depressive symptoms	NR	P
Role physical	NR	N
General Health	NR	N
Mental component summary	N	N
Vitality	NR	N
Social functioning	N	N
Role emotional	N	N
Mental health	N	N

P=Positive Correlation

N=Negative Correlation

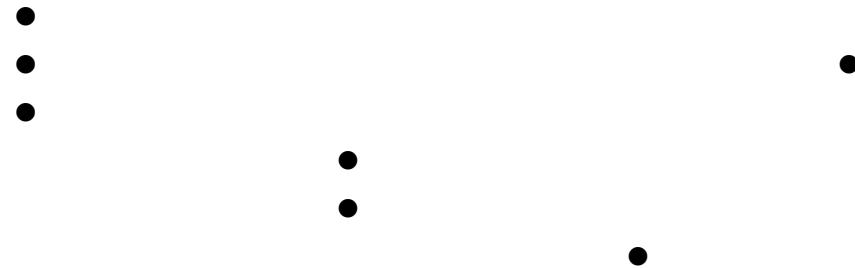
NR=No Relevant

**Table 3.** Influenced Factors \ Caregiver's Perception

	Denial/Angry	Burden	Quality of life	Anxiety	Depression	Distress	Self-perceived burden
Being younger	●	●	●	●			
Social support	●				●		
Environmental	●		●		●		
Patients with functional deterioration	●				●		
Adapting poorly		●			●		
At the beginning of home care					●		
Caregiver's perception of health				●	●		
Caring for a patient with poor ECOG	●		●		●		
Degree of kinship(partner/other)					●		
Geographic location					●		
Hospitalized patients					●		
Poor health					●		
Shorter Length Of Stay					●		
The spouse of the patient					●		
Unable to function normally					●		
Younger age and poorer self-rated global health			●		●		
Psychological distress	●						
Caregiver's educational level			●				
Emotional distress			●				
Having no previous experience of caring			●				
Hospitalized patients			●				
Not being the spouse			●				
Physical function			●				
Feeling burdened	●						

Prefer palliative care  
Symptoms of CMD  
Women  
Caregiver's perception of money  
Grief  
The relational and cultural factors

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●: possible relevance

**Table S1.** Descriptive studies evaluating psychosocial outcomes of cancer family caregivers during the palliative, hospice, and post-death bereavement phases

Phase of disease: palliative, hospice, and “terminally ill”				
Author	Sample	Study design	Outcome measures	Synopsis of results and uncovering
Seon Hee Kim[25]	Mean age: not report %female: not report Ethnicity: not report N=195 Patient's CA type: various study site: South Korea %spouse: 50%	Retrospective cohort study	a model modified from Elisabeth Kübler-Ross (Kübler-Ross, 1969, On death and dying. London, New York: Macmillan)	A total of 198 patient - FC pairs were identified. The median length of stay (LOS) was 18 days. A multivariate analysis with adjustment for potential variables revealed significant differences in LOS according to cancer type and time since cancer diagnosis. The denial/angry FC category was independently associated with a shorter LOS (vs. acceptance, adjusted hazard ratio (aHR) 2.11; 95% confidence interval (CI), 1.11 – 4.03). It found that terminally ill cancer patients who were referred late had FCs who were in denial or were angry about the anticipated death of their loved one. The emotional status of FCs should be considered when patients with terminal cancer are referred to palliative care.

		The Revised Clinical Interview Schedule	
		Caregiving Burden Interview	Multivariate analyses revealed that carers who perceived their caring experience as more burdening had more symptoms of common mental disorder(CMD) while caring for their loved one. Carer mental health during the caregiving experience was predictive of their mental health at three and six months after death. No relationships were observed between family relations, levels of social support, levels of religious or spiritual beliefs, carers' coping strategies, quality of death in the patient, and caregiving and bereavement outcomes.
		Work and Social Adjustment Scale	
		Significant Others Scale	
		Family Adaptability and Cohesion Evaluation Scales	
		Quality of death	
		Bereavement	
		Phenomenology	
		Questionnaire	
		Royal Free Interview for Spiritual and Religious Beliefs	
		Brief COPE	
Marcia Kapari[26]	N=100 Patient's CA type: various study site: United Kingdom %spouse: 85%	Longitudinal study	

			Caregivers completed burden and quality of life instruments at the start of patient radiotherapy (T1), 5 weeks into radiotherapy (T2), and 1 month post-radiotherapy (T3) and instruments for perceived social support and support preferences at T2 only.
Chandylen L Nightingale[10]	Mean age: 57 %female: 85% Ethnic: 88% White N=56 Patient's CA type: head and neck cancer study site: USA %spouse: 74%	pilot study	The Caregiver Reaction Assessment The Caregiver Quality of Life Index-Cancer scale The Medical Outcomes Study Social Support Survey Caregivers showed a trend toward increased burden and worsened quality of life for the majority of subscales at T2 or T3 than at T1. Caregivers reported significantly lower esteem and significantly greater disruption at T2 than at T1 and significantly worse health at T3 than at T2. Higher perceived social support was typically associated with lower burden and higher quality of life at T2. Spouses/partners were the most commonly preferred source of support. These pilot findings suggest that caregivers experience psychosocial impairments during and shortly after patient radiotherapy.

			Korean version of the Caregiver QOL Index-Cancer Hospital Anxiety and Depression Scale The Korean version of the Medical Outcome Study Social Support Survey Korean version of the family Adaptation, Partnership, Growth, Affection, and Resolve Korean version of the Quality Care Questionnaire-End of Life	Variance in each Caregiver Quality Of Life Index-Cancer domain was explained by different factors. Family caregivers(FCs) of younger patient felt more burden but were more likely to adapt positively. Emotional distress of FCs was strongly associated with total Quality of life(QOL), burdensomeness, and disruptiveness. Positive adaptation was related to more visits for care, FCs' religiousness, more social support, and satisfactory perceived quality of care. Financial concerns were more likely in married FCs, FCs with less social support, or low incomes. Emotional distress of FCs was the most important factor determining the overall and negative aspects of FCs' QOL, whereas various environmental factors were associated with positive coping. Appropriate support programs directed at these factors are needed to maintain and improve FCs' QOL.
Youn Seon Choi[18]	Mean age: 49.1 %female: 74.6% Ethnic: not report N=299 Patient's CA type: not report study site: South Korea %spouse: 82%	cross-sectional study		

Christantie Effendy[15]	Mean age: 41.1 %female: 48% Ethic: not report N=100 Patient's CA type: various study site: Yogyakarta %spouse: 42%	cross-sectional study	Family Caregivers Involvement in Caring— Cancer FAMCARE questionnaire Caregiver QoL Index— Cancer	<p>One hundred of 120 invited caregivers (83%) completed the questionnaire. Being involved in psychological issues in caring (<math>\beta = 0.374</math>; <math>p = 0.000</math>), younger age (<math>\beta = 0.282</math>; <math>p = 0.003</math>), no previous caring experience (<math>\beta = 0.301</math>; <math>p = 0.001</math>), and not being the spouse (<math>\beta = 0.228</math>; <math>p = 0.015</math>) negatively influenced the QoL and explained 31% of the variation (adjusted <math>R^2 = 0.312</math>; <math>F = 12.24</math>; <math>p = 0.000</math>). Gender, education level, and time spent on caring did not influence the QoL of family caregivers.</p> <p>Findings identified modifiable factors such as dealing with psychological issues and lack of experience in caring that negatively influenced the QoL of family caregivers.</p>
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Alexi A. Wright[27]	Mean age:51.3 %female: 75.2 Ethic: not report N=333 Patient's CA type: various study site: USA %spouse: 55.4%	Prospective, longitudinal, multisite study	Quality of Dying and Death scale Prolonged Grief Disorder scale McGill Quality of Life Index Brief Religious Coping Scale Medical Outcomes Study Short-Form Health Survey The Caregiving Burden Scale and Covinsky Family Impact Survey Stressful Caregiving Response to Experiences of Dying scale	<p>In adjusted analyses, patients with cancer who died in an intensive care unit (ICU) or hospital experienced more physical and emotional distress and worse quality of life(QoL) at the end of life(EOL) (all <math>P &lt; .03</math>), compared with patients who died at home with hospice. ICU deaths were associated with a heightened risk for posttraumatic stress disorder, compared with home hospice deaths</p> <p>McGill Quality of Life Index (21.1% [four of 19] v 4.4% [six of 137]; adjusted odds ratio [AOR], 5.00; 95% CI, 1.26 to 19.91; <math>P &lt; .02</math>), after adjustment for caregivers' preexisting psychiatric illnesses. Similarly, hospital deaths were associated with a heightened risk for prolonged grief disorder (21.6% [eight and Covinsky Family Impact of 37] v 5.2% [four of 77], AOR, 8.83; 95% CI, 1.51 to 51.77; <math>P &lt; .02</math>), compared with home hospice deaths.</p> <p>Patients with cancer who die in a hospital or ICU have worse QoL compared with those who die at home, and their bereaved caregivers are at increased risk for developing psychiatric illness. Interventions aimed at decreasing terminal hospitalizations or increasing hospice utilization may enhance patients' QoL at the EOL and minimize bereavement-related distress.</p>
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<p>Yong Joo Lee[8] N=178</p> <p>Mean age: 50 %female: 72.3 Ethnic:</p> <p>Patient's CA type: study site: South Korea %spouse: 35.5%</p>	<p>cross-sectional study</p>	<p>European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 15 for Palliative Care Korean version of the Caregiver QOL Index-Cancer European Cooperative Oncology Group Performance Status Hospital Anxiety and Depression Scale Korean version of the Medical Outcome Study Social Support Survey Korean version of the Family Adaptation, Partnership, Growth, Affection, and Resolve</p>	<p>The Quality of life(QOL) of family caregivers did not correlate significantly (<math>P= 0.227</math>) with QOL in terminally ill cancer patients. As well, poor emotional function in patients was significant factor associated with the only poor patient QOL group [adjusted odds ratio (aOR), 4.1; 95 % confidence interval (CI), 1.5 – 11.5]. However, emotionally distressed family caregivers (aOR, 10.2; 95 % CI, 2.8 – 37.5), family caregivers who professed a religion (aOR, 4.1; 95 % CI, 1.5 – 11.3), and family caregivers with low social support (aOR, 3.9; 95 % CI, 1.5 – 10.6) were independent predictors for the only poor family caregiver QOL group.</p> <p>Assessing the respective emotional status of both the patient and family caregiver is needed in hospice care to reduce the gap in QOL between the two groups. Further, more attention should be paid to the lack of social support for family caregivers.</p>
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			Burden was significantly higher in women. Hope was the most significant protective factor against burden in both genders, together with perceived fulfilment of support needs. Only in women emotion-oriented coping and being in employment while caring were significantly predictive of higher burden in the multivariate analysis. The model explained 36% of the variance in burden in men and 29% in women.
Beate Schrank[20]	<p>Mean age: 53.3 %female: 60.1% Ethic: not report N=308 Patient's CA type: not report study site: Austria %spouse: 82</p> <p>cross-sectional study</p>	<p>The Zarit Caregiver Burden Interview The Family Inventory of Needs The Coping Inventory for Stressful Situations The Integrative Hope Scale</p>	<p>Psychological support interventions for family caregivers should take gender-specific risk factors into account. Interventions focusing on keeping up hope while caring for a terminally ill family member may be a valuable addition to palliative services to improve support for family carers. Women may benefit from interventions that address adaptive coping and strategies to deal with the dual demands of employment and caring.</p>

Young Sun Rhee[9]	Mean age:	cross-sectional study	Beck Depression Inventory Caregiver's QOL Index - Cancer the Medical Outcomes Study 36-item Short-Form Health Survey the Eastern Cooperative Oncology Group performance status	The majority (67%) of caregivers had high depression scores ( $BDI > 13$ ), and 35% had very high depression scores ( $BDI > 21$ ). In a multiple logistic regression model, caregivers who were women, the spouse of the patient, in poor health, feeling burdened, adapting poorly, unable to function normally, or caring for a patient with poor Eastern Cooperative Oncology Group performance status were more likely to experience depression ( $P < .01$ for all values).
	%female: 64.2%			
	Ethic: not report			
	N=310			
	Patient's CA type: various			
	study site: South Korea			
	%spouse: 53.2%			

			The Functional Assessment of Cancer Therapy—General	
Linda E. Francis[19]	Mean age: 54.8 %female: 81.4% Ethic: 74.9% White+ N=199 Patient's CA type: not report study site:USA %spouse: not report	cross sectional study	Version The Functional Assessment of Chronic Illness Therapy— Spiritual Well-Being The Caregiver Reaction Assessment The Short Form of Profile of Mood States Bereavement Experience Questionnaire	Grief severity was predicted by caregiving circumstances, but bereavement depressed mood was largely unrelated to caregiving. Grief was the main predictor of depressed mood and mediated almost all other effects. We conclude that while grief may trigger depression, the dissimilar connection to context means that the two emotional states should not be equated based purely on similarity of expression.

Debra Parker Oliver[13]	Mean age: 60.6 %female: 62.28% Ethnicity: 91.65% White N=395 Patient's CA type: study site: Midwest or Southeast, USA %spouse: 30.38%	cross-sectional study	Patient Health Questionnaire 9-item scale Generalized Anxiety Disorder 7-item scale
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Nearly one-quarter of caregivers were moderately to severely depressed, and nearly one-third reported moderate to severe symptoms of anxiety. Risk factors for both depression and anxiety included younger age and poorer self-rated global health. Depression-specific risk factors included being married and caring for a patient with a diagnosis other than cancer. The sole anxiety-specific risk factor identified was geographic location, as caregivers living in the Southeast were found to have greater anxiety than those in the Midwest.

Hospice providers' recognition of family caregivers as both providers and coreipients of care underscores the need to more fully assess and respond to depression and anxiety among caregivers.

Sing-Fang Ling[17]	Mean age: 47.14	CES-D  Medical Outcomes Study  Social Support Survey  Caregiver Reaction Assessment scale	Caregivers' depressive symptoms peaked at one month and decreased significantly during the first 13 months after the patient's death. Bereaved caregivers experienced a lower level of depressive symptoms if they had cared for older patients, reported a higher level of subjective caregiving burden during the patient's dying process, and had greater social support. Caregivers reported a higher level of depressive symptoms after bereavement if they had a higher level of depressive symptoms before the patient's death, had poorer health, and were the patient's spouse. Caregivers' depressive symptoms improved significantly from one month before to 13 months after the patient's death.
	%female: 69.3		
	Ethic: not report		
	N=186		
	Patient's CA type: various		
	study site: Taiwan		
	%spouse: 45%		

	Mean age: 46.8 %female: 66.7% Ethic: not report	N=381 Patient's CA type: various(39.2% GI cancer) study site: Soth Korea %spouse: 50.9	Prospective cohort study	Quality Care Questionnaire-End of Life	<p>481 terminal cancer patients and 381 caregivers completed the questionnaire. Care burden was not insubstantial in both and the caregiver group felt more burden than the patient group (<math>P&lt;0.001</math>). While the patient group needed financial support most (39.0%), the caregiver group placed greatest emphasis on discussion about further treatment plans (44.8%). Stepwise multiple logistic regression analyses showed that in the patient group, patient's health status (OR, 2.03; 95%CI, 1.16-3.56) and burden (OR, 2.82; 95%CI, 1.76-4.50) influenced satisfaction about overall care, while in the caregiver group, high education level (OR, 1.84; 95%CI, 1.76-4.50), burden (OR, 2.94; 95%CI, 1.75-4.93) and good family function (OR, 1.94; 95%CI, 1.24-3.04) were important.</p> <p>Our study showed that burden was great in both terminal cancer patients and their caregivers and was perceived to be more severe by caregivers. Our study also showed that burden was the factor most predicting satisfaction about overall care in both groups.</p>
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Ji Eun Lee[29]	Mean age: 50.3 %female: 68.1% Ethnicity: not reported N=326 Patient's CA type: various study site: South Korea %spouse: 57.1%	cross-sectional study	Caregiver Burden Inventory developed by Novak EORTC QLQ-C30	Caregivers and patients who preferred palliative care to life sustaining treatment reported higher caregiver's burden(CB) and self-perceived burden(SPB) scores, respectively. Caregivers who felt more of a burden were more likely to prefer palliative care over life sustaining treatment for their patients (adjusted odds ratio [aOR] = 1.67, 95% CI: 1.21 – 2.31). In addition, patients who perceived their caregivers' burden as large tended to prefer palliative care (aOR = 1.61, 95% CI: 1.16 – 2.22). Both CB and SPB increased preference for palliative care. This could be interpreted that high CB can lead to preference for palliative care in both patients and their caregivers, potentially threatening patient autonomy. Efforts to relieve CB and SPB are needed.
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Sun Young Rha[30]	Mean age: 46.2	cross-sectional descriptive study	The Zarit Burden Interview World Health Organization QOL-BREF The Eastern Cooperative Oncology Group	Caregiving burden explained 30.3% of variance of the QOL ( $b = 0.534, p < 0.001$ ). Caregivers caring for patients with functional deterioration experienced higher burden. Caregivers providing care for hospitalized patients demonstrated lower QOL. The caregiver's educational level was a positively contributing factor for the QOL. Caregiving burden was the influential, negatively affecting factor for the QOL. Assessment of caregiving burden with special attention being paid to caregivers caring for patients with functional decline would help to identify caregivers in need of support. Supportive care needs to be sought to alleviate caregiving burden and improve the QOL of caregivers, especially for the caregivers of hospitalized patients.
	%female: 79.2%			
	Ethic: not report			
	N=212			
	Patient's CA type: various			
	study site: South Korea			
	%spouse: 48.6%			

Linda E. Francis[19]	Mean age: 54.6 %female: 77% Ethic: 74.2% White N= 199 Patient's CA type: not report study site: USA %spouse: not report	cross-sectional study	Functional Assessment of Cancer Therapy—General Version Functional Difficulties Index Medical Outcomes Study on Social Support Caregiver Reaction Assessment Short Form of Profile of Mood States Bereavement Experience Questionnaire	<p>Among caregivers of middle-aged patients (40 – 59), grief mediated the relationship between baseline caregiving and bereavement depressed mood, with grief increasing risk of depression in bereavement. Among caregivers of young old patients (60 – 79), grief had a suppressor effect on the relationship between caregiving and bereavement depressed mood, showing greater distress during caregiving than at bereavement.</p> <p>Caregiving for middle-aged cancer patients may increase the risk for severe grief and depression, whereas caregivers of young-old cancer patients appeared to experience relief at bereavement. After bereavement, continued observation may be warranted for caregivers of a middle-aged patient; grief, added to the ongoing demands of their lives (which may include those left behind by a middle-aged patient), may put such caregivers at risk for greater psychological and emotional distress.</p>
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Tanguy Leroy[12]	Mean age: 55.3 %female: 65% Ethic: not report N=60 Patient's CA type: various study site: northern France %spouse: 65.0%	cross-sectional study	<p>French version of the Caregiver Reaction Assessment</p> <p>French version of the very common Hospital Anxiety and Depression Scale</p> <p>French version of the Family Relationship Index</p> <p>Karfnofsky Performance Scale</p> <p>the Functional Independence Measure</p> <p>Patients had a good perception of their caregiver's burden(CB), although a little overestimated, except for their difficulties in managing their time. Caregivers overestimated patients' distress. The minimization by patients of CB was a source of emotional distress for the latter, and the perception of being a burden to others was a source of depression for patients. These results did not depend on the nature of the relationship between patients and their caregivers.</p> <p>This data confirmed the need to study the experiences of the patient – caregiver dyad as well as their communication of their respective experiences, with a prospect to offer clinical interventions to optimize the quality of life and health of patients and their close relatives.</p>

	Mean age: 48.33 %female: 61.8% Ethnic: not report N=285 Patient's CA type: not report study site: Taiwan %spouse: 52.6%	longitudinal study	Center for Epidemiological Studies Depression Scale Caregiver Reaction Assessment scale Medical Outcomes Study Social Support Survey	Bereaved family caregivers' prevalence of severe depressive symptoms peaked one month postloss(73.3%) and significantly decreased to 15.2% 24 months after the patient' s death. After adjusting for confounders, bereaved caregivers were more likely to have severe depressive symptoms if they had heavy objective caregiving load and higher preloss depressive symptom levels. However, their likelihood of severe depressive symptoms was buffered by being better prepared for the patients' death and having greater social support. Bereaved family caregivers' severe depressive symptoms decreased significantly over the first two years postloss. Healthcare professionals should appropriately assess at-risk bereaved caregivers when patients are still alive and provide effective interventions to facilitate caregivers' return to normal life.
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			Of patients to responding caregivers (n = 3635), 89 % suffered from cancer, predominantly lung cancer (23 %). Of responding caregivers, 62 % were partners and 29 % were adult children. In total, one third of caregivers reported severe outcome, 15 % reported severe pre-loss grief symptoms, 16.1 % had moderate to severe depressive symptoms, and 12 % experienced high caregiver burden. Partners had the highest levels of pre-loss grief and depressive symptoms, while adult children reported the highest levels of caregiver burden.
Mette Kjaergaard Nielsen[14]	immigrant/descendant N=3560  Patient's CA type: various study site: Danish %spouse: 62.0 %	cohort study	Prolonged Grief-13 scale Beck' s Depression Inventory-II Short Form Health Survey Burden Scale for Family Caregivers Couples' Communication about Illness and Death scale From this cohort, which was estimated to be representative of caregivers to terminally ill relatives in the general population, we found high levels of pre-loss grief, depressive symptoms, and/or caregiver burden in one third of all caregivers. These findings call for increased focus on caregivers' need of support.

Siew Tzuh Tang[32]	Mean age: 51.6 %female: 67.6% Ethnic: not report N= 253 Patient's CA type: various study site: Taiwan %spouse: 46.6%	cross-sectional study	Center for Epidemiological Studies-Depression Scale Symptom Distress Scale Caregiver Reaction Assessment Antonovsky's SOC scale	Family caregivers scored high on the CES-D [mean (S.D.)=22.24 (11.36)]. Results from the R2 change in the hierarchical multiple regression model indicated that the incremental variance explained by each block of variables for (1) the characteristics of family caregivers, (2) the characteristics of cancer patients, (3) objective caregiving loads, (4) confidence in caregiving, and (5) subjective caregiving burden was 20.5%, 6.8%, 1.5%, 3.7%, and 11.9%, respectively. In the final step of regression, SOC of caregivers increases the explained variation in depressive symptoms by 21.5%. This study confirms that, among the independent variables examined in this study, variations in SOC are comparatively important in explaining the variation of depressive symptoms experienced by Taiwanese family caregivers. Developments and evaluations of the effectiveness of clinical interventions aimed at augmenting caregivers' coping capability (such as SOC) to facilitate positive appraisal and finding meaning, to improve understanding of the demands and challenges of caregiving, and to mobilize resources available to manage caregiving tasks are highly recommended.
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H. Götze[16]	Mean age: 65.0 %female: 69.4% Ethnicity: not reported N=72 Patient's CA type: not reported study site: German %spouse: 89.1%	cross-sectional study	Hospital Anxiety and Depression Scale Short Form-8 Health Survey Oslo Social Support Scale
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It examined psychological parameters in family caregivers of palliative cancer patients before and after the death of the patients. Caregivers' data about depression and anxiety (Hospital Anxiety and Depression Scale), quality-of-life (Short Form-8 Health Survey), and social support (Oslo Social Support Scale) were collected at the beginning of home care (t1) and 2 months after the patient had died (t2). Regression models were employed to examine factors related to depression and anxiety in the bereaved caregivers. It interviewed 72 relatives, who were the primary caregiver of a patient. One-third (31.9%) of caregivers had high anxiety levels and 29.2% had high depression levels (t1, cut-off = 10). At t2, anxiety and depression had decreased significantly. There were no changes in quality-of-life over time. At both points of assessments, quality-of-life was lower than in the general population. Relevant factors for higher anxiety and depression in the bereaved caregivers were high levels of distress at t1, insufficient social support and low physical function. Bereaved caregivers were particularly depressed when they had been the spouse of the patient. Healthcare professionals should consider social isolation of caring relatives both during homecare and afterwards. Thus, it

seems to be important to routinely offer support to spouses.

Jamie M. Jacobs[11]	Mean age: 57.37 %female: 69.1% Ethnicity: 93% White N=275 Patient's CA type: Gastrointestinal cancer and Lung cancer study site: USA %spouse: 66.2%	cross-sectional study	Hospital Anxiety and Depression Scale
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Comparing patients with caregivers, patients reported more depressive symptoms ( $M_{diff} = .84$ ;  $t[274] = 3.17$ ,  $p = .002$ ,  $d = .22$ ) and caregivers reported more anxiety symptoms ( $M_{diff} = 1.62$ ,  $t[274] = 4.91$ ,  $p < .001$ ,  $d = .39$ ). Dyads' anxiety symptoms were positively associated, as were depressive symptoms ( $r_s = .21$ ,  $p \leq .001$ ). Actor – partner interdependence modeling showed that patients' anxiety symptoms were positively associated with their own depressive symptoms, with an equal effect for caregivers (actor effect  $\beta_s = 0.52$ ,  $p < .001$ ). Patients' own anxiety was concurrently positively associated with their caregivers' depressive symptoms, with an equal effect for caregivers to patients (partner effect  $\beta_s = 0.08$ ,  $p = .008$ ).

In the context of newly diagnosed incurable cancer, caregivers experience more pronounced anxiety, while patients report greater depressive symptoms. Findings indicate that anxiety and depressive symptoms are interrelated among dyads facing newly diagnosed incurable disease. Results emphasize the importance of addressing distress in both patients and caregivers. Future research should discern when dyadic versus individual psychosocial interventions would be optimal.

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