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ORIGINAL ARTICLE

Determinants of complicated grief in caregivers who cared for terminal cancer patients

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Abstract

Purpose There is little research on determinants and the grief that caregivers experience after their relatives die of cancer. This study evaluated factors which influence complicated grief among caregivers who cared for patients who died of cancer in Taiwan.

Methods This prospective study recruited 668 caregivers who cared for terminally ill cancer patients in the hospice ward or who received shared-care consultation. Caregivers were interviewed on the telephone an average 8.9 months after the cancer patients passed away. The Inventory of Complicated Grief (ICG), modified for use in a Chinese population, was used to assess the grief status of caregivers. ICG >25 was defined as complicated grief.

Results Our study found that female gender (odds ratio (OR), 2.27; 95% confidence interval (CI), 1.75–2.82), spouse relationship (OR, 1.20; 1.01–1.40), parents–children relationship (OR, 1.70; 1.11–2.31), lack of religious belief (OR, 1.47; 1.19–1.75), unavailable family support (OR, 1.42; 1.03–1.83), and history of mood co-morbidity (OR, 1.41; 1.02–1.83) were risk factors that would predispose towards complicated grief; whereas, longer duration of caring (months, OR, 0.79; 0.69–0.91), medical disease history in the carer (OR, 0.77; 0.57–0.99), and patients being cared for on the hospice ward (OR, 0.60; 0.44–0.77) were factors that would mitigate against complicated grief.

Conclusions These results suggest that clinical professionals who care for terminal cancer patients and their caregivers should pay particular attention to caregivers with these predisposing factors.

Keywords Caregivers · Complicated grief · Hospice · Terminal cancer patients

Introduction

Cancer is the leading cause of mortality in Taiwan [1]. There were more than 38,000 patients who died of cancer in the year 2008 [2]. Palliative care for terminal cancer patients in Taiwan has been well developed for at least two decades, and the first hospice ward was set up in 1990 in Taiwan [3]. It has become the main care way for terminal cancer patients [4, 5]. After the patient passed away, caregivers may probably suffer from depressed mood, so-called grief, and related sequel such as social withdraw. Literature concerning the palliative medicine provided some experiences on how to care for the bereaved family or caregivers, in particular, the aspect of mental health. An appreciation of bereavement care of caregivers' would increase the quality of palliative medicine and would be an important issue in hospice care. This would be based on the

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complete realization of the predisposing factors for grief reaction among caregivers.

A review article by Grassi identified a general trajectory of grief reactions evaluated by stages, phases, and tasks of grief [6]. Growing literature tend to identify the reason or the manifestation of "unusual" grief such as psychiatric disorder following bereavement, avoidance, prolonged or delayed grief, and inhibited grief [7, 8]. However, some people showed more severe reactions than others when facing a loved one passed away. Therefore, complicated grief would refer to an over or unusual expression of grief or even inability to interact with and manage the external world after a loss [9, 10]. Complicated grief can also be defined as a cluster of experiences that includes separation distress, post-traumatic stress, and an inability to cope with the loss of a loved one [9, 10]. Early identifying high-risk group of complicated grief among caregivers would be helpful to increase the quality of supportive care in cancer patients and their caregivers.

More and more literature provided the experience on grief care for caregivers after the cancer patient die [6, 11, 12]. There were some aspects discussed about bereavement, such as family and social relationships, the nature of caregivers, and the duration of caring patient. Bernard and Guarnaccia implicated that the family role relationship between patient and caregiver influence the bereavement, and complicated bereavement of spouse was stronger than parent–adult daughter relationship [11]. Rossi Ferrario et al. illustrated that the maladjustment problem of bereavement were associated with female and substantial emotional burden [12]. Burton et al. showed that fewer months of caregiving, lower level of social activities, smaller social networks, and lower satisfaction with social support were factors that were predictors of higher post-loss depression [13]. Kelly et al. demonstrated that the level of psychological symptoms experienced before the patient died and the number of adverse concurrent life events were the significant predictors of short-term bereavement distress [14]. However, literature studying the complicated grief in caregivers of cancer patients in the eastern country particularly in Taiwan is relatively scarce. Furthermore, there would be a lack of study concerning simultaneously the multidimensional risk factors which will influence the bereavement of family or caregivers.

The above background led us to undertake this study and to describe and compare the demographic variables between caregivers who cared for terminally ill patients residing on the hospice ward and caregivers who cared for the patients receiving shared-care for terminal stage of cancer. Furthermore, we assessed and compared the variables of demographics and determinants between caregivers with complicated grief and uncomplicated grief. The predisposing factors that would affect the complicated grief were investigated eventually by adjusting potential determinants and employing biostatistics analysis.

Materials and methods

This study was approved by the Institutional Review Board of Kaohsiung Medical University Hospital, Taiwan. Five hundred eleven terminal cancer patients resided in our hospice ward, and 405 patients received shared-care hospice consultation, which means the patients were mainly cared by specialists but received opinion by palliative consultants, in 2007 and 2008. We administered a telephone interview to these 916 main caregivers (spouse, descents, brothers or sisters, and daughters in law) of the terminal cancer patients. Though there might be more than one caregiver for one patient, we only selected the key carer who was responsible for most of the care. Subjects were excluded if they had a history of drug abuse or a diagnosis of a psychiatric disorder. Finally, a total of 668 subjects completed the interviews with a 73% response rate, among whom, 386 (75.5%) were caregivers of patients who stayed on the hospice ward, and 282 (69.6%) were caregivers of patients who received shared-care consultations. Non-responses were due to the three failed telephone calls. According to the literature, complicated grief should not be diagnosed within the first half year of bereavement [15]. Therefore, we carried out the interview for caregivers with bereavement more than half a year later. The bereavement durations in our study were from 6 to 14 months, with an average of 8.9 months.

Trained interviewers administered a structured telephone interview, and the interviews had an average duration of 20 min. Data collected included demographic information of caregivers, relationship with patients who passed away, patient characteristics (including age, gender, cancer type, and terminal symptoms), duration of care, religion, positive feelings of available family or social supports, medical history of caregivers, and mood and psychotic problem histories.

The grief status of caregivers was assessed using Chinese variations of the Inventory of Complicated Grief (ICG) modified for use in a Taiwanese setting. Literature has demonstrated a good validity of this Chinese version instruments and showed that this version is suitable for use in our sampling subjects [16]. Complicated grief was defined as ICG scores >25 [10, 17].

The null hypothesis for all statistical tests is that there is no significant, independent relationship between variables. The level of statistical significance is 0.05, and all tests are two-tailed. Statistical Package for the Social Sciences for Windows Version 14.0 was employed for the statistical analysis. Statistics used include frequencies, means, standard deviations, X^2-tests, and *t* tests. Logistic regression with full model and reduced model by stepwised method were performed to estimate the relative contributions of independent variables after adjusting for potential confounding factors.

Results

Six hundred and sixty-eight caregivers, 263 males (39.4%) and 405 females (60.6%), were included in the analyses. Demographic variations between caregivers of patients who resided on the hospice ward (group 1) and those who cared for the patients only receiving shared-care consultations (group 2) are demonstrated in Table 1. Age for caregivers ranged from 18.7 to 62.1 years of age. The mean age of the caregivers enrolled in this study was 42.9 years old (SD=9.9); group 1 was 41.8±8.9 and group 2 was 44.5±12.1. The gender distribution of caregivers and cancer type are also shown in Table 1. Lung cancer, buccal cancer (head and neck cancer), and hepatocellular carcinoma ranked as the three most frequent types of terminal stage cancer in our study. The education level showed no difference between groups. The caregiver relationships in this study were 194 spouses (29.0%), 261 parent–child relationships (39.1%), and 213 others (31.9%) including brothers, sisters, friends, daughters-in-law, or nephews. No significant statistical relationship was found between caregiver relationship and group.

Table 1 Demographics of recruiting subjects

	Caregivers of patients who ever lived in hospice ward (n=386)	Caregivers of patients who received shared-care only (n=282)	p value[a]
Age (mean±SD)	41.8±8.9	44.5±12.1	0.082
Patients' age (mean±SD)	61.6±14.4	60.6±13.9	0.119
Gender (M/F)	147/239	116/166	0.422
Diagnosis of patients			
Lung	88 (22.8%)	43 (15.2%)	0.030
Buccal cancer	66 (17.1%)	43 (15.2%)	
HCC	36 (9.3%)	37 (13.1%)	
Colon cancer	31 (8.0%)	16 (5.7%)	
Esophageal cancer	28 (7.3%)	18 (6.4%)	
Pancreatic cancer	24 (6.2%)	12 (4.3%)	
Breast cancer	20 (5.2%)	15 (5.3%)	
Hypopharyngeal cancer	19 (4.9%)	12 (4.3%)	
Gastric cancer	16 (4.1%)	13 (4.5%)	
Rectal cancer	7 (1.8%)	8 (2.8%)	
Others	51 (13.2%)	65 (23.0%)	
Education			
>12 years	118 (30.6%)	77 (27.2%)	0.389
≤12 years	268 (69.4%)	205 (72.8%)	
Family status			
Married	291 (75.4%)	201 (71.3%)	0.248
Single	95 (24.6%)	81 (28.7%)	
Caregiver relationship			
Spouse	108 (28.0%)	86 (30.5%)	0.582
Parent–child	149 (38.6%)	112 (39.7%)	
Others	129 (33.4%)	84 (29.8%)	

Married: including widowed

Single: including unmarried and divorced

[a] *t* test or Chi-squared test

Variation between enrolling caregivers with complicated grief and uncomplicated grief are shown in Table 2. The average age of subjects with complicated grief was 45.8±13.2 years and uncomplicated grief, 41.9±8.1 years (p=0.127). The patients' average age of subjects with complicated grief was 55.1±11.6 years, which was younger than the uncomplicated grief of 63.2±9.9 years (p=0.041). Three out of four complicated grief (43/121) sufferers were female, whereas 56% of uncomplicated grief carers were female. Therefore, females more commonly experienced complicated grief (p<0.001). There was no statistical significance of education levels between the complicated and uncomplicated grief groups. Regarding the caregiver relationships, the prevalence of spouse (35%) and parent–child (60%) relationships were higher in complicated grief compared with uncomplicated grief (p<0.001). The average income of complicated grief subjects was slightly lower than that of uncomplicated grief (p=0.049), and the caring durations for complicated grief subjects were shorter than the uncomplicated group subjects (10.6 vs 17.8 months, p=0.017). The proportion of religious belief in complicated grief subjects (82.9%) was lower than that of uncomplicated grief subjects (96.4%) with p<0.001. The proportion of positive feelings of available family support in complicated grief subjects (56.1%) was lower than in uncomplicated grief subjects (68.7%) with p=0.004. With regard to mental problem traits, the proportion of mood co-morbidity was higher in complicated grief subjects (10.4%) than in uncomplicated grief subjects (1.4%) with p<0.001; and the proportion of psychotic co-morbidity was higher in complicated grief subjects (2.4%) than in uncomplicated grief subjects (0.4%) as well with p=0.035. The proportion of history of medical diseases of caregivers in complicated grief subjects (24.4%) was lower than that of uncomplicated grief subjects (33.1%) with p=0.041. The caregivers who cared for patients on the hospice ward were less likely to become complicated grief sufferers (70/386), whereas caregivers who cared the patients receiving shared-care

Table 2 Varieties between subjects with complicated grief and uncomplicated grief

	Complicated grief ($n=164$)	Uncomplicated grief ($n=504$)	p[b]
Age (mean, SD), years	45.8±13.2	41.9±8.1	0.127
Patients' age (mean, SD), years	55.1±11.6	63.2±9.9	0.041
Gender (M/F)	43/121	220/284	<0.001
Education (>12/≤12 years)	38/126	157/347	0.06
Caregiver relationship			
(Spouse/parent–child/others)	57/98/9	137/163/204	<0.001
Average income per month (290 USD)	2.9±1.1	3.9±3.4	0.049
Average durations of caring patients (months)	10.6±8.4	17.8±14.2	0.017
Religions (yes/no)	136/28	486/18	<0.001
Family support[a] (available/unavailable)	92/72	346/158	0.004
Social support[a] (available/unavailable)	45/119	98/406	0.037
History of mood co-morbidity (yes/no)	17/147	7/497	<0.001
Caregivers with medical diseases (yes/no)	40/124	167/337	0.041
Care the patients who lived in hospice ward (yes/no)	70/94	316/188	<0.001

[a] Subjective feeling

[b] *t* test or Chi-squared test

were more likely to suffer from complicated grief (94/282) with $p<0.001$.

Relationships among complicated grief and potential determinants by logistic regressions are illustrated in Table 3. The factors entered into the model included age, gender, education level, caregiver relationship (spouse, patient–child, and others), income, caring durations, religious belief, family support, history of mood co-morbidity, history of psychotic co-morbidity, medical disease history, and residence on the hospice ward. The reduced model by stepwise method showed that female gender (odds ratio (OR), 2.27; 95% confidence interval (CI)=1.75–2.82), spouse relationship (OR, 1.20; 95% CI=1.01–1.40), parent–child relationship (OR, 1.70; 95% CI=1.11–2.31), no religious belief (OR, 1.47; 95% CI=1.19–1.75), unavailable family support (OR, 1.42; 95% CI=1.03–1.83), and history of mood co-morbidity (OR, 1.41; 95% CI=1.02–1.83) were risk factors that would predispose towards complicated grief; whereas, longer duration of caring for patients (months, OR, 0.79; 95% CI=0.69–0.91), carer with medical disease history (OR, 0.77; 95% CI=0.57–0.99), and hospice ward stays (OR, 0.60; 95% CI=0.44–0.77) were protective factors that would prevent complicated grief.

Table 3 The logistic regression analyses of the considering effective factors for developing complicated grief, presenting as odds ratio (95% confidence interval)

Factors	Complicated grief	
	Full model	Reduced model[a]
Age (years)	1.02 (0.99–1.07)	
Gender (female)	2.27** (1.75–2.81)	2.27** (1.75–2.82)
Education (≥12 years/<12 years)	0.98 (0.89–1.09)	
Caregiver relationship 1, spouse	1.20* (1.01–1.41)	1.20* (1.01–1.40)
Caregiver relationship 2, parent–child	1.69** (1.11–2.29)	1.70** (1.11–2.31)
Caregiver relationship 3, others	0.94 (0.67–1.24)	
Current income per month (290 USD)	1.02 (0.78–1.26)	
Longer duration of caring for patients (months)	0.79* (0.68–0.92)	0.79* (0.69–0.91)
No religious belief	1.45** (1.19–1.73)	1.47** (1.19–1.75)
Family support unavailable	1.41* (1.03–1.81)	1.42* (1.03–1.83)
Social support unavailable	1.06 (0.97–1.17)	
History of mood co-morbidity	1.40* (1.01–1.82)	1.41* (1.02–1.83)
Caregivers with medical diseases	0.77* (0.57–0.98)	0.77* (0.57–0.99)
Care the patients who stays on the hospice ward	0.61** (0.46–0.77)	0.60** (0.44–0.77)

*$p<0.05$

**$p<0.01$

[a] By stepwise method

Discussion

Bereaved people develop severe reactions to their loss, and the strength is larger than the average. This reaction may be associated with adverse health outcomes which will be considered as complicated grief [10]. This study provides the first attempt to describe the determinants of complicated grief of caregivers by taking into account most of the potential risk factors simultaneously as a result of cancer bereavement in Taiwan. Our results demonstrated that female gender, spouse and parent–child relationship, shorter caring duration, no religious belief, unavailable family support, history of mood co-morbidity, no medical disease history, and no hospice ward stays were significant determinants of complicated grief for caregivers. The prevalence of complicated grief in our study was 24.6%, which was similar to other studies reviewed by Grassi [6].

In East Asian countries, caregivers are usually the relatives, which may be different from caregivers in western countries. The literature on the association between complicated grief and family relationship of caregivers is limited [11]. Only Bernard and Guarnaccia try to establish a model to clarify the association between family relationship of caregivers and bereavement using a dataset from breast cancer hospice patients. Their result revealed that the family relationship between caregiver and patient influences bereavement adjustment. Our study found the same and provides more detailed insight that both the parent–child relationship and the spouse relationship result in complicated grief but that the contribution of parent–child relationship (OR=1.69, 95% CI=1.11–2.29) is heavier than the spouse relationship (OR=1.2, 95% CI=1.01–1.41). We made an interpretation regarding this interesting result here. There is a different culture in parent–offspring relationship between eastern and western countries. For instance, in the western world, off-springs are independence from their parents after they grow up. Differently, off-springs and parents live together in the eastern world even the children grow up. This may strengthen the parent–child relationship and explain the distinct result in our study that the parent–child relationship was heavier than the spouse relationship in contributing to complicated grief which might be resulted from cultural varieties.

In our study, the caregiver who has a high degree of family/social support experience fewer stress reactions than subjects with a low degree of social support. Though the available suggestions from literature are limited [6, 18], the study by Ringdal et al. revealed that social support might work as a buffer against reactions toward external stressful events on the second assessment at 2 months after the bereavement but provides little by way of stress reactions at the baseline assessment [18]. In their study, furthermore, family support was defined as one kind of social support; however, in our study, we divided the family support (means the support from inter-family) and social support (means the resource coming from outside the family members such as government or non-government organization). Our result showed that family support would be a determinant protecting from complicated grief. Therefore, if a high probability of complicated grief is detected in an individual, family supports would valuable in prevention. The cross-cultural distinction of tighter parent–child relationship in the eastern countries may provide explain why the family support was more significant in complicated grief prevention than social support. On the other hand, social support in our culture might be helpful but not strongly as family support.

Our study suggested that female gender is a risk factor of complicated grief and should be valued. Literature demonstrated an association between female gender and increased grief experience [12, 19–22]. The study by Neria et al. showed that complicated grief was associated with female gender in adults who experienced loss during the September 11, 2001 terrorist attacks in New York City in the USA [21]. Another study by Summers et al. revealed that the bereaved women living with HIV may be at increased risk for bereavement, psychiatric morbidity, and thoughts of suicide [20]. Three other literature (two of which studying caregivers of cancer patients) also demonstrated that severe psychological distress or symptoms resulted from bereavement were more likely to occur in female gender [12, 19, 22]. Therefore, our finding provided another support on the hypothesis that female gender might be of increased risks for complicated grief compared with male. Though the reason has not been clearly identified in the literature, one literature has hypothesized that women are more likely to define their relationship to others [20]. Therefore, they may be more sensitive on self-identity once their loved one dies.

Though literature showed a probably positive effect of religious belief on bereavement [23, 24], the study regarding the association between religious belief and complicated grief is limited. One study demonstrated that religious beliefs, practices, and attendance are associated with better mental health in family caregivers of persons with dementia [24]. Other literature demonstrated that the available data do not allow for a definite answer on whether religious/spiritual beliefs influence bereavement [23, 25]. Result in our study that no religious belief would be related with complicated grief (OR, 1.47; 95% CI, 1.19–1.75) suggested that a religious belief might be helpful when one caregiver is detected high risk of complicated grief. In the literature, many factors would influence the relationship between religion and bereavement adjustment, and the influence especially vary by the measurement and assessment [25]. The gradation, intensity, coping, and even different nature of religious belief would influence the grief reaction. In our study, we only identified the presence/absence of religious beliefs (dichotomized data). This restricted the possibility to completely interpret the extents of religious belief on bereavement reaction. Furthermore, cross-cultural difference between the western and eastern countries is identified including the nature of religion. This distinction should also influence the religious belief working on grief adjustment. Therefore, we start to implement the ongoing research and wish that we may identify the extents of religious beliefs on the bereavement reactions particularly under our eastern cultural background.

Shorter caring durations were found to be related to complicated grief in our study. A past study regarding the grief shortly after suicide and natural death concluded that the complicated grief syndrome is more common after unexpected and violent deaths such as suicide [26]. In this case, our finding matches this theory that such sudden loss would result in a higher risk of complicated grief. Probably, a longer caring duration would provide the caregivers with more adequate time and resources to prepare for the coming bereavement. This would result in a lesser chance of the occurrence of complicated grief.

Regarding the period or duration of bereavement, it might be another important factor that would influence the grief reaction and strength. Literature by Horowitz et al. suggested that the frequency of grief symptoms declined in the interval between 6 and 14 months after the bereavement [27]. In order to clarify the grief reaction and bereavement duration in our study, Pearson's correlation were analyzed and showed little correlation between these two factors (table not shown). Test for comparing mean by dichotomizing the bereavement duration according to the mean of 8.9 months also showed that though the ICG of longer duration group had less mean scores compared with shorter duration, it did not reach statistical significance. We recognized that the cross-sectional study design of the present research might restrict the possibility to clarify this important issue, which would be better identified by a longitudinal study. Therefore, further follow-up research connecting the present study is warranted in the near future.

The opinions from the literature concerning the co-morbidity of mood disorder and complicated grief are equivocal, and it might be hard to distinguish one from the other. Our results demonstrated that mood disorder co-morbidity of caregivers had a slightly increased risk (OR, 1.41; 95% CI=1.02–1.83) for complicated grief. Growing literature tend to separate the psychiatric classification of grief as pathological problems [27, 28], and more researches are warranted for this investigation.

In conclusion, female gender, spouse relationship, parent–child relationship, no religious belief, unavailable family support, and history of mood co-morbidity were risk factors of complicated grief; whereas, durations of caring patients (months), medical disease history, and patient stays on the hospice ward were protective factors from complicated grief.

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Conflicts of interest The authors declared that they have no conflict interest.

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