RESEARCH ARTICLE

Burdens among Caregivers of Older Adults with Advanced Cancer and Risk Factors

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Abstract

Family caregivers of older cancer patients face many challenges in managing illness. The burden impacts physical, emotional, spiritual, and social health. The objective of this study was to identify burden among caregivers of older patients with advanced cancer, and associated factors. Materials and Methods: Caregivers of older cancer patients were randomly interviewed from March-September 2012. Information on baseline characteristics and caregiver burden using the Zarit Burden Inventory (ZBI) was collected. Descriptive statistics were used to analyze baseline data, with univariate and multiple linear regression to analyze factors associated with higher burden. Results: One hundred and fifty participants were assessed. The mean ZBI was 19.2±12.9 (95%CI, 17.1, 21.2). Two-thirds of caregivers reported no burden (63%) and the main impact variable on ZBI was guilt. High burdens were associated with single caregiver, relationship with the patient as siblings, presence of migraines, and cancer types of the patients. Conclusions: Caregiver burden of Thai cancer patients is low. This unexpected small number could be the result of the socio-cultural viewpoint. Assessment of caregivers and focusing on related factors should be incorporated into treatment plans.

Keywords: Caregiving - neoplasms - older adult - social support - Thai caregivers

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Introduction

A diagnosis of cancer often leads to physical, mental, and social challenges for both patients and their families, especially the older populations (Sharpe et al., 2005; Kim and Given, 2008). Caregivers are involved in many aspects starting from dealing with the diagnosis of cancer, treatment-related adverse events, disease-related symptoms, recurrence, and end-of-life care. Since active cancer treatment requires only a short-term hospital stay, family members become the key persons in taking care of the patients at home. The average time of caregiving for cancer patients was 8.8 hours per day Van et al. (2011) At the same time, the family members still needed to maintain their routine work and responsibilities. If the demands from taking care of the patients could not be handled by the caregivers, this would lead to a burden. The burden of caregiving impacts quality of physical, emotional, spiritual, and social health. In caregivers, insomnia, decreased appetite, high blood pressure and altered lipid profiles have been reported (Vitaliano et al., 2002; Given et al., 2011a; 2011b). Low immune response, slow wound healing and even increased mortality have also been observed (Kiecolt-Glaser et al., 2003). The degree of mental health disturbance including depression in cancer caregivers may not be severe as those taking care of dementia (Mor et al., 1994). One meta-analysis showed that emotional distress does not become more severe during terminal stages. On the other hand, caregivers tended to report more distress during the treatment phase and shortly after diagnosis than during subsequent care (Hodges et al., 2005). High financial cost is another important factor that could lead to a huge burden. One report stated a total cost of USD 1200 per patient per year for an informal caregiver (Hayman et al., 2001). Other factors associated with high caregiver burdens were younger caregiver with odds ratio (OR) of 1.46, 95% confidence interval (CI) of 1.11 and 1.93, number of activities of daily living needed from the patients (OR 1.35, 95%CI 1.13,1.61), and restricted daily activities (OR 23.13, 95%CI 5.94, 90.06) (Goldstein et al., 2004; Garlo et al., 2010).

Many tools are being used to assess caregiver burden presently. One of the commonly used scales, the Zarit caregiving Burden Interview (ZBI), has been validated widespread and also in the Thai version. It consists of 22

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items and the scale is ranged from 0 (never) to 4 (nearly always), wherein the final score is from 0 to 88; the higher the score, the bigger the burden. It is a user-friendly scale with an internal consistency (Cronbach's Alpha) of 0.85 (Arai et al., 1997; Carod et al., 2009; Van et al., 2012). The Thai burden interview for caregivers of patients with chronic illness was validated with the Cronbach's Alpha coefficient of 0.92 (Toonsiri et al., 2011).

The level of caregiving varies among different cultures. African American cancer patients received more support from family than white populations (Martin et al., 2012). Among Thai caregivers, only a small burden was observed while caring for older adults with chronic illnesses (Limpawattana et al., 2013). Little is known about caregiver burden in Asian countries for cancer patients (Turkoglu and Kilic, 2012; Chang et al., 2013; Shih et al., 2013). Thus, the purpose of this study was to assess the caregiver burdens of older cancer patients in Thailand and to identify the factors related to high burden.

Materials and Methods

Study participants

This study represented 150 participants. They were the informal caregivers of older adults who had advanced cancer who were admitted to Srinagarind Medical School Hospital, Thailand during March to September 2012. The inclusion criteria were that the informal caregiver was of older persons with advanced cancer (stage 3 or 4) who were aged 65 years old or over, they spoke Thai or local language, and they were willing to participate in the study. All patients had confirmed cancer by histopathology.

Instrument

The instrument used in this study was the Thai version of Zarit Burden Inventory (ZBI) (Toonsiri et al., 2011). It consists of 22 items. There are 5-point scale responses. The questions focus on areas of caregivers' health, psychosocial well-being, finances, social life and the relationship between the caregiver and the one or ones being care for. The subscale used in this tool consisted of the 4 aspects which are personal strain, privacy conflicts, guilt and uncertain attitude. The answer for each item ranges from "not at all descriptive" (zero) to "very descriptive" (Toonsiri et al., 2011). The total scores range from 0-88. The higher ZBI scores indicate the greater the burden. No burden at scores of less than 21, mild burden at 21 to 40, moderate burden at 41-60, and severe burden at 61-88.

Procedure

The potential subjects were asked about their willingness to participate in the study. When the subjects agreed, they completed an informed consent sheet. Then, the caregivers were asked about the questionnaires by the team of researchers. There were 3 trained persons for interviewing the subjects. The baseline characteristics of the participants were collected including age, gender, marital status, educational level, self-reported health status of caregivers, relationship to patients, living status of patients, employment status, average income, self-reported income, duration of caregiving, comorbidities of caregivers, numbers of basic activities with daily living (ADL) needed, and underlying diseases of the patient in need of care. The ZBI was then used to assess caregiver burden.

Statistical analyses

Demographic data variables which included baseline characteristics and ZBI scores were divided into dichotomous or polytomous variables. All variables used descriptive statistics, presentation in percentage, mean and standard deviation. If the distribution of these data was not a normal distribution, then medians, and inter-quartile ranges were used instead. The effects of baseline characteristics on the ZBI scores were evaluated using univariate and multiple logistic regressions. For univariate analysis was used to examine all associated factors. Factors with $p<0.20$ were then entered into a multiple logistic regression model. $p<0.05$ was considered to indicate statistically significant differences and coefficient and their 95% confidence intervals (CI) were reported to consider the strength of association between possible factors and caregiver burden of older adults with advanced cancer based on the ZBI scores. All the data analyses were carried out using STATA version 10.0 (StataCorp, College Station, Texas).

Sample size

Sample size calculations were based on the estimated prevalence of the caregiver burden using ZBI among the older adults with cancer. The estimation of a population proportion with a specified absolute precision formula was used to calculate this (Chirawatkul, 2008). A sample size of at least 150 participants was sufficient to achieve this at the significance level of 0.05. Regarding the secondary objective, it was anticipated that there would be 4 factors associated with caregiver burden among older adults with advanced cancer: age, financial support, number of activities of daily living needed from the patients, and restricted daily activities (Goldstein et al., 2004 ;Garlo et al., 2010; Yusuf et al., 2011). The sample size estimation was based on the current recommendation among statisticians for multiple logistic regression analysis, i.e., that the number of caregivers of older adults with advanced cancer being five to ten times the number of risk factors in the multiple logistic model (Katz, 1999). Therefore, approximately 40 subjects were needed. Using the previous sample size calculation of 150, the overall sample size of at least 150 would be adequate for both objectives of this study.

Ethics approval was provided by Ethics Committee of the Faculty of Medicine, Khon Kaen University as instituted by the Helsinki Declaration and the Good Clinical Practice Guidelines.

Results

Caregiver and patient population

There were 150 participants who were informal caregivers of cancer patients enrolled in this study. Baseline characteristics of them were summarized in Table

Table 1. Baseline Characteristics of Study Population

Caregiver factors			
Age in years (median(IQR1,IQR3)		48	(41, 59)
Female, n (%)		122	-81.33
Marital status, n (%)	Single	15	-10
	Married	124	-82.67
	Divorced/separated/Widow	11	-7.33
Education, n (%)	Primary school or lower	72	-48
	>Primary school	78	-52
Self-health status	Ill	37	-24.67
	Healthy	113	-75.33
No. of self-reported illness, median (IQR1, IQR3)		0	(0, 1)
Illness, n (%)	Hypertension, n(%)	22	-14.7
	Diabetes mellitus, n(%)	8	-5.33
	Musculoskeletal pain, n(%)	8	-5.33
	Peptic ulcer disease, n(%)	15	-10
	Osteoarthritis, n(%)	7	-4.67
	Migraine, n(%)	3	-2
	Depression/anxiety, n(%)	2	-1.33
Relationship to patient, n (%)	Son/daughter	93	-62
	Son/daughter-in-law	8	-5.33
	Spouse	39	-26
	Grandchildren	3	-2
	Sibling	6	-4
	Others	1	-0.67
Living status, n(%)	With spouse	33	-22
	Alone	5	-3.33
	With family	112	-74.67
Employment status	Work at home	38	-25.33
	Unemployed	26	-17.33
	Work outside home	54	-36
	Others	32	-21.33
Caregiver income/month in baht, median (IQR1, IQR3)		5000	(1500, 15000)
Self-reported income in baht, n(%)	Not enough	79	-52.67
	Enough	53	-35.33
	Saving	18	-12
Duration of being a caregiver, (months), median (IQR1, IQR3)		7	(3, 14)
Patient factors			
No. of basic ADLs needed, median (IQR1, IQR3)		2	(1, 5)
Types of cancer, n(%)	Breast cancer	7	-4.67
	Colorectal cancer	22	-14.67
	Lung cancer	57	-38
	Liver cancer	7	-4.67
	Sarcoma	1	-0.67
	Stomach	4	-2.67
	Head and neck	11	-7.33
	Thyroid	2	-1.33
	Lymphoma	7	-4.67
	Other	30	-20
	Multiple cancers	2	-1.33
Common co-morbid diseases	Hypertension	35	-23.33
	Diabetes mellitus	23	-15.33
	Dyslipidemia	3	-2
	Heart disease	10	-6.67
	Cerebrovascular disease	3	-2
	Dementia	1	-0.67
	Musculoskeletal disease	5	-3.33
	Chronic kidney disease	5	-3.33

*SD; standard deviation, IQR; inter-quartile range, basic ADLs; activities of daily living including bathing and showering, bowel and bladder management, eating, feeding, functional mobility, personal hygiene and toilet hygiene

Table 2. Prevalence of the Impact Variables on the Partners of Cancer Patients: Percentage Experiencing Consequences in 4 Domains Based on ZBI

Domains	Prevalence of impact variables on ZBI score (%)
Personal strain	16.50±15.86
Privacy conflicts	13.18±19.94
Guilt	38.60±23.15
Uncertain attitudes	21.06±18.18

1. Most of caregivers were female and in their middle age. Seventy-five percent of patients lived with family, 22% lived with spouse, and 3% lived on their own. Of the total caregivers, 62% were the patient's child, 26% a spouse, 5% an in-law, and 4% a sibling. Overall, most of the caregivers reported themselves to be healthy with about 15% reported having hypertension, which was the most common disease among the participants. Nearly half of participants had not finished high school and worked at home or were unemployed. More than half of them reported having financial problems. The average numbers of basic activities of daily living (bADLs) needed was 2, mainly in meal preparation and feeding (72%) and mobility (46.7%). The three most common cancers were lung, colorectal, and head and neck cancer. The caregivers reported the underlying chronic illnesses of older adult patients were hypertension, diabetes and heart disease.

Caregiver burden scales

The participants completed the Thai version of 22-item Zarit Burden Inventory (ZBI). The mean ZBI scores were 19.15+12.85, 95%CI 17.07, 21.22. They were 19.7+ 12.88, 95%CI 17.4, 22.01 in females and 16.71+ 12.64, 95%CI 11.81, 21.61 in males. There was no statistical significant difference in ZBI scores between genders (p=0.27). Classifying severity of caregiver burden based on the ZBI scores, the majority of participants reported no caregiver burden (63%), followed by mild burden (31%), moderate burden (5%), and severe burden (1%). According to the ZBI scores, the prevalence of the impact variables on the caregivers of older adults with cancer in the 4 domains; personal strain, privacy conflicts, guilt, and uncertain attitudes are shown in Table 2. Guilt is the most frequent factor, followed by uncertain attitudes, the strain on personal life, and privacy conflicts.

Factors associated with caregiver burden among cancer patients

The associated factors of caregiver burden using the ZBI scores using univariate analysis models adjusted for socio-demographic, underlying diseases of caregivers, and other caregiver burden variables described in methodology part were evaluated. Eleven factors were found to be statistically significant (p<0.2) which were caregiver factors: marital status, educational level, financial support, types of relationship with the patient, caregiver with presence of migraine, anxiety disorder, musculoskeletal disorder, and patient factors: types of activities of daily living needed, and cancer types of the patients. With stepwise multiple logistic regression, only 4 of these factors were found to be independently related to high caregiver burden; caregiver factors: marital status, the presence of migraine, and relationship with the patient, and patient factor: cancer type (Table 3).

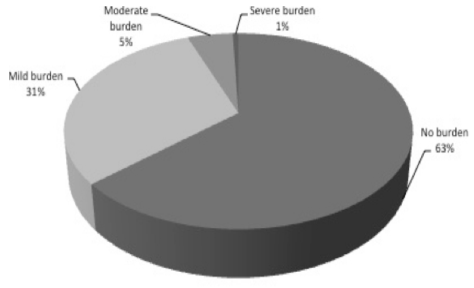

Figure 1. Severity of Caregiver Burden by ZBI Scores

Table 3. Factors Influencing Caregiver Burden by Multiple Linear Regression Analysis

Variables	coefficient	SE	p-value	95%CI
Caregiver factors				
Marital status				
Single	1			
Married	-8.12	3.48	0.02	-15.00,-1.25
Divorced/separated/Widow	-12.92	4.83	0.01	-22.5, -3.35
Education level				
Primary school or lower	1			
Higher than primary school	-3.42	2.16	0.12	-7.7, 0.85
Relationship to patient				
Son/daughter	1			
Son/daughter-in-law	3.03	4.38	0.45	-5.62, 11.7
Spouse	3.48	2.42	0.15	-1.3, 8.27
Siblings	14.48	5.35	0.01*	3.88, 25.07
Other	-17.21	11.55	0.14	-40.1, 5.64
Underlying disease				
Migraine	16.1	7.27	0.03*	1.71, 30.46
Anxiety disorder	16.9	9	0.06	-0.9, 34.69
Family income	0	0	0.24	0, 0
Patient factors				
Cancer type				
Breast cancer	1			
Colorectal cancer	6.01	3.54	0.09	-1, 13.02
Lung cancer	7.08	2.95	0.02*	1.24, 12.92
Sarcoma	41.6	11.66	0.001*	18.54, 64.7
Others	8.21	3.62	0.02	1.04, 15.38
Stomach cancer	15.49	6.36	0.02*	2.91, 28.08
Head and neck cancer	4.71	4.4	0.29	-3.99, 13.41
KUB cancer	16.9	9	0.06	-0.9, 15.81
Multiple cancers	14.22	8.71	0.11	-3.01, 31.45
Underlying disease				
Chronic kidney disease	-6.84	5.29	0.2	-17.31, 3.63
Musculoskeletal disease	9.86	5.75	0.09	-1.52, 21.24
Type of help in bADLs				
Personal hygiene	4.32	2.75	0.12	-1.13, 9.76
Functional mobility	3.57	2.22	0.11	-0.81, 7.96

*SE; standard error, *indicated p-value was significant at $p<0.05$, bADLS: basic activities of daily living, personal hygiene: facial washing, combing, and tooth brushing

Discussion

Palliative care for advanced cancer patients differs greatly from resource-rich countries to resource-limited countries (Lamas and Rosenbaum 2012). In Thailand, older adults usually stay at home even with the advanced illness (Chunharas, 2007). No hospice or nursing homes, high financial burden for hospitalization, and lack of palliative services have resulted in the caregiver roles of family. Supported by the findings from the current study, family members, particularly adult daughters took the main responsibility, similar to the study of older adults with other chronic illnesses in Thailand (Limpawattana et al., 2013). Different cultures result in different outcomes. In the study from the UK, 90% of caregivers were spouses, while only 4% were children (Higginson and Gao, 2008). Nevertheless, the main responsibilities of taking care of advanced cancer patients remained in the family.

Most of the caregivers of older adults with advanced cancer in this study reported no burden as defined by the Zarit inventory with the ZBI less than 21, indicating a mild burden. This is not a surprising finding, as the patients had small disabilities and the average numbers of the basic ADL needed were only 2. The mean ZBI score was comparable to the result from the study from Higginson 18.5 (Higginson and Gao, 2008). The burden, however, was much lower than the results from outpatient African cancer caregivers with the mean ZBI of 29.16+12.8 with nearly half of the participants reporting a high burden (Yusuf et al., 2011). This is in comparison to the results from a study from Garlo, which included cancer, heart failure and chronic obstructive lung disease patients, only 10% reported no burden (Garlo et al., 2010). Thai caregivers may not reveal the real burden due to guilt feelings and the belief that taking care of parents is mandatory according to the Buddhist teachings. Other studies found that caregivers for cancer patients were depressed and reported more symptom burdens (Given et al., 2004; Braun, et al., 2007; Palos et al., 2011). Since the tools used to assess the burdens were different (Beck Depression Inventory-II, symptom burden, and Caregiver Reaction Assessment), the results could not be directly compared with the current study.

The risk factors associated with caregiver burden in this study could be classified as caregiver factors and patient factors. For caregiver factors, caregivers with migraines demonstrated the strongest risk factors among other factors. Comparing to other reports, depression and anxiety showed as an associated factor (Higginson and Gao, 2008; Northouse et al., 2012). The interpretation; however; should be careful because there were few caregivers with migraines and depression/anxiety in this study. The relationship to the patient as siblings also demonstrated a significant risks among other factors. The possible explanation was the influence of socio-cultural background. As family is a central value for Asian societies, take caring spouse and parents is a willing burden and inevitable duty. Thus, spouse, children and children-in-law reported insignificant burden comparing to the siblings whom are more apart in term of the relationship to the family (Limpanichkul and Magilvy 2004; Casado and Sacco 2011). Additionally, being married, divorced/separated/widow showed fewer burdens than caregiver with single marital status. Most people may possibly assume that persons who are never married have more times to informally take care the patients than the others. Therefore, focusing on the marital status of the caregiver is needed. For patient factors, different types of cancer showed significant burden comparing to breast cancer; sarcoma, stomach cancer and lung cancer. The patients with these cancers may have a possibility to experience greater time of uncomfortable feeling such as respiratory distress and gastric obstruction which could affect on caregiver burdens. This study could not demonstrated the relationship among caregiver burden and the types, numbers of daily tasks needed to help the patients, and poor family support as some earlier reports (Faison et al., 1999; Garlo et al., 2010; Limpawattana et al., 2013).

The findings of this study may help healthcare workers understand caregivers of older adults with advanced cancer better in diverse views. Assessment of caregiver burdens may not be implied directly since the cultural background and the potential guilt feelings may underestimate the real impact of the problem. Physicians should be concerned more for the caregivers who are never married and those as siblings and their physical symptoms particularly the presence of migraines, since there was a strong relationship between burden and those caregivers' characteristics, not only for the patient's characteristics.

There are some limitations in the current study. First, this was a cross-sectional study which could not explore the variations of burden during the course of the disease or at the end-of-life period. Second, in general, the patients with very advanced disease, end-of-life, and poor performance status who could not tolerate aggressive radiation or chemotherapy were therefore treated as outpatients, which may have contributed to an underestimation of the burden. Finally, the diversity of patients such as types of tumor and symptoms may have affected the results.

In conclusion, the burdens among Thai caregivers of older adults with advanced cancer patients were small. The findings, however, could be underestimated due to the socio-cultural background. Identifying caregivers who are at risks; caregivers with single marital status, relationship to the patients as siblings, underlying migraines, cancer types of the patients, and early exploring the effective ways to alleviate their symptom burden should be a main concern in the treatment plan of cancer patients.

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