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Prevalence of and Risk Factors for Caregiver Burden in Palliative Care in Thailand

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ABSTRACT

OBJECTIVE Caregivers are highly important in both conventional and palliative care. Their responsibilities, which include biological, psychological, and social aspects, can lead to stress and other complications. The objectives of this study were to determine (i) the prevalence of caregiver burden in palliative care and its severity, and (ii) risk factors associated with caregiver burden in palliative care settings.

METHODS This cross-sectional study was conducted with palliative care patients and main caregivers in palliative care in both in- and out-patient departments of a hospital in Thailand. Baseline characteristics of caregivers and patients, including patients' quality of life, caregivers' self-efficacy, and caregiver burden were collected using Zarit Burden Interview (ZBI) scores. Linear regression was used to determine the association between caregiver burden and potential risk factors.

RESULTS One hundred and two caregivers and their patients were included in the analysis. Caregivers' mean age was 48.2±13.1 years. Most were female (77.5%) and married (65.7%). The mean age of the 102 patients of those caregivers was 64.9±13.8 years. The majority were female (57.8%) and most lived together with their caregiver (72.6%). The mean ZBI score of the caregivers was 13.4±13.9 of whom one-fourth had experienced caregiver's burden (23.53%), with most having mild severity (17.7%). Factors negatively associated with ZBI scores were the patient's quality of life (coefficient -0.46, 95% CI -0.89 to -0.04, *p* = 0.027) and the caregiver's self-efficacy (coefficient -0.17, 95% CI -0.31 to -0.02, *p* = 0.033).

CONCLUSIONS The prevalence of caregiver burden in Thai palliative caregivers is relatively small. Greater caregiver self-efficacy and improved patient quality of life may help reduce caregiver burden. Assessment of caregiver burden level should be included as an integral aspect of the patient-care process.

KEYWORDS caregiver, burden, burnout, palliative care, hospice care

INTRODUCTION

According to the World Health Organization (WHO), palliative care is "the prevention and relief of suffering of patients and their families facing problems associated with life-threatening illness. These problems include the physical, psychological, social, and spiritual suffering of patients, and psychological, social, and spiritual suffering of family members (1)." Palliative care can be integrated with conventional care, including clinical assessment and management, to help relieve suffering through communication between the patient, the patient's family, and the health care team. Palliative care can provide a better quality of life, including increased patient and caregiver satisfaction and can help in the development of a plan of management. It can also lead to improved medical resources distribution (2, 3). Thailand has been classified by the World Health Organization as an aging society, with the proportion of older adults increasing annually (4), resulting in an increase in age-related disability which may consequently lead to increased demand for palliative care (5).

Caregivers are irreplaceable and arguably one of the most important factors in both conventional and palliative care. Their responsibilities almost always include biological, psychological, and social factors related to the patient. Commonly the role of the caregiver includes decision making, assistance with daily activity, caring for other family members, and economic management. The presence of a caregiver can also result in emotional dependency of the patient on the caregiver (6, 7). Research in older populations has found that approximately one-fourth of caregivers for older adults had poor mental health scores. Significant factors related to caregivers' poor mental health include the functional dependence of the patient on the caregiver, the duration of care, and the caregiver's financial status (8, 9). In Thailand, placing older patients in a nursing home is sometimes considered as "abandonment" (10). All these factors sometimes pressure children to take care of the older adults themselves in addition to being responsible for other roles, which can lead to caregiver burden.

Caregiver burden is defined as a feeling of burden "including the caregiver's health, psychological well-being, finances, and social life as well as the relationship between the caregiver and the impaired person" (11). The level of caregiver burden is a subjective appraisal of objective experience from the caregiver's point of view. The caregiver burden affects both the caregiver and the care receiver (12). For caregivers, caregiver burden is significantly associated with caregiver burnout and strain, terms which are sometimes used interchangeably (13-15). Caregiving strain is significantly associated with a higher estimated stroke risk and mortality rate. Highly strained caregivers were almost two times more likely to die than caregivers reporting some strain over an average period of 5.29 years (16, 17). The caregiver burden is also associated with negative psychological health such as depression and anxiety (18-20). In terms of the social aspect, caregiver burden has negative consequences on physical activity and work productivity (21). Overall, caregiver burden is associated with lower quality of life (22). It is important to note that care-receivers also experience the impact of caregiver burden, including mistreatment and abusive behavior (23-25). Exploring potential risk factors for caregiver burden could potentially be beneficial for planning strategies for the reduction and prevention of caregiver burden.

Caregiver burden affects multiple dimensions of the individual, including physical, psychological, social, and spiritual aspects. Sleep disturbance is the most prominent physical effect. Other symptoms include fatigue, weakness, weight loss, and back pain among others. Depression is also common in the psychological domain. Socially, the caregiver spends time on caregiving, which leads to limited opportunities for interaction with others. Reduced work hours and high financial demands may result in financial problems. Caregiver burden can also have an impact on the spiritual well-being of the caregiver. These effects are often present in both palliative and non-palliative caregivers (26).

Although the caregiver burden in palliative care has recently been studied in many countries, the latest study in Thailand was done almost ten years ago. That study included informal caregivers of older adults with advanced cancer (27). The prevalence of caregiver burden in the present study was 37% of whom 31% had a mild burden. Internationally the prevalence of caregiver burden in palliative care has been higher (47.4% to 96.2%) (28-31). Risk factors found in previous studies include, e.g., age, gender, education, caregiver income, relation with the patient, hours of care per day, and the caregiver's self-efficacy and satisfaction as well as the patient's functional status and their quality of life (27, 28, 32-41). Changes in resources, management, and policies, including cultural changes, may result in different outcomes. The objective of this study is to conduct an exploratory investigation to determine (i) the prevalence and severity of caregiver burden in palliative care and (ii) risk factors associated with caregiver burden in the case of palliative care patients.

METHODS

Study design and setting

This cross-sectional study was conducted at Maharaj Nakorn Chiang Mai Hospital, a tertiary care hospital which has one of the largest palliative care units in northern Thailand providing both in-patient and out-patient care. The palliative care unit accepts both cancer and non-cancer patients through consultations with other medical specialties.

Study population

Participants included dyads of caregivers and their care receivers. For the caregivers, the inclusion criteria were (i) age ≥ 18 years old, (ii) being a main caregiver and (iii) being able to communicate in Thai. The exclusion criteria were (i) diagnosed with schizophrenia, bipolar disorder, psychosis, or dementia, (ii) appearing to be in emotional distress or situation, e.g., immediately after receipt of bad news, after an acute life-threatening event, or the end-of-life process, and (iii) not currently working as a caregiver. For the patients, the inclusion criteria were (i) age ≥ 18 years and (ii) undergoing palliative care during the information-gathering period.

Sampling method

Non-probability, convenience, and consecutive sampling methods were used. The caregivers were approached individually by research assistants during the patient's admission to the hospital or outpatient clinic. The details of the study were explained to the eligible participants. If they agreed to participate, consent regarding the study protocol was obtained via the digital (RedCap program) or as a written consent form.

Study tools

Data were obtained on caregivers' characteristics (e.g.,age, gender, income status), care-receivers' characteristics (e.g., age, gender, insurance status), palliative performance scale (PPS), patient's functional status and quality of life (EQ-5D-5L, Thai version (EuroQol Group)), caregivers' perceived self-efficacy and Zarit Burden Interview (ZBI) results. The PPS tool requires professional evaluation which was provided by health care providers. Other tools and questionnaires were administered by the study researchers.

Palliative Performance Scale (PPS)

The PPS is an assessment form for measuring health decline in palliative patients and their prognosis. It consists of five dimensions: ambulation, activity level and evidence of disease, self-care, intake, and level of consciousness. The scale ranges from 0 percent (deceased) to 100 percent (maximum health and function) with 10 percent increments. This study used the Thai version of PPS (Chiang Mai University, Thailand) (42). The Cohen's kappa reliability test score from a study of Thai nurses and physicians was 0.55, indicating moderate agreement (43). This tool is available for public use.

The 5-level EQ-5D version (EQ-5D-5L)

The EQ-5D-5L questionnaire, developed by the EuroQol Group in 2009, includes five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension has five levels ranging from no problems to extreme problems (score 1 to 5). The visual analog part uses a qualitative scoring system ranging from 0 to 100. Respondents are asked to 'mark an X on the scale to indicate how your health is TODAY'. From a study of Thai patients, the intraclass correlation coefficient of the EQ-5D-5L was 0.89 and the weighted kappa coefficients ranged from 0.44 to 0.60 in the five dimensions of the EQ-5D-5L (44). The present study used the visual analog part of this questionnaire (45). Written permission was obtained from the EQ-5D-5L group.

The Perceived Self-Efficacy Score (PSE)

The PSE assessment consists of ten items, for example, 'I can always resolve difficult problems' and 'I can face problems calmly'. Using a 4-point scale from 1 (very true) to 4 (false), the maximum total score is 40. Higher scores indicate perceived better self-efficacy. The Thai version of the tool was developed by Sukmak et al., and its Cronbach alpha coefficient is 0.84 (46).

Zarit Burden Interview (ZBI), Thai version

The ZBI consists of 22 items, using a 5-point scale ranging from 0 (never) to 4 (always). ZBI scores (range 0 to 88) are classified as no burden (0-20), mild burden (21-40), moderate burden (41-60), and severe burden (61-88). These can be categorized dichotomously as no burden (0-20) and burden (21-88). The Thai version of the 22-Zarit burden scale was developed by Toonsiri et al. and has been used in a study of a in chronic disease population, showing a Cronbach's alpha of 0.92 (47).

Data collection and procedures

Caregivers and patients (if conscious) were approached by a research assistant to obtain their consent to participate in the study. Caregivers were then interviewed separately from their patient to minimize response bias. Data collection was conducted from August 2022 through September 2023. Data was collected by the researcher and research assistants (nurses). Research assistants asked participants for consent and also assisted in data collection. Prior to the data collection process, a meeting with the assistants was held to clarify the objectives of the study, to familiarize them with the study tools, and to review the questionnaire. The first few interviews were supervised by the researcher after which the research assistants conducted interviews alone to minimize variability.

Questionnaire administration

Participants were interviewed by the researcher or an assistant and were advised to ask if they had any questions and to stop if they began feeling uncomfortable. Participants took approximately 15 minutes to complete the questionnaire with help from a research assistant, e.g., to clarify the meaning of words.

Sample size calculation

Sample size was calculated using Statulator (https://statulator.com/SampleSize/ss1P.html). The infinite population proportion with 95% confidence interval and 10% precision was used. Based on the 2012 study Burden among Caregivers of Older Adults with Advanced Cancer and Risk Factors by Chindaprasirt et al. (27) which was conducted with older adults with advanced cancer in Srinagarind Medical School Hospital, the expected incidence of caregiver burden was 37%, suggesting a sample size of 90 participants. Available data was collected from 100 caregivers-patient pairs.

Statistical analysis

Data analysis was done using Stata 16 (StataCorp, College Station, TX, USA). Categorical variables, e.g., gender, highest educational level, and marital status, are presented as numbers and percentages, and continuous variables are presented as means and standard deviations (SD). Inferential statistics utilizing the Chi-square and t-test were used to evaluate correlation. Linear regression was used to analyze the association between caregiver burden score (ZBI) and other variables using an exploratory approach. P values < 0.05 were considered statistically significant. Correlation coefficients and 95% confidence intervals (CI) are reported to indicate the strength of association between variables.

RESULTS

One hundred and two patient-caregiver pairs were included in this study.

Caregivers' characteristics

Categorizing caregivers into those with caregiver burden and those without, the caregivers' mean age was 49.3±2.6 and 47.8±1.5 years, respectively. More than one-third were female in both groups (79.2% in the group with caregiver burden and 76.9% in the group without). The mean value of perceived self-efficacy was 29.9±1.7 in the group with caregiver burden and 33.4±0.7 in the group without caregiver burden ($p = 0.024$). Caregivers' career change after caring, confidence in their caregiving ability, and perceived self-efficacy were statistically significantly different between the groups, while there was no difference in other variables, e.g., age, gender, education level, marital status, income, etc. Details of caregivers' characteristics are presented in Table 1.

Patient characteristics

The mean age of patients of caregivers with caregiver burden and those without was 67.7±2.3 and 64.1±1.6 years, respectively. More than half the patients were female (75.0% in the burdened

Table 1. Caregiver characteristics by caregiver burden status

Demographic characteristics	Frequency n (%)		*p*-value
	Burden (n=24)	No burden (n=78)	
Age (years) (Mean±SD)	49.3±2.6	47.8±1.5	0.648
Gender			0.818
Male	5 (20.8)	18 (23.1)	
Female	19 (79.2)	60 (76.9)	
Highest education level			0.261
None	0 (0.0)	1 (1.3)	
Primary school	2 (8.3)	15 (19.2)	
Middle school	4 (16.7)	4 (5.1)	
High school	2 (8.3)	6 (7.7)	
(High) Vocational Certificate	5 (20.8)	7 (9.0)	
Bachelor's degree	9 (37.5)	33 (42.3)	
Higher than Bachelor's degree	2 (8.3)	12 (15.38)	
Marital status			0.606
Married	18 (75.0)	49 (62.8)	
Unmarried	5 (20.8)	23 (29.5)	
Divorced	1 (4.2)	3 (3.9)	
Widowed	0 (0.0)	3 (3.9)	
Household income (THB per month)			0.576
< 5000	4 (16.7)	8 (10.3)	
5,000-10,000	3 (12.5)	7 (9.0)	
> 10,000	17 (70.8)	63 (80.8)	
Career change after caring			0.030
Yes	9 (37.5)	13 (16.7)	
No	15 (62.5)	65 (83.3)	
Underlying diseases			0.640
Yes	10 (41.7)	28 (36.4)	
No	14 (58.3)	49 (63.6)	
Other caregivers			0.885
Yes	20 (83.3)	64 (82.1)	
No	4 (16.7)	14 (18.0)	
Living with the patient			0.758
Yes	18 (75.0)	56 (71.8)	
No	6 (25.0)	22 (28.2)	
Relationship with patient			0.609
Spouse	6 (25.0)	16 (20.5)	
Parent	0 (0.0)	5 (6.4)	
Child	14 (58.3)	37 (47.4)	
Grandchild	1 (4.2)	9 (11.5)	
Sibling	2 (8.3)	5 (6.4)	
Others	1 (4.17)	6 (7.69)	
(e.g., In-laws, Neighbor)			0.249
Duration of care per day	7 (29.2)	33 (42.3)	
<14 hours	17 (70.8)	45 (57.7)	
≥14 hours			
Health care service satisfaction level			0.654
Lowest	0 (0.0)	0 (0.0)	
Low	0 (0.0)	0 (0.0)	
Middle	0 (0.0)	1 (1.3)	
High	6 (25.0)	14 (18.0)	
Highest	18 (75.0)	63 (80.8)	
Confidence in caring			0.006
Lowest	2 (8.3)	1 (1.3)	
Low	0 (0.0)	1 (1.3)	
Middle	7 (29.2)	5 (6.4)	
High	10 (41.7)	35 (44.9)	
Highest	5 (20.8)	36 (46.2)	
Perceived self-efficacy (Mean±SD)	29.9±1.7	33.4±0.7	0.024

group and 52.6% in the non-burdened group). There was a statistically significant difference in quality of life on the visual analog scale between groups: 33.2±3.5 in the burdened caregiver group and 52.2±2.4 in the non-burdened caregiver group (p = <0.001). Other characteristics, gender, insurance, and PPS, revealed no statistically significant difference. Table 2 shows patient characteristics.

Caregiver burden among palliative caregivers

The ZBI scores were categorized into non-burdened (0-20) and burdened caregivers (21-88), with three levels of severity: mild (21-40), moderate (41-60), and severe (61-88). About three-fourths showed no burden (76.47%). Caregivers (23.53%) were further categorized as having mild burden, moderate burden, and severe burden which were 17.7%, 4.9%, and 1.0%, respectively. The mean ZBI score was 13.4±13.9. There was a statistically significant inverse association between ZBI score and the caregivers' perceived self-efficacy (coefficient -0.46, 95%, CI -0.89 to -0.04) as well as patients' quality of life by analog scale (coefficient -0.17, 95% CI -0.31 to -0.02) ($p < 0.05$). Both variables appeared to be protective factors against caregiver burden. Other caregivers' sociodemographic and patients' characteristics did not show a statistically significant association with ZBI scores. The data are shown in Table 3.

DISCUSSION

Palliative caregivers were mainly middle-aged females with an education level above bachelor's degree, most were married and lived together with the patient. Half the caregivers were patients' children age under xx and approximately one-fourth were the spouse of the caregiver patients. Care-receivers were mostly elderly females who were eligible for Thailand's Universal Health-care Coverage and who had a PPS score of 30-40. Approximately one-fourth of the caregivers had caregiver burden. Caregiver burden was statistically significantly inversely associated with the caregivers' perceived self-efficacy and the patients' quality of life.

The caregivers' characteristics are similar to previous studies in Asian countries (27). Unsurprisingly, most of the caregivers were female, a common prevalence among caregivers in many countries (48-50). Culturally, females often have a gender ideal of a "nurturing" role that puts them at a disadvantage in caregiving arrangements, while males have a more "masculine" image and are more flexible in such arrangements (51).

Table 2. Caregiver characteristics by caregiver burden status

Demographic characteristics	**Frequency n (%)**		***p*-value**
	Burden (n=24)	**No burden (n=78)**	
Age (years) (Mean±SD)	67.7±2.3	64.1±1.6	0.261
Gender			0.052
Male	6 (25.0)	37 (47.4)	
Female	18 (75.0)	41 (52.6)	
Insurance			0.553
Government officer	12 (50.0)	32 (41.0)	
Social service	3 (12.5)	7 (9.0)	
Universal coverage	9 (37.5)	39 (50.0)	
Palliative Performance Scale			0.290
10	2 (8.3)	2 (2.6)	
20	4 (16.7)	6 (7.7)	
30	8 (33.3)	19 (24.4)	
40	6 (25.0)	19 (24.4)	
50	0 (0.0)	8 (10.3)	
60	2 (8.3)	13 (16.7)	
70	2 (8.3)	6 (7.7)	
80	0 (0.0)	5 (6.4)	
Quality of life (EQ-5D-5L) – Visual analog scale (Mean ± SD)	33.2±3.5	52.2±2.4	<0.001

Table 3. Association between caregiver burden and caregiver and patient characteristics

Caregiver burden	Coefficient	*p*-value	95% confidence	Interval
Caregiver characteristics				
Age	-0.07	0.592	-0.31	0.17
Male	-2.61	0.425	-9.10	3.87
Education level	0.31	0.756	-1.67	2.29
Marital status	-3.33	0.097	-7.27	0.62
Household income	-3.83	0.177	-9.43	1.77
Career change	5.04	0.162	-2.06	12.15
Underlying disease	3.47	0.270	-2.74	9.78
Other caregivers	-0.42	0.909	-7.74	6.90
Living with the patient	-0.30	0.926	-6.77	6.17
Relation	-0.45	0.628	2.27	1.37
Duration of care	3.68	0.288	-3.16	10.51
Healthcare service satisfaction level	-4.08	0.206	-10.44	2.28
Confidence in caring	-0.80	0.640	-4.17	2.58
Perceived self-efficacy	-0.46	0.033	-0.89	-0.04
Patient characteristics				
Age	-0.02	0.856	-0.23	0.19
Gender	-1.39	0.631	-7.12	4.34
Insurance	0.46	0.770	-2.64	3.55
Palliative Performance Scale	-1.04	0.289	-2.98	0.90
Quality of life-VA	-0.17	0.027	-0.31	-0.02

Whether male or female, caregivers were almost always a member of the family of the patient.

Approximately one-fourth of the caregivers in this study were classified as having caregiver burden, and in more than half the cases, the burden was of mild severity. This result is consistent with another study in Thailand conducted by Chindaprasirt et al., in which the prevalence of caregiver burden among informal caregivers of elderly patients with advanced cancer was also around one-third (37%), with more than half having a mild burden (31%) (27). Studies in Thailand of caregiver burden in cases of patients with more severe conditions, however, showed a higher prevalence of caregiver burden, e.g., around half the caregivers of stroke patients and eighty percent of the caregivers of elderly individuals with physical disabilities had caregiver burden (33, 52-53). Studies in Malaysia, Spain, Brazil and Saudi Arabia have reported a higher prevalence of palliative caregiver burden at 47.4%, 63.7%, 88% and 96.2%, respectively (28-31).

The ZBI score's mean value in this study was 13.4±13.9. This is on the low side compared to ZBI scores in many other studies, but is consistent with a previous study in Thailand where the mean ZBI score was 19.15 + 12.85 among palliative caregivers, with one-third having experienced caregiver burden (27). Both the ZBI scores and the incidence of caregiver burden are also consistent with many studies of palliative caregivers, e.g., a study in Malaysia showed a mean ZBI score of 23.33±13.7 with half of the caregivers found to have caregiver burden (28). A study from Turkey, however, had a mean ZBI score of 52.12±16.1 (54).

Variables included in the present study were selected based on risk factors included in previous studies conducted in both palliative and non-palliative care settings. For example, a study in Malaysia conducted in palliative care units showed that being highly educated and spending more than 14 hours per day on caregiving was related to a higher risk of caregiver burden (28). On the other hand, in another study less educated caregivers were found to be associated with a lower incidence of caregiver burden (34). The age and gender of both the caregiver and care-receiver have been identified as risk factors, as has a spousal relationship with the care-receiver and the financial status of the caregiver (34-36). The caregiver's self-efficacy, confidence and satisfaction level as well as the patient's quality of life were also found to be inversely associated with caregiver burden (32, 37-39, 55). In Thailand, the caregiver's age, gender, marital status, educational level, and the care-receiver's functional status have been reported to be associated with caregiver burden (27, 33, 40, 41). However, none of these factors were found to be associated with caregiver burden in the present study.

In this study, factors found to be protective against caregiver burden include caregiver's perceived self-efficacy and patient's quality of life. Contrarywise, a study in Turkey of caregivers of cancer patients reported that self-efficacy was found to have a negative association with the caregiver burden score (56). Studies using a different tool (FACIT-Pal) have reported that higher patient quality of life is associated with a higher caregiver burden (57). However, in this study, the correlation was minimal, suggesting that this relationship should be carefully considered before taking action.

A study of caregivers for cancer patients showed that an individualized caregiver training intervention focused on infection prevention, pain control, nutrition, and specific care issues significantly increased caregiver self-efficacy (58). A 4-session online psychoeducation program, "Learning Skills Together," showed an improvement in mean caregiver self-efficacy in caregivers of dementia patients (59). Establishing the existence of a causal relationship between caregiver self-efficacy, the patient's quality of life, and caregiver burden might not be possible due to the cross-sectional nature of the present study. Greater caregiver self-efficacy, defined as "a person's perception of their ability to perform tasks related to caregiving competently, capably, and with control" (60), and better patient quality of life might mitigate caregiver burden. Further prospective studies to follow up patients might be beneficial.

This study has some limitations. First, being a cross-sectional study limits interpretation of the causality of relationships. Second, the relatively small sample size might lead to an increased error rate and less precise data interpretation. Third, due to time limitations for interviews and the emotional state of some of the caregivers, the selection of participants focused primarily on the more stable patient-caregiver pairs among the Thai participants' results may be different in other palliative situations, e.g., end-of-life care. Finally, using data from a single hospital setting may reduce the study's generalizability. A qualitative study exploring caregivers' perspectives might be beneficial in increasing understanding of underlying problems related to caregiver burden.

CONCLUSIONS

Although the prevalence of caregiver burden in this study could be considered relatively small, identification of factors associated with caregiver burden should be considered a crucial part of holistic care and palliative care. Increased caregiver self-efficacy and patient quality of life could potentially reduce caregiver burden. Caregiver burden assessment and management should be included in the patient care process. Appropriate and timely intervention may result in better care and better health for both patients and caregivers.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to report.

ADDITIONAL INFORMATION

Author contribution

C.R.: conceptualization, methodology, data collection, analysis, writing–review and editing; N.B.: methodology, analysis, writing–review and editing; K.P.: conceptualization, analysis, writing–review and editing; N.D.: data collection, analysis, writing–review and editing; L.C.: supervision, writing–review and editing; T.R.: supervision, writing – review and editing; A.C.: conceptualization, methodology, analysis, writing – review and editing.

Data availability statement

"The data that support the findings of this study are available from the corresponding author upon reasonable request."

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