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Self-efficacy, social support, and quality of life among primary family-member caregivers of patients with cancer in Thailand

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Abstract

Purpose – In Thailand, most patients with cancer primarily receive in-home care from their family members. However, information regarding the quality of life (QoL) of the primary family-member caregivers is scarce. The purpose of this paper is to assess primary family-member caregivers' QoL and its association with selfefficacy and social support using a Thai version of the Caregiver Quality of Life Index-Cancer (CQOLC). **Design/methodology/approach** – This hospital-based cross-sectional study was performed at a teaching hospital in Bangkok. Questionnaires were administered to 178 primary family-member caregivers of patients with cancer between June 2015 and July 2016, and their QoL was measured using a Thai translation of the CQOLC made by the research team. Hierarchical multiple regression analyses were performed using SPSS software (version 18). Findings - Approximately 79.8 percent of primary family-member caregivers were female, 86.0 percent were 18-51 years old. In total, 52.8 percent reported having a good QoL, 60.1 percent reported a moderate level of perceived self-efficacy, and 56.7 percent reported a high level of perceived social support for providing care. Primary family-member caregivers, who provided care for male cancer patients and were co-responsible for covering the patient's cost of care, had a lower level of perceived self-efficacy and perceived social support. They also reported having poorer QoL. The patients' characteristics were more strongly associated with the family-member caregivers' QoL, than the family-member caregivers' characteristics, perceived self-efficacy, and perceived social support.

Originality/value – Approximately 50 percent of primary family-member caregivers reported having a good QoL. Healthcare providers should incorporate the self-efficacy concept to help improve primary family caregiver's self-efficacy to provide care to patients with cancer, especially for individuals who are caring for male patients, and provide counseling for primary family-member caregivers regarding ways to obtain the necessary social and financial support to improve their QoL.

Keywords Self-efficacy, Social support, Quality of life, Primary family-member caregiver, Cancer patient **Paper type** Research paper

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Introduction

Cancer is a leading cause of morbidity and mortality. It accounted for 8,800,000 deaths worldwide in 2015[1]. The International Agency for Research on Cancer has also reported that the incidence of cancer-related death will continue to increase[2]. In 2012, 14.1 million new cancer cases were reported worldwide and 32,600,000 people within five years of their diagnosis were living with cancer. In Thailand, cancer is a national public health issue because of behavioral and lifestyle factors including environmental pollution[3]. Cancer-related morbidity and mortality rates have steadily increased in Thailand from a morbidity rate of 134.2/100,000 people and a mortality rate of 87.6/100,000 people in 2008 to 154.5/100,000 and 98.5/100,000 in 2012, respectively[4]. The Hospital-based Cancer Registry Annual Report 2013[5] by the National Cancer Institute of Thailand revealed that there were 3,925 new cancer cases in 2012. Among men, the leading cancers are trachea, bronchus, and lung cancer (18.4 percent), followed by liver and intrahepatic bile ducts cancer (15.6 percent). The leading cancers among women are breast cancer (39.3 percent) and cervical cancer (15.1 percent).

Cancer affects the quality of life (QoL) of both patients and their family members[6, 7]. Furthermore, the increases in the incidence of cancer and the five-year survival rate, as well as healthcare system changes, have shifted cancer care from the inpatient setting to the ambulatory and home settings [4, 8]. However, most patients with cancer experience complications and need continuous specialized care[9]. Moreover, patients and caregivers are expected to manage new cancer treatments, their side effects, and concerns regarding efficacy[7]. Most caregivers must also manage feelings of being unprepared to provide inhome care for patients with cancer[10]. Unfortunately, caregivers receive relatively little support and advice from healthcare providers[11], and some caregivers resign from their job or hire additional help to provide patient care, both of which are associated with a heavy economic burden (independent of treatment costs)[12]. Most patients with cancer receive in-home care from family-member caregivers. However, the patient's chronic condition can lead to caregiver burnout, which affects both the caregiver's and the patient's care. Thus, caregiver health is an important issue that merits attention from healthcare providers[13], as a lack of support for caregivers can affect their health and lead to illness. These caregivers can be considered "hidden-patients" who may require attention similar to the patient with cancer[14]. A previous study reported using the Caregiver Quality of Life Index-Cancer (CQOLC) scale to assess caregivers' QoL found that caregivers in America and Europe had higher QoL scores than their counterparts in Asia[15]. In Thailand, health professionals are concerned that providing care for patients with cancer poses a threat to the overall health of caregivers.

In western countries, studies have evaluated the QoL of caregivers for patients with cancer and have developed interventions to improve or maintain their QoL[11]. For example, caregiver self-efficacy and social support have been found to be key determinants of caregiver QoL, in addition to the caregiver's and the patient's characteristics[16-18]. Perceived self-efficacy is a psychological model that aims to understand how a person's optimistic self-belief allows them to achieve favorable outcomes[19, 20]. In the present study, we defined self-efficacy as caregivers' perceived ability to provide care to patients with cancer. Social support is another variable that affects the QoL of caregivers for family members with chronic diseases[4], and is an essential moderator for caregivers with good indicators of well-being[21]. We defined social support as support that caregivers received from family members, friends, and significant others while providing care to patients with cancer. To the best of our knowledge, few studies have evaluated QoL among familymember caregivers in Thailand, and there is no specific tool for measuring QoL among Thai family-member caregivers[22]. Therefore, we adapted the CQOLC scale, a global tool for measuring QoL among cancer caregivers [15], to assess the primary family-member caregivers' QoL and its association with self-efficacy and social support to fit the

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Thai context. We selected caregivers of patients who were treated for cancer at a teaching hospital in Bangkok. It is hoped that the information gathered will help healthcare professionals provide better support and education to family-member caregivers.

Methods

Research design and sample

This hospital-based cross-sectional study was performed in nine inpatient units (two specialty medicine wards, two therapeutic radiology wards, and five private wards) and one outpatient unit (a chemotherapy and blood transfusion unit) at a teaching hospital in Bangkok. The study population was defined as family members who primarily provided care to patients with cancer who were hospitalized between June 2015 and July 2016. Family member can cover both blood relatives and those by marriage such as a daughter-inlaw. The required sample size was estimated using the single proportion formula with finite population correction[23] and a 95% confidence interval. Based on the unknown prevalence of poor QoL, a P of 50 percent was used to provide the maximum sample size[23, 24]. Precision was set at 7.3 percent and the sample size was estimated to be 175 caregivers, based on a population of 5,388 new cancer cases [5]. The inclusion criteria were: adults (≥ 18 vears old) who primarily provided care to patients with cancer for ≥ 3 months, caregivers whose family member had been hospitalized for cancer treatment (i.e. surgery, radiotherapy, and/or chemotherapy), caregivers who were able to communicate and provide information in Thai, and caregivers who provided written informed consent. Caregivers with underlying psychotic or mental disorders were excluded. The participants were recruited in the waiting areas of inpatient and outpatient departments of the teaching hospital, while they were accompanying their family member to receive treatments or with their family member in a private room in the inpatient units.

Research instrument

The questionnaire included five parts. Part 1 consisted of 11 close-ended questions regarding the patient's general characteristics (gender, age, marital status, education level, employment status, payment for medical services, cancer type, stage of disease, treatment, time after diagnosis and co-morbidities). Part 2 consisted of 11 close-ended questions regarding the primary family caregiver's general characteristics (gender, age, marital status, education level, employment status, relationship to patient, household monthly income, duration of caregiving, availability of an assistant caregiver, cost of care, and underlying diseases). Part 3 assessed the primary caregiver's QoL. This part was a 35-item questionnaire based on the CQOLC[25]. The questionnaire was translated into Thai by the research team and modified to fit the Thai context. Permission to translate the original version of the CQOLC into Thai was granted by Michael A. Weitzner (via e-mail on October 4, 2012). The primary family-member caregivers' QoL was assessed in four domains: psychological burden, disruption of daily living, positive adaption, and financial concerns, and was scored using a five-point scale: 0 (not at all), 1 (a little bit), 2 (somewhat), 3 (quite a bit), and 4 (very much). The total possible scores were 0-140, with higher scores representing better QoL. Responses were categorized as poor QoL (scores of 0-89) and good QoL (scores of 90-140). The CQOLC scale has a Cronbach's α coefficient of 0.87, and coefficients of 0.78 for burden, 0.73 for disruptiveness, 0.64 for positive adaptation, and 0.89 for financial concerns. Part 4 consisted of the generalized self-efficacy scale[26], translated into Thai by Sukmak et al.[16]. This scale included ten items that are scored using a four-point scale: 1 (not at all true), 2 (hardly true), 3 (moderately true), and 4 (completely true). The possible scores were 10-40, with higher scores representing greater perceived self-efficacy, and the responses were categorized as low perceived self-efficacy (10-19), moderate perceived self-efficacy (20-30), and high perceived self-efficacy (31-40). The self-efficacy scale has a Cronbach's α coefficient of 0.85. Part 5 addressed perceived social

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IHR support using the multidimensional scale of perceived social support from family members, 32.2 friends, and significant others[27]. This scale includes 12 items that are scored using a fivepoint scale: 1 (strongly disagree), 2 (mildly disagree), 3 (neutral), 4 (mildly agree), and 5 (strongly agree). The total possible scores were 12-60, with higher scores representing better perceived social support, and the responses were categorized as low perceived social support (12-27), moderate perceived social support (28-44), and high perceived social support (45-60). The perceived social support scale has a Cronbach's α coefficient of 0.94. 114

Data collection

Before collecting data, the questionnaire was pre-tested on 30 family-member caregivers at a general hospital. All participating primary caregivers were interviewed using the questionnaire by the principal investigator and two trained research assistants between June 2015 and July 2016.

Statistical analysis

The collected data were reported as a mean \pm standard deviation or number (percentage), and were analyzed using SPSS software (version 18). Differences were considered statistically significant at a *p*-value of < 0.05. Hierarchical multiple regression was used to evaluate associations of the caregivers' and patients' characteristics with the caregivers' perceived self-efficacy, perceived social support, and QoL after testing for multicollinearity among study variables. The four blocks of variables entered into the model were based on theoretical considerations and previous studies[7, 8, 22, 28-30]. Step 1 was entering the patients' general characteristics into the first block of variables. Step 2 was entering the caregivers' characteristics into the second block, Step 3 was entering the caregivers' perceived self-efficacy into the third block, and Step 4 was entering the caregivers' perceived social support into the fourth block. The analysis proceeded in stages, successively including multiple blocks of independent variables in the regression model. Blocks of variables entered at later stages were tested for their extra effects after controlling for the effects of earlier entered variables. The variables retained in the final regression model explained the variance in QoL.

Ethical considerations

The study's protocol was approved by the Siriraj Institutional Review Board, Faculty of Medicine Siriraj Hospital, Mahidol University (COA No. Si568/2014). All participants provided written informed consent, were interviewed in a private room, and were assured that their information would be kept strictly confidential.

Results

Among the 200 caregivers who were invited to participate, 178 primary family-member caregivers fulfilled the inclusion criteria and completed the questionnaire. Approximately 78.1 percent of the 178 patients were male. The mean patient age was 51.1 years (range: 15-86), 68.5 percent were living with their spouse, 60.7 percent had an education level of secondary school or higher, and 60.7 percent were working. Medical expenses were paid using the universal health care coverage scheme (UCS) or other health cards in 90.4 percent of the cases. The patients generally had solid tumor cancers (61.8 percent), early-stage disease (50.6 percent), one previous treatment (50.6 percent), and 3-24 months of treatment after their diagnosis (83.7 percent). Approximately 40.4 percent of patients had at least one comorbidity (Table I).

Approximately 79.8 percent of the 178 primary family-member caregivers were female, 86.0 percent were 18-51 years old (mean age: 43.6 years, range: 18-84 years), 37.6 percent

General characteristic	Number	%	Self-efficacy, social support,
<i>Gender</i> Male	139	78.1	and QoL
Age (years) 15-59 ≥60 Mean ± SD = 51.1°18.1, range = 15-86	108 70	60.2 39.3	115
Marital status Single/widowed/divorced/separated Living together/married	56 122	31.5 68.5	
<i>Education level</i> Primary school or lower Secondary school or higher	70 108	39.3 60.7	
Employment status Working	108	60.7	
Payment for medical service Universal coverage scheme/others health cards Private health insurance/self-paid	161 17	90.4 9.6	
<i>Cancer type</i> Hematological Solid tumor	68 110	38.2 61.8	
<i>Stage of disease</i> Early stage Late stage	90 88	50.6 49.4	
<i>Treatment</i> 1 treatment ≥2 treatments	90 88	50.6 49.4	
Time after diagnosis (months) 3-24 ≥ 25 Median: 8.0, mean \pm SD: 15.9 \pm 19.3, range: 3-120	149 29	83.7 16.3 40.4	Table I.
<i>Co-morbidities</i> Yes	72		General characteristics of the 178 patients with cancer

were the patient's spouse and 32.6 percent were living with their spouse. Approximately 56.2 percent had received a bachelor degree. The caregivers were generally working (73.0 percent), had a household monthly income of \leq 30,000 baht (\leq US\$858) (67.4 percent), had been providing care for 3-24 months (85.4 percent), had no assistant caregivers (56.7 percent), were co-responsible for the care costs (56.2 percent), and did not have underlying diseases (79.8 percent) (Table II).

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Table III shows the scores for each study scale. The mean score for the Thai version of the CQOLC scale was 89.6 ± 16.9 (range: 36-129). The mean perceived self-efficacy score was 29.5 ± 4.9 (range: 16-40). The mean perceived social support score was 44.5 ± 10.0 (range: 15-60). Among the three subscales for social support, the family subscale had the highest mean score (16.1). Table IV shows the total scores for the CQOLC, modified perceived

JHR 32,2	General characteristic	Number	%
02,2	<i>Gender</i> Female	142	79.8
116	Age (years) 18-59 ≥60 Mean±SD=43.6±13.9, range=18-84	153 25	86.0 14.0
	Marital status Single/widowed/divorced/separated Married and living together	120 58	67.4 32.6
	<i>Education level</i> Lower than bachelor degree Bachelor degree	78 100	43.8 56.2
	Employment status Working	130	73.0
	<i>Relationship to patient</i> Spouse Non-spouse	67 111	37.6 62.4
	Household monthly income $(baht)^a$ $\leq 30,000$ > 30,000 Median = 25,000, range = 2,000-200,000	120 58	67.4 32.6
Table II. General characteristics of the 178 primary family-member caregivers	Duration of caregiving (months) 3.24 ≥ 25 Median = 7.0, range = 3.84	152 26	85.4 14.6
	Assistant caregiver No	101	56.7
	<i>Cost of care (including medical cost)</i> No co-responsibility Co-responsibility shared with other family members	78 100	43.8 56.2
	Underlying disease(s) No Note: ^a 1 US dollar = 35 baht	142	79.8

	Scale	Total items	Mean	SD	Range
Table III. Mean scores, standard deviation and range of a Thai translation of the CQOLC, modified perceived self-efficacy and modified perceived social support among the 178 primary family- member caregivers	CQOLC Burden Disruptiveness Positive adaption Financial concerns Modified perceived self-efficacy	35 10 7 7 3 10 12	89.6 15.0 11.6 19.2 5.3 29.5 44.5	16.9 6.3 4.9 19.2 3.6 4.9	36-129 0-37 2-23 3-28 0-12 16-40 15-60
	Modified perceived social support Family Friends Significant other	$\begin{array}{c} 12\\ 4\\ 4\\ 4\\ 4\end{array}$	44.5 16.1 13.4 15.0	$ 10.0 \\ 3.6 \\ 4.1 \\ 3.6 $	4-20 4-20 4-20

Scale	Number	%	Self-efficacy, social support,
CQOLC (score)			and QoL
Good quality of life $(\geq 89.0)^a$	94	52.8	
Poor quality of life (< 89.0)	84	47.2	
Modified perceived self-efficacy			
High (31-40)	69	38.8	117
Moderate (20-30)	107	60.1	117
Low (10-19)	2	1.1	
Modified perceived social support			Table IV.
High (45-60)	101	56.7	Total CQOLC score,
Moderate (28-44)	64	36.0	modified perceived self-efficacy score, and
Low (12-27)	13	7.3	modified perceived
Note: "The cut-off point for good quality of life was defined as the median score		social support score	

self-efficacy, and modified perceived social support scales. Approximately 52.8 percent of the primary family-member caregivers had good QoL, 60.1 percent had moderate perceived self-efficacy, and 56.7 percent had a high level of perceived social support.

Factors associated with caregiver QoL

Hierarchical multiple regression analysis was performed using QoL as the dependent variable and the independent variables were from the four blocks, according to the theoretical considerations and previous studies[7, 8, 22, 28-30] (Table V). The results indicate that poor QoL, low perceived self-efficacy, and low perceived social support were associated with providing care for a male patient with cancer and co-responsibility for care costs. The final regression model explained 31.3 percent of the variance in the caregivers' QoL ($R^2 = 0.313$, p = 0.011). The R^2 change suggested that the patients' general characteristics provided the greatest contribution to caregiver QoL variance (12.5 percent), which was followed by the caregiver's perceived self-efficacy (8.6 percent). All four blocks of independent variables made significant contributions to caregiver QoL variance. The overall prediction model contained four factors that were significantly associated with caregiver QoL: patient gender (p = 0.004), cost of care (p < 0.018), perceived self-efficacy (p < 0.013), and perceived social support (p < 0.011).

Discussion

The study revealed that just over half the primary family-member caregivers (52.8 percent) had a good QoL. The high proportion of good QoL among primary caregivers in this study may be related to filial piety and "obligatory care" as motivations for caregiving in Thai society which is similar to other Asian countries[31, 32]. Generally, most Thai people believe that families must provide care for sick family members (e.g. patients with cancer), and that this support should be both shared and committed. Family-member caregivers are generally a spouse or parent[28], and the Thai belief is that families can provide the best possible care for sick family members, based on their close relationship, understanding, and affection. Although some caregivers provide support willingly, other caregivers may provide it out of a sense of obligation or social pressures from friends and neighbors[22, 28].

Approximately 79.8 percent of the primary family-member caregivers in the study did not have any underlying disease, which implies that they remained in good health while they provided care. Furthermore, their self-efficacy was a significant predictor of QoL, with greater perceived self-efficacy being associated with better QoL and relatively advanced education (56.2 percent had obtained a bachelor degree). Therefore, the caregivers likely had

JHR 32,2	Variable	Standardized coefficient (β)	R^2	R ² change	<i>F</i> change
-)	Variable	(ϕ)	Λ	change	change
	Block 1		0.125	0.125	1.964
118	Cancer patient characteristics Gender (female = 1, male = 0) Age (continuous data) Marital status (other = 1, living together/married = 0) Education level (\geq bachelor degree = 1, < bachelor degree = 0) Employment status (other = 1, working = 0) Payment for medical service (self-paid = 1, UCS ^a /others' health cards = 0) Cancer type (solid tumor = 1, hematological = 0) Stage of disease (late stage = 1, early stage = 0) Number of treatments (\geq 2 treatments = 1, 1	0.223^{**} 0.030 -0.098 0.028 0.123 -0.097 -0.129 -0.012	0.120	0.120	1.507
	treatment = 0)	0.118			
	Time after diagnosis (continuous data)	0.305			
	Co-morbidities (yes $= 1$, no $= 0$)	-0.052			
	Block 2		0.196	0.071	1.127
Table V.	Family-member caregiver characteristics Gender (female = 1, male = 0) Age (continuous data) Marital status (other = 1, living together/married = 0) Education level(\geq bachelor degree = 1, < bachelor degree = 0) Relationship to patient (spouse = 1, other = 0) Duration of caregiving (continuous data) Underlying disease (yes = 1, no = 0) Employment status (other = 1, working = 0) Cost of care (co-responsible = 1, other = 0)	$\begin{array}{c} 0.022 \\ -0.030 \\ 0.050 \\ -0.095 \\ 0.013 \\ -0.276 \\ 0.033 \\ 0.015 \\ -0.173^* \end{array}$			
Hierarchical multiple	Block 3		0.282	0.086	
regression analyses for predicting the	Perceived self-efficacy of family-member caregiver ^b	0.213*	0.010	0.020	
primary family-	Block 4 Perceived social support of family-member caregiver ^b	0.223*	0.312	0.030	
member caregivers' overall quality of life	Notes: ^a UCS, universal coverage scheme; ^b continuous data. *				

a better understanding of their roles and responsibilities, as well as the ability to obtain additional information to help both themselves and the patient manage their situation. Similarly, de Castro *et al.*[33], Cramm *et al.*[34], and Meecharoen *et al.*[22] reported that self-efficacy is positively associated with family-member caregivers' QoL.

Perceived social support also significantly predicted QoL, and caregivers with greater social support enjoyed a better QoL. In total, 56.7 percent of primary family-member caregivers reported high levels of perceived social support, which may be related to the strong relationships between family-member caregivers, patients with cancer, other family members, and friends[33, 34]. In this context, strong relationships may evoke feelings of love, sympathy, and reciprocity that can motivate other family members and friends to support the primary family caregiver. Social support can take a variety of forms, including emotional support, caregiving support, informational support, and material or financial support. These results confirm the findings of Choi *et al.*[35], Meecharoen *et al.*[22], Shieh *et al.*[36], Son *et al.*[37], and Teixeira and Pereira[38], who reported that positive relationships exist between perceived social support and family-member caregivers' QoL.

Patient gender was associated with caregiver QoL, and providing care to a male patient with cancer was generally associated with poor QoL. However, relatively few patients were

female (21.9 vs 78.1 percent) and a relatively high proportion of the caregivers were female (79.8 vs 20.1 percent). Furthermore, we did not consider the effects of patients and caregivers being of the same gender. Thus, it is difficult to conclude that female patients are associated with better caregiver QoL. Moreover, in Thai society, women are expected to act as caregivers and support the other family members' daily activities, as caregiving is considered a feminine activity[28]. Similarly, Lim and Zebrack[39] reported that female patients were positively associated with family-member caregivers' QoL. However, conflicting results were reported by Kim et al [40] and Padmaja et al [41] who found that male patients predicted better family caregiver QoL. We conclude that the gender of patients contributes to their family-member caregivers' QoL. Other studies have shown both male and female patients being positively and negatively associated with the family-member caregivers' QoL[40, 41]. This lack of clarity is due to the vast variety of possible cancer patient and family-member caregiver situations and contexts. Caring for a cancer patient, of either gender, affects the QoL of the family-member caregivers across several wellness dimensions, including physical, psychological, and social. Healthcare professionals should incorporate the role of gender into the discussion when providing counseling for primary family-member caregivers. It is important for caregivers to understand the physical and mental changes in a patient with a chronic disease, such as cancer, because being male or female can negatively impact the caregivers' QoL.

Cost of care was also associated with caregiver QoL, as 56.2 percent of caregivers reported being co-responsible for the cost of care. This is despite 90.4 percent of cancer treatment costs being covered by the UCS. This association likely reflects the non-medical expenses that are required to care for patients with cancer, such as travel and food costs. Furthermore, it may be stressful for caregivers to ask others for financial assistance, as they may believe that they are placing a burden on other family members. In Thailand, although the majority of medical costs are covered by the UCS or other health cards, the non-medical costs associated with providing care are not covered. The reports of Xie *et al*[30] and Wu *et al*.[42] from China showed that high medical costs are associated with poor QoL among family-member caregivers; this is likely to be true for the non-medical costs of providing care as well.

Limitations

This study had three major limitations. First, the results were obtained using self-administered questionnaires. Second, the cross-sectional study design precludes any conclusions regarding the causality of the associations that were observed. Third, the study was performed at a single center, which introduces the possibility of selection bias. Therefore, the findings can be generalized only in the study area.

Conclusion and recommendations

In conclusion, approximately one-half of primary family-member caregivers reported having a good QoL. The primary family-member caregivers who provided care for male cancer patients and were co-responsible for covering the patient's cost of care, had a lower level of perceived self-efficacy, and perceived social support reported having poorer QoL. As primary family-member caregivers play an important role in caring for patients with cancer, and have significant effects on their health and well-being, healthcare professionals should incorporate the self-efficacy concept to help enhance caregiver self-efficacy and QoL, especially for individuals who are caring for male patients with cancer. For example, healthcare providers could discuss the social support experience and needs of familymember caregivers, and provide counseling regarding ways to obtain the necessary social and financial support. Few studies have used specific tools to measure the QoL of family primary caregivers of Thai patients with cancer, and further studies are needed with larger samples to confirm the findings of this study.

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