

Quality of Life of Family Caregivers of Cancer Patients in a Developing Nation

Gin Gin Gan^{1*}, Kevin Wen Fei Tey¹, Sumaiyah Mat¹, Marniza Saad², Ping Chong Bee¹, Rozita Abd Malik², Gwo Fuang Ho², Chong Guan Ng³

Abstract

Background: Quality of life (QOL) of family caregivers of cancer patients is usually affected due to increase in caregiver burden. Their QOL has not garnered much attention by many including the health professionals and community. This study aims to explore the QOL of family caregivers of cancer patients in a multi-ethnic country in Asia and to investigate its associate factors. **Methods:** This is a cross-sectional study where family caregivers and patients who were diagnosed of cancers within 12 months were recruited. QOL of caregivers were measured using The Caregiver Quality of Life Index-Cancer (CQOLC). Psychological distress was measured using Hospital anxiety and depressive scale. Logistic regression analysis was performed to determine the related factors of QOL of caregivers. **Results:** A total of 458 patients/caregiver pairs were included. Symptoms of anxiety and depression reported by caregivers were 24.9% and 24.2% respectively. Caregivers of patients with solid tumors have better CQOLC score compared to those who cared for patients with hematological cancers (91.25 vs 86.75). Caregivers of non-Malay ethnicity, those caring for patients with advanced stage cancer and with hematological cancers had significantly poorer QOL. QOL of caregivers are also significantly affected when patients demonstrated anxiety symptoms. **Conclusion:** This study provides detailed evaluation of the QOL of caregivers of cancer patients in Malaysia. The significant psychological distress and low caregiver QOL indicate the urgent need for comprehensive supports for caregivers with cancer patients, especially those caring for patients with haematological cancers.

Keywords: Caregivers- anxiety- depression- quality of life- cancer

Asian Pac J Cancer Prev, 23 (11), 3905-3914

Introduction

Cancer is ranked as the second leading cause of death worldwide and the continuous rise in the incidence especially in the less developed countries is of cancer warrants further study (Fitzmaurice et al., 2019). In Malaysia, cancer is the fourth leading cause of death, contributed to 12.6% of all deaths in public hospitals and 26.7% in private hospitals (Registry, 2018). Although survival rates of cancer patients have improved with the advances of treatment, both patients and their family members continue to experience enormous burden in physical health and psychosocial wellbeing (Kimman et al., 2015, Ochoa et al., 2020). Caring for cancer patients had been shown to be more labour intensive compared to other chronic illnesses, and those who provide more intense support usually experienced worse outcome (Kim et al., 2008, Ochoa et al., 2020). In addition, majority of these family caregivers have no or little training in caring and are sometimes expected to assist in medication

administration, symptoms management as well as financial and emotional support (Given et al., 2001).

Quality of life (QOL) of patients and caregivers are generally difficult to maintain once a diagnosis of cancer is made (Kim et al., 2008, Vrettos et al., 2012). In recent years, attention had been given to the QOL of caregivers of cancer patients, which was previously neglected by many including the health professionals and community. It has been reported that as many as 60% of caregivers experienced some form of distress and worse mental and physical health (Dumont et al., 2006; Haun et al., 2014; Selamat et al., 2017). The decline of QOL of caregivers is mainly due to the emotional stress associated with caring loved one suffering from cancer, increasing financial burden associated with treatment, loss of income and the limitation of their social life (Kim et al., 2008; Geng et al., 2018; Turkoglu et al., 2012, Vashistha et al., 2019). Importantly, it had also been shown that QOL of caregivers has an impact on QOL of patients and vice versa (Shahi et al., 2014).

¹Department of Medicine, Faculty of Medicine, University of Malaya, Kuala Lumpur, Malaysia. ²Department of Oncology, Faculty of Medicine, University of Malaya, Kuala Lumpur, Malaysia. ³Department of Psychological Medicine, Faculty of Medicine, University of Malaya, Kuala Lumpur, Malaysia. *For Correspondence: gangg@ummc.edu.my

A recent study in Malaysia reported that caregivers to patients with malignant disease experienced significant caregiver burden when compared to those who cared for non-malignant disease (Ahmad et al., 2020). Similarly, QOL of caregivers to cancer patients in Singapore and other Asian countries were also reported to be worse when compared with the western counterparts (Lim et al., 2017). It was postulated that the different cultural practices and upbringing, where filial piety and “obligatory care” emphasized in an eastern culture, may have been the possible explanation (Lim et al., 2017). In Malaysia, where there is a diversity of population in terms of ethnicity as well as cultures and religions, there are only few studies which specifically looked at QOL of caregivers of cancer patients. Although Singapore has similar cultural background as Malaysia, the family size is generally smaller and socioeconomic status is higher when compared to Malaysian population. Hence, it is important to determine if QOL of caregivers of cancer patients in a middle income country such as Malaysia is indeed worse and to identify any other possible factors, such as household income, education level and psychological status, which may influence the QOL of caregivers. To further understand the possible psychosocial factors which may affect the QOL of caregivers will be instrumental in introducing appropriate training or education program. This is especially pertinent when it had been demonstrated that caregivers who received intervention had higher QOL rating (Northouse et al., 2010).

Materials and Methods

This is a cross sectional study which was conducted in a tertiary centre in Kuala Lumpur, Malaysia over a period of 2 years from November 2016 to October 2018. Patients who had been diagnosed of any form of cancers within 12 months of the study and being treated in the centre are identified at the ward and outpatient clinics. Main caregiver was defined as member of family who was the main person identified by patient as the carer, living with the patient and involved in the care for more than 3 months. The inclusion criteria for the caregivers were: 1) age 18 years and above and 2) main caregivers. Both patients and caregivers must not have any cognitive impairment which would limit their ability to complete the questionnaires. Domestic maid was excluded as the main caregiver. All patients and caregivers provided written informed consent. The study was approved with the local institution ethics committee, 2016717-4017.

Study Instrument

Caregivers QOL were measured using The Caregiver Quality of Life Index-Cancer (CQOLC). CQOLC is a widely used validated disease specific questionnaire to measure caregiver’s QOL (Weitzner et al., 1999). It consists of 35 items relate to mainly burden, disruptiveness, positive adaptation and financial concerns which are rated on a five-point Likert-type scale. The total score was obtained by adding up all the scores of each item and higher score translate into better QOL (Weitzner et al., 1999). The total score ranges from 0 to 88, with higher

scores indicating greater caregiver burden. The CQOLC demonstrated good internal consistency and the Mandarin version of CQOLC has been previously validated and demonstrated good internal consistency reliability of 0.87 (Tang et al., 2009). The Malay version had been validated and demonstrated a good reliability, with a Cronbach’s alpha of 0.90 (Lua et al., 2013).

Hospital anxiety and depressive scale (HADS), a self-screening questionnaire for psychopathological comorbidities was used to determine the psychological stress of both patients and caregivers (Zigmond et al., 1983). HADS had a total of 14 items which is divided into 2 subscales, anxiety subscale (7 items) and depression subscale (7 items). A score of ≥ 8 for each subscale indicates clinical distress. The questionnaire was validated and available in the two other languages used in Malaysia, i.e. Mandarin and Malay (Yong et al., 2016). The internal consistency for the Malay version was 0.87, for the anxiety subscale was 0.81 and for depression subscale was 0.73 whereas the scales on Chinese version, the Cronbach’s alpha (α) was 0.81, for the anxiety subscale was 0.67 and for the depression subscale was 0.70 (Yong et al., 2016).

These questionnaires were delivered to patients and caregivers according to their preferred language and returned on the same day. The questionnaires were all self-rated and took approximately 40 minutes to complete.

Socio-demographic of patients and caregivers were collected included age, gender, marital status, education level, household income and relationship to each other. Patients’ clinical characteristics of patients include performance status (ECOG), underlying diagnosis, stage of disease and type of treatment received.

Statistical Analysis

Descriptive statistics of the data are presented with n (%) and, for normalized variables are shown as “mean \pm SD. The psychological status based on the HADS scores was compared between the patients and their caregivers. The normality of the distribution of the outcome variables namely, the HADS and CQOLC were examined using the Kolmogorov-Smirnov test. The univariate association analysis was conducted using a non-parametric test – Chi-Square test for categorical data. The outcome variables were categorized into two categories. For both subscales of HADS, eight (8) was used as the cut off scores. For the CQOLC, the means score of 92 was used as the cut off. For each subscale of the CQOLC, the means was also used for the division into two categories. The means burden was 25, disruptive was 20, adaptation was 20 and finance concern was 8. All the statistically significant variables in the univariate analysis were included into the logistic regression analysis. $\alpha = 0.05$ was taken as the level of significance. Analysis was conducted using the Statistical Package for Social Sciences (IBM SPSS) version 20.

Results

Patients and caregivers’ characteristics

A total of 512 patients/caregiver pair were approached

Table 1. Clinical Characteristics and Psychological Status of Patients and Caregivers

	Patients	Caregiver
Age, years, Mean ±SD	55.76 ±14.88	46.98±14.77
Female gender, n (%)	268 (59)	248 (54.6)
Race, n (%)		
Malay	137 (30.2)	140 (30.8%)
Chinese	266 (58.6)	260 (57.3%)
Indian	45 (9.9)	47 (10.4%)
Others	6 (1.3)	7 (1.5%)
Education		
Primary School	96 (21.1%)	42 (9.3%)
Secondary School	197 (43.4%)	180 (39.6%)
College/University	154 (33.9%)	228 (50.2%)
None/Unknown	7 (1.5%)	4 (0.9%)
Household Income		
< RM5000	206 (45.4%)	221 (48.7%)
> RM5000	101 (22.2%)	139 (30.6%)
Unknown	147 (32.4%)	94 (20.7%)
Marital status		
Single	92 (20.3%)	115 (25.3%)
Married	362 (79.7%)	339 (74.7%)
Concomitant Illness		
Yes	NA	308 (67.8%)
Relationship with Patient		
Parent	NA	53 (11.7%)
Child	NA	132 (29.1%)
Spouse	NA	213 (46.9%)
Other	NA	56 (12.3%)
Only Caregiver, Yes	NA	146 (32.2%)
Main caregiver, Yes	NA	203 (65.9%)
ECOG		
Good (0-1)	355 (82.8%)	NA
Intermediate (2)	42 (9.8%)	NA
Poor (3-4)	32 (7.5%)	NA
Diagnosis		
Solid Tumor	336 (74.0)	
Breast	129 (38.4%)	NA
Lung	19 (5.7%)	NA
Gastrointestinal	80 (23.8%)	NA
Prostate	6 (1.8%)	NA
Nasopharyngeal	22 (6.5%)	NA
Gynaecologic	25 (7.4%)	NA
Pancreatic	13 (3.9%)	NA
Others	42 (12.5%)	NA
Haematological Malignancy	118 (26%)	NA
Acute Leukemia	29 (24.6%)	NA
Lymphoma	72 (61%)	NA
Myeloma	13 (11%)	NA
Others	4 (3.4%)	NA

Table 1. Continued

	Patients	Caregiver
Stage		
Early (I - II)	138 (30.4%)	NA
Advanced (III - IV)	279 (61.5%)	NA
Others*	18 (4%)	NA
On Treatment	436 (96%)	NA
Psychological status		
Anxiety		
TOTAL HAS score, Mean (SD)	5.99 (4.19)	6.80 (4.07)
HAS≥11	91 (20.0)	118 (26.0)
Depression		
TOTAL HDS score, Mean (SD)	5.78 (4.07)	5.48 (3.83)
HDS≥11	86 (18.9)	72 (15.9)

but only 458 gave consents and had complete information for analysis. The mean age of caregivers was 47 years and 46.9% of the caregivers were spouses of patients. More than half of the caregivers were female. The mean age of patients was older than the caregivers (55.7 years vs 46.98 years respectively). More than half of the caregivers were female. Performance status of most patients (83%) was good (ECOG PS 0-1). Majority of the patients (74%) had solid tumours and only 26% had haematological cancers. Table 1 showed the socio-demographic characteristics of patient and caregivers.

Symptoms of anxiety and depression were reported in 26% and 15.9% of caregivers respectively. There was significant difference between anxiety of patients and caregivers in which more caregivers reported anxiety compared to patients, $p < 0.001$. The mean score of CQOLC is 91.25 ± 20.79 . The mean score for burden was 24.19 ± 8.61 ; Disruptive (0-28) 19.12 ± 6.38 ; Adaptation (0-28), 9.00 ± 5.23 ; and Financial Concern (0-12), 7.99 ± 3.4 .

Predictors of psychological status of caregiver

Caregivers who were not of Malay race reported more anxiety and depression symptoms. Caregivers who looked after male patients and patients with poor performance status reported more anxiety symptoms. Caregivers reported significant depressive symptoms when patients exhibited anxiety and depression symptoms (Table 2 and 3).

Predictors of QOL among caregiver

We then further analysed associated risk factors of caregiver's QOL measured by CQOLC and its domains using logistic regression model. Caregiver QOL was significantly associated with ethnicity and patients factors such as cancer types, stage of disease and anxiety symptoms. Caregivers of non-Malay ethnicity, those caring for patients with haematological cancers, more advanced stage and patients who were anxious had significantly poorer QOL (Table 4)

Table 5 demonstrated the different subdomains of the CQOLC. Non-Malay caregivers reported significantly

Table 2. Factors associated with Anxiety of the Caretakers (n=454)

Caregiver's factors	Univariate analysis			Multivariate analysis	
	HADS-Anxiety scoring, n (%) ≤ 8	HADS-Anxiety scoring, n (%) > 8	OR (95% CI)	p value	Adjusted OR (95% CI) p value
Age, years					
< 50	163 (67.6)	78 (32.4)	1.16	0.456	
≥ 50	137 (64.3)	76 (37.5)	(0.79-1.71)		
Gender					
Male	139 (67.5)	67 (32.5)	1.12	0.567	
Female	161 (64.9)	87 (35.1)	(0.76-1.66)		
Malay					
Yes	102 (72.9)	38 (27.1)	1.57	0.042	1.7 0.031
No	198 (63.1)	116 (36.9)	(1.02-2.44)		(1.05-2.75)
Muslim					
Yes	103 (73.0)	38 (27.0)	1.6	0.035	- -
No	197 (62.9)	116 (37.1)	(1.03-2.47)		
Patient's factor					
Age, years					
< 50	84 (66.1)	43 (33.9)	1	0.986	
≥ 50	216 (66.1)	111 (33.9)	(0.65-1.55)		
Gender					
Male	108 (58.1)	78 (41.9)	0.54	0.003	0.58 0.013
Female	192 (71.6)	76 (28.4)	(0.37-0.81)		(0.37-0.89)
Cancer type					
Solid	231 (68.8)	105 (31.3)	1.56	0.043	1.12 0.681
Hematological	69 (58.3)	49 (41.5)	(1.01-2.41)		(0.66-1.89)
Stage					
< III	122 (69.7)	53 (30.3)	1.31	0.195	
III and IV	178 (63.8)	101 (36.2)	(0.87-1.96)		
ECOG					
0 and I	249 (70.1)	106 (29.9)	2.21	0.001	1.81 0.032
II and above	51 (51.5)	48 (48.5)	(1.40-3.49)		(1.05-3.10)
HADS-Anxiety					
8 and less	252 (73.9)	89 (26.1)	3.83	<0.001	3.29 <0.001
More than 8	48 (42.5)	65 (57.5)	(2.46-5.98)		(1.96-5.51)
HADS-Depression					
8 and less	247 (71.8)	97 (28.2)	2.74	<0.001	1.35 0.268
More than 8	53 (48.2)	57 (51.8)	(1.76-4.26)		(0.79-2.29)

OR, odds ratio; CI, confidence interval; HADS, Hospital Anxiety and Depression Scale

more disruptiveness and financial concerns. Caregivers of patients with haematological cancers reported significantly more disruptiveness whereas those who cared for more advance stage cancer patients reported more disruptiveness, burden and financial concerns. Caring for patients who were more anxious was associated with more burden and disruptiveness for the caregivers. Caregivers reported significantly more adaptation problems in low household income groups and caring for patients who exhibited depressive symptoms. Caregivers who reported anxiety and depression had significantly poorer QOL and in all subdomains of CQOLC.

Discussion

In this study, the QOL of caregivers are better than what was reported from majority of the Asian countries but comparable to Thailand and western countries (Turkoglu et al., 2012; Northouse et al., 2010; Warapornmongkholkul et al., 2018). This may be due to the different patients' cohort, although cultural differences and family dynamics and structures may have been other possible contributory factors, which unfortunately were not explored. In this study, caring for patients with haematological cancers appeared to have significantly worse QOL than those caring for solid tumours. This

Table 3. Factors Associated with Depression of the Caretakers (n=454)

Caregiver's factors	Univariate analysis				Multivariate analysis	
	HADS-Depression scoring, n (%) ≤ 8	HADS-Depression scoring, n (%) > 8	OR (95% CI)	p value	Adjusted OR (95% CI)	p value
Age, years						
< 50	193 (80.1)	48 (19.9)	1.23	0.358		
≥ 50	163 (76.5)	50 (23.5)	(0.78-1.93)			
Gender						
Male	163 (79.1)	43 (20.9)	1.08	0.737		
Female	193 (77.8)	55 (22.2)	(0.69-1.69)			
Malay						
Yes	125 (89.3)	15 (10.7)	2.99	<0.001	2.83	0.001
No	231 (73.6)	83 (26.4)	(1.66-5.41)		(1.54-5.20)	
Muslim						
Yes	126 (89.4)	15 (10.6)	3.03	<0.001	-	-
No	230 (73.5)	83 (26.5)	(1.68-5.48)			
Patient's factor						
Age, years						
< 50	106 (83.5)	21 (16.5)	1.56	0.103		
≥ 50	250 (76.5)	77 (23.5)	(0.91-2.65)			
Gender						
Male	138 (74.2)	48 (25.8)	0.66	0.069		
Female	218 (81.3)	50 (18.7)	(0.42-1.03)			
Cancer type						
Solid	266 (79.2)	70 (20.8)	1.18	0.511		
Hematological	90 (76.3)	28 (23.7)	(0.72-1.95)			
Stage						
< III	145 (82.9)	30 (17.1)	1.56	0.068		
III and IV	211 (75.6)	68 (24.4)	(0.97-2.51)			
ECOG						
0 and I	280 (78.9)	76 (21.1)	1.13	0.653		
II and above	76 (76.8)	23 (23.2)	(0.66-1.92)			
HADS-Anxiety						
8 and less	285 (83.6)	56 (16.4)	3.01	<0.001	1.9	0.026
More than 8	71 (62.8)	42 (37.2)	(1.87-4.85)		(1.08-3.33)	
HADS-Depression						
8 and less	291 (84.6)	53 (15.4)	3.8	<0.001	2.68	0.001
More than 8	65 (59.1)	45 (40.9)	(2.53-6.14)		(1.54-4.69)	

OR, odds ratio; CI, confidence interval; HADS, Hospital Anxiety and Depression Scale

has not been well documented elsewhere as majority of the studies included only patients with solid cancers. However, a recent abstract reported a low mean CQOLC score of caregivers of patients with haematological cancers (78.34 ± 15.53) which is consistent with our findings (Mishra et al., 2018). Another study in China has also demonstrated that the QOL of caregivers of leukaemia patients were worse although the measurement method is different (Wang et al., 2020). Prolonged hospitalization due to the more intensive chemotherapy that these patients underwent was postulated as one of the possible explanations (Wang et al., 2020). This likely posed more distress and limitation to the caregivers' normal activities

as evident by significantly more disruptiveness reported by caregivers in the study (Wang et al., 2020).

The prevalence of anxiety and depression symptoms in the caregivers in this study was 24.9% and 24.2% respectively. When compared to other studies, it appeared to be slightly lower than what have been reported (Vrettos et al., 2012; Haun et al., 2014; Song et al., 2011). According to the meta-analysis by Geng et al., (2018), anxiety and depression symptoms of caregiver can be as high as 46.5% and 42.3% respectively. The QOL of caregiver is closely related to the presence of psychological stress and we found similar findings consistent with many other reported studies globally (Haun et al., 2014; Geng et al.,

Table 4. Factors associated with Quality of Life of Caretakers (n=454)

Caregiver's factors	CQOLC, n (%)		Univariate analysis		Multivariate analysis	
	<92	≥92	OR (95% CI)	p value	Adjusted OR (95% CI)	p value
Age, years						
< 50	113 (46.9)	128 (53.1)	1.25	0.233		
≥ 50	88 (41.3)	125 (58.7)	(0.86-1.82)			
Gender						
Male	80 (38.8)	126 (61.2)	0.67	0.033		
Female	121 (48.8)	127 (51.2)	(0.46-0.97)			
Malay						
Yes	48 (34.3)	92 (65.7)	0.55	0.004	0.45	0.001
No	153 (48.7)	161 (51.3)	(0.36-0.83)		(0.29-0.72)	
Muslim						
Yes	48 (34.0)	93 (66.0)	0.54	0.003	-	-
No	153 (48.9)	160 (51.1)	(0.36-0.82)			
Patient's factor						
Age, years						
< 50	59 (46.5)	68 (53.5)	1.13	0.559		
≥ 50	142 (43.4)	185 (56.6)	(0.75-1.71)			
Gender						
Male	99 (53.2)	87 (46.8)	1.85	0.001	1.48	0.068
Female	102 (38.1)	166 (61.9)	(1.27-2.71)		(0.97-2.24)	
Cancer type						
Solid	137 (40.8)	199 (59.2)	0.581	0.011	0.49	0.013
Hematological	64 (54.2)	54 (45.8)	(0.38-0.89)		(0.28-0.86)	
Stage						
< III	60 (34.3)	115 (65.7)	0.51	0.001	0.42	<0.001
III and IV	141 (50.5)	138 (49.5)	(0.35-0.76)		(0.27-0.67)	
ECOG						
0 and I	142 (40.0)	213 (60.0)	0.452	0.001	0.65	0.112
II and above	59 (59.6)	40 (40.4)	(0.287-0.72)		(0.38-1.11)	
HADS-Anxiety						
8 and less	131 (38.4)	210 (61.6)	0.38	<0.001	0.49	0.008
More than 8	70 (61.9)	43 (38.1)	(0.25-0.59)		(0.29-0.83)	
HADS-Depression						
8 and less	132 (38.4)	212 (61.6)	0.37	<0.001	0.64	0.094
More than 8	69 (62.7)	41 (37.3)	(0.24-0.58)		(0.38-1.08)	

OR, odds ratio; CI, confidence interval; HADS, Hospital Anxiety and Depression Scale

2018; Song et al., 2011). Although the prevalence of psychological distress is lower and this may translate to the better QOL of caregivers in our study, further evaluation of the caregivers' psychological stress is still important to further improve their QOL.

The higher prevalence of anxiety amongst caregivers when compared to patients in this study are consistent with what were reported previously (Haun et al., 2014; Kehoe et al., 2019; Mitchell et al., 2013). According to Haun et al., (2014), this could be explained by the lack of open communications and perceived non-disclosure of the disease by patients. It is important to realise that anxiety symptoms tend to be longer lasting compared

to depression and with its negative effect on QOL, it is critical that the underlying causes of anxiety, which may include poor social support and financial burden, be further explored (Mitchell et al., 2013).

In our study, female caregivers tend to have lower QOL score and experienced more burden and disruptiveness, although this was not demonstrated to be statistically significant after multivariate analysis. This is consistent with the recent meta-analysis where gender was also not found to be a factor associated with QOL (Geng et al. 2018). Other factors such as stage of cancer which had previously reported to affect QOL of caregivers are also demonstrated in this study (Lim et al., 2017). It is

Table 5. Factors associated with Domains of CQOLC (Burden, Disruptive, Adaptation and Finance Concern) of the Caretakers (n=454)

Patient's factors	Univariate analysis			Multivariate analysis		
	CQOLC (Burden), n (%)		OR	p value	Adjusted OR	p value
	<25	≥25	(95% CI)		(95% CI)	
Gender						
Male	101 (54.3)	85 (45.7)	1.56	0.021	1.42	0.084
Female	116 (43.3)	152 (56.7)	(1.07-2.27)		(0.95-2.11)	
Stage						
< III	63 (36.0)	112 (64.0)	0.61	<0.001	0.47	< 0.001
III and IV	154 (55.2)	125 (44.8)	(0.39-0.95)		(0.32-0.70)	
ECOG						
0 and I	160 (45.1)	195 (54.9)	0.61	0.028	0.73	0.19
II and above	57 (57.6)	42 (42.4)	(0.39-0.95)		(0.43-1.17)	
HADS-Anxiety						
8 and less	147 (43.1)	194 (56.9)	0.47	0.001	0.54	0.015
More than 8	70 (61.9)	43 (38.0)	(0.30-0.72)		(0.32-0.89)	
HADS-Depression						
8 and less	150 (43.6)	194 (56.4)	0.5	0.002	0.75	0.271
More than 8	67 (60.9)	43 (39.1)	(0.32-0.77)		(0.45-1.25)	
Caregiver's factors						
	CQOLC (Disruptive)					
	<20	≥20				
Gender						
Male	80 (38.8)	126 (61.2)	0.65	0.022	0.92	0.689
Female	123 (49.6)	125 (50.4)	(0.44-0.94)		(0.59-1.41)	
Malay						
Yes	43 (30.7)	97 (69.3)	0.43	<0.001	0.33	<0.001
No	160 (51.0)	154 (49.0)	(0.28-0.65)		(0.20-0.53)	
Muslim						
Yes	44 (31.2)	97 (68.5)	0.44	<0.001	-	-
No	159 (50.8)	154 (49.2)	(0.29-0.67)			
Patient's factors						
Gender						
Male	100 (53.8)	86 (46.2)	1.86	0.001	1.48	0.083
Female	103 (38.4)	165 (61.6)	(1.28-2.72)		(0.95-2.31)	
Cancer type						
Solid	137 (40.8)	199 (59.2)	0.54	0.004	0.47	0.008
Hematological	66 (55.9)	52 (44.1)	(0.36-0.83)		(0.27-0.82)	
Stage						
< III	66 (37.7)	109 (62.3)	0.63	0.018	0.52	0.005
III and IV	137 (49.1)	142 (50.9)	(0.43-0.92)		(0.33-0.83)	
ECOG						
0 and I	143 (40.3)	211 (59.7)	0.44	<0.001	0.59	0.057
II and above	60 (60.6)	39 (39.4)	(0.28-0.69)		(0.35-1.02)	
HADS-Anxiety						
8 and less	133 (39.0)	208 (61.0)	0.39	<0.001	0.44	0.002
More than 8	70 (61.9)	43 (38.1)	(0.25-0.61)		(0.26-0.75)	
HADS-Depression						
8 and less	138 (40.1)	206 (59.9)	0.46	<0.001	0.88	0.648
More than 8	65 (59.1)	45 (40.9)	(0.30-0.72)		(0.52-1.50)	

Table 5. Continued

Patient's factors Caregiver's factors	Univariate analysis			Multivariate analysis		
	CQOLC (Adaptation), n (%)					
	<20	≥20				
Income						
< RM5000	124 (56.1)	97 (43.9)	1.67	0.007	1.62	0.011
≥ RM5000	101 (43.3)	132 (56.7)	(1.15-2.42)		(1.12-2.36)	
Patient's factors						
HADS-Depression						
8 and less	158 (45.9)	186 (54.1)	0.55	0.006	0.57	0.011
More than 8	67 (60.9)	43 (39.1)	(0.35-0.85)		(0.36-0.88)	
Caregiver's factors						
CQOLC (Finance concern), n (%)						
	≤8	>8				
Malay						
Yes	51 (36.4)	89 (68.6)	0.55	0.003	0.56	0.006
No	161 (51.3)	154 (48.7)	(0.36-0.82)		(0.37-0.84)	
Muslim						
Yes	51 (36.2)	90 (63.8)	0.54	0.003	-	-
No	161 (51.4)	152 (48.6)	(0.36-0.81)			
Patient's factors						
Stage						
< III	69 (39.4)	106 (60.6)	0.62	0.014	0.63	0.021
III and IV	143 (51.3)	136 (48.7)	(0.42-0.91)		(0.43-0.93)	
HADS-Depression						
8 and less	151 (43.9)	193 (56.1)	0.63	0.034	0.68	0.089
More than 8	61 (55.5)	49 (44.5)	(0.41-0.97)		(0.44-1.06)	

OR, odds ratio; CI, confidence interval; HADS, Hospital Anxiety and Depression Scale

understandable that caring for family members with advance stage of cancer may pose more stress to caregivers and this increase as patient loses autonomy (Dumont et al., 2006).

Caregiving experiences had been shown to be complex and multidimensional. It is depended on many factors, not limited to religious beliefs, family dynamics as well as sociocultural background (Pharr et al., 2014). Different experience of caregiving among the different ethnicities had also been recently reported (Cook et al., 2018). A recent study in Malaysia reported that caregivers of Indian ethnicity for patients with gastrointestinal cancer had worse QOL (Abdullah et al., 2019). Similarly, in this present study we found that Malay caregivers had better QOL and mental health. This may have been partly due to the underlying religion and coping mechanism, however, further study ought to be conducted to explore this.

Advances in cancer treatment had translated into longer overall survival for patients, and many of these novel therapies are expensive. According to the ACTION study, a prospective longitudinal study in Southeast Asia, 48% of patients' experienced financial catastrophe 12 months after diagnosis (Kimman et al., 2015). This illustrated the severe stress that patients and family members having to go through, not only from the psychosocial aspect but also financial aspect. Caregivers of non-Malay ethnicities and those caring for advanced stage cancer reported significantly more financial concerns.

Financial concerns have consistently shown to be one of the major challenges faced by family of cancer patients and this further contributed to their psychological stress (Geng et al., 2018; Bradley, 2019). Other factors which may be indirectly related to financial status such as accessibility to information and resources have also been demonstrated to significantly impacted QOL of patients and caregivers (Qan'ir et al., 2022). However, this was not specifically explored in this study.

This study has several limitations. Firstly, only caregivers of patients receiving treatment in hospital were recruited and those who were under palliation were not captured. Secondly, this study only captured the data at one point in time. It is well documented that QOL is dynamic, and changes with time depending on patients' health, and family dynamics. Lastly, this is a single centre study which may not be representative of the true situation in Malaysia. However, this is the first study in the South East Asia region which included a wide range of cancers patients and a relatively large number of patient-caregiver dyads.

In conclusion, this study highlighted the importance of screening for psychological distress amongst caregivers of cancer patients. It illustrates the importance of creating awareness amongst physicians and policy makers of the psychological and social challenges, including financial concerns, which caregivers are facing and the need for additional support. As concluded by Northouse et al., (2010), targeted and specific interventions including

education program and support group may be helpful to improve their QOL. This is especially relevant in developing country such as Malaysia where advanced hospice and community support is lacking. Thus, relevant stakeholders should attempt to address this pertinent issue and to develop relevant program to mitigate the psychological stress faced by the caregivers.

Author Contribution Statement

GGG conceived, designed, interpret data and drafted the manuscript. TKWF collected and analysed data. MS performed the statistical analysis. SM, BPC, AMR and HGWF provided patients and reviewed the manuscript. Ng CG analysed, interpret the data and reviewed the manuscript. All authors read and approved the final manuscript. All authors declare no conflict of interest and have nothing to disclose.

Acknowledgements

We would like to acknowledge Dr Jesinda Paul for assisting in collecting data in the beginning of study and Ms Najihah Hussein for collating the references.

Funding

The study is partially funded by Malaysian Society of Haematology.

Ethic

The study is approved by University Malaya Medical Centre Medical Research Ethics committee 2016717-4017.

Availability of data and Materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

References

- Abdullah NN, Idris IB, Shamsuddin K, Abdullah NMA (2019). Health-related quality of life (HRQOL) of gastrointestinal cancer caregivers: The Impact of Caregiving. *Asian Pac J Cancer Prev*, **20**, 1191-7.
- Bradley CJ (2019). Economic burden associated with cancer caregiving. *Semin Oncol Nurs*, **35**, 333-6.
- Cook SK., Snellings L, Cohen SA (2018). Socioeconomic and demographic factors modify observed relationship between caregiving intensity and three dimensions of quality of life in informal adult children caregivers. *Health Qual Life Outcomes*, **16**, 169.
- Din SHS, Jaafar NRN, Zakaria H, et al (2017). Anxiety disorders in family caregivers of breast cancer patients receiving oncologic treatment in Malaysia. *Asian Pac J Cancer Prev*, **18**, 465-71.
- Dumont S, Turgeon J, Allard P, et al (2006). Caring for a loved one with advanced cancer: determinants of psychological distress in family caregivers. *J Palliat Med*, **9**, 912-21
- Fitzmaurice C, Abate D, Abbasi N, et al (2019). Global, Regional, and National Cancer Incidence, Mortality, Years of Life Lost, Years Lived With Disability, and Disability-Adjusted Life-Years for 29 Cancer Groups, 1990 to 2017: A Systematic Analysis for the Global Burden of Disease Study. *JAMA Oncol*, **5**, 1749-68
- Geng HM, Chuang DM, Yang F, et al (2018). Prevalence and determinants of depression in caregivers of cancer patients: A systematic review and meta-analysis. *Medicine (Baltimore)*, **97**, e11863.
- Given BA, Given CW, Kozachik S (2001). Family support in advanced cancer. *CA Cancer J Clin*, **51**, 213-31.
- Haun MW, Sklenarova H, Brechtel A, Herzog W, Hartmann M (2014). Distress in cancer patients and their caregivers and association with the caregivers' perception of dyadic communication. *Oncol Res Treat*, **37**, 384-88.
- Kehoe LA, Xu H, Duberstein, et al (2019). Quality of life of caregivers of older patients with advanced cancer. *J Am Geriatr Soc*, **67**, 969-77
- Kilic ST, Oz F (2019). Family caregivers' involvement in caring with cancer and their quality of life. *Asian Pac J Cancer Prev*, **20**, 1735-41.
- Kim Y, Given BA (2008). Quality of life of family caregivers of cancer survivors: across the trajectory of the illness. *Cancer*, **112**, 2556-68.
- Kimman M, Jan S, Yip CH., et al (2015). Catastrophic health expenditure and 12-month mortality associated with cancer in Southeast Asia: results from a longitudinal study in eight countries. *BMC Med*, **13**, 190.
- Lim HA, Tan JY, Chua J, et al (2017). Quality of life of family caregivers of cancer patients in Singapore and globally. *Singapore Med J*, **58**, 258-61.
- Lua PL, Wong SY (2012). The reliability of the Malay versions of hospital anxiety depression scale (HADS) and McGill Quality of Life Questionnaire (MQOL) among a Group of Patients with Cancer in Malaysia. *Malaysian J Psychiatry*, **21**, 1-13.
- Mishra VS, Chandrakala S, Saranath D (2018). Assessing the quality of life among caregivers of patients with haematological cancer. *J Glob Oncol*, **4**, 104.
- Mitchell AJ, Ferguson DW, Gill J, Paul J, Symonds P (2013). Depression and anxiety in long-term cancer survivors compared with spouses and healthy controls: a systematic review and meta-analysis. *Lancet Oncol*, **14**, 721-32.
- Northouse LL, Katapodi MC, Song L, Zhang L, Mood DW (2010). Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. *CA Cancer J Clin*, **60**, 317-39.
- Ochoa C, Buchanan Lunsford N, Lee Smith J (2020). Impact of informal cancer caregiving across the cancer experience: A systematic literature review of quality of life. *Palliat Supportive Care*, **18**, 220-40.
- Pharr JR, Francis CD, Terry C, Clark MC (2014). Culture, Caregiving, and Health: Exploring the Influence of Culture on Family Caregiver Experiences. *Int Scholarly Res Notices*, **2014**, Article ID 689826, 8 pages
- Qan'ir Y, Guan T, Idiagbonya E, et al (2022). Quality of life among patients with cancer and their family caregivers in the Sub-Saharan region: A systematic review of quantitative studies. *PLoS Glob Public Health*, **2**, e0000098.
- Registry NC (2018). Malaysian Study on Cancer Survival.
- Shahi V, Lapid, MI, Kung S, et al (2014). Do age and quality of life of patients with cancer influence quality of life of the caregiver?. *J Geriatr Oncol*, **5**, 331-6.
- Song JI, Shin DW, Choi JY, et al (2011). Quality of life and mental health in family caregivers of patients with terminal cancer. *Support Care Cancer*, **19**, 1519-26.
- Tang WR, Tang, ST, Kao CY. (2009). Psychometric testing of the Caregiver Quality of Life Index-Cancer on a Taiwanese family caregiver sample. *Cancer Nurs*, **32**, 220-9.
- Turkoglu N, Kilic D (2012). Effects of care burdens of caregivers

- of cancer patients on their quality of life. *Asian Pac J Cancer Prev*, **13**, 4141-5.
- Vashistha V, Poullose R, Choudhari C, Kaur S, Mohan A (2019). Quality of life among caregivers of lower-income cancer patients: A Single-Institutional Experience in India and Comprehensive Literature Review. *Asian Pac J Cancer Care*, **4**, 87-93.
- Vrettos I, Kamposioras K, Kontodimopoulos N, et.al. (2012). Comparing health-related quality of life of cancer patients under chemotherapy and of their caregivers. *Sci World J*, **2012**, 135283.
- Wang C, Yan J, Chen J, et al (2020). Factors associated with quality of life of adult patients with acute leukemia and their family caregivers in China: a cross-sectional study. *Health Qual Life Outcomes*, **18**, 8.
- Warapornmongkholkul NHA, Howteerakul N, Suwannapong N, Soparattanapaisarn N (2018). Self-efficacy, social support, and quality of life among primary family-member caregivers of patients with cancer in Thailand. *J Health Res*, **32**, 111-22.
- Weitzner MA, Jacobsen PB, Wagner H, Friedland J, Cox C. (1999). The caregiver quality of life Index-Cancer (CQOLC) scale: development and validation of an instrument to measure quality of life of the family caregiver of patients with cancer. *Qual Life Res*, **8**, 55-63.
- Zigmond AS, Snaith RP (1983). The hospital anxiety and depression scale. *Acta Psychiatr Scand*, **67**, 361-70.
- Zubaidi AZS, Ariffin F, Oun CTC, Katiman D (2020). Caregiver burden among informal caregivers in the largest specialized palliative care unit in Malaysia: a cross sectional study. *BMC Palliat Care*, **19**, 186



This work is licensed under a Creative Commons Attribution-Non Commercial 4.0 International License.