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ORIGINAL ARTICLE

Health-related quality of life in Malaysian gastrointestinal cancer patients and their family caregivers—a comparison study

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Abstract

Purpose Gastrointestinal (GI) cancer has emerged as a major health problem. Cancer patients receive informal care from their families beyond formal care. There has been little evidence showing how the health-related quality of life (HRQOL) of the caregivers differs from that of the GI patients in Malaysia. A cross-sectional study was conducted in three referral hospitals in Malaysia. The objectives of this study were to determine the HRQOL of GI cancer patients and their family caregivers, and assess whether there is any significant relationship between the demographic factors, and the physical component summary (PCS) and mental component summary (MCS) scores for patients and caregivers.

Methods A total of 323 dyads of GI cancer patients and their caregivers completed the Medical Outcomes Study 12-item Short Form (MOS SF-12) questionnaire to measure their HRQOL during face-to-face interviews. The analyses were performed using SF-12 scoring software to compute PCS and MCS scores (HRQOL parameters). The independent *t* test, one-way ANOVA, and the Pearson correlation test were conducted to determine the demographic factors related to the HRQOL of the dyads.

Results The caregivers had higher scores in all domains for the SF-12 than the patients. There were significant differences found in the MCS scores of the patients according to ethnicity, origin of cancer, duration of cancer, and surgery. None of these factors had a significant relationship with the caregivers' HRQOL.

Conclusion Caregivers had better HRQOL than cancer patients. Early intervention for cancer patients in the form of counselling and personalised pain management may enhance the HRQOL of patients.

Keywords Health-related quality of life · Caregivers · Malaysia · Gastrointestinal cancer

Introduction

Gastrointestinal (GI) cancer, also known as digestive cancer, is a leading cause of death in Asia [1]. In the Asia-Pacific region, including Malaysia, the epidemiology of GI cancer has changed as wealth has increased [2]. GI cancer affects patients' health-related quality of life (HRQOL) and their productivity [3] and thus is a major public health concern.

Cancer patients experience high levels of psychological stress as a reaction to cancer and its treatment, among a range of other feelings, all of which have a significant impact on their HRQOL [4]. Colorectal cancer patients experience direct consequences, both emotionally and physically, and this can affect the HRQOL of the family caregivers [5]. Spousal caregivers of patients of esophageal cancers who participated in a study in the Netherlands experienced more anxiety than patients [6].

"HRQOL is a multidimensional construct that covers the patients' perceptions of his or her physical, emotional, social, and cognitive functions" [7]. The HRQOLs of cancer patients

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and their caregivers are assessed in cancer research, and the results are useful for multiple purposes. For example, it can help researchers understand the physical, mental, and emotional implications of cancer more clearly and the effects of treatments such as chemotherapy, radiotherapy, and surgery [8].

SF-12 has recently been used to measure physical and mental health in dyadic studies of cancer patients and their caregivers [9, 10]. This generic instrument assesses a broad range of aspects of QOL, such as role performance; perceived health; and physical, emotional, and social functioning [11].

The SF-12 is a shorter version of SF-36, and it covers similar domains as SF-36 [12]. Because it is brief, it does not burden respondents, and it is a practical and reliable tool [13].

Only a few studies have compared the HRQOLs of cancer patients and their family caregivers and reported significantly different total HRQOL scores between groups [14]. In another study, caregivers had better HRQOLs than patients [9].

Abroad study reported correlations between the HRQOLs of patients and their spouses [9]. Good physical well-being in patients may be associated with better caregiver HRQOLs [15]. An interdependence between colorectal cancer patients' and their caregivers' physical and mental health at the time of diagnosis and years after the diagnosis has also been documented [10]. This supports the theory that the well-being of one spouse influences the other spouse's well-being [16].

Many factors impact patients' and caregivers' physical and mental well-being. For cancer patients, studies have found that demographics of the patient, i.e. age [17], sex s18], employment [19, 20], education [19, 21], and ethnicity [21, 22] and cancer characteristics such as type of cancer [21, 23] and duration of cancer [9], were associated with physical health. As for pancreatic cancer patients, physical health was associated with later stages of cancer [22].

Likewise, similar characteristics such as age and education [21], ethnicity [24], and type and duration of cancer [20, 23] were significantly associated with their mental health including those who had undergone surgery [25, 26].

Moreover, age [27, 28], sex [29, 30], income, relationship between the patient and caregiver, and education [27, 28] affect the caregiver's physical health. The age of caregivers is a significant factor associated with their mental well-being scores [25, 28].

Methods

Sample

A cross-sectional study was conducted at three main tertiary hospitals in the centre of Kuala Lumpur. Two hospitals were ordinary public hospitals, and the other was a public teaching hospital. Purposive sampling was used to recruit GI cancer patients from outpatient clinics and wards. The patients were selected through purposive sampling according to the diagnosis listed in the patients' registry at the respective study locations.

The inclusion criteria for the patients were as follows: Malaysian citizen or permanent resident, 18 years old and older, not in distress, and without psychiatric disorders. Distress was a subjective assessment made by the treating physician. The physicians defined distressed patients as being visibly upset or in pain. Patients identified as in distress were not recommended to participate in the study. We excluded them because we do not want to trigger additional stress. Furthermore, they may not be able to provide full cooperation in this study. All eligible GI cancer patients and their caregivers were invited to participate in the study, which was conducted from July 2017 to February 2018. The caregivers were required to be 18 years old or older, free from any cancer or psychiatric disorder, and willing to participate. We asked the patient to identify the caregiver who gave the most care especially in terms of duration of care.

The researchers explained the purpose of the study, and the respondents were asked to give written consent. Dyads of 323 GI cancer patients and their caregivers completed the questionnaires during face-to-face interviews. These interviews were conducted separately and took an average of 10 min for each respondent.

The study received ethical approval from the following responsible bodies: the Medical Research and Ethics Committee of the Ministry of Health of Malaysia and the National University of Malaysia Ethics Committee, UKM PPI/111/8/JEP-2017–433.

Instruments

Independent variables

The demographic factors of age, sex, ethnicity, educational level (primary = 6 years; secondary = 5 years, tertiary = according to years at colleges, universities), marital status, and working status of the patients and caregivers were obtained. The household income (MYR), number of young children (age less than 18 years old), relationship to patient, and duration of care (hours/week) were obtained for each caregiver. Information on the clinical characteristics, namely origin of cancer, duration of cancer (months), and the treatments received (surgery, radiotherapy, chemotherapy), was taken from clinical records.

Dependent variables

Medical Outcomes Study 12-item Short Form (MOS SF-12) version 2 measures HRQOL. It measures eight domains of HRQOL: physical functioning (PF), role-physical (RP), bodily pain (BP), general health (GH), vitality (VT), role-emotional (RE), social functioning (SF), and mental health

(MH). These eight domains form two dimensions, the physical component summary (PCS) and the mental component summary (MCS) [9]. Scores for the MOS SF-12 vary from 0 to 100, with a score of 100 indicating optimal health. Scores below 50 identify lower HRQOL than the general population.

This SF-12 is widely available in multiple languages. It has been validated in a Malay study of Malaysian postpartum mothers. Cronbach's alpha for the PCS was found to be 0.749, and for the MCS, it was 0.701 [31]. In our study, the Cronbach alpha for PCS of the patients was 0.846, and MCS was 0.855. For the caregivers, the PCS's Cronbach alpha was 0.843 while the MCS was 0.803. It was found to be reliable and valid for both studies.

Statistical analysis

The SF-12 summary scores were computed using SF-12 scoring software [13]. Data analyses were performed using Statistical Package for the Social Science version 20.0. An independent t test was used to compare the mean SF-12 scores between patients and caregivers. The correlation between the paired SF-12 scores was obtained using Pearson correlation analysis. The independent t test, one-way ANOVA, and Pearson's correlation tests were used to determine whether there were any significant differences between the HRQOLs (MCS and PCS) of each patient and caregiver pair. Values of $p < 0.05$ were considered statistically significant.

Results

Most patients (65%) were male, but a majority of caregivers were females. The mean age of the patients was 59.59 (11.98) years (range, 22–86 years) (Table 1). On average, the patients were older than their caregivers, whose mean age was 44.50 (13.29) years (range, 18–77 years) (Table 2).

Among patients, 72% had been diagnosed with colorectal cancer, and 53.6% were in stage 4 of their cancer. The mean duration of their illness was 20.27 (26.19) months (range, 17.40–23.14 months). About 81.7% of them underwent surgery and 66.6% had received chemotherapy.

Nearly half of caregivers were spouses. Approximately 52% of them were Malays, 35% were Chinese, and 13% were others. More than half of them were employed while caring for the patients (Table 2).

The PCS scores for patients and their caregivers were 38.03 (12.67) and 54.81 (7.34), respectively. The MCS scores were 45.12 (11.75) and 47.69 (10.08), respectively.

Table 1 Sociodemographics of GI cancer patients ($N = 323$)

Variables	Patients, n (%)
Age (years), s.d	Mean = 59.59 (11.98)
	Range = 22–86
Gender	
Male	209 (64.7)
Female	114 (35.3)
Ethnicity	
Malay	167 (51.7)
Chinese	113 (35.0)
Other	43 (13.3)
Education level	
No formal education	23 (7.1)
Primary	91 (28.2)
Secondary	152 (47.1)
Tertiary	57 (17.6)
Marital status	
Single	68 (21.1)
Married	242 (74.9)
Other	13 (4.0)
Working status	
Yes	70 (21.7)
No	253 (78.3)
Duration of cancer (months), s.d	Mean = 20.27 (26.19)
	Range = 17.40–23.14
Origin of cancer	
Upper GI	65 (20.1)
Lower GI	231 (71.5)
Hepatobiliary, pancreas	27 (8.4)
Cancer stage	
1	16 (4.9)
2	41 (12.7)
3	93 (28.8)
4	173 (53.6)
Treatments received	
Surgery	
Yes	264 (81.7)
No	59 (18.3)
Radiotherapy	
Yes	86 (26.6)
No	237 (73.4)
Chemotherapy	
Yes	215 (66.6)
No	108 (33.4)

Comparison of HRQOL between patients and caregivers

Patients had poorer HRQOL than caregivers in PF ($t = -18.87$, $p = 0.00$), RP ($t = -18.86$, $p = 0.00$), and BP ($t = -$

Table 2 Sociodemographic characteristics of caregivers ($N = 323$)

Variables	Caregivers, *n* (%)
Age (years), s.d	Mean = 44.50 (13.29)
	Range = 18–77
Gender	
Male	103 (31.9)
Female	220 (68.1)
Ethnicity	
Malays	167 (51.7)
Chinese	113 (35.0)
Other	43 (13.3)
Education level	
No formal education	13 (4.0)
Primary	29 (9.0)
Secondary	139 (43.0)
Tertiary	142 (44.0)
Marital status	
Single	68 (21.1)
Married	242 (74.9)
Other	13 (4.0)
Relationship to patient	
Spouse	150 (46.4)
Child	118 (36.6)
Parent	30 (9.3)
Other	25 (7.7)
Duration of care (h/week), s.d	Mean = 47.8 (33.27)
	Range = 3.25–128.8
Working status	
Yes	195 (60.4)
No	128 (39.6)
Household income (MYR, s.d)	Mean = 4216.97 (3659.122)
	Range = 350–16000
Number of young children (s.d)	Mean = 0.83 (1.24)
	Range = 0–6
Number of chronic diseases (s.d)	Mean = 0.54 (0.88)
	Range = 0–6

17.96, $p = 0.00$). There was a larger discrepancy between caregivers and patients in the PCS ($t = -21.40$, $p = 0.00$) than in the MCS ($t = -3.25$, $p = 0.00$) (Table 3). The caregivers had higher scores than the patients for most of the domains in SF-12. However, the highest scores for caregivers were for VT and the lowest were for RE. For patients, the highest scores were for MH, and the lowest were for GH.

Correlation between patients' and caregivers' HRQOL

As shown in Table 4, there was a moderate correlation between caregivers and patients for SF ($r = 0.35$, $p = 0.00$), RE ($r = 0.28$, $p = 0.00$), and MH ($r = 0.29$, $p = 0.00$). Other paired variables (PF, RP, BP, and GH) had small correlations that ranged from 0.12 to 0.23. However, the correlation between the two groups for PCS was not significant ($p = 0.13$).

We analysed PCS and MCS according to different types of dyads, i.e. MCS patient vs MCS caregiver and PCS patient vs PCS caregiver, using bivariate correlations. There were small positive correlations between MCS patient vs MCS caregiver (p value > 0.05). On the other hand, there were very small negative correlations between the physical health of the patients and caregivers. However, none of the correlations for MCS and PCS were significant.

Factors related to PCS and MCS in patients and caregivers

No factors were significantly related to patients' PCS scores. However, significant differences were found in cancer site ($F = 7.71$, $p = 0.001$), ethnicity ($F = 2.87$, $p = 0.04$), duration of cancer ($r = 0.12$, $p = 0.04$), and surgery ($t = -2.38$, $p = 0.02$) in regard to the MCS of patients (Table 5). No significant factors were related to caregivers' PCS or MCS scores (Table 6). Further analysis with Bonferroni tests showed that the mean difference in upper GI vs lower GI was significant ($t = -4.17$ [95% CI −8.06, −0.27], $p = 0.03$).

Discussion

According to the National Cancer Registry Report 2007–2011 [32], colorectal, liver, and stomach cancers are in the top ten most common cancers. It was estimated that 13.2% were colorectal, 4.2% was liver cancers, and stomach cancers accounted for 3.4%. Our study found that colorectal cancers in the lower GI category had the highest proportion (71.5%) while upper GI cases were 20.1%. Our findings were comparable to the cancer registry which reported that lower GI cases were higher than upper GI cases.

Comparison of HRQOL between patients and caregivers

There was a significant difference in all domains of HRQOL between patients and caregivers. Caregivers had better HRQOLs than patients. This finding is in accordance with studies in Turkey and China [9, 14, 33]. Caregivers with good HRQOL are in a better position to provide help and support for patients [14].

All eight domains and the MCS were significantly correlated between patients and caregivers, with the exception of the PCS. Other studies have found no significant correlation for RP [9] or MH [10], and one study of Chinese caregivers and patients found no significant correlations for any SF-12 item [9].

Table 3 Mean scores for SF-12 for patients and their caregivers

Domains of SF-12	Patients' mean score (s.d.)	Caregivers' mean score (s.d.)	*t*	*p* value
Physical functioning	39.32 (12.52)	53.77 (7.45)	− 18.87	< 0.001
Role-physical	39.02 (12.53)	53.44 (7.70)	− 18.86	< 0.001
Bodily pain	40.50 (13.00)	54.29 (6.93)	− 17.96	< 0.001
General health	37.88 (10.80)	48.35 (9.37)	− 14.93	< 0.001
Vitality	43.95 (11.11)	55.83 (9.00)	− 15.86	< 0.001
Social functioning	40.10 (14.57)	49.91 (11.02)	− 11.82	< 0.001
Role-emotional	41.94 (13.40)	47.56 (10.61)	− 6.91	< 0.001
Mental health	45.42 (11.71)	48.12 (10.11)	− 3.71	< 0.001
PCS	38.03 (12.67)	54.81 (7.34)	− 21.40	< 0.001
MCS	45.12 (11.75)	47.69 (10.08)	− 3.25	< 0.001

Higher scores mean better HRQOL; *t*, independent *t* test

Our correlation between domains was somewhat or moderately similar to another finding [9], which reported a positive, moderate, linear correlation between patients and caregivers in SF. If a patient's social functioning is affected by his or her physical health, to a certain extent, the caregivers will be too. A Turkish study found a lower correlation in this relationship [14].

The highest scores among patients were in MH, but the lowest scores were in GH. The patients had lower scores for the physical aspects of HRQOL than the caregivers. This finding supports earlier studies [10, 15, 23]. It is well understood that the limitations of patients' physical well-being are closely related to the direct consequences of the illness and the treatments received. Nevertheless, this result is incongruent with a study that reported that advanced cancer patients had better VT than found in our study but lower scores for RE [9].

For caregivers, the highest scores were for VT and the lowest were for RE, as was also found in a previous study [9]. We also found better physical than mental health among caregivers, in line with previous studies [34, 35]. Another study also found that mental health was affected more than physical health among male spouses of breast cancer patients [35]. However, our results are not in accordance with a study that reported that the mental health of caregivers of colorectal cancer patients was better than their physical health [20].

Role emotional domain was a concern for our caregivers because cancer and its treatments may challenge the families of the patients. The emotional impact requires greater adjustment to daily activities and work roles of the caregivers [9].

Mental health scores were higher in caregivers than that in patients, in line with one previous study [10] but not with other studies that found mental health to be lower in caregivers than in patients [36] and lower than in the general population [20].

Although MH was better in caregivers, only a small difference was seen between the groups. This may be due to the acceptance of the disease by the patient and the caregiver. MH was not greatly affected because caregivers may have adapted effectively to their caregiving role. This finding supports the supposition that there is interdependence between the mental health of the patient and caregiver [37], where the mental health status of patients is correlated with the caregiver's psychological well-being.

Table 4 Correlations in SF-12 mean scores between GI cancer patients and their caregivers

Domains	*r*	*p* value
Physical functioning	0.123	0.027
Role-physical	0.142	0.011
Bodily pain	0.146	0.009
General health	0.226	0.00
Vitality	0.116	0.038
Social functioning	0.348	0.00
Role-emotional	0.277	0.00
Mental health	0.288	0.00
PCS	0.085	0.128
MCS	0.287	0.00

r = bivariate correlate

Relationship between demographic factors and the PCS and MCS scores of patients

Patient PCS

No demographic factors or cancer characteristics had a significant effect on the PCS of patients. This result is inconsistent with a Malaysian study [23] that found that the type of cancer significantly impacted PCS. In addition, an earlier study reported that employment and education had significance relative to patient PCS [19].

Patient MCS

The duration of illness and the cancer site were significantly related to the MCS of patients. This is similar to the findings of

Table 5 Relationship between demographic variables and PCS and MCS of patients

Variable	Mean (s.d.)	Statistical tests	*p* value	Mean (s.d.)	Statistical tests	*p* value
Component summary scores	PCS			MCS		
Age		$r = -0.07$	0.21		$r = 0.03$	0.55
Gender		$t = 0.36$	0.55		$t = 0.59$	0.44
Male	37.72 (12.50)			44.74 (12.13)		
Female	38.61 (12.22)			45.80 (11.04)		
Ethnicity		$F = 2.92$	0.05		$F = 3.89$	0.02*
Malay	37.30 (12.03)			45.64 (12.47)		
Chinese	37.38 (12.96)			46.17 (10.84)		
Other	42.14 (13.58)			40.78 (10.54)		
Marital status		$F = 2.90$	0.06		$F = 0.32$	0.73
Single	35.69 (9.35)			43.42 (15.06)		
Married	38.79 (12.95)			45.02 (11.62)		
Other	34.05 (10.99)			46.19 (11.83)		
Education		$F = 0.91$	0.44		$F = 0.36$	0.78
No formal education	38.61 (10.89)			43.44 (12.39)		
Primary	37.62 (12.53)			44.50 (10.68)		
Secondary	39.01 (12.53)			45.44 (12.52)		
Tertiary	35.86 (13.25)			45.91 (11.20)		
Working	39.27 (12.12)	$t = 0.92$	0.44	45.29 (12.81)	$t = 0.14$	0.89
Not working	37.69 (12.82)			45.07 (11.47)		
Duration of cancer (months)		$r = 0.02$	0.66		$r = 0.12$	0.04*
Origin of cancer		$F = 0.09$	0.91		$F = 7.71$	< 0.01*
Upper GI	38.60 (13.21)			42.44 (11.01)		
Lower GI	37.93 (12.45)			46.61 (11.37)		
Hepatobiliary, pancreas	37.56 (13.65)			38.83 (13.80)		
Stage of cancer		$F = 1.02$	0.39		$F = 1.26$	0.29
1	39.32 (10.88)			45.69 (9.39)		
2	40.38 (12.06)			45.75 (8.87)		
3	38.73 (11.80)			46.85 (10.98)		
4	36.98 (13.38)			43.98 (12.85)		
Surgery		$t = -1.83$	0.07		$t = -2.38$	0.02*
No	35.31 (11.40)			41.85 (11.11)		
Yes	38.64 (12.88)			45.85 (11.79)		
Chemotherapy		$t = -1.24$	0.21		$t = -0.08$	0.93
No	36.80 (11.76)			45.04 (11.62)		
Yes	38.65 (13.08)			45.16 (11.85)		
Radiotherapy		$t = 0.58$	0.56		$t = -0.19$	0.85
No	38.28 (12.52)			45.04 (11.81)		
Yes	37.36 (13.12)			45.33 (11.67)		

*Significant, p value < 0.05

r, bivariate correlation; t, independent t test; F, one way ANOVA

other studies [20, 23]. We found a significant positive relationship between the duration of cancer and the mental well-being of patients. It may be that patients eventually adapt to diseases, which results in better mental health. However, another study found that the duration of cancer was a significant factor for physical health in advanced cancer patients [9]. In our study, compared with the primary cancer sites, hepatobiliary, pancreatic cancers showed the lowest MCS scores, less than upper and lower GI cancers. The high mortality rates associated with hepatobiliary cancer could result in greater emotional problems. A study in Mexican cancer caregivers reported mental health scores according to broader types of cancers.

Table 6 Relationship between demographic variables and PCS and MCS of caregivers

Variables	Mean (s.d.)	Statistical test	*p* value	Mean (s.d.)	Statistical test	*p* value
Component summary scores	PCS			MCS		
Age		$r = 0.07$	0.23		$r = -0.05$	0.34
Gender		$t = -1.20$	0.23		$t = -0.03$	0.97
Male	54.09 (6.89)			47.66 (10.46)		
Female	55.14 (7.53)			47.70 (9.92)		
Ethnicity		$F = 0.09$	0.91		$F = 0.46$	0.63
Malay	54.91 (7.52)			48.20 (9.35)		
Chinese	54.83 (7.09)			47.06 (10.91)		
Other	54.38 (7.38)			47.33 (10.65)		
Marital status		$F = 0.98$	0.38		$F = 0.41$	0.67
Single	54.16 (7.35)			48.36 (8.28)		
Married	55.11 (7.32)			47.61 (10.26)		
Other	52.76 (7.65)			45.71 (14.90)		
Education		$F = 0.62$	0.60		$F = 2.13$	0.10
No formal education	55.66 (8.09)			49.03 (10.86)		
Primary	55.08 (9.39)			44.25 (12.69)		
Secondary	54.18 (7.68)			48.94 (9.35)		
Tertiary	55.29 (6.43)			47.04 (9.99)		
Working	54.67 (6.96)	$t = 0.41$	0.68	54.67 (6.96)	$t = 0.48$	0.55
Not working	55.02 (7.89)			55.02 (7.89)		
Household income		$r = -0.03$	0.62		$r = 0.002$	0.96
Number of chronic diseases		$r = 0.02$	0.69		$r = -0.03$	0.60
Relationship to cancer patient		$F = 0.28$	0.84		$F = 0.13$	0.94
Spouse	54.75 (7.85)			47.50 (10.53)		
Child	54.73 (7.02)			47.58 (9.33)		
Parent	55.91 (5.32)			48.57 (10.56)		
Other	54.26 (7.97)			48.31 (10.64)		
Number of young children		$r = -0.05$	0.32		$r = -0.03$	0.56
Duration of care (h/week)		$r = -0.02$	0.72		$r = -0.01$	0.84

Gastrointestinal cancer patients' mental health was slightly poorer than genital cancers but better than respiratory and intrathoracic cancers [34].

In our study, higher MCS scores were seen in patients who had undergone surgery. We found that patients who had undergone surgery experienced less anxiety. Other studies, however, have found otherwise. In one study, the anxiety level was significantly higher after surgery [26], and in another, the type of treatment was not significantly associated with MCS scores [23]. Having had chemotherapy and/or radiotherapy did not affect HRQOL for rectal cancer patients [18].

Patient ethnicity in our study was also significantly related to MCS. Chinese patients had the highest MCS scores, and the difference was significant compared with Malays and others. More Malays had attained secondary and tertiary education than Chinese patients, but the Chinese reported better mental health. The impact of cancer on mental health varies across ethnicities [38]. In the USA, the HRQOL of breast cancer patients differed according to ethnicity: black women reported higher mental health scores than white and Hispanic women [24]. A similar study also indicated that different ethnicities were related to different PCS scores [21]. However, a local study found that ethnicity had no significant impact on HRQOL of palliative cancer patients [23].

Relationship between demographic factors and PCS and MCS scores of caregivers

Our study found no factors significantly related to caregivers' PCS and MCS scores. This is similar to the results of other studies [39, 40]. However, our result is not in accordance with another study, which found age and education to be significantly related with PCS scores [27].

The sex of the caregiver or the patient did not significantly impact caregiver HRQOL. This is not in line with a study that documented that the sex of the caregiver is a significant

predictor of the caregiver's PCS [30]. Moreover, it has been reported that age [28] and relationship to the patient [28, 41] have a significant effect on the MCS of the caregiver.

Limitations

The main strength of the study is that it focused on dyads of a specific type of cancer, which enabled robust comparisons of HRQOL. Due to the purposive sampling, these findings could not be generalised to all GI cancer populations in Malaysia as patients were only recruited from Peninsular Malaysia. Furthermore, the cross-sectional design was unable to show changes in PCS or MCS scores over time. SF-12 is a brief screening tool that measures multidimensional HRQOL; however, bodily pain is a physical health component, which constitutes only one dimension in the HRQOL. Therefore, a better tool for pain assessment is needed to highlight the interference of pain with HRQOL. Besides that, a specific screening tool could also be used to validate the emotional problems experienced by caregivers. The other limitation was that patients who appeared emotionally distressed or physically distressed might have worse HRQOL but they were excluded from becoming respondents. This exclusion may result in us not being able to capture their HRQOL.

The HRQOL of the patients and their caregivers can be measured by using other specific questionnaires respectively. However, due to the interest of the study, a generic tool which was SF-12 was used to compare the dyad's HRQOL. This tool also enables comparison to be made with previous studies. A future research with a qualitative design is suggested to explore emotional issues and how caregivers adapt to them. Further study should also include all patients irrespective of their distress level, and document if they decline to participate.

Implications

This finding is not surprising as many chronically ill patients have lower HRQOL than their caregivers. To increase the HRQOL or to prevent the HRQOL from deteriorating, early anticipation and intervention of the patients' problems are essential. Comprehensive palliative care should be initiated as soon as possible and tailored to each patient's need. Negative and fatal perception of palliative care should be eliminated among the public and also the medical professionals. Palliative care is not merely the end-of-life care but an extensive multi-disciplinary effort in ensuring the patient has good HRQOL. The palliative care team should intervene early in the care of these patients by providing information about the illness, the course of the treatment, counselling for both patient and caregiver, and most importantly to provide pain management adequately. Pain management consists of pain assessment by the patient and adequate pain control. Delivery of these services should be timely to improve the patients' physical well-being and indirectly bring positive impact to the caregivers' HRQOL.

Conclusion

Patients had worse HRQOL than their caregivers. All domains of HRQOL and the MCS scores were significantly correlated between the patients and caregivers, while PCS scores were not. Significant relationships were found between patient ethnicity, duration of cancer, primary cancer site, and surgery and the MCS scores of patients. No demographic factors had significant effects on the PCS scores of patients or the PCS or MCS scores of caregivers.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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