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Original Research Article

Predicting factors affecting the Quality of Life (QoL) among Malaysian caregivers of cancer patients

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Abstract

This study evaluated the socio-demographic characteristics of Malaysian caregivers of cancer patients in order to predict the factors most likely to affect their QoL and subsequently, of those under their care. This was a cross-sectional, randomized purposive study of 137 Malaysian caregivers of cancer patients conducted over a six month period in June 2012 in Kelantan, a state within Malaysia. The (QoL) of these caregivers were assessed by a self-administered questionnaire: Quality of Life in Life-Threatening Illness – Family Carer Version (QOLLTI-F). Multiple linear regression analyses in SPSS (v20) of 137 caregivers of cancer patients showed that a lower quality of life was associated with a widowed and/or divorced status (p=0.015,p= 0.013). Unshared care also had a negative impact on QoL as shown by significantly lower QOLLTI-F scores (p= 0.014). Caregiver quality of life is multidimensional and may vary from different individuals under different conditions. This study demonstrating that the main character of Malaysian caregivers of cancer patients that health care system should pay attention to, are marital status and description of care.

Keywords: Cancer patient, Caregiver, Factor, Malaysian, Quality of life

INTRODUCTION

Cancer considered as a group of diseases described as uncontrolled growth and spread of harmful cells which may lead to death if not controlled. Many factors known to cause cancer such as consuming tobacco, exposure to chemicals or radiation, hormones, immune system conditions, and cell mutations that occur from metabolism. Any individual can develop cancer any time (Jemal et al., 2010). Even though Cancer became global health problems, affecting every region and every socioeconomic level (Jemal et al., 2010). Recently the nature of cancer care has been changed dramatically; this includes many factors such as, increase survival rates, shorter inpatient length of stay. A significant improvements in treatment modalities and it is effective outcomes lead to be majority of cancer patients getting treatment and can be managed in outpatient setting (Downing, 2001; Pearce et al., 2001).

As medical care progressively more shifted from the hospital to the patient’s home, responsibility for health care providers has also shifted from the state from paid formal care, to the family members who provide informal unpaid care (Coyte and McKeever, 2001; Donner and Pederson, 2004; Fast et al., 1999; Stabile et al., 2006). As a result family member may suffer a burden, constrained social life, anxiety and burn out while taking care of cancer patient (Coristine et al., 2003). Cancer affects quality of life not limited to patients but their family member, Quality of life is a multidimensional construct involved physical, mental, psycho-logical, social, and spiritual functioning of the individual

(Rummans et al., 2006).

Many socio demographic factors has been found to correlate with quality of life of caregiver such as age, level of income, gender, level of education and marital status, (MZ and ZZ, 2011; Rosdinom et al., 2013). Being Malaysian caregivers, when they developed distressing symptoms or burden they do not report it, (Salleh, 1990). Thus comprehensive assessment including positive and negative aspects of caregiving is required to investigate the factors that influencing quality of life among Malaysian caregivers of cancer patient. Furthermore, the results would enhance the health status of caregiver and health care supporting system in Malaysia.

METHOD

This study was a part of "Care4U, caring for carer" project conducted by BRAINetwork centre for neuro-cognitive science, Universiti Sains Malaysia. A cross sectional study on a group of caregivers of cancer patients who sake treatment at oncology clinic, Hospital Universiti Sains Malaysia (HUSM) was conducted over duration of six months, June 2012 a probability sampling method was carried out from a sampling frame which included all cancer patients who had received treatment and were discharged from HUSM in Kelantan in the year 2010 and 2011. Patients were contacted by telephone and requested to estimate the number of their caregivers, The caregivers were selected randomly, after obtaining informed consent, (QOLLTI-F) consists of 16 items covering seven domains: environment, patient condition, carer's own state, carer's outlook, relationships, quality of care and financial worries with response scale 11- point numerical rating scale (range from 0 through 10)was used to assess overall quality of life of caregiver of cancer patient (Cohen et al., 2006). This study defined caregiver as any individual who assumes responsible of taking care of patients, which determined by patients himself/herself regardless of kinship (excluding any health care professionals).

All caregiver fulfilling the inclusion criteria was selected to be a part of this study, the Inclusion criteria were Male and female 18 years and above willing to participate in this study, Comply with caregiver definition in this study and cognitively intact. Any caregiver had history of chronic disease or unable to speak Malay language were excluded.

Primary author issued permission to use and translate the instrument, the original English QOLLTI-F was translated into Malaysian language by two professional translators (Speak English and Malay language fluently), then back-translation by two different professional translators to approve last content and format was done. In order to explore the structure of the translated QOLLTI-F questionnaire, exploratory factor analysis with orthogonal rotation based on Promax was performed. In a 7-factor solution, the total matrix sampling adequacy was 0.72. Reliability analysis was applied to the questionnaire. An alpha value of 0.78 indicated good reliability.

Data analysis

Descriptive statistic was used to describe study sample and test the result of this study, using multi regression analysis by Statistical Package for Social Studies (SPSS) version 20 with a significance level of p=0.05 at the 95% confidence interval.

RESULTS

Sample characteristics, This current study includes 137 caregivers of cancer patients of mean age 35.78, of 82 women and 55 men caregivers majority were Malay 93.4%, Muslims 92%, married 59.1% and had completed their secondary education level 41.6%. In the current study around majority the surveyed caregivers were unemployed 84.9%, the relationship of the caregiver to cancer patients were parents 42.1%, spouse/partner 16.1%, child 17.1% or other relatives 24.1%. The entire sample primarily caregivers were providing informal un-paid care 83.2%, the care mainly shared with others 75.2%, majority were living with recipient at same house 76.6%.

More than half of the caregivers rated their monthly income as unsatisfied 56.9%. Duration of care was ranged from one month to seventy two months with mean duration 19.30 (Table 1).

Burden QOLLTI-F score

Overall general linear regressions analysis of independent variables on QOLLTI-F score showed three significant factors table 2 below. caregiver of cancer patients who provide unshared care has significant lower scores of QOLLTI-F compared to one who provide shared care; p=0.014.

QOLLTI-F scores decreased when a caregiver marital status changed from single to being either divorced or widowed (p=0.015, *p*= 0.013) respectively. This indicates that all divorced and widowed Malaysian caregivers from this current study who provide unshared care tended to have lower QOLLTI-F scores than others, *p* value for unshared care was (p= 0.014).

The prediction model identified by multiple linear regressions as follows:

Caregiver Quality of life=92.801-7.089 (Unshared care) -12.670 (Divorced caregiver) -18.529 (Widowed caregiver).

Table 1. Sample characteristics

Variables	Frequency	(%)
Gender		
Male	55	40.1
Female	82	59.9
Religion		
Islam	126	92
Non Muslim	11	8
Ethnicity		
Malay	128	93.4
Non Malay	9	6.6
Marital Status		
Single	42	30.7
Married	81	59.1
Divorced	9	6.6
Widow	5	3.6
Occupation		
Full time	30	21.9
Part time	26	19
Unemployed	67	48.9
Retired	14	10.2
Educational level		
University	41	29.9
Secondary School	57	41.6
Primary School	17	12.4
No formal teaching	10	7.3
Others	12	8.8
Living arrangement		
With recipient	105	76.6
separately	32	23.4
Salary		
Satisfy	59	43
Do not satisfy	78	56.9
Variables	Frequency	(%)
Relationship with patient		
Spouse/partner	22	16.1
parents	58	42.3
Child	24	17.1
Others	33	24.1
Care description		
Formal-paid	23	16.8
Informal-unpaid	114	83.2
Care status		
Shared	103	75.2
Unshared	34	24.8

Table 2. Predictive factors of QOL

Variable	Adjusted b (95% CI)	t statistic	P value
Care status			
○ shared	0.00	-	-
○ Unshared care	-7.089(-12.688,-1.484)	-2.502	0.014
Marital status			
○ Single	0.00	-	-
○ Married	-2.440(-7.783,2.903)	-.903	0.368
○ Divorced	-12.670(-22.826,-2.515)	-2.468	0.015
○ Widowed	-18.529(-33.007,-4.052)	-2.532	0.013

Multiple linear regression; the model reasonably fits well, Model assumptions were met, there were no Interaction and multicollinearity problem.

DISCUSSION

Several studies have been documented positive aspects of being caregiver including enhancing self-esteem, gaining satisfaction, and improve the spiritual and intellectual conditions (Kramer, 1997), despite that Family member experiences many demands ranging from the daily tasks to the psychosocial pressures related to the patient's condition (Glajchen, 2004; Kim and Given, 2008). Researchers often face many problems when conducting their studies with caregivers within the context of cancer survivors. Firstly, cancer is multi-faceted and has many variable trajectories, including different treatment modalities and prognoses (Friedman, 2012). Secondly, 'informal caregiving' that is used in the context of this current study, is typically complex, multi-dimensional and related to a wide range of social meanings, definitions, factors and processes (Raina et al., 2004). This current study reported that caregivers who provided unshared care were experienced more burden and lower scores of QOLLTI-F, this has been replicated in Malaysian study of caregiver for Parkinson disease patients (Razali et al., 2011). Sharing responsibility and activities with other family member or caregiver leads to reduce burden and relief demands. However, unlike previous study done on caregiver of dementia patients, which reported no significant difference of Zarit Burden Interview score between shared or un-shared caregivers tasks (Rosdinom et al., 2011).

Studies examined the effects of chronic and life threatening disease, revealed the negative impacts on marital status, family functioning, and mental health of spouses. These in turn adversely lead to family violence, affect quality of care, quality of life, divorce and feeling burden (Calhoun et al., 2002; Glantz et al., 2009). Current study showed that divorced and widowed caregivers of cancer patients were experienced higher burden compared to single and married. This results comply with the result of study of caregiver of Parkinson disease patients done in Malaysia (Razali et al., 2011).

As divorce or widow described as devastating more than grief experience, lose a job, and life threatening disease which no cure, widowed and divorced caregiver have different reactions to psychological stressors, they start thinking and gave concern about their own condition and future (Hetherington and Kelly, 2003).

Malaysian Islamic Development Department (JAKIM) and the National Registration Department (NRD), (SIPALAN, 2012) reported that more than 33.000 couples ended in divorce 2010. This increased rate should take measurement and attention from policy makers and stakeholders to share responsibility of care between private, public and family caregiver to provide a comfortable life and reduce their demand.

CONCLUSIONS

Study on Malaysian caregiver of cancer patients complied with previous studies on caregiver of other chronic diseases such as Parkinson. Marital status, being widowed, divorced and providing unshared care of cancer patient playing central role on quality of life and was strongly associated with higher burden. In order to improve better quality of caregiver of cancer patients, they should be screened and involved with social and community support program. More importantly community institutions must heighten attention to enable caregiver meets their needs.

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