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Self-Control as a Mediator between Caregiver Burden and Quality of Life in Cancer Patient Primary Caregivers

Wanda Kiyah George Albert[1]*, **Adi Fahrudin**[2], **Steward Lindong**[3]
Husmiati Yusuf[4]
[1] Universiti Malaysia Sabah, Malaysia
[2] Universitas Bhayangkara Jakarta Raya, Indonesia
[3] Universiti Kebangsaan Malaysia, Malaysia
[4] Badan Riset dan Inovasi Nasional, Indonesia
wanda@ums.edu.my*

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Abstract

This study was conducted to identify the influence of the burden of care on the quality-of-life dimensions and examine the role of self-control as a mediator on the burden of care and the quality-of-life dimensions among primary caregivers of cancer patients who are in the terminal phase. This cross-sectional study involves 97 primary caregivers of terminal-phase cancer patients who were selected using purposeful sampling. The Adult Carer Quality of Life Questionnaire (AC-QoL), Zarit Burden Interview (J-ZBI-8), and Pearlin's Sense of Mastery questionnaires were used in this study. Based on data analysis using Smart-PLS-Structural Equation Modeling (SEM) the direct analysis showed that subscale in care load, that is role strain had a significant negative influence on the quality of life in terms of support for caring, caring stress, personal growth, and the ability to care. Meanwhile, the subscale under the burden of care, that is personal strain, had a significant negative influence on the quality of life in terms of caring stress. Additionally, the analysis of indirect relationships revealed that self-control was found not to act as a mediator in the relationship between burden, caring stress and quality of life of the primary caregiver. This study has implications for the family of caregivers who experience the burden of care, especially in terms of role strain and personal strain, thus affecting several dimensions of their quality of life. Thus, in order to improve the quality of life among the primary caregivers of those cancer patients at the terminal stage, social workers in the helping profession field need to implement some appropriate approaches, methods, and techniques that will help to give sufficient mental, emotional, social and family support among the caregivers.

INTRODUCTION

Cancer is a chronic disease that is considered one of the most critical health problems as it is the leading cause of death worldwide (Ferrell, 2019; Fujinami et al., 2015; Mattiuzzi & Lippi, 2020). The increase in the number of patients in Malaysiais also increasingly worrying as this situation may place Malaysia among the developing countries with the highest percentage of cancer patients. During the period of 2012 to 2016, Malaysia recorded a total of 115,238 cancer cases (Ministry of Health Malaysia, 2016). Of these, it was reported that cancer

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patients with end-stage cancer showed the highest percentage at 40.9%, followed by cancer in the third stage (22.8%), the second stage (20.8%) and first stage (15.5%). A total of 82, 601 deaths were reported because of cancer.

Typically, patients who have been diagnosed with advanced cancer are expected to live a relatively long time because to medical advancements in cancer treatment. Patients and caregivers may have significant needs and issues as a result of this shift in prognosis (Priscilla et al., 2011; Wan Puteh et al., 2013). Long-term effects of cancer and its treatment include physical dysfunction, cognitive dysfunction, psychological dysfunction, and concerns about finances, insurance, and the economy require intensive and ongoing care from caregivers consisting of family members (Fujinami et al., 2012; Kim et al., 2007).

Thus, the disease would not only have an impact on the patients, but it would also have an indirect impact on their family members, especially on their overall lives and quality of life (Loke et al., 2003). This is because family members are the closest individuals to the patient who would be by now no longer able to manage themselves because of their deteriorating health condition, especially for end-stage cancer patients (Loke et al., 2003).

Advances in medicine have also triggered changes in the health care system (Jemal et al., 2010). These changes include shifting the care among the end-stage cancer patients from hospital-care to home-care (Girgis & Lambert, 2009). Many cancer patients are now cared for at home by their family members with monitoring provided by health care providers (Girgis & Lambert, 2009). There are studies stating that end-stage cancer disease has a greater impact on the primary caregivers compared to the patients themselves especially concerning the aspect of the caregivers' quality of life (Balboni et al., 2007; Fujinami et al., 2015; Morishita & Kamibeppu, 2014; Nguyen et al., 2015; Weitzner et al., 1999). Family members who are caregivers of these patients are said to have quality of life that ranged between moderate to low especially for caregivers of end-stage acute cancer patients (Kim et al., 2007).

Family members who act as primary caregivers typically often place the needs of their loved ones as the top priority compared to their own needs (Given et al., 2012). They are willing to sacrifice their rest time, activities related to their own self-care and will often only seek medical help if the situation urges them to do so (Ang & O, 2011; DuBenske et al., 2008; Teschendorf et al., 2007). This situation puts a burden upon the caregivers as a whole. Moreover, most of them are not well-equipped with in-depth knowledge and experience related to cancer and in the caring of patients suffering from the disease (Ferrell et al., 2013).

In a study conducted by the Malaysian Hospice Public Awareness Unit in 2016, it was found that more than half of the Malaysian population (53%) lived with an individual suffering from a chronic illness, which was equivalent to about 53% of the population in Malaysia (Malaysian Hospice Report, 2016). Of the total, 61% of the chronic patients preferred to be cared for at home, while 31.8% were cared for at home with the help of a family doctor. These percentages directly indicate that families have become the primary caregivers of these chronic patients.

Rationale of the Study

Caregiver burden is a significant problem in healthcare. Caregivers, who are frequently family members or close friends, are essential in supporting people with disabilities, chronic illnesses, or age-related disorders. The burden of care and the emotional cost of providing care can have a high impact on carers' lives (Elliott et al., 2010; Ellis et al., 2017). It's critical to comprehend the effects of caregiver burden on the both the qualityrangestient care and the well-, being of the caregivers. It is recognized that caregiver burden is linked to a number of destructive effects for caregivers, including problems with their bodily and mental health, a decline in their social participation, and a lower quality of life (Kim et al., 2007; Lee et al., 2016; Northouse et al., 2012). In order and to distinguish areas where assistance and interventions can be targeted to improve caregivers' well-being, it is important to focus into the specific aspects of quality of life that are influence by caregiver burden.Equal attention and concern should therefore be given to the caregivers as the quality of care received by the cancer patients is determined by them (Elliott et al., 2010; Ellis et al., 2017; Kim et al., 2007; Lee et al., 2016; Northouse et al., 2007; Stenberg et al., 2010).

Additionally,previous studies have found that support sources such as social support and coping strategies such as self-control or self-regulation act as mediators between burden and quality of life (Ellis et al., 2017; Fletcher et al., 2012; Hagedoorn et al., 2011; Kahriman & Zaybak, 2015; Newth & E, 2012; Pearce et al., 2006; Thielemann & Conner, 2009). A person's capacity to control their ideas, emotions, and behaviors is referred to as self-control. It may be able to alleviate the link between caregiver burden and quality of life (Ellis et al., 2017; Fletcher et al., 2012). It's crucial to comprehend how self-control functions in this situation since it could help explain how caregiver burden affects quality of life (Hagedoorn et al., 2011). A high level of self-control, for instance, may enable caregivers to handle stress more effectively and maintain a higher standard of living (Hagedoorn et al., 2008).

Purpose of the Study

Therefore, this study was conducted to evaluate the influence of caregiver burden on quality of life dimensions and the roles of self-control as the mediator between caregiver burden and quality of life dimensions as a result of lifestyle and emotional changes while providing care (Cameron et al., 2002; Cassidy et al., 2015; Ellis et al., 2017; Fletcher et al., 2012; Stenberg et al., 2010).

METHODS

Research Design

This study is a quantitative study that used a cross-sectional approach. The study was conducted in May 2017 to March 2018 in the homes of end-stage cancer patients seeking palliative care and hospice services around Penang and Sabah, Malaysia. Data were collected to obtain sociodemographic profiles of the primary caregivers of end-stage cancer patients, dimensions of caregiver quality of life using the Adult Carer Quality of Life Questionnaire (AC-QoL), caregiver burden using Zarit Burden Interview (J-ZBI-8) and primary caregiver self-control using Pearlin’s Sense of Mastery.

Respondents

A total of 97 primary family caregivers of 97 adult cancer patients receiving care at palliative care in 2 states in Malaysia participated in the parent study. The inclusion criteria were: (1) family caregiver of an adult cancer patient (aged ≥18 years) and (2) primary caregiver for the cancer patient.

The sampling method used to collect data was purposive sampling in which the criteria for the selection of respondents were determined by the willingness of the respondents to be involved in the study as well as the respondent being the primary caregiver, is a family member of end-stage cancer patients and has no history of mental problems. Before data were collected, the ethics application process was proposed to the Human Ethics Committee at Universiti Malaysia Sabah as well as the palliative care centers and hospices involved. To ensure there was no violation of research ethics, informed consent forms were also provided to the respondents who were willing to be involved in the study.

Table 1. Codes of Variables

Variable	Codes
Caregiver Burden	BPJ
Roles Strain	BPR
Personal Strain	BPS
Self-control	KWD
Quality Of Life	KUL
Support For Caring	SKP
Caring Choice	PUM
Caring Stress	TUM
Money Matters	KKW
Personal Growth	PMD
Sense of Value	NKD
Ability to Care	KUM
Carer Satisfaction	KPP

Instruments

The Adult Carer Quality of Life Questionnaire (AC-QoL) contained 40 items consisting of 8 subscales, namely support for caring, caring choice, caring stress, financial implications, personal growth, sense of value, ability to care and carer satisfaction. Each sub-scale contained 5 question items (Elwick et al., 2010). The total score for each subscale in a dimension of quality of life was in the range of 0 to 15 for each subscale. While the highest score overall, with the highest score of 15 for each dimension indicating a state of high quality of life, while the lowest score of 1 represents a state of poor quality of life. The response format of the items in the AC-QoL instrument used for this study was based on a four-point Likert scale (0-never, 1-sometimes, 2-often, and 3-always).

The Zarit Burden Interview (J-ZBI-8) used in this study was a simplified version containing 8 question items divided into 2 subscales, namely personal strain and role strain (Arai et al., 1997). The response format of the items in this instrument was based on a five-point Likert scale (0-never, 1- rarely, 2-sometimes, 3-always, and 4- very often). The total score was in the range of 0 to 32, with the highest score representing a severe load.

The Sense of Mastery Scale was used to evaluate self-control coping strategies, and it contained 7 items (Pearlin & Schooler, 1978). The response format of the items in this instrument was based on a four-point Likert scale (1- strongly disagree, 2- disagree, 3- agree, and 4- strongly agree). The total score of the primary caregiver's self-control was in the range of 1 to 28, with the highest score of 28 indicating a state of high self-control, while the lowest score of 1 represents a state of poor self-control. The highest score of 28 indicated a state of high self-control, and the lowest score of 1 represented a state of poor self-control.

Data Analysis

A structural equation model was tested on primary caregiver cancer patients receiving palliative care in Penang and Sabah Malaysia where patients received palliative care. A model was tested using structural equation modeling, which allows the researcher to find empirical evidence by testing a measurement model and a structural model. The model comprised three variables which are care burden, self-control, and quality of life. Among the variables, self-control was the endogenous and mediating variable. In this study, PLS-SEM analysis was used to obtain the study results. The choice of the analysis was made based on the criterion of this study's data which was normally distributed. In addition, the study also used a reflective model and involved a moderator variable which was self control. The choice made to conduct this PLS-SEM analysis was also due to several other factors that can predict and explain the target constructs (Hair, 2019), and may also explore the relationships between constructs. In addition, PLS-SEM is also capable of conducting analysis of complex structural equation models consisting of many constructs and indicators (Hair, 2019; Urbach, 2010).

RESULTS AND DISCUSSION

Results

Before data analysis was performed using SEM-PLS analysis, coding of the study's data was conducted. Table 1 shows the codes used for each variable.

Profile of the Respondents

Table 2 shows the profile of the respondents involved in this study, of which show 68.0% of the respondents were from palliative care centre and hospices in Penang and 32.0% from palliative care centre in Sabah. The average age of the respondents involved in this study is within 45 years age range (respondents' age ranged between 27 to 80 years). In terms of the highest level of education, the majority of the respondents, i.e., 41.2 %, have *Sijil Pelajaran Malaysia* qualifications. Out of the total of 97 respondents, 70.1% are female. Regarding marital status, 79.4 % of the caregivers of these cancer patients reported that they are married. In terms of racial background, most of the respondents are Chinese (34.4 %). Concerning their religious background, most of the respondents in this study are Buddhists (32.0%). Additionally, most primary caregivers consisted of wives to patients (30.9 %).

In terms of their employment, many of the caregivers stated being employed in the private sector (34.0%) with the majority earning income of around RM 1000 to RM 1500 (28.9%). In this study, caregivers of breast cancer patients recorded the highest percentage (25.8%), followed by caregivers of lung cancer patients (24.7%), caregivers of colon cancer patients (12.4%), caregivers of nasal cancer patients (9%), caregivers of liver cancer patients (7%) and caregivers of cervical cancer patients (7.2%). In terms of time spent with patient, the highest percentage (19.6 %) was recorded for respondents who spent 10 hours or more a day with the patient. Further details on the demographic profiles of the respondents can be referenced in Table 2.

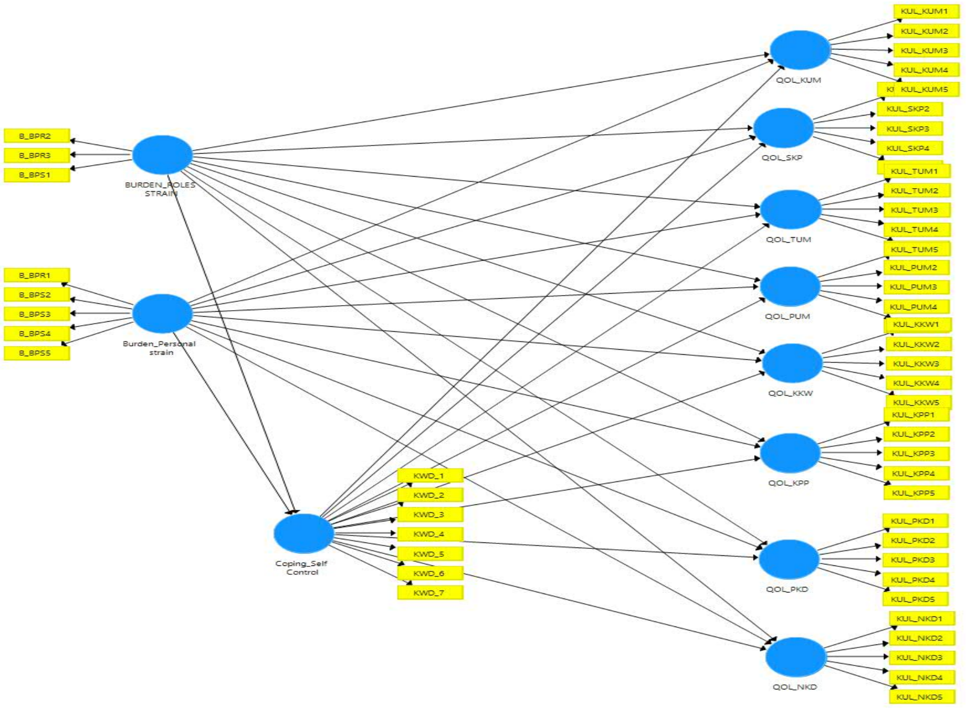
Table 2. Sociodemographic Profile

Profile	Frequency (N=97)	Percentage (%)
Gender		
Male	29	29.9
Female	68	70.1
Age	Mean: 45 years old (range of 23 to 80 years old)	
Religion		
Islam	28	28.9
Buddhist	31	32.0
Hinduism	13	13.4
Christian	25	25.8
Others	0	0
No record	0	0
Relationship with patient		
Parent	13	13.4
Children	26	26.8
Sibling	7	7.2
Husband	16	16.5
Wife	30	30.9
Father/Mother-in-law	1	1.0
Son/Daughter-in-law	4	4.1
No record	0	0
Race		
Malay	17	17.5
Chinese	33	34.0

Indian	23	23.7
Sabah Native	23	23.7
Sarawak Native	1	1.0
Others	0	0
Employment Status		
Government	10	10.3
Private	33	34.0
Self-employed	20	20.6
Student	3	3.1
Unemployed	22	22.7
Pensioner	9	9.3
No Record	0	0
Types of Cancer	25	25.8
Breast Cancer	13	13.4
Colon Cancer	23	23.7
Lung Cancer	7	7.2
Cervix Cancer	5	5.2
Ovary Cancer	2	2.1
Prostate Cancer	7	7.2
Liver Cancer	6	6.2
Rectal Cancer	1	1.0
Leukaemia	3	9.3
Nasopharynx Cancer	5	5.2
Others	0	0
No Record	0	0
Level of Education		
Master/ PhD	0	0
Degree	1	1.0
Diploma/ STPM	10	10.3
SPM	40	41.2
SRP/PMR	27	27.8
Others	19	19.6
No Record	0	0
Marital Status		
Single	24	24.7
Married	73	75.3
Single Parent/Widow	0	0
No Record	0	0
Household Income		
No salary	20	20.6
RM 1000 and below	18	18.6
RM 1001 to RM 1500	28	28.9
RM 1501 to RM 2000	20	20.6
RM 2001 to RM 2500	8	8.2
RM 2501 to RM 3000	2	2.1
RM 3000 and above	1	1.0
No Record	0	0
Time Spent with Patient (daily)		
0 to 1 hours	8	8.2
1 to 2 hours	11	11.3
3 to 4 hours	14	14.4
4 to 5 hours	10	10.3
5 to 7 hours	7	7.2
7 to 8 hours	17	17.5
8 to 10 hours	11	11.3
10 hours and above	19	19.6
No Record	0	0

Path Coefficients

Figure 1 shows the results of the path coefficient for the direct relationship, while Table 3 presents the hypothesis testing analysis for the direct relationship structural model. The R^2 value for the quality of life in terms of support for caring (SKP) was at .350, which indicated that 35% of the variance in quality of life could be explained by personal strain (BPS) and role strain (BPR). Based on Cohen (1988), the range of R^2 value between .02 to .12 is considered weak, .13 to .25 is considered moderate, and .26 and above is considered a large influence. BPS (β= -.212, p<.05) had a moderate negative influence on SKP, while BPR (β= .010, p>.05) had no significant influence on SKP.



BPR = Role Strain, BPS = Personal Strain, KKW = Financial Implications, KPP = Carer Satisfaction, KUM = Ability to Care, NKD = Sense of Value, PMD = Personal Growth, PUM = Caring Choice, SKP = Support for Caregivers, TUM = Caring Stress, KWD = Self-control

Figure 1. Path Coefficients for the Direct Relationship between Caring Burden, Self -control and Quality of Life Dimensions

Direct Effect between Caring Burden and Dimensions of Quality of Life

R^2 value for quality of life in terms of caring stress (TUM) was .361, indicating that 36.1% of the variance in quality of life could be explained by personal strain (BPS) and role strain (BPR). Further evaluation showed that R^2 was significant and had a large influence based on the guideline of R^2 evaluation by Cohen (1988). It was found that BPS (β= -.432, p<.01) and BPR (β= -.179, p<.05) had a negative influence on TUM.

Next, the R^2 value obtained for quality of life in terms of sense of value (NKD) was at .205 which indicated that 20.5% of the variance in quality of life could be explained by personal strain (BPS) and role strain (BPR). Further examination revealed that R^2 was significant and was of moderate influence based on Cohen's (1988) R^2 evaluation guideline. It was found that BPR (β= .229, p<.05) had a moderate positive influence on NKD while BPS (β= -.143, p>.05) did not have any influence on NKD.

The R^2 value obtained for quality of life in terms of personal growth (PMD) was .164, indicating that 16.4% of the variance in quality of life could be explained by personal strain

Table 3. Path Coefficients for the Direct Effect between Caring Burden and Dimensions of Quality of Life

Effect	Alpha Beta	R^2	S.E	t-value	Result
BPS -> SKP	-.212*	.350	.100	2.121	Significant
BPS -> TUM	-.432**	.361	.087	4.977	Significant
BPS -> NKD	-.101	.205	.112	.901	Not Significant
BPS -> PMD	-.245*	.164	.115	2.141	Significant
BPS -> PUM	.072	.245	.118	.608	Not Significant
BPS -> KPP	-.090	.204	.119	.757	Not Significant
BPS -> KUM	-.289*	.269	.100	2.892	Significant
BPS -> KKW	-.170	.208	.107	1.593	Not Significant
BPR -> SKP	.010	.350	.120	.087	Not Significant
BPR -> TUM	-.179*	.361	.108	1.654	Significant
BPR -> NKD	.229*	.205	.110	2.084	Not Significant
BPR -> PMD	.214	.164	.153	1.397	Not Significant
BPR -> PUM	-.121	.245	.158	.768	Not Significant
BPR -> KPP	.028	.204	.141	.199	Not Significant
BPR -> KUM	.245*	.269	.119	2.058	Not Significant
BPR -> KKW	.036	.208	.118	.308	Not Significant

Note: *Significant at p<.05; **Significant at p<.01, Bootstrapping (n=97)
BPR = Role Strain, BPS = Personal Strain, KKW = Financial Implications, KPP = Carer Satisfaction, KUM = Ability to Care, NKD = Sense of Value, PMD = Personal Growth, PUM = Caring Choice, SKP = Support for Caregivers, TUM = Caring Stress, KWD = Self-control

(BPS) and role strain (BPR). Further examination revealed that R^2 was significant and was of moderate influence based on Cohen's (1988) R^2 evaluation guideline. It was found that BPS (β= -.245, p<.05) had a non-significant negative influence on PMD while BPR (β= .214, p>.05) did not have any influence on PMD.

The R^2 value obtained for quality of life in terms of caring choice (PUM) was .245, indicating that 24.5% of the variance in quality of life could be explained by personal strain (BPS) and role strain (BPR). Further evaluation showed that R^2 was significant and had a large influence on PUM based on the R^2 evaluation guideline by Cohen (1988). It was found that the constructs of BPS (β= .072, p>.05) and BPR (β= -.121, p>.05) did not have any significant influence on PUM.

Next, the R^2 value for quality of life in terms of carer satisfaction (KPP) was .204, indicating that 20.4% of the variance in quality of life could be explained by personal strain (BPS) and role strain (BPR). Further evaluation revealed that R^2 was significant and had a moderate influence based on Cohen's (1988) R^2 evaluation guideline. It was found that the constructs of BPS (β= -.090, p>.05) and BPR (β= .028, p>.05) did not have any significant negative influence on KPP.

The R^2 value for quality of life in terms of ability to care (KUM) was found to be .269 and this indicated that 26.9% of the variance in quality of life could be explained by personal strain (BPS) and role strain (BPR). Further examination revealed that R^2 was significant and had a large influence based on Cohen's (1988) R^2 evaluation guideline. It was found that BPS (β= -.289, p<.01) had a significant negative influence on KUM while BPR (β= .245, p<.01) had a positive influence with KUM. Even though BPR had a positive influence on KUM, it is still considered to contribute value to the model indirectly.

The value of R^2 obtained for the last subscale of quality of life in terms of money matters (KKW) was .208, indicating that 20.8% of the variance in quality of life could be explained by personal strain (BPS) and role strain (BPR). Further evaluation showed that R^2 was not significant and was of moderate influence based on Cohen's (1988) R^2 evaluation guideline. It was found that carers' experience of BPS (β= -.170, p>.05) and BPR (β= .036, p>.05) did not have any negative influence on KKW.

Table 4 presents the hypothesis testing analysis for the direct relationship structural model. The R^2 value for the quality of life in terms of support for caring (SKP) was .350, indicating that 35% of the variance in quality of life could be explained by self-control (KWD). Further evaluation showed that the R^2 value was significant and of a large influence based on Cohen's (1988) R^2 evaluation guideline where R^2 value in the range of .02-.12 is interpreted as weak influence, .13-.25 is moderate and .26 and above is large. In addition, it was found that KWD (β= -.017, p>.05) had a significant positive influence on SKP. Thus, the hypothesis that states self-control has a significant influence on SKP was not supported.

Direct Effect between Self -control and Dimensions of Quality of Life

Next, the R^2 value obtained for quality of life in terms of caring stress (TUM) was .361, indicating that 36.1% of the variance in quality of life could be explained by self-control (KWD). Further evaluation revealed that R^2 was significant and of a large influence based on Cohen's (1988) R^2 evaluation guideline. It was found that KWD (β= .057, p>.05) did not have a significant influence on TUM.

The R^2 value for quality of life in terms of sense of value (NKD) was .205, indicating that 20.5% of the variance in quality of life could be explained by self-control (KWD). Further evaluation showed that R^2 was significant and of a moderate influence based on Cohen's (1988) R^2 evaluation guideline. It was found that KWD (β= .046, p>.05) did not have a significant positive relationship with NKD.

The R^2 value obtained for quality of life in the aspect of personal growth (PMD) was .164 and this indicated that 16.4% of the variance in quality of life could be explained by self-control (KWD). Further evaluation revealed that R^2 was significant and of a moderate influence based on Cohen's (1988) R^2 evaluation guideline. It was found that KWD (β= .031, p>.05) did not exert a significant positive influence on PMD.

Next, the R^2 value for the quality of life in terms of caring choice (PUM) was .245, indicating that 24.5% of the variance in quality of life could be explained by self-control (KWD). Further examination showed that R^2 was significant and of a large influence based on Cohen's (1988) R^2 evaluation guideline. It was found that KWD (β= .275, p<.05) had a positive relationship with PUM.

The R^2 value obtained for quality of life in terms of the aspect of carer satisfaction (KPP) was .204, indicating that 20.4% of the variance in quality of life could be explained by self-control (KWD). Further examination revealed that R^2 was significant and was of moderate influence based on Cohen's (1988) R^2 evaluation guideline. It was found that KWD (β= .147, p>.05) did not exert a significant positive influence on KPP.

The R^2 value for quality of life in terms of ability to care (KUM) was .269, indicating that 26.9% of the variance in quality of life could be explained by self-control (KWD). Further

Table 4. Path Coefficients for Direct Effect between Self -control and Dimensions of Quality of Life

Effect	Alpha Beta	R2	SE	t-value	Result
KWD -> SKP	-.017	.104	.350	.163	Not Significant
KWD -> TUM	.057	.101	.361	.570	Not Significant
KWD -> NKD	.046	.123	.205	.375	Not Significant
KWD -> PMD	.031	.106	.164	.297	Not Significant
KWD -> PUM	.275	.123	.245	2.237	Significant
KWD -> KPP	.147	.120	.204	1.222	Not Significant
KWD -> KUM	-.071	.104	.269	.683	Not Significant
KWD -> KKW	-.040	.124	.208	.324	Not Significant

Note: *Significant at p<.05; **Significant at p<.01, Bootstrapping (n=97)

BPR = Role Strain, BPS = Personal Strain, KKW = financial implications, KPP = Carer Satisfaction, KUM = Ability to Care, NKD = Sense of Value, PMD = Personal Growth, PUM = Caring Choice, SKP = Support for Caregivers, TUM = Caring Stress, KWD = Self-control evaluation revealed that R^2 was significant and of a large influence based on Cohen's (1988) R^2 evaluation guideline. It was found that KWD (β= -.071, p>.05) did not have a significant influence on KUM.

The R^2 value for the last subscale of quality of life in terms of the aspect of money matters (KKW) was .208, indicating that 20.8% of the variance in quality of life could be explained by self-control (KKWD). Further examination revealed that R^2 was not significant and was of moderate influence based on Cohen's (1988) R^2 evaluation guideline. It was found that KWD (β= -.040, p>.05) did not have a significant relationship with KKW.

Testing the Mediating Effect

The bootstrapping analysis presented in Table 5 shows the indirect effect of BPR on all the dimensions of quality of life, namely KKW (β = .000), KPP (β = .011), KUM (β = -.004), KUM (β = -.004), NKD (β = .004), PMD (β = .002), PUM (β = .010), SKP (β = -.001), and TUM (β = .007, t = .368) are not significant with t-value.

Next, based on the bootstrapping analysis, it was found that there was no the indirect effect of BPS on KKW (β = .000, t =.001), KPP (β = .002, t = .102), KUM (β = -.001, t = .057), NKD (β = .001, t = .054), PMD (β = -.001, t = .035), PUM (β = .002, t = .082), SKP (β = .000, t = .018) and TUM (β = .002, t = .083). If the 95% confidence limits include zero, the indirect effect test is not significant. Thus, it can be concluded that there was no mediation effect for all the constructs of BPS and BPR with the eight dimensions of quality of life (KKW, KPP, KUM, NKD, PMD, PUM, SKP, and TUM).

Discussion

Personal strain refers to the stressful situation experienced by an individual because of the individual's reluctance to shoulder a responsibility or task (Williams & Bakitas, 2012). In this study, the caregivers who were family members were reluctant to assume the duties as the primary caregiver but had to shoulder the responsibility because of family ties or forced by some circumstances, such as the absence of other family members to carry out the responsibility. According to several researchers including (Boehmer & Clark, 2001; Drageset

Table 5. Path Coefficients for the Indirect Effect between Caring Burden, Self control and Dimensions of Quality of Life

Relationship	SB	SE	T	M	Bias	Confident Interval		Mediation
						LL (2.5%)	UL (97.5%)	
BPR -> KWD -> KKW	.000	.018	.002	-.003	-.003	-.038	.043	No
BPR -> KWD -> KPP	.011	.025	.425	.014	.003	-.027	.070	No
BPR -> KWD -> KUM	-.004	.016	.224	-.003	.001	-.060	.014	No
BPR -> KWD -> NKD	.004	.020	.216	.007	.003	-.018	.071	No
BPR -> KWD -> PMD	-.002	.019	.128	.003	.006	-.081	.019	No
BPR -> KWD -> PUM	.010	.028	.352	.014	.004	-.031	.077	No
BPR -> KWD -> SKP	-.001	.013	.068	.000	.001	-.033	.019	No
BPR -> KWD -> TUM	.007	.018	.386	.006	-.001	-.015	.072	No
BPS -> KWD -> KKW	.000	.016	.001	-.002	-.002	-.025	.042	No
BPS -> KWD -> KPP	.002	.024	.102	.002	.000	-.040	.058	No
BPS -> KWD -> KUM	-.001	.014	.057	-.001	.000	-.042	.020	No
BPS -> KWD -> NKD	.001	.018	.054	.002	.001	-.026	.054	No
BPS -> KWD -> PMD	-.001	.016	.035	-.001	.000	-.046	.027	No
BPS -> KWD -> PUM	.002	.028	.082	.004	.002	-.041	.078	No
BPS -> KWD -> SKP	.000	.011	.018	-.001	-.001	-.030	.018	No
BPS -> KWD -> TUM	.002	.020	.083	.003	.001	-.025	.060	No

Note: *Significant at p<.05; **Significant at p<.01, Bootstrapping (n=97) BPR = Role Strain, BPS = Personal Strain, KKW = Financial Implications, KPP = Carer Satisfaction, KUM = Ability to Care, NKD = Sense of Value, PMD = Personal Growth, PUM = Caring Choice, SKP = Support for Caregivers, TUM = Caring Stress, KWD = Self-control et al., 2012; Williams & Bakitas, 2012), personal strain results from the unwillingness of the patient's own family members to shoulder the responsibility that have been entrusted on them. Personal strain has a negative influence on the quality of life's dimension in terms of support for caregiver.

The findings of this study are in line with the findings of (Vrontaras, 2018) as personal strain that is experienced by a caregiver will reduce the acceptance of their support, especially in terms of emotional support, practical, information and professional support. The compulsion to take on the duties as caregivers reduces their initiative to seek such support. Moreover, professionals and the surrounding community often assume that these cancer patient caregivers have the knowledge and understand the needs of the patients being cared for (Northouse et al., 2012). Most caregivers assume that the support given to them is something that helps but at times such support is perceived as a burden or distraction (Northouse et al., 2012), in this study, personal strain also exerted a significant negative influence on quality of life in terms of caring stress.

Responsibilities of caring require the caregiver to adapt to a variety of situations in caring for the cancer patient that result in changes in the caregiver's life patterns and quality of life (Hagedoorn et al., 2008). The personal strains that occur in caregivers during the care of cancer patients at this late stage also have a negative impact on their ability to cope with the caring stress (Williams & Bakitas, 2012). In this study, personal strain was also found to have a significant negative influence on quality of life in terms of self -development. The findings of this study are in line with the findings of (Burridge et al., 2007). The findings of (Burridge et al., 2007) show that the family's reluctance to care affects the caregiver's relationship with the patient, thus lowering the quality of care. The reluctance of families to shoulder this responsibility is also due to their perception that this responsibility to care will require them to sacrifice their time, social activities as well as their lives.

Furthermore, personal strain also has a significant negative influence on quality of life in terms of ability to care. This finding is supported by (Burridge et al., 2007) who argued that the conflicts that occur between caregivers and patients in turn will affect the quality of care as well as their ability to care for patients. Yet, the finding is inconsistent with the findings of (Girgis et al., 2013) who reported the personal strain that occurs in caregivers has a negative influence on their overall quality of life.

The discrepancy between the findings of this study and previous studies is likely due to the cultural factors in the Malaysian society itself. In Asian family tradition, a large part of the caring role must be provided by the immediate family and this situation resulted in family members having no choice but to accept the assigned role. All patient care matters are also seen as more personal matters and are associated with the traditional functions of the family. This situation gives rise to the tendency for caregivers to keep personal matters secret and not to discuss all problems concerning the care of patients with others especially those related to the patients' health and financial condition to avoid society perceiving them negatively (Pinquart & Sorensen, 2011). Moreover in Asian practice, any bad aspect of family should not be discussed openly with anyone as to protect the honour of the family.

Contrary to the concept of personal strain, role strain refers to the changes experienced by an individual in terms of tasks because of their role as the primary caregiver and the role exceeding the existing workload. Taking on the role as a caregiver requires the caregiver to adapt to various changes in their daily life situations especially those involving their role as a caregiver (Hagedoorn et al., 2008). Similar to personal strain, role strain also has a significant negative influence on quality of life, especially from the aspect of caring stress. The role strain that occurs within the caregivers affects their control over stress in providing care. The findings of this study are in line with the findings of (Bevans & Sternberg, 2012; Kizza & Muliira, 2020;

Krug et al., 2016), where all the findings in these studies indicate that role strain will affect the quality of the caregivers' lives.

When caregivers feel that the tasks of caring assigned to them are burdensome and difficult, it then tends to cause difficulty in controlling the pressure to care (Krug et al., 2016). According to (Krug et al., 2016), this occurs because of the lack of preparation or the lack of confidence in performing the tasks of caring well. Additionally, society's expectations or views also contribute to the burden of care as many other family members and outsiders assume that the task of caring for such cancer patients involving family members has to be carried out perfectly (Kizza & Muliira, 2020). This situation causes the caregiver to experience strain in terms of their role as carers especially when the patient in their care suffers from deteriorating health as well as physical disability and is completely dependent on the help from the caregiver.

Role strain also has a significant positive influence on the quality of life, especially from the aspect of sense of value and the aspect of ability to care. The findings of this study do not support the research hypothesis and they also contradict the findings of a previous study by (Girgis et al., 2013). The increase in the role or duties of the primary caregiver does not place any burden on the caregiver; instead, it has a positive impact on their ability to provide for the needs of the patients, especially in this terminal phase. This may also be influenced by the sense of responsibility or bond that exists in the family itself as well as help from the hospice.

Although the caregivers need to find alternatives to understand and learn patient care procedures, the situation is not considered a burden to them. On the contrary, they feel the action will facilitate their task of monitoring and managing patient needs. The knowledge and skills related to patient management will also enhance the ability of the primary caregivers to carry out the responsibilities entrusted on them, especially those related to medication intake, hospital appointments, dietary intake, management of patient's transport to the hospital, management of patient's daily needs as well as monitoring of patient's state of health and ways to manage the symptoms of pain. The ability of the caregivers to perform their duties also increases with the home visit programmes conducted by palliative care centre and hospices.

Although role strain is said to have an influence on quality of life as stated by (Karabulutlu, 2014), it is different in the findings of this study. Role strain was found to have a non-significant negative influence on quality of life in terms of support for caring, personal growth, caring choice, carer satisfaction, and money matters. This inconsistency in findings may also occur because of the values inherent in the caregiver where they assume that this caring role is their responsibility as a family member. According to (LeSeure & Chongkham-Ang, 2015), the culture of a community also contributes to the inconsistency of these findings. The culture in some places like Asian countries often place the responsibility to fulfill the needs of the patients among the family members even if they are not ready or prepared to care.

In addition, the findings of the study revealed that role strain did not exert a negative influence on quality of life in terms of support for caregiver. This is likely due to the sharing of role burdens by caregivers with hospitals, palliative care centres and other family members. According to a study by (Tan et al., 2018), the support received by caregivers in terms of emotional, practical, and also professional support helps to reduce the burden found in caregivers, especially those related to matters involving care. In this study, the nurses and doctors from the hospice often perform health monitoring for the patients by making home visits and conducting health examinations on the patients.

They also help to identify the needs of the caregivers in managing the patients. Sharing the strain of this role with hospices and palliative care centre helps to alleviate the strain that occurs within the caregivers and makes the caregivers feel that they can manage all their tasks. In this study, it was found that role strain that occurred did not affect the caregiver's quality of life in terms of sense of value. The inconsistency of these findings with the findings from other studies may be attributed to the religious values and beliefs that the caregivers hold, similar to the findings in the study of (Lkhoyaali et al., 2015). According to Lkhoyaali and colleaques, family caregivers often do not care about the rewards or appreciation that they will receive in this world for the role they have contributed. This is due to their religious belief that emphasizes more on the rewards given in the hereafter.

In this study, it was also found that role strain did not exert any influence on the quality of life in terms of caregiver satisfaction. The findings of this study are inconsistent with those of (Kim et al., 2007) and a plausible reasoning could be due to the age factor of the respondents in this study. The age range of the respondents in this study were between 23 to 80 years old. At this age range, most caregivers would be more likely to focus on their future and family than on their personal interests and social life. They no longer see their satisfaction as a priority at this point; the patients they are taking of return to health as before. Yet, what happens is the opposite as often the patient's state of health deteriorates further and only waits for a second to return to his Creator.

Implications

This study is expected to be able to contribute in terms of knowledge on care among families who experience the burden of care, especially on aspects of their role and personal strain that would affect some dimensions of their quality of life. In these situations, social workers and medical social workers play an important role in providing psychosocial support and connecting these caregivers with the network of resources available in the community so that the dimensions in the quality of life of the primary caregivers of end-of-life cancer patients can be enhanced. Psychosocial support can be provided by the people in the helping profession through social work and counselling to help end-stage of cancer patients and their caregivers deal with the issues faced because the issues in caring are issues that will have no end even after the patient has passed away.

Limitations and Suggestions for Further Research

Although there are limitations of the study that have been described in the previous section, this study can be extended further by making some improvements so that it can benefit the helping profession especially social workers and other researchers. Therefore, it is suggested that studies related to the dimensions of quality-of-life of cancer patient caregivers especially in the field of social work, are further explored in the future. Longitudinal follow-up studies or cohort studies should be conducted on caregivers' experiences in caring for cancer patients and after the patients have recovered or passed away to understand the real phenomenon of whether the caregiver's quality of life remains the same or changes because it is also influenced by the factors mentioned previously. Studies using a qualitative research approach with phenomenological design or case studies can also be performed. This is highly relevant since the number of caregivers among families who are willing to involve in such studies is generally low. Finally, future studies will be more interesting if can use research models that combine various variables or constructs in demographic characteristics, personality traits, spirituality and environmental elements that affect the quality of life of end-stage cancer caregivers either directly or indirectly.

CONCLUSION

Problems in the field of health not only affect patients, as it is common knowledge that they also affect families and other support systems. Families, as the primary caregiver of end-stage cancer patients, will always face various challenges and burdens that will affect the dimensions in their quality of life. Studies have found that the quality of life of caregivers of end-stage cancer patients is influenced by several factors. However, the results of this study indicate that not all variables or constructs formulated in the study's model were proven to influence significantly the quality of life among caregivers of terminally ill cancer patients either directly or indirectly. These results indicate the need to restructure and review research models or theoretical models that examine the factors influencing the quality of life of caregivers of cancer patients who are in this final stage.

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AUTHOR CONTRIBUTION STATEMENT

This work was conducted in collaboration with all authors. All authors are involved in the conception and design, collection and assembly of data, data analysis and interpretation, and manuscript writing. All authors WKAG, AF, SL, and HY reviewed carefully and approved the final version of the manuscript.

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