BURDEN IN FAMILY CAREGIVERS OF CANCER PATIENTS: THE ASSOCIATION WITH DEPRESSION, RELIGIOSITY AND RELIGIOUS COPING

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ABSTRACT

Background: Cancer caregiving is a challenging task and often associated with significant burden in the family caregivers, comparable to the distress experienced by the cancer patients. Yet, the healthcare providers often overlook the needs of the caregivers. In line with the increasing trend of cancer cases worldwide, there is a need to examine factors influencing the caregiver burden, and to find ways to improve the quality of life of the caregivers.

Objectives: The study aimed to validate the Malay version of Zarit Burden Interview (MZBI) for use in determination of the caregiver burden rate among the local family caregivers of cancer patients, and to examine the associations between the caregiver burden and their sociodemographic factors, clinical factors, levels of depression, religiosity, and religious coping.

Methodology: In total, 177 family caregivers of cancer patients in a government tertiary hospital in Sarawak were recruited in this two-phased cross-sectional study using non-random sampling method. The first phase involved validation process in which 50 caregivers were given the following measures: 1) Sociodemographic and clinical questionnaire, 2) MZBI, 3) Malay version of Center for Epidemiologic Studies – Depression (MCES-D), and 4) English version of Zarit Burden Interview (EZBI). The second phase (main phase) involved examination of the associations in which 127 caregivers completed the following measures: 1) Sociodemographic and clinical questionnaire, 2) MZBI, 3) MCES-D, 4) Malay version of Duke University Religion Index (DUREL-M), and 5) Malay version of Brief RCOPE (M-RCOPE). The associations between the variables were determined through bivariate analyses (Chi-Square test), followed by multivariate analysis to find out the factor(s) that remained significantly associated with the caregiver burden.

Results: The MZBI demonstrated good reliability with high internal consistency (α = 0.898) and split-half correlation of 0.912, and significant positive correlation with MCES-D (rs = 0.58, p < 0.01). Median caregiver age in the main study was 42 years (range, 19 - 67 years). Caregivers were mostly women (67.7%), spouses of cancer patients (44.9%), married (80.3%), unemployed (52.0%), and with household income less than RM 3,000 per month (56.7%). Median duration as caregiver was nine months and median time spent on caregiving was 128 hours per week. Majority (78.7%) had shared caregiving but only 0.8% sought external support e.g. maids or private nursing services. The caregiver burden rate among cancer caregivers was 55.6%. Caregivers who were the children/grandchildren of cancer patients experienced significantly fewer burden than non-children/grandchildren caregivers (OR 0.41, CI 0.18 – 0.94, p = 0.035). The caregiver depression was significantly associated with the caregiver burden (OR 4.26, CI 1.87 – 9.72, p = 0.001). However, no significant associations were found between the religiosity and religious coping with the caregiver burden.

Conclusion: Caregiver burden is common among family caregivers of cancer patients. Caregivers who are the children or grandchildren of cancer patients are less likely to experience caregiver burden, whereas caregivers who have probable depression are more likely to experience caregiver burden. Future studies should assess the effects of specific intervention strategies in helping these caregivers.

Keywords: Family caregiver, cancer, burden, depression, religiosity, religious coping

ABSTRAK

Latar belakang: Penjagaan penyakit kanser merupakan satu tugas yang mencabar dan sering dikaitkan dengan beban yang ketara di kalangan penjaga keluarga, sebanding dengan kesusahan yang dialami pesakit kanser. Namun, pihak anggota kesihatan sering terlepas pandang keperluan golongan penjaga. Seiring dengan peningkatan kes-kes kanser di serata dunia, timbulnya keperluan untuk memeriksa faktor-faktor yang mempengaruhi beban penjaga, dan mencari jalan penyelesaian bagi meningkatkan kualiti kehidupan golongan penjaga.

Objektif: Kajian ini bertujuan untuk mengesahkan Temuramah Beban Zarit versi Bahasa Melayu (MZBI) yang digunakan dalam penentuan kadar beban penjaga di kalangan penjaga keluarga tempatan bagi pesakit kanser, di samping untuk memeriksa hubung-kait di antara beban penjaga dengan faktor-faktor sosio-demografi, faktor-faktor klinikal, kemurungan, keagamaan dan penyesuaian agama di kalangan penjaga.

Metodologi: Keseluruhannya, 177 penjaga keluarga bagi pesakit kanser di sebuah hospital kerajaan di Sarawak telah menyertai kajian keratan rentas dua fasa ini melalui kaedah persampelan bukan rawak. Fasa pertama melibatkan proses pengesahan di mana 50 penjaga diberikan soal-selidik yang berikut: 1) Soal-selidik sosio-demografi dan klinikal, 2) MZBI, 3) *Center for Epidemiologic Studies – Depression* versi Bahasa Melayu (MCES-D), dan 4) Temuramah Beban Zarit versi Bahasa Inggeris (EZBI). Fasa kedua (fasa utama) melibatkan pemeriksaan hubung-kait di mana 127 penjaga dikehendaki menjawab soal-selidik yang berikut: 1) Soal-selidik sosio-demografi dan klinikal, 2) MZBI, 3) MCES-D, 4) Indeks Agama *Duke University* versi Bahasa Melayu (DUREL-M), dan 5) *Brief* RCOPE versi Bahasa Melayu (M-RCOPE). Hubung-kait di antara variabel ditentukan melalui analisis bivariat (ujian Chi-Square), diikuti oleh analisis multivariat untuk mengenal pasti faktor(-faktor) yang kekal berkaitan secara signifikan dengan beban penjaga.

Keputusan: MZBI menunjukkan kebolehpercayaan yang baik dengan ketekalan dalaman tinggi (α = 0.898) dan koefisien bahagi dua bernilai 0.912, di samping korelasi positif yang signifikan dengan MCES-D (rs = 0.58, $p < 0.01$). Umur median penjaga dalam kajian utama adalah 42 tahun (lingkungan, 19 – 67 tahun). Kebanyakan penjaga terdiri daripada wanita (67.7%), pasangan kepada pesakit kanser (44.9%), berkahwin (80.3%), tidak bekerja (52.0%), dan mempunyai pendapatan isi rumah kurang daripada RM 3,000 sebulan (56.7%). Tempoh median sebagai penjaga adalah sembilan bulan dan masa penjagaan median adalah 128 jam seminggu. Majoriti (78.7%) berkongsi penjagaan tetapi hanya 0.8% meminta bantuan luar seperti pembantu rumah atau jururawat peribadi. Kadar beban penjaga di kalangan penjaga bagi pesakit kanser adalah 55.6%. Penjaga yang merupakan anak/cucu kepada pesakit kanser mengalami beban yang kurang secara signifikan berbanding dengan penjaga yang bukan anak/cucu (OR 0.41, CI 0.18 – 0.94, $p = 0.035$). Kemurungan penjaga berkaitan secara signifikan dengan beban penjaga (OR 4.26, CI 1.87 – 9.72, $p = 0.001$). Namun, tiada kaitan yang signifikan didapati di antara keagamaan dan penyesuaian agama dengan beban penjaga.

Kesimpulan: Beban penjaga amat kerap dialami penjaga keluarga bagi pesakit kanser. Penjaga yang merupakan anak atau cucu kepada pesakit kanser kurang berisiko untuk mengalami beban penjaga, manakala penjaga yang berkemungkinan mengalami kemurungan lebih berisiko untuk mengalami beban penjaga. Kajian pada masa depan perlu menilai keberkesanan strategi spesifik dalam usaha membantu golongan penjaga yang berkenaan.

Kata kunci: Penjaga keluarga, kanser, beban, kemurungan, keagamaan, penyesuaian agama

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LIST OF ABBREVIATIONS

AUC	Area Under the Curve
BDI	Beck Depression Inventory
CES-D	Center for Epidemiological Studies – Depression scale
DASS	Depression, Anxiety and Stress Scale
DSM	Diagnostic and Statistical Manual of Mental Disorders
DUREL	Duke University Religion Index
DUREL-M	Malay version of Duke University Religion Index
ECOG	Eastern Cooperative Oncology Group
EZBI	English version of Zarit Burden Interview
GLOBOCAN	Global Burden Of Cancer study
HADS	Hospital Anxiety and Depression Scale
IARC	International Agency for Research on Cancer
IqR	Interquartile Range
IR	Intrinsic Religiosity
MCES-D	Malay version of Center for Epidemiological Studies – Depression scale
MREC	Medical Research and Ethics Committee
M-RCOPE	Malay version of Brief Religious Coping Questionnaire
MZBI	Malay version of Zarit Burden Interview
NMRR	National Medical Research Registry
NORA	Non-Organizational Religious Activity
NRC	Negative Religious Coping
ORA	Organizational Religious Activity
PRC	Positive Religious Coping
RCOPE	Religious Coping questionnaire
ROC	Receiver Operating Characteristics
rs	Spearman’s rho
RTU	Radiotherapy Unit
SD	Standard Deviation
SGH	Sarawak General Hospital
ZBI	Zarit Burden Interview

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CHAPTER 1

INTRODUCTION

1.1 BACKGROUND OF THE STUDY

Cancer is among the leading causes of morbidity and mortality in most parts of the world. In 2012, approximately 14 million new cases of cancer were diagnosed based on the Global Burden of Cancer (GLOBOCAN) study conducted by the International Agency for Research on Cancer (IARC) of the World Health Organization. This number is postulated to increase to over 20 million by 2025, with the low and middle-income countries bearing most of the cancer burden (Ferlay et al., 2015).

According to the Malaysian National Cancer Registry, a total of 103,507 new cancer cases were diagnosed between 2007 and 2011 in Malaysia. This incidence rate was much lower than the estimated rate reported in GLOBOCAN 2012, as the latter was based on the Penang and Sarawak Cancer Registries with different ethnic distributions (Manan, Tamin, Abdullah, Abidin, & Wahab, 2016). From the same authors, Sarawak documented 9,734 new cancer cases or equivalent to about 9.4% of the national figures, and ranked fourth in the total cancer cases following Johor, Selangor and Penang.

It is well known that cancer causes significant physical and emotional impairments in its sufferers (Stein, Syrjala, & Andrykowski, 2008; Silver, Baima, & Mayer, 2013). Not only the patients, cancer also indirectly affects their significant others, many of whom are the primary informal caregivers (Blanchard, Albrecht, & Ruckdeschel, 1997; Lim, Kim, & Lee, 2013; Wozniak & Izycki, 2014). Cancer patients and their caregivers are frequently exposed to the complications of the disease itself, as well as the side effects of the various cancer treatments available.

According to Family Caregiver Alliance based in the United States, family (or informal) caregiver refers to any person, e.g. spouse, adult children, other relatives, neighbour or friend, who has a personal relationship with, and provides a wide range of unpaid assistance for, an older person or an adult with a chronic or disabling condition (Family Caregiver Alliance, 2014). This is different from a professional (or formal) caregiver, who is either a paid carer or a volunteer with no personal relationship with the person he or she is looking after.

Caring for a loved one can be associated with significant stress or burden, more so in caring for patients with chronic or terminal illnesses such as dementia and cancer. Among the difficult and time-consuming tasks faced by the family caregivers involve provision of emotional support to the patients, transportation of patients to the hospital for treatment, and management of the behavioural aspects, as well as the disease symptoms of the patients (Bakas, Lewis, & Parsons, 2001).

There is a significant reciprocal relationship between the emotional distress of cancer patients and their caregivers (Hodges, Humphris, & Macfarlane, 2005; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Northouse, Katapodi, Schafenacker, & Weiss, 2012). Thus, the management of cancer patients would be compromised if the caregivers’ well-being is affected (Mahadevan et al., 2013). Despite caregiving has a significant impact on the caregivers' well-being, the needs of the caregivers are often overlooked or considered secondary to those of the patients (Payne, Smith, & Dean, 1999).

Recent advancement in the diagnostic and therapeutic modalities has resulted in a paradigm shift in the cancer course and care plan (Rowland & Ganz, 2011; Shekarian, Valsesia-Wittmann, Caux, & Marabelle, 2015). The course of cancer has changed from being an acute condition with rapid or direct consequences, usually fatality, to a chronic illness with variable outcomes (Nijboer et al., 1998). This may translate to a need for long-term and continuous care for the cancer patients, with the integration of both informal and formal care systems.

Consequently, the family caregivers are at increased risk of being burdened with multiple stressful physical and psychosocial problems (Girgis, Lambert, Johnson, Waller, & Currow, 2013). Psychological problems such as anxiety, depression, or loneliness, are the most commonly recognised burdens in caregivers (Stenberg, Ruland, & Miaskowski, 2010). In line with the increasing trend of cancer cases and caregiver burden worldwide, there is now a need to look into the caregiving aspects and to find ways to improve the well-being of the family caregivers.

One suggested solution is through the study of religious or spiritual beliefs and practices, which is present in most human cultures since ancient times. Yet, research on the roles of religion and its relation to the human well-being accounts only a small fraction of the current literature in psychology (Ano & Vasconcelles, 2005). Religiosity, spirituality and religious coping have been shown to play important buffering roles in helping cancer patients to deal with psychological distress (Weaver & Flannelly, 2004). Thus, it is possible that these benefits might be extended to the cancer caregivers as well.

1.2 RATIONALE OF THE STUDY

There were many studies done overseas on the subject of caregiver burden among the family caregivers of cancer patients (Nijboer et al., 1998; Given et al., 2004; Northouse et al., 2012; Chua et al., 2016). However, most of the studies only identified the caregiver burden in general, but did not specifically look at the factors associated with the high burden among the caregivers (Hsu et al., 2014). In Malaysia, local published data about this subject is still lacking despite the increasing trend of cancer burden nationwide. There is also no validated scale in Malay language suitable for the measurement of cancer caregiver burden in local setting.

As to date, majority of the related studies on cancer caregiver burden in Malaysia were conducted in Peninsular Malaysia (Ambigga, Sherina, & Suthahar, 2005; Mahadevan et al., 2013; Jaafar et al., 2014), with only one qualitative study being carried out in Sarawak thus far (Cheong & Putit, 2011). The Sarawak study explored the caregiving experience of nine Chinese cancer caregivers, and implied the roles of nursing support in easing the suffering of the caregivers. However, the study did not determine the rate of caregiver burden and look into the various factors affecting this burden.

Sarawak, situated on the island of Borneo, is the largest state in Malaysia. It has more than 40 sub-ethnic groups with distinct cultures, religions, languages and lifestyles (Sarawak Tourism Federation, 2015). Due to its unique geographical location and substantial indigenous population, Sarawak holds different demographic profiles from Peninsular Malaysia (Lockard, Bee, Leinbach & Ahmad, 2017). The main five ethnic groups are Iban, Malay, Chinese, Bidayuh and Melanau (“State statistics”, 2014). Christianity makes up the largest religion in Sarawak, followed by Islam. Despite majority of the indigenous people have converted to Christianity, they still hold strong to their many traditional beliefs and rituals (Sarawak Tourism Federation, 2015). The diverse religious pluralism in Sarawak makes it suitable to study religiosity and religious coping with unique perspectives among the Sarawak people.

Thus, it is high time that a local study should be carried out in Sarawak, looking into the aspects of cancer caregiving burden as mentioned above. This research study will hence be able to provide the much needed baseline data for the Sarawak population. In addition to determining the rate of caregiver burden, the study will help us to explore and to identify the links between the caregiver burden and potential predictors such as the sociodemographic profiles, the level of depression, religious commitment and religious coping patterns in our local setting.

A better understanding of the unique association between all these factors is crucial to shed light on previously unrecognized issues that may affect the caregiving outcomes. It is hopeful that the findings from this study can guide the policy makers and the healthcare professionals on how to implement targeted intervention strategies to help the family caregivers in the future. In addition, this preliminary study might also provide some direction for future research in this area relevant to the local setting.

1.3 RESEARCH QUESTIONS

This study was designed to address the following research questions:

1. What is the rate of caregiver burden among the family caregivers of cancer patients?

2. What is the rate of depression among the family caregivers of cancer patients?
3. What are the levels of religiousness (or religiosity) and religious coping among the family caregivers of cancer patients?
4. Is the caregiver burden associated with the level of depression in the family caregivers?
5. Is the caregiver burden associated with the level of religiousness in the family caregivers?
6. Is the caregiver burden associated with the level of religious coping in the family caregivers?

1.4 RESEARCH OBJECTIVES

In relation to the above research questions, this study has the following objectives in mind:

1.4.1 General Objectives

1. To determine the rate of caregiver burden among the family caregivers of cancer patients
2. To determine the rate of depression among the family caregivers of cancer patients
3. To determine the level of religiousness and religious coping among the family caregivers of cancer patients

1.4.2 Specific Objectives

1. To establish the validity and reliability of the Malay version of the Zarit Burden Interview (MZBI) scale among the family caregivers of cancer patients
2. To determine a statistically valid cut-off score for the MZBI scale in order to identify the presence of significant caregiver burden
3. To examine the association between the caregiver burden with the sociodemographic factors, such as age, gender, ethnicity, marital and employment status etc.
4. To examine the association between the caregiver burden with the clinical factors, such as types and severity of cancer, treatment settings, functional status, caregiving duration etc.
5. To examine the association between the caregiver burden with the levels of depression, religiousness and religious coping in the family caregivers of cancer patients

1.5 RESEARCH HYPOTHESES

Based on the preceding specific objectives, the following research hypotheses were formulated:

1. There are significant associations between the cancer caregiver burden and their sociodemographic factors such as age, gender, ethnicity, marital, and employment status etc.

2. There are significant associations between the cancer caregiver burden and the clinical factors such as types and severity of cancer, treatment settings, functional status, caregiving duration etc.
3. There is a significant association between the cancer caregiver burden and their level of depression; i.e. higher depressive score is associated with higher caregiver burden, and vice versa
4. There is a significant association between the cancer caregiver burden and their level of religiosity; i.e. higher level of religiosity is associated with lower caregiver burden, and vice versa
5. There is a significant association between the cancer caregiver burden and their religious coping; i.e. positive religious coping is associated with lower caregiver burden *or* negative religious coping is associated with higher caregiver burden

1.6 CONCEPTUAL FRAMEWORK

The primary framework for this study was adapted and modified from the model framework of the caregiving process proposed by Nijboer et al. (1998). According to that model, the outcome differences of the caregiver burden can be influenced by exposure to either a stressor or a mediator. Stressors refer to factors that positively induce stress, and thus potentially increase the caregiver burden. On the other hand, mediators refer to factors that negatively reduce stress and may potentially lower the caregiver burden. Figure 1.1 illustrates the conceptual framework of the present study.

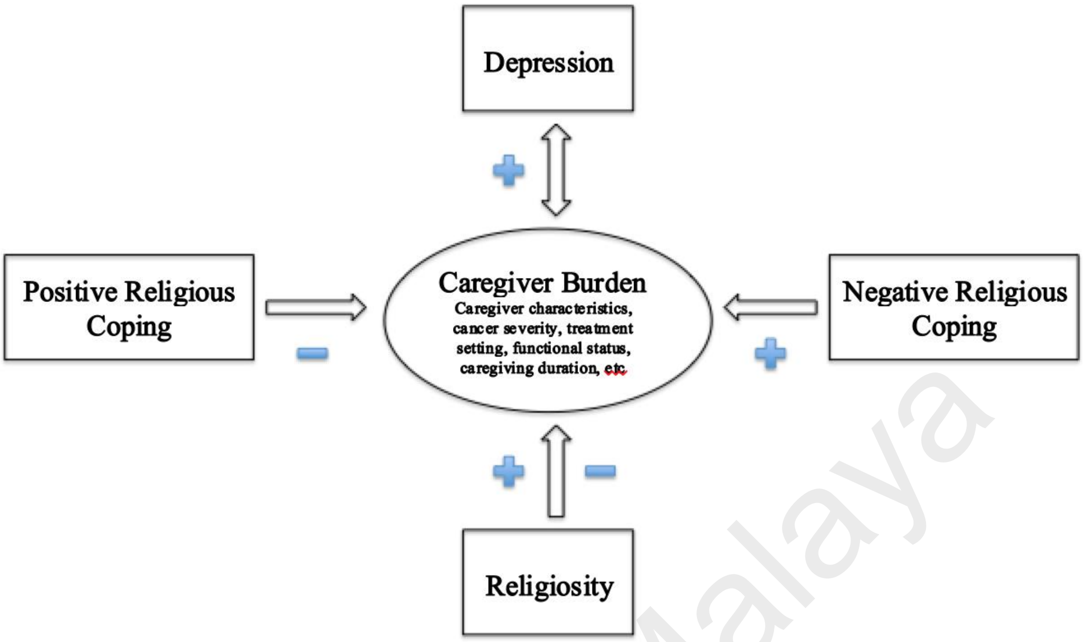


Figure 1.1: Conceptual framework of the research study

CHAPTER 2

LITERATURE REVIEW

2.1 CAREGIVER BURDEN

2.1.1 Definition and Setting of Caregiver Burden

In practice, the term ‘caregiver burden’ is frequently used interchangeably with other terms such as ‘caregiver strain” or ‘caregiving stress’. Across the literature, various studies mentioned about these terms together, but none had attempted to differentiate the meaning of each individual term (Amen, 2010; Merluzzi, Philip, Vachon, & Heitzmann, 2011; Bevans & Sternberg, 2012). According to Kramer, research that utilizes the concept of ‘caregiver burden’ is essentially focusing on the stress/strain posed by the caregiving role (as cited in Bastawrous, 2013). For the purpose of simplicity and to avoid confusion, only the term ‘caregiver burden’ will be used throughout this dissertation.

Caregiver burden is an important outcome and measure commonly investigated in both observational and interventional literatures associated with caregiving of patients. Yet, the term is still poorly understood and not well-defined to date (Bastawrous, 2013). One of the earliest interpretations was by Zarit, Reever, & Bach-Peterson (1980), who defined caregiver burden as the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning.

A more comprehensive definition of caregiver burden is "a multidimensional biopsychosocial reaction resulting from an imbalance of care demands relative to caregivers' personal time, social roles, physical and emotional states, financial resources, and formal care resources given the other multiple roles they fulfill" (Given, Kozachik, Collins, DeVoss, & Given, 2001, as cited in Given et al., 2004).

There are many studies conducted on the topic of caregiver burden in different clinical diseases and settings. Alzheimer's disease is the index condition for the study of caregiver burden (Markman, 2014). Over the years, the study scope gradually expanded to include caregivers of other conditions such as cancer, stroke and other mental illnesses (Etters, Goodall, & Harrison, 2008; Rigby, Gubitz, & Phillips, 2009; Girgis et al., 2013). In comparison, the caregiver burden of cancer patients had been reported to be comparable to that of dementia patients, but more than the burden in caregivers of diabetes or elderly patients (Kim & Schulz, 2008). The distress level reported by caregivers can be equal to or even greater than that of the cancer patients (Hodges et al., 2005).

2.1.2 Measurement of Caregiver Burden

The measurement of caregiver burden is a challenging task in view of the cultural, ethical, religious and personal values of different caregivers influencing their understandings on the meaning and consequences of burden (Chou, Chu, Tseng, & Lu, 2003). Many measurement tools, consisting mostly self-administered questionnaires, were invented over the years to assess the level of caregiver burden (Chou et al., 2003; Markman, 2014; Stagg & Larner, 2015). Among them are: Zarit Burden Interview (ZBI), Montgomery's Burden Scale, Screen for Caregiver Burden (SCB), Caregiver

Burden Inventory (CBI), Caregiver Assessment Tool (CAT), Caregiver Stress Scale (CSS), Caregiver Strain Index (CSI), etc.

ZBI was the most popular and the most extensively evaluated caregiver burden tool in the literature (Stagg & Larner, 2015). Since the publication of the original 29-item version in 1980, various translated versions and shorter revised versions of the ZBI (e.g. ZBI-12 and ZBI-4) have been produced (Bédard et al., 2001). Compared to other measurement tools, the popularity of the ZBI provides the added advantage in which the data obtained across different studies can be easily compared and examined. More details of the ZBI scale are described further in the sub-topic heading *3.8.2 Zarit Burden Interview*.

Despite the abundance of measurement tools, there is no uniform approach or consensus achieved on what constitutes a significant caregiver burden (Bastawrous, 2013). It is therefore insufficient to rely on the scores of a single instrument for the diagnosis of caregiver burden without careful consideration of other factors affecting the outcomes of caregiving. Nevertheless, the scores can guide the clinicians in identifying at-risk caregivers who might need further assessment and intervention (Chou et al., 2003).

2.1.3 Factors Associated with Caregiver Burden

Several factors are associated with significant caregiver burden as identified by the many studies conducted on the caregivers of cancer patients. Among these factors, sociodemographic characteristics of the caregivers are important predictors. Higher level of psychological distress has been reported in caregivers who are women, young, spouses of the patients, employed, and those with lower socioeconomic status or poor social support (Nijboer et al., 1998; Kim & Given, 2008). Ethnicity of the caregiver has also been found to be one of the contributing factors (Rivera, 2009; Hsu et al., 2014), although caution should be exercised when generalizing this finding to other ethnic populations.

Additionally, clinical characteristics of the cancer patients and the caregiving process also play significant roles in predicting the caregiver burden. Patient factors such as the cancer types, cancer phases, treatment setting, duration of treatment, patients' quality of life and functional status have all been implicated in previous studies (Gaugler et al., 2005; Pellegrino et al., 2010; Hsu et al., 2014; Lukhmana, Bhasin, Chhabra, & Bhatia; 2015; Chua et al., 2016). For example, Hsu et al. (2014) reported higher level of burden in caregivers who cared for patients with solid tumours, in comparison with haematological malignancies. In particular, brain tumour was significantly linked to caregiver stress (Gaugler et al., 2005). Caregiver distress has been demonstrated even in the early phases of cancer when the patient was just diagnosed (Pellegrino et al., 2010).

Compared to curative treatment, caregivers of patients receiving palliative treatment or end-of-life care were reported to have lower scores in quality of life and physical health domains, which corresponded to higher caregiver burden (Weitzner, McMillan, & Jacobsen, 1999; Grov, Dahl, Moum, & Fossa, 2005). This finding is closely related to the patients' poorer functional status, which indicates increase in the care demands and longer caregiving hours per week, thus predicting higher caregiver burden (Weitzner et al., 1999; Hsu et al., 2014). Gaugler et al. (2005) also demonstrated that patients who received shorter duration of treatment were associated with higher burden in their caregivers.

2.1.4 The Local Setting

Locally, Mahadevan et al. (2013) found that sharing of caregiving burden and patient’s functional status were significantly associated with caregiver burden among family caregivers of breast cancer patients in Kuala Lumpur Hospital. In that study, caregivers who did not share their caregiving burden were 2.8 times more likely to feel distressed. Shared caregiving was presumed to be protective, as it allows time-off for caregivers to engage in leisure activities as well as to look after their own health (Mahadevan et al., 2013).

2.2 CAREGIVER DEPRESSION

2.2.1 Definition and Impact of Caregiver Depression

Caregiver depression refers to the affective disturbance experienced by the caregiver as a result of stress in the caregiving process (Given et al., 2004). Similar to the general population, depression in caregivers may include low mood, insomnia, fatigue, reduced appetite or libido, pessimism, feeling of guilt, hopelessness, and suicidal thought (American Psychiatric Association, 2013). Some individuals with depression may only present with somatic complaints such as headache, joint pain, and gastrointestinal problems (Trivedi, 2004).

If go unrecognized, caregiver depression can be an extremely disabling condition with a negative impact on the physical health of the caregivers (Kurtz, Kurtz, Given, & Given, 2004). For example, depression has been linked to coronary heart disease and even early death in the caregivers (Rivera, 2009). Not only that, depressive symptoms and their consequences have been found to be relatively constant and may persist even after caregiving has ended (Haley et al., 2008).

2.2.2 Measurement of Caregiver Depression

Depressive disorders are commonly diagnosed clinically based on the diagnostic criteria in the Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) or the Tenth Revision of the International Classification of Diseases and Related Health Problems (ICD-10). However in the research setting, short, valid and reliable screening tools for depression are usually preferred in view of time and resource constraints (Rivera, 2009). According to Sheehan & McGee (2013), the commonly used depression screening measures include Patient Health Questionnaire-9 (PHQ-9), Center for Epidemiological Studies – Depression Scale (CES-D), Geriatric Depression Scale (GDS), Hospital Anxiety and Depression Scale (HADS), Beck Depression Inventory-II (BDI-II), and depression subscale of the Symptom Checklist-90 (SCL-90-D).

2.2.3 The Association with Cancer Caregiving and Caregiver Burden

The association between cancer caregiving and caregiver depression is well documented. In a study done by Rhee et al. (2008) using the BDI, as many as two-thirds of the cancer caregivers had high depression scores (BDI > 13), while 35% had very high depression scores (BDI > 21). Price et al. (2010) concluded there was significantly higher prevalence of borderline or clinical depression among caregivers of women with invasive ovarian cancer compared with patients' rates and community in general.

Relationship between caregiver burden and caregiver depression has been a constant debate among researchers in the caregiving industry. Early researchers believed that both concepts are the same and can be used interchangeably (Baillie, Norbeck, & Barnes, 1988, as cited in Stommel, Given, & Given, 1990). Nevertheless, recent literatures have concluded that they are two distinct constructs explained by different variables, thus should be targeted separately by individual intervention strategies (Given et al, 2004; Butler, Turner, Kaye, Ruffin, & Downey, 2005).

Many studies have found that caregiver depression is highly correlated with caregiver burden (Hérbert, Bravo, & Préville, 2000; Butler et al., 2005; Grov, Fossa, Sorebo, & Dahl, 2006; Rivera, 2009). In fact, care burden may be the best predictor for the development of depression (Rhee et al., 2008). This relationship can be bi-directional, in which the presence of depression invariably increases the risk for perceived burden in caregiving (Stommel et al., 1990). It is however noteworthy that causal relationship between these two constructs is still not established to date as majority of the studies done were cross-sectional in design (Pirraglia et al., 2005).

A review by Rivera (2009) has identified various factors contributing to depressive symptoms in the cancer caregivers. Among them are caregiver’s age, gender, race, health status, history of previous psychiatric illness, care burden, social support, and mastery on caregiving. In addition, patient’s functional status, patient depression and number of patient symptoms are also related. According to Kurtz et al. (2004), risk of caregiver depression is higher if there are more severe patient symptoms, greater patient depression, greater impact on caregiver’s schedule and diminished caregiver social functioning. Increasing number of patient symptoms was also found to be significantly related to caregiver depression by Given et al. (2004).

2.2.4 The Local Setting

In the context of local setting, Jaafar et al. (2014) reported that 17.7 percent of the family caregivers were depressed while caring for breast cancer patients in Kuala Lumpur Hospital. In that study, patient’s functional status and caregiver’s education level were found to be significantly associated with caregiver depression. The authors explained that the increased risk for depression might be due to the anticipatory grief and the impending loss of loved one associated with advanced stage of the cancer. Low education in the caregivers may lead to patients’ late presentation to the healthcare services, thus indirectly increases the caregiving demands expected from the more severe symptoms in the patients (Jaafar et al., 2014).

Another earlier local study by Ambigga et al. (2005) reported a much higher prevalence of caregiver depression at 48.6%. Education level of the caregivers and duration of illness of the patients were found to have significant associations with the caregiver depression in this study. Substantial difference in the rate of caregiver depression between the two local studies may be due to the different instruments being used to assess depressive symptoms. In the latter, HADS, a screening tool, was used to measure the levels of depression; as compared to the use of Mini International Neuropsychiatric Interview (MINI), a diagnostic instrument, in the study by Jaafar et al.

2.3 RELIGIOSITY

2.3.1 Definition and Roles of Religiosity

In the historical context, religiosity is commonly equated to another popular term ‘spirituality’, and the distinction between these two terms is often unclear (Miller & Thoresen, 2003; King & Crowther, 2004). According to Koenig, McCullough, & Larson, religiousness is considered “a measure of an individual’s belief in, adherence to, and practice of a given religion”, whereas spirituality “corresponds to the personal quest for meaning and purpose in life, which may or may not be associated with religions” (as cited in Paiva, Carvalho, Lucchetti, Barroso, & Paiva, 2015). In this dissertation, ‘religiosity’ will be used interchangeably with ‘religiousness’.

Religiosity (or religiousness) refers to the multidimensional aspects of the religious beliefs and involvement, encompassing subjective, cognitive, behavioural, social and cultural dimensions (Bergan & McConatha, 2000). Ironically, religion was once viewed as a unidimensional construct and considered as neither helpful nor functional by early researchers or psychologists, most notably Sigmund Freud and Albert Ellis (Ward, 2010). However, religious factors are increasingly being examined in recent years as various researchers focused on the role that religion plays in the medical frontiers (Hackney & Sanders, 2003; Stefanek, McDonald, & Hess, 2005; Amadi et al., 2016).

2.3.2 Measurement of Religiosity

There are various religious instruments available in psychology research. Among the more commonly used measures are Religious Orientation Scale (ROS), Intrinsic Religious Motivation Scale, Duke University Religion Index (DUREL), Bardis' Religion Scale, Religious Values Scale (RVS), Brief Multidimensional Measure of Religion and Spirituality (BMRS), etc. (King & Crowther, 2004). All these measures have their own strengths and limitations as they cover different components of the religion, such as involvement in religious activities (organizational and non-organizational), intrinsic orientation, extrinsic orientation, religious attitudes and practices, and religious identification and affiliation (King & Crowther, 2004; Ng, Mohamed, Sulaiman, & Zainal, 2016).

2.3.3 The Association with Caregiver Burden

The potential influence of religion on caregiver burden is increasingly being recognized. Many family caregivers of cancer patients reported that religion and spirituality help them to cope better with their stress (Weaver & Flannelly, 2004; Delgado-Guay et al., 2012; Paiva et al., 2015). A prospective cohort study involving 175 caregivers of cancer patients found that the caregivers with high religiousness score were found to be significantly less likely to have major depression at 13-month follow-up (Fenix et al., 2006).

Nevertheless, majority of studies reported no or a mixed association (i.e. a combination of positive, negative, or non-significant results) between religion and well-being of informal caregivers (Hackney & Sanders, 2003; Hebert, Weinstein, Martire, &

Schulz, 2006). Intrinsic religiosity and organizational religious activity were associated with lower perceived burden, while non-organizational religious activity was associated with poorer mental health (Herrera, Lee, Nanyonjo, Laufman, & Torres-Vigil, 2009). Variation in the outcomes of religious studies may be explained by the use of non-uniform and single-item measures in these studies, which failed to address the multidimensional nature of religiosity (Stefanek et al., 2005).

2.3.4 The Local Setting

To date, there is yet any local study that specifically examines the relationship between religiosity and caregiver burden in Malaysia. Nevertheless, local data on religiousness is available among cancer patients and psychiatric patients. In particular, Nurasikin et al. (2012) found that higher religious commitment as measured with DUREL among outpatient psychiatric patients in *Universiti Malaya* Medical Centre, Kuala Lumpur, was significantly associated with lower distress level as measured with Depression, Anxiety and Stress Scale (DASS).

Another recent local study by Ng et al. (2016) also reaffirmed the association between religiosity and psychological distress in cancer patients. In that study, patients with depression as measured with HADS, were reported to have lower non-organizational religious activity, such as prayer, meditation, or reading religious scriptures, as measured with DUREL. This finding remained significant after adjusted for confounders with the multiple logistic regression analysis (Ng et al., 2016).

2.4 RELIGIOUS COPING

2.4.1 Definition and Religious Coping Styles

Tix and Frazier (1998) defined religious coping as “the use of cognitive or behavioural techniques, in the face of stressful life events, that arise out of one’s religion or spirituality”. In simple terms, religious coping is the use of religious means to deal with stress, and the coping strategies can be either positive or negative (Pargament, Smith, Koenig, & Perez, 1998). In a review of literature by Harrison, Koenig, Hays, Eme-Akwari, & Pargament (2001), religious coping was noted to be widely used, especially in medically ill, hospitalized patients to cope with their illness or with life in general.

According to Pargament et al. (1998), positive religious coping strategies include appraising a secure relationship with a benevolent God, a belief that there is meaning in life, and seeking support from clergy/church members; while negative coping strategies include attributions of situations to a punishing God and feelings of abandonment by God, a less secure relationship with God, a tenuous and pessimistic view of the world, and religious struggle in the search for significance. In response to a particular stressful situation for example, a person who uses positive religious coping strategies may perform prayer, confess his or her sins, or seek strength and comfort from God (Tix & Frazier, 1998).

Religious coping and religiosity are two separate constructs, although they are closely related to each other (Tix & Frazier, 1998; Ng et al., 2016). Holland et al. (1999) have found a significant association between greater reliance on religious and spiritual beliefs, and the use of active-cognitive coping style. This kind of coping is defined as a person’s acceptance of his or her illness, and the attempt to view its effects in a positive, meaningful manner (Fawzy et al., 1990, as cited in Holland et al., 1999). Religiosity components such as religious affiliation and religious orientation have also been identified as important moderators of the effects of religious coping during stressful events (Tix & Frazier, 1998).

2.4.2 Measurement of Religious Coping

The measurement of religious coping has gradually expanded and gained more precision over the years (Harrison et al., 2001). In the past, religious coping was measured based on the frequency of religious prayer or congregational attendance, but this method did not address the functional roles of religion in coping (Pargament, Koenig, & Perez, 2000). Subsequent scales such as Ways of Coping Scale and Religious Coping Activities Scale were refined to become more comprehensive, multidimensional, empirically based and yet clinically valid (Pargament et al., 2000). This eventually led to the development of a short measure of religious coping (Brief RCOPE), which is now widely used in most research studies on religious coping (Pargament, Feuille, & Burdzy, 2011).

2.4.3 The Association with Caregiver Burden

Despite a growing body of evidence suggesting the increase use of religious coping in stressful events, research on the efficacy of religious coping in general has yielded mixed results (Harrison et al., 2001; Ano & Vasconcelles, 2005). A review by Harrison et al. (2001) reported that negative religious coping has consistently been associated with more depressive symptoms, whereas positive religious coping strategies have been consistently related to self-esteem, life satisfaction and quality of life. These findings were confirmed quantitatively in a meta-analysis of 49 studies, which concluded that positive and negative styles of religious coping were associated with positive and negative psychological adjustment to stress respectively (Ano & Vasconcelles, 2005).

Similar mixed results were also seen in the studies of the effects of religious coping pattern on the caregiver burden in particular. In a study of hospice caregivers, those who appraised their situation in a positive outlook with God reported positive mental health outcomes, while caregivers who appraised their situation as punishment or abandonment by God had negative outcomes (Mickley, Pargament, Brant, & Hipp, 1998). Pearce, Singer, & Prigerson (2006) reported that the use of negative religious coping was associated with more burden and less satisfaction; while surprisingly, the use of positive coping was also associated with more burden, but with more satisfaction in the caregiving. Increased use of positive religious coping strategies and diminished use of negative coping strategies were associated with posttraumatic growth among the family caregivers of cancer patients in India (Thombre, Sherman, & Simonton, 2010).

Herrera et al. (2009) however found that only negative religious coping was significantly associated with higher levels of caregiver burden and worse mental health outcomes. These findings were similar to a study done by Hebert, Zdaniuk, Schulz, & Scheier (2009) in women with breast cancer. In contrast, other studies reported that only positive religious coping showed significant correlation with caregivers' psychological well-being, whereas negative religious coping had no effect on any outcomes (Gholamzadeh, Hamid, Basri, Sharif, & Ibrahim, 2014; Heo, 2014).

2.4.4 The Local Setting

In Malaysia, the two local studies that examined the religiosity component also studied the association between religious coping with psychological distress level (Nurasikin et al., 2012; Ng et al., 2016). Both studies have discovered and agreed that negative religious coping was significantly associated with higher distress level, but there was no significant correlation found between positive religious coping and the level of distress. Cancer patients with depression were reported to be using more negative religious coping mechanisms, however, the causal relationship cannot be established as the study was limited by a cross-sectional design and a relatively small sample size (Ng et al., 2016).

CHAPTER 3

METHODOLOGY

3.1 STUDY DESIGN

This was a hospital-based, cross-sectional, and association study on the burden of the cancer caregivers; and also looking at its association with caregiver depression, religiosity, and religious coping styles.

3.2 STUDY SUBJECTS

The source population of this study was the family (or informal) caregivers of any cancer patients, either outpatients or inpatients, in a local government hospital.

3.3 STUDY SETTING

This study was carried out at the Department of Radiotherapy, Oncology and Palliative Care of Sarawak General Hospital (SGH) located in Kuching, Sarawak, Malaysia. Kuching is the capital and the most populous city in the Sarawak state with a population of 598,617 people from various ethnic groups ("State statistics", 2014). As SGH is the state hospital for Sarawak, the Department of Radiotherapy, Oncology and Palliative Care thus functions as a tertiary centre for the referral and treatment of cancer cases from all over the state of Sarawak.

The department consists of outpatient clinics, chemotherapy daycare centre, radiotherapy unit (RTU), and three inpatient oncology wards (Male RTU ward, Female RTU ward and Palliative ward). Based on the SGH Annual Report in 2014, total numbers of new oncology cases seen in outpatient clinics and daycare centre were 1725, while total numbers of follow-up cases were 14786. As for inpatient cases, total admissions in 2014 were 2623 cases, with the palliative care consisting of 1354 cases, and this corresponded to a bed occupancy rate of 74% (Sarawak General Hospital, 2015). This information indicated the suitability of SGH to be the study site for data collection in this study.

The study involved family caregivers of any cancer patients that were receiving oncology treatments at the chemotherapy daycare or the outpatient clinics; as well as those that were admitted to the inpatient wards either for active chemotherapy or radiotherapy treatment, or to receive palliative care. The study was also conducted at the hematology daycare and hematology ward of SGH for recruitment of caregivers of patients with hematological malignancies.

3.4 STUDY PERIOD

Data for this research study was collected within four months from early January 2017 until end of April 2017. The sample was accessed from the study site on random days from Monday to Friday based on the convenience of the investigator.

3.5 STUDY CRITERIA

In circumstances where there was presence of more than one family caregiver for a particular cancer patient, the core or principal caregiver was selected. Those caregivers who gave their consent to participate in the study were screened for the following inclusion and exclusion criteria.

3.5.1 Inclusion Criteria

1. Family caregivers aged 18 years and above
2. Caregivers identified by cancer patients as informal caregiver, irrespective of whether they are primary or secondary caregivers
3. Caregivers able to understand and converse in Malay or English language
4. Caregivers able to give written informed consent to participate in the study

3.5.2 Exclusion Criteria

1. Paid, professional or formal caregivers
2. Caregivers who were diagnosed with any pre-existing major psychiatric disorder based on DSM-5 criteria

3.6 SAMPLE SIZE

Based on the formula proposed by Kish (1965), the sample size of this cross-sectional study (Phase II) was calculated as follow:

$n = (Z_{\alpha/2})^2 [P (1-P)/D^2]$

where α is the level of significance ($\alpha = 0.05$)

$Z_{\alpha/2}$ is the z-statistic for 95% confidence interval ($Z_{\alpha/2} = 1.96$)

D is the absolute precision (D = 10%)

P is the estimated prevalence rate of caregiver burden in cancer patients (P = 43.5%, based on the study by Lukhmana et al., 2015)

Therefore, $n = 1.96^2 [0.435 (1 - 0.435) / 0.1^2]$

$= 94.4$

After taking into account the dropout or non-response rate of 20%, a reasonable sample size of at least 115 subjects was planned for this study.

3.7 STUDY PROCEDURE

This research study was conducted in two phases – Phase I and Phase II. Phase I was a cross-sectional validation study with the aim to validate the Malay version of the Zarit Burden Interview (MZBI) scale. Rosdinom, Norzarina, Zanariah, & Ruzanna (2011) had previously translated the MZBI from the original English version in a study involving caregivers of dementia patients in Kuala Lumpur, but the scale was not validated by the authors. Permission to use and validate the MZBI scale was obtained from the corresponding author, Associate Professor Dr. Rosdinom Razali from *Universiti Kebangsaan Malaysia* Medical Centre.

Few changes on the original MZBI by Rosdinom et al. (2011) were made to standardize the scale with the English version of ZBI. First, the MZBI by Rosdinom et al. only has 21 items compared to the 22-item English version, as the former has omitted item no. 11 which reads: "Do you feel that you do not have as much privacy as you would like, because of your relative?" This item was translated into the Malay language and added into the revised version of MZBI, which now has 22 items. Second, the scoring used in the MZBI by Rosdinom et al. ranges from 1 to 5, different from the scoring in the English version that ranges from 0 to 4. The scoring in the revised MZBI was made similar to the English version (range 0 to 4), so that direct comparison of the total scores can be made between these two versions of ZBI.

After the above corrections, the finalized version of the MZBI was used to interview 50 family caregivers who were bilingual (knowing both English and Malay language). At the same time, the caregivers were also given the sociodemographic and clinical questionnaire; the Malay version of Center for Epidemiological Studies – Depression Scale (MCES-D) to assess for convergent validity and to determine the cut-off scores of MZBI; followed immediately by the English version of Zarit Burden Interview (EZBI) for comparison and to examine for criterion validity. The sample size of 50 subjects was chosen based on a similar validation study of the Chinese version of Zarit Burden Interview by Wang et al. (2008), who recruited 42 caregivers of dementia patients in their validation study.

Phase II, a cross-sectional association study, was the main phase of this study. The aim of this phase was to examine the objectives and research hypotheses as mentioned in Chapter 1. The subjects were administered with the following questionnaires and measures to answer: 1) Sociodemographic and clinical questionnaire, 2) MZBI, 3) MCES-D, 4) Malay version of Duke University Religion Index (DUREL-M), and 5) Malay version of Brief RCOPE (M-RCOPE). With the exception of the sociodemographic and clinical questionnaire, the rest of the measures were self-rated questionnaires.

In view of time and resource constraints, the two phases were carried out concurrently throughout the study period using convenience sampling method. A single investigator carried out the data collection procedure in this study. The sample was collected from the family caregivers that were conveniently available at the study site and were willing to participate. Phase I involved recruitment of the first 50 subjects who could comprehend both the English and Malay languages. At the same time, Phase II recruited those subjects who comprehend mainly the Malay language regardless of their level of English language proficiency. The summary of the study flow chart is shown in Figure 3.1.

The family caregivers of cancer patients from the above setting were approached and invited to participate in the study. Participation was based on voluntary basis. Explanation was given to the study subjects regarding the indication of this study and what information would be required from them. Subjects were told that the entire task would take approximately half an hour, and that their decision on whether to participate in the study or not would in no way affect the treatment of the patients under their care.

The subjects were then given ample time to read and understand the information sheet (refer to Appendix C & D) which further explained the details of the study. Any queries from the subjects were addressed accordingly by the investigator. Once they have consented for their participation, the subjects were required to fill in the informed consent form (refer to Appendix E & F) attached together with the information sheet. Thereafter, the subjects were administered with the relevant questionnaires and measures by the investigator. All data were collected independently with full confidentiality assured. Out of the total 177 family caregivers who consented for this study, 50 caregivers were recruited into Phase I and 127 caregivers were recruited into Phase II.

3.8 STUDY MEASURES

3.8.1 Sociodemographic and Clinical Questionnaire

The sociodemographic and clinical questionnaire consists of sociodemographic component and clinical component combined together. This questionnaire was rated by the investigator through interviews with the subjects in order to ensure uniformity of the data collected. The sociodemographic questionnaire asked about the age, gender, ethnicity, marital status, religion, dwelling types, employment status, education, household income levels and relationship of the subjects in relation to the cancer patients under their care.

On the other hand, the clinical questionnaire consists of data on the types of cancer, cancer severity, treatment setting, and functional status of cancer patients; together with caregiving parameters such as duration as a caregiver, duration of caregiving in a week, and presence of any shared caregiving and/or external support. In the presence of shared caregiving, the number of other family caregivers assisting in caregiving was also assessed. As far as possible, the clinical information was obtained from the caregivers directly. In case there was ambiguity of the information provided by the subjects, patients' medical record would be referred for confirmation.

Further explanations of the individual sociodemographic and clinical variables are available under the topic heading *3.9 Operational Definitions*. Please refer to Appendix G to view sample of the sociodemographic and clinical questionnaire used in this study.

3.8.2 Zarit Burden Interview

Zarit Burden Interview (ZBI) is the oldest and the most widely used measure for assessment of caregiver burden (Hérbert et al., 2000). It was originally a 29-item questionnaire used to assess subjective burden in caregivers of impaired elderly (Zarit et al., 1980). The measure was later revised to the current self-administered, validated, 22-item scale that evaluates caregiver's physical health, psychological and social well-being, finances, and relationship between caregiver and care recipient (Zarit, Orr, & Zarit, 1985). The English version of ZBI was given the acronym 'EZBI' throughout this dissertation to differentiate it from the translated Malay version with the acronym 'MZBI'.

In this scale, each item consists of a question in which the caregiver is asked to respond using a 5-point sliding scale, ranging from 0 to 4. The response options are 0 = 'Never' or '*Tidak pernah'*, 1 = 'Rarely' or '*Jarang sekali'*, 2 = 'Sometimes' or '*Kadang-kala'*, 3 = 'Frequently' or '*Agak kerap'*, and 4 = 'Nearly always' or '*Hampir sentiasa'*. The scores on the items are summed for the total score, with higher scores indicating greater caregiver burden. The maximum total score is 88. Zarit and Zarit

(1987) proposed an arbitrary division of the total score into four roughly equal portions: score 0 – 20 = little or no burden, 21 – 40 = mild to moderate burden, 41 – 60 = moderate to severe burden, and 61 – 88 = severe burden (as cited in Hérbert et al., 2000).

In a validation study on Canadian caregivers of elderly dementia patients, the ZBI scale had shown good internal consistency, with a Cronbach's alpha of 0.92 that was not modified by removal of any of the 22 items. The study also demonstrated that the ZBI scores were not significantly associated with the age, gender, marital status, employment status and living arrangement of the caregivers, thus making the scale suitable to be used in a variety of populations (Hérbert et al., 2000).

The factor structure of ZBI is still not clear with many different models existing in the literature (Knight, Fox, & Chou, 2000). In this study, the 3-factor model by Bianchi, Flesch, da Costa Alves, Batistoni, & Neri (2016) was adapted. The three factors emerged from the exploratory factor analysis were "Tensions related to the role" (Factor 1), "Intra-psychic tensions" (Factor 2), and "Competencies and expectations" (Factor 3) respectively. These factors explained 44% of the total variability and showed good internal consistency (Cronbach's alphas ranging from 0.72 to 0.83) when tested on the senior caregivers in Brazil (Bianchi et al., 2016).

The EZBI was translated to the Malay version (MZBI) for local use by Rosdinom et al. (2011) after obtaining permission from the original author, Professor Steven H. Zarit. However, the study did not attempt to validate the MZBI scale at that time. For this study, permission to use the MZBI scale was obtained from the principal author, Associate Professor Dr. Rosdinom via email. No permission required for the use of the EZBI as it was used for non-profitable research in this study, and the scale is accessible freely on the internet.

The process to validate the MZBI scale among the caregivers of cancer patients in this study was explained in details in the previous topic heading *3.7 Study Procedure*. Please refer to Appendix H and Appendix I to view samples of the EZBI and MZBI scales respectively.

3.8.3 Center for Epidemiological Studies – Depression Scale

Center for Epidemiological Studies – Depression (CES-D) scale was initially designed by Radloff (1977) to screen for depressive symptoms in the general population, but was later recommended by the author to be used as screening tool in epidemiological studies of depression. It demonstrated good internal consistency of 0.85 in the general population and of 0.90 in a sample population consisting of psychiatric patients (Radloff, 1977).

The original English version of the CES-D scale consists of 20 items, with each item made up of a short statement in which the response is rated according to a 4-point Likert scale. The scale runs from 0 to 3 to indicate how often the respondent felt that way over the previous one week. As in the English version, the Malay version of CES-D (MCES-D) is also rated the same way. The response options in the MCES-D are '*Jarang atau Tidak Pernah (Kurang dari 1 hari)*', '*Sedikit Dari Masa (1 – 2 hari)'*, '*Kadang-kadang atau Sederhana (3 – 4 hari)'*, and '*Sepenuh atau Setiap Masa (5 – 7 hari)'*.

This scale is unique in a way that not all the items are worded as negative statements. In fact, the item no. 4, 8, 12, and 16 are worded as positive statements to control for response bias. Therefore, these four items are rated in a reverse order from 3 to 0 compared to the rest of the items. The scores on the items are then summed for the total score, with higher scores indicating more depressive symptoms. The total score ranges from 0 to 60. A cut-off score of 16 is suggested for identification of potential clinical depression in the respondents (Radloff, 1977).

CES-D has been translated and validated in many languages such as Arabic, Brazilian, French, Korean, Portuguese and Spanish with good psychometric properties (Mazlan & Ahmad, 2014; Sabki, Zainal, & Ng, 2014). The original English version was also translated and validated in Malay language by a few local studies. Mazlan and Ahmad (2014) demonstrated good internal consistency (Cronbach’s alpha 0.75) and satisfactory test-retest reliability (Pearson’s correlation 0.69) in their Malay-translated version of CES-D tested among 90 female inmates from local prisons. However, the study was limited by its gender bias and relatively smaller sample size.

Another validation study of MCES-D by Sabki et al. (2014) showed better generalizability as it was tested in a group of 117 junior doctors consisting of both genders. The study reported good internal consistency (Cronbach’s alpha 0.78), and its exploratory factor analysis suggested four factors that were all significantly related to HADS and the English version of CES-D (Sabki et al., 2014). The same scoring method as the English version was used in this Malay version.

Permission to use the MCES-D scale was approved by the corresponding author in Sabki et al. (2014), Associate Professor Dr. Ng Chong Guan, who also served as the principal supervisor for this research study. Please refer to Appendix J to view the sample for MCES-D scale used in this study.

3.8.4 Duke University Religion Index

The Duke University Religion Index (DUREL) is designed to measure religious commitment or religiosity of the respondent (Koenig, Parkerson, & Meador, 1997; Koenig & Büssing, 2010). It consists of five items covering three major dimensions of religiosity: organizational religious activity (ORA, 1 item); non-organizational religious activity (NORA, 1 item); and intrinsic religiosity (IR, 3 items).

ORA consists of public religious activities e.g. frequency of attending religious services or participation in group-related religious activities. NORA involves religious activities performed in private, e.g. prayer, reading the religious scripture or watching religious television show. On the other hand, IR refers to the degree of personal religious commitment or motivation, whereby persons with high IR regard religion as the ultimate significance compared to other personal needs (Koenig & Büssing, 2010).

ORA and NORA are scored from 1 to 6, whereas the 3 items in IR are scored from 1 to 5. Thus, the total score for DUREL ranges from 5 to 27. However, the authors of the original DUREL recommended the measure to be interpreted separately within the three subscales of ORA, NORA and IR, corresponding to the three distinct religious dimensions measured by them (Koenig et al., 1997). Koenig and Büssing (2010) reported that the DUREL has high internal consistency (Cronbach’s alpha ranged from 0.78 to 0.91) and high test-retest reliability (intra-class correlation 0.91).

According to Koenig and Büssing (2010), the DUREL scale is available in up to ten different languages and has been used in over 100 published studies since its introduction. The scale has been translated into the Malay language (DUREL-M) and was validated by Nurasikin, Aini, Aida, & Ng (2010) among a group of nursing students. The study showed good Cronbach's alpha of 0.80 and fair test-retest reliability (Spearman's correlation 0.68, $p < 0.01$).

Permission to use the DUREL-M scale was approved by the corresponding author in Nurasikin et al. (2010), Associate Professor Dr. Ng Chong Guan, who also served as the principal supervisor for this research study. Please refer to Appendix K to view the sample for DUREL-M scale used in this study.

3.8.5 Brief Religious Coping Questionnaire

The Brief Religious Coping questionnaire (Brief RCOPE) is the concise version of the original RCOPE, and both RCOPE and Brief RCOPE were developed based on Pargament's theory on religious coping (Pargament, 1997, as cited in Pargament et al., 2011). The Brief RCOPE consists of 14 items (seven positive coping items and seven negative coping items) used to measure the religious coping pattern associated with major life stressors in the respondent (Pargament et al., 2011).

The positive religious coping (PRC) items were generated from seven different subscales of the original RCOPE: spiritual connection (e.g. looking for stronger connection with God), seeking spiritual support (e.g. looking for God's care and support), religious forgiveness (e.g. seeking help from God in letting go of one's anger), collaborative religious coping (e.g. putting plans into action together with God), benevolent religious reappraisal (e.g. seeing how God might be trying to strengthen a person in difficult situation), religious purification (e.g. asking forgiveness for one's sins) and religious focus (e.g. focusing on religion to find solution for a problem).

On the other hand, the seven negative religious coping (NRC) items originated from five different subscales of the RCOPE: spiritual discontent (e.g. wondering whether God or the religious institution had abandoned a person), punishing God reappraisal (e.g. felt being punished by God for lack of devotion), interpersonal religious discontent (e.g. questioning God's love or wondering what a person did for God to punish him or her), demonic reappraisal (e.g. deciding that the devil was responsible for what had happened) and reappraisal of God's power (e.g. questioning the power of God). NRC subscale was consistently related to poor functioning in psychological well-being of the respondents e.g. anxiety, depression, negative affect, and pain, thus making it suitable to be a strong predictor for health-related outcomes (Pargament et al., 2011).

The scoring for each of the 14 items ranges from 1 to 4 as follows: 1 = 'Not at all' or '*Langsung tidak'*, 2 = 'Somewhat' or '*Jarang-jarang'*, 3 = 'Quite a bit' or '*Agak kerap'*, 4 = 'A great deal' or '*Sangat banyak'*. The total score thus ranges from 7 to 28 for each of the PRC and NRC subscales. Based on all the studies reviewed by Pargament et al. (2011), the actual mean scores for PRC ranged from 17 to 21, whereas for NRC, the mean scores ranged from 8 to 14. The scale also demonstrated good internal consistency with the PRC subscale having a higher Cronbach's alpha than the NRC subscale generally (median alpha 0.92 versus 0.81).

The Brief RCOPE was translated into the Malay language (M-RCOPE) and validated by Yusoff, Low, & Yip (2009) in 68 Malaysian women who had breast cancer and were being treated with adjuvant chemotherapy. The study showed good internal consistencies for the two domains in M-RCOPE, although the Cronbach’s alpha was slightly higher in the NRC subscale for this version (Cronbach’s alpha 0.87 for PRC and 0.88 for NRC).

The M-RCOPE questionnaire used in this study was obtained from Associate Professor Dr. Ng Chong Guan, who used this scale in his previous studies (Nurasikin et al., 2010; Nurasikin et al., 2012; Ng et al., 2016). Please refer to Appendix L to view the sample for this scale.

3.9 OPERATIONAL DEFINITIONS

Throughout this dissertation as well as in the study questionnaires, the following terms and operational definitions were applied to ensure uniformity and to facilitate clear understanding.

1. Family caregiver – also known as informal caregiver, defined as any person who has a personal relationship with, and provides a broad range of unpaid assistance and informal care for, a person with a chronic or disabling condition (Family Caregiver Alliance, 2014). Therefore, based on this definition, the caregivers in this study do not necessarily need to be related to the cancer patients by blood or marriage, and may include neighbours or close friends of the patients. However, the patients must identify the caregivers as their primary carers who provide majority of the informal care.

2. Burden – similar to ‘Strain’ or ‘Load’, defined as a duty or responsibility borne by a person, in this context, the caregiver of cancer patient. In this study, the burden of the caregivers is measured quantitatively with the Zarit Burden Interview scale as mentioned above.

3. Depression – defined as a mental condition associated with low or depressed mood, which covers a broader spectrum of depressive disorders under the DSM-5 criteria. In the context of this study, the condition is experienced by the caregiver and not the cancer patient. MCES-D scale was used in this study to measure the level of depression objectively.

4. Coping – defined as “the cognitive and behavioral efforts made to master, tolerate, or reduce external and internal demands and conflicts among them”. (Folkman & Lazarus, 1980). In short, coping is a method to reduce the stress level. In the setting of this study, the use of religious means for coping is measured objectively among the caregivers using the M-RCOPE scale.

5. Age – a continuous numerical variable expressed in years. The lower limit of age in this study was 18 years old. There was no upper limit of age set in this study.

6. Gender – a categorical variable grouped into either ‘Male’ or ‘Female’ only.

7. Race/Ethnicity – a categorical variable grouped into four groups: ‘Malay’, ‘Chinese’, ‘*Bumiputera Sarawa*k’, and ‘Others’. ‘*Bumiputera Sarawak*’ warrants a separate column, as it is the largest ethnic group in Sarawak where the study was based. ‘Others’ may include ethnicity groups such as Indian, Sabah natives,

Peninsular natives, Javanese and other foreign ethnicities that are relatively rare in Sarawak.

8. Marital status – a categorical variable grouped into four categories: ‘Single’, ‘Married’, ‘Divorced’ and ‘Widowed’.

9. Religion – a categorical variable grouped into five groups: ‘Muslim’, ‘Christian’, ‘Buddhist’, ‘Other religion’ and ‘No religion’. ‘Other religion’ may include religions such as Hinduism, Judaism, and other related ethnic religions. ‘No religion’ group caters to those without a religious or spiritual belief.

10. Types of dwelling – a categorical variable grouped into six categories: ‘Bungalow or Condominium’, ‘Semi-detached house’, ‘Terraced house’, ‘Flat house’, ‘Village house’ and ‘Squatter’. The grouping was decided based on the housing structures and presumed costs of dwelling, which correspond roughly to the socio-economic status of the particular dweller. “Village house’ or ‘*Rumah kampung*’ refers to the self-built wooden or cemented house that is commonly found in Sarawak as a number of residents here built their homes on the land that they owned. This type of dwelling is relatively rare in Peninsular Malaysia.

11. Employment status – a categorical variable grouped into five categories: ‘Self-employed’, ‘Working full-time’, ‘Working part-time’, ‘Retired’ and ‘Unemployed’. ‘Working full-time’ is defined loosely as employment in which a person works for his or her employer a certain number of hours as specified in the job contract, and often comes with benefits such as annual leave and health insurance. In contrast, these benefits are not usually offered to part-time workers. However, there was no

specific number of working hours set in this study to differentiate full-time from part-time employment objectively. Housewife (or homemaker) and student are placed under the ‘Unemployed’ category.

12. Household income – a continuous numerical variable expressed in Ringgit Malaysia, referring to the monthly combined earnings of all the people sharing a place of residence. The total income amount is further classified into three categories of income level: ‘Low income’, ‘Mid-range income’ and ‘High income’. ‘Low income’ is defined as total household income of less than RM 3,000 a month. ‘Mid-range income’ ranges between RM 3,000 to RM 10,000, whereas ‘High income’ refers to total household income of more than RM 10,000 per month. The above cut-off numbers were derived from the statistics of the Malaysian middle class incomes in 2012 (Chi, 2014).

13. Education level – a categorical variable classified into four categories: ‘Tertiary’, ‘Secondary’, ‘Primary’ and ‘No formal education’.

14. Socioeconomic status – a categorical variable with two rudimentary groups created during data analysis and based loosely on the types of dwelling. Higher status e.g. staying at bungalow, condominium, semi-detached or terraced house; lower status e.g. staying at flat, village house or squatter.

15. Types of primary cancer – a categorical variable, referring to the first tumour in the body where the cancer cells originated. It was categorised into two main groups: ‘Solid’ and ‘Hematological’. Solid cancer refers to any malignancy that forms a discrete tumour mass, and it is named according to the types of cancer cells and

organ from which the cancer cells arise. In contrast, hematological or blood cancer refers to malignancy that arises from blood-forming tissues such as bone marrow, or cells of the immune system. Examples include leukemia, lymphoma, multiple myeloma and aplastic anemia.

16. Severity or stages of cancer – a categorical variable classified into three main groups: 'Mild or equivalent to Stage 1', 'Moderate or equivalent to Stage 2 or 3' and 'Severe or equivalent to Stage 4'. Another category titled 'Unsure stage' was later added during the data analysis phase to include those patients who were unsure of the stages or severity of their cancer pending further investigation.

17. Treatment setting – categorical variable which includes categories such as 'Inpatient' and 'Outpatient' based on patient types, as well as 'Active treatment' and 'Palliative treatment' based on treatment types. Examples of active treatment include chemotherapy, radiotherapy, hormonal therapy etc. Another two categories, 'Not yet plan for treatment' and 'Completed treatment, under follow-up' were added to the treatment types during the data analysis phase to cater for those patients who were not on either active or palliative treatment at the time of assessment.

18. Functional status of cancer patients – an ordinal categorical variable, classified into six categories according to the Eastern Cooperative Oncology Group (ECOG) performance scale (refer to Appendix M). ECOG performance status scale is a reliable measure commonly used in cancer research study to assess patients' level of functioning in terms of their ability for self-care, physical capacity, as well as ability to carry out daily activities including working (Oken et al., 1982). The scale

runs from 0 to 5, with 0 denotes perfect health or a fully active person, 1 denotes restriction in physical strenuous activity but ambulatory and able to carry out light duty or office work, 2 denotes ambulatory and capable of full self-care but unable to work, 3 denotes limited self-care capacity as one is mostly confined to bed or chair, 4 denotes complete disability, and 5 denotes death.

19. Duration as caregiver – a continuous numerical variable expressed in months. The duration was counted from the time the caregiver started providing care until the time of assessment. This duration usually coincides with the time of onset of patient's symptoms or from the time the patient was diagnosed with cancer.

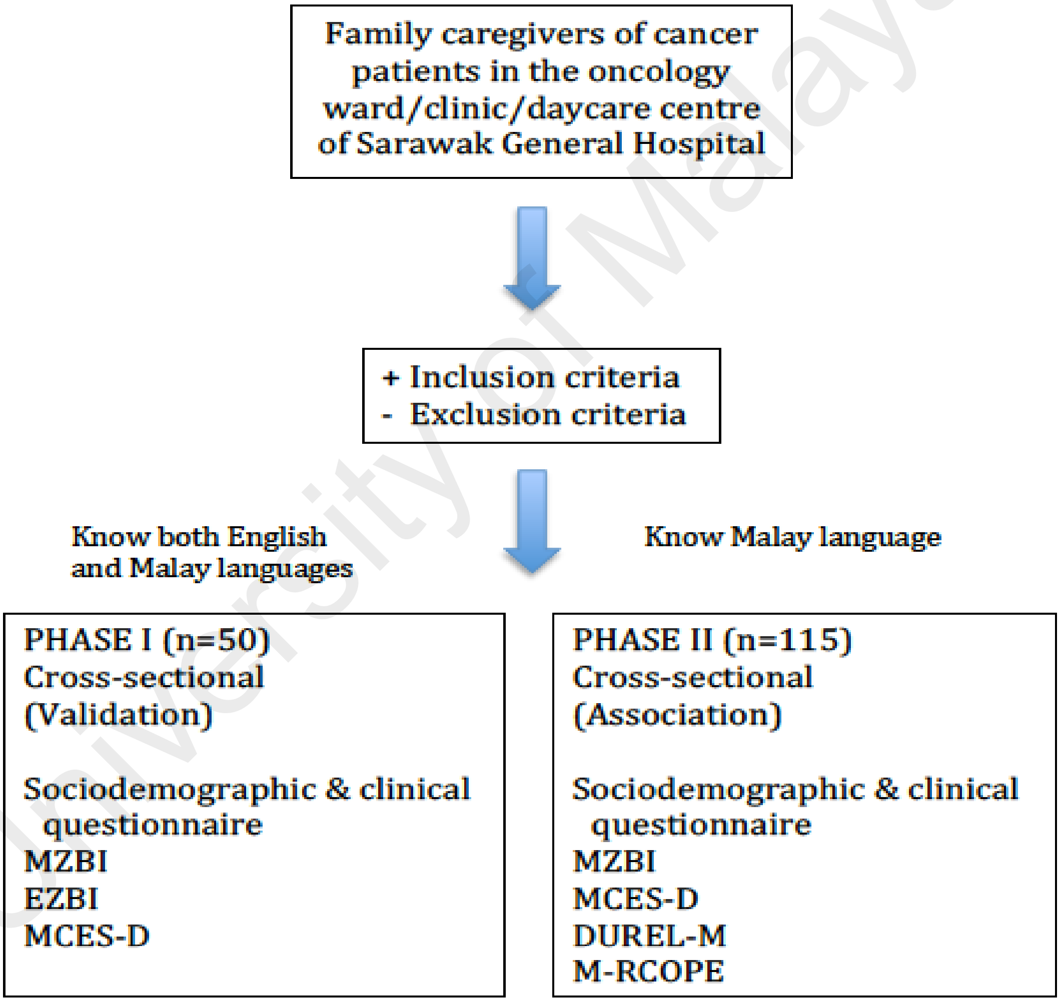
20. Total time spent on caregiving – a continuous numerical variable expressed in number of hours per week. This variable gives a crude estimation of the caregiver's workload in care provision. Maximum hours of caregiving are 168 hours per week or equivalent to full-time caregiving.

21. Shared caregiving – this variable was assessed in discrete number of other family caregivers assisting in caregiving. The number starts from 0 and increases depending on how many more family caregivers are available to look after the same patient. '0' means absence of shared caregiving. The higher the number, the more assistance the subject is getting in providing care to the cancer patient.

22. Presence of external support – a categorical variable of either 'Yes' or 'No'. External support in this context was referring to additional formal care support in the form of housemaid, private nurse or nursing home care from non-governmental organizations.

23. Relative or '*Saudara'* – this term is used in the English or Malay version of Zarit Burden Interview to represent the cancer patient (care recipient) under the care of the subjects in this study.

3.10 STUDY FLOW CHART



MZBI – Malay version of Zarit Burden Interview
EZBI – English version of Zarit Burden Interview
MCES-D – Malay version of Center for Epidemiologic Studies - Depression Scale
DUREL-M – Malay version of Duke University Religion Index
M-RCOPE – Malay version of Brief Religious Coping Questionnaire

Figure 3.1: Flow chart of the research study

3.11 STATISTICAL ANALYSIS

All statistical analyses were performed using the Statistical Package for the Social Sciences (IBM SPSS) version 24. Descriptive statistics were used to summarize the sociodemographic and clinical characteristics, and the scoring for MZBI, EZBI, MCES-D, DUREL-M, and M-RCOPE scales. Median and interquartile range (IqR) were used to describe the continuous variables, as the data were not normally distributed due to the non-randomized sampling design. Nevertheless, values for mean and standard deviation were displayed as well for comparison.

Cronbach's alpha coefficient and split-half correlation coefficient were determined to measure the internal consistency of the MZBI scale. A value above 0.80 is indicative of a good internal consistency. To assess the convergent and criterion validity, Spearman's correlations between the MZBI and MCES-D, and between the MZBI and EZBI were computed. Receiver Operating Characteristics (ROC) curve was used to compare the sensitivity and specificity of the MZBI scores across a range of values. The optimal cut-off score for MZBI was then determined for research use, based on the presence of probable depression as measured with MCES-D score of 16 or more. This was carried out with the assumption that caregiver burden is closely related to depression. As there is no gold standard test available for direct comparison of caregiver burden, depression level is used as the determinant for the burden cut-off. The area under the curve (AUC) would indicate the accuracy level of the scale's ability to differentiate individuals with significant caregiver burden from those without.

Correlations between MZBI score with MCES-D, DUREL-M, and M-RCOPE scores were examined using Spearman's correlation. Bivariate analyses using Chi-Square test for categorical data were carried out to determine the association between caregiver burden with all the other variables. Non-parametric tests were used since the data were not normally distributed. Multiple logistic regression analysis (Multivariate analysis) was then performed by including the significant factors from the bivariate analyses. A p-value of less than 0.05 (two-sided) with 95% confidence interval was considered as statistically significant for all analyses. It should be noted that the denominators were not always equal throughout this dissertation because of missing values. For incomplete datasets, only the missing values were excluded from the analysis, whereas the remaining data were still being used and included in the SPSS analyses.

3.12 ETHICAL CONSIDERATION

The study proposal for this research project was first presented to the Master Student Thesis Working Committee of the Department of Psychological Medicine in University of Malaya for approval. After obtaining departmental approval, this study was then registered online under the National Medical Research Registry (NMRR) with the registration number NMRR-16-1968-32639. Ethical approval was obtained from the Medical Research and Ethics Committee (MREC) of Ministry of Health Malaysia with the reference number (6)KKM/NIHSEC/P16-1601 (refer to Appendix A).

The permission to conduct the study in the Department of Radiotherapy, Oncology and Palliative Care of SGH was granted by the head of department and approved by the hospital director of SGH (refer to Appendix B). Written informed consent was obtained from all the subjects who participated in this study. All responses were kept strictly confidential. The data collected would be stored in a safe place for duration of five years and be safely destroyed after the retention period.

CHAPTER 4

RESULTS

4.1 OVERVIEW OF THE SUBJECTS' PARTICIPATION

A total of 230 subjects were approached for this study during the data collection period from January 2017 until April 2017. Fifty-three subjects (23.0%) were excluded from this study due to the following reasons: Caregivers refused participation in the study (n = 31), caregivers could not understand Malay or English language (n = 18), caregivers aged less than 18 years old (n = 3) and caregiver who was a paid or formal carer (n = 1).

As a result, 177 subjects consisting of family caregivers of cancer patients participated in the study. All the subjects completed the study questionnaires successfully with the exception of one caregiver, who submitted one questionnaire (MZBI scale) with a missing data. This missing data was excluded from the data analysis although the remaining complete data from other questionnaires were still being analysed as appropriate. Fifty caregivers of the total 177 subjects were recruited into the validation study (Phase I), while 127 caregivers were included in the association study (Phase II). A summary of the enrollment process of the study subjects is shown in Figure 4.1.

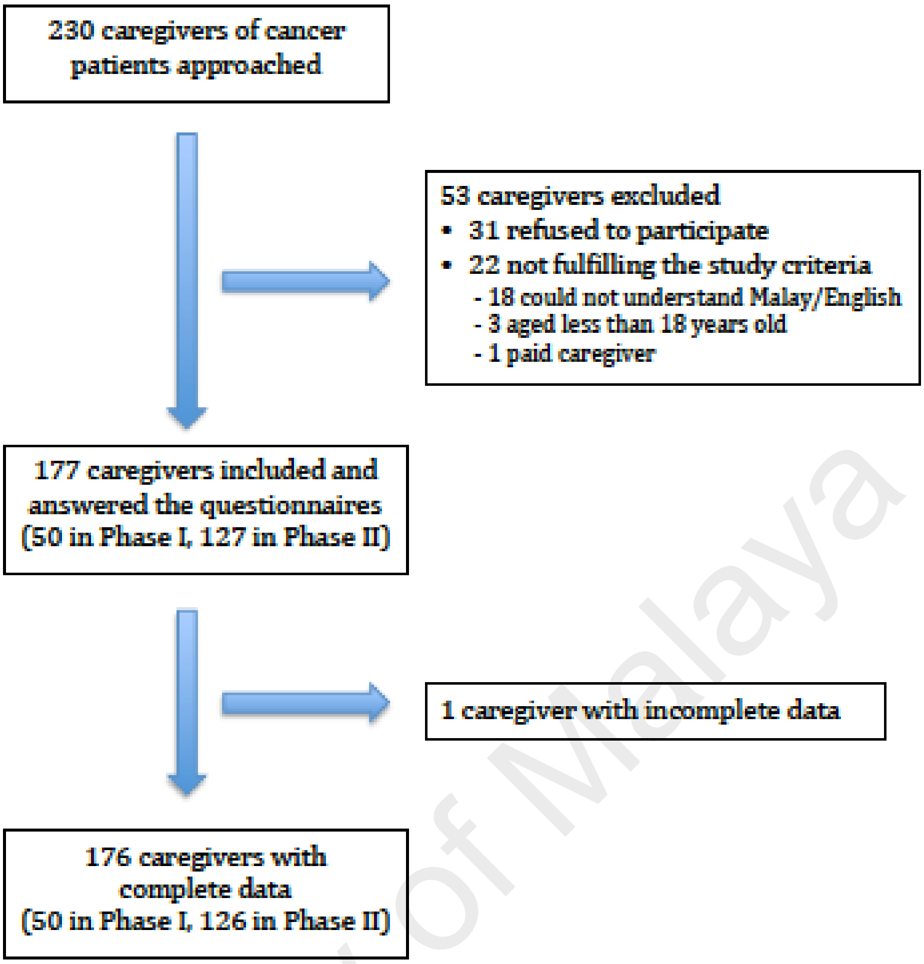


Figure 4.1: Enrollment of family caregivers in the study

4.2 RESULTS FOR PHASE I

4.2.1 Sociodemographic Characteristics

The median age of the 50 family caregivers in Phase I was 34 years old (range 18 – 78 years, IqR = 31.25 years), whereas the mean age was 39.4 years (SD = 16.57 years). Thirty caregivers were female (60%), which was about 1.5 times the number of male caregivers. Chinese ethnic (40%) constituted the majority of the caregivers, followed immediately by *Bumiputera* Sarawak (36%) and Malay (22%). Among the 18

Bumiputera Sarawak caregivers, majority were Ibans (n = 9) and Bidayuhs (n = 7). Figure 4.2 depicts the ethnic distribution of the caregivers in Phase I.

The commonest religion was Christianity (54%), followed by Islam (24%) and Buddhism (16%). One of the caregivers (2%) had no religion. Majority of the caregivers were married (56%), employed (54%), and from middle-income group with household income between RM 3,000 and RM 10,000 per month (54%). Most of them stayed in terraced houses (48%), semi-detached houses (20%) and village houses (20%).

A substantial portion of the caregivers was well-educated with 66% had tertiary education and 32% were educated up to secondary level. Only one caregiver (2%) had primary education and none was without formal education. Majority were either the children or grandchildren of the cancer patients (62%), followed by the spouses (24%) and the parents (6%). Table 4.1 summarizes the sociodemographic characteristics of the study subjects.

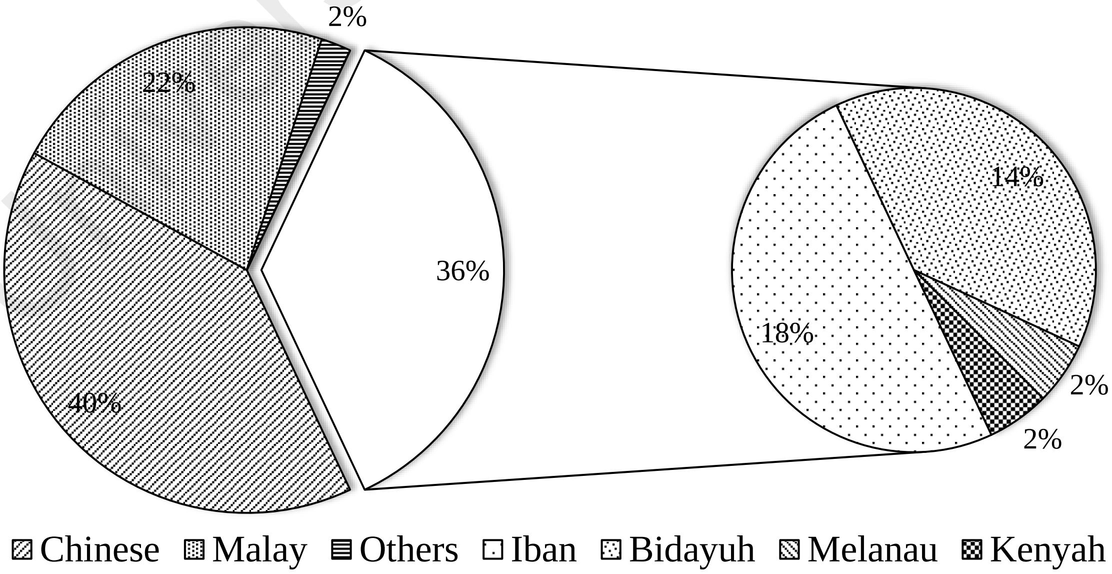


Figure 4.2: Ethnic distribution of the study subjects (N = 50)

Table 4.1: Sociodemographic characteristics of family caregivers (N = 50)

Characteristics	**n (%)**	**Mean ± SD**	**Median (IqR)**
Age (years)		39.4 ± 16.57	34.0 (31.25)
< 34	25 (50.0)		
≥ 34	25 (50.0)		
Gender			
Male	20 (40.0)		
Female	30 (60.0)		
Ethnicity			
Malay	11 (22.0)		
Chinese	20 (40.0)		
Bumiputera Sarawak	18 (36.0)		
Others	1 (2.0)		
Marital status			
Single	21 (42.0)		
Married	28 (56.0)		
Widowed	1 (2.0)		
Religion			
Muslim	12 (24.0)		
Christian	27 (54.0)		
Buddhist	8 (16.0)		
Others	2 (4.0)		
No religion	1 (2.0)		
Types of dwelling			
Bungalow/Condominium	4 (8.0)		
Semi-detached	10 (20.0)		
Terraced	24 (48.0)		
Flat	2 (4.0)		
Village house	10 (20.0)		
Employment			
Yes	27 (54.0)		
No	23 (46.0)		
Household income (per month)			
< RM3,000	18 (36.0)		
Between RM3,000 to RM10,000	27 (54.0)		
≥ RM10,000	5 (10.0)		
Education level			
Tertiary	33 (66.0)		
Secondary	16 (32.0)		
Primary	1 (2.0)		
Relationship to relative with cancer			
Spouses	12 (24.0)		
Children/Grandchildren	31 (62.0)		
Parents	3 (6.0)		
Siblings	2 (4.0)		
Others	2 (4.0)		

IqR, Interquartile range; SD, Standard deviation

4.2.2 Clinical Characteristics

Majority of the caregivers in this study were looking after relatives with solid cancer (92%), while the rest were caring for relatives with hematological malignancies. Among the solid cancer group, breast cancer (n = 11) was the commonest cancer suffered by relatives of the caregivers. This was followed by colorectal cancer (n = 10), lung cancer (n = 4) and cervical cancer (n = 3). As for those with hematological malignancies (n = 4), two had leukemia, and another two had aplastic anemia. The distribution of types of primary cancer is depicted in Figure 4.3.

In terms of cancer stages or severity in relatives of the caregivers, twenty (40%) were of moderate severity, or in Stage 2 and 3 of their illness. This was followed by severe cancer or Stage 4 (38%), and mild cancer or Stage 1 (16%). About two-thirds of the relatives were receiving oncology treatment as outpatient (n = 32), and the rest as inpatient (n = 18). Majority of the relatives were on active treatment (82%), while only two (4%) were on palliative care. Some of the relatives were on neither active nor palliative treatments, as 10% of them were still awaiting treatment plan and 4% of them already completed their treatments.

As for the functional status of the relatives based on ECOG scoring, most of them scored 1 (48%) and 2 (38%), whereas the rest scored 4 (8%), 3 (4%), and 0 (2%) respectively. The ECOG scores of 0 and 1 correspond to relatives that were still able to work or perform house chores, whereas a score of 2 or less indicates the relatives were still capable of caring for themselves. In this study, half of the relatives of the caregivers were able to work or do house chores (50%), but most were still capable of self-care (88%).

Looking at the caregiving aspects, majority of the caregivers have shared caregiving responsibilities with other family caregivers (86%), with average having two other caregivers assisting in the care of their relatives. In contrast, however, only three caregivers (6%) have shared caregiving in the form of external support such as housemaids or private nurses. The median duration as caregiver in this study was ten months (range 1 – 96 months, IqR 14 months). As for the total time spent on caregiving in a week, the median time was 84 hours (range 5 - 168 hours, IqR 113.8 hours). Table 4.2 summarizes the clinical characteristics of the study subjects.

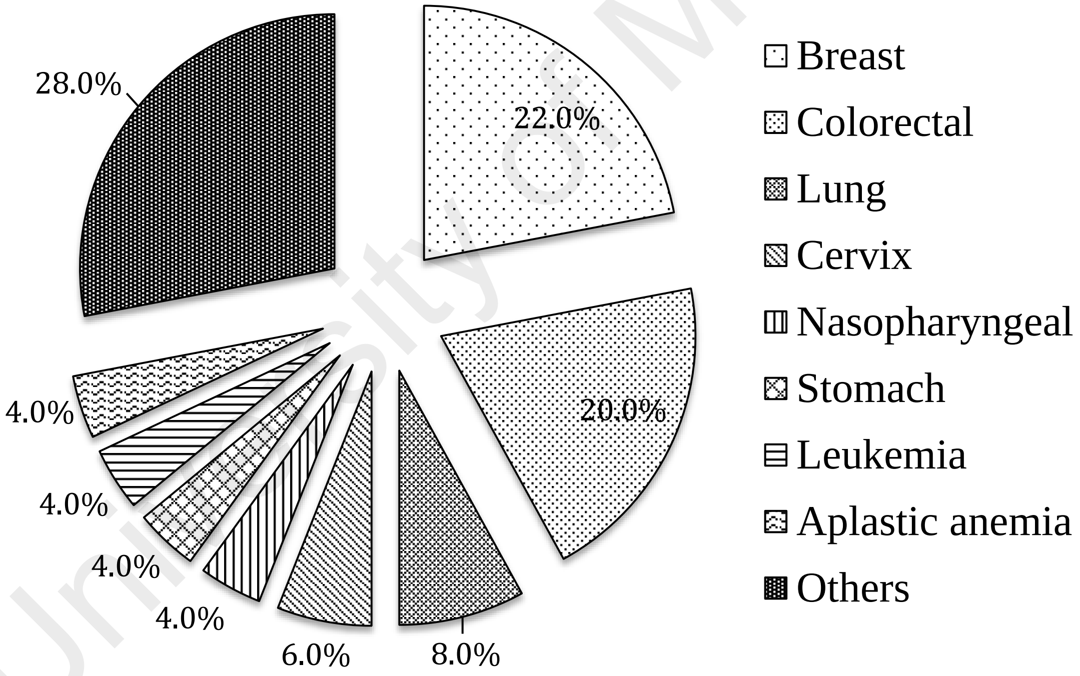


Figure 4.3: Types of primary cancer in relatives of the study subjects (N = 50)

Table 4.2: Clinical characteristics of family caregivers (N = 50)

Characteristics	**n (%)**	**Mean ± SD**	**Median (IqR)**
Types of primary cancer in relative			
Solid	46 (92.0)		
Hemotological	4 (8.0)		
Stages of cancer in relative			
Stage 1/Mild	8 (16.0)		
Stage 2-3/Moderate	20 (40.0)		
Stage 4/Severe	19 (38.0)		
Unsure stage	3 (6.0)		
Treatment setting of relative			
In-patient	18 (36.0)		
Out-patient	32 (64.0)		
Treatment types received by relative			
Active treatment	41 (82.0)		
Palliative treatment	2 (4.0)		
Not yet plan for treatment	5 (10.0)		
Completed treatment	2 (4.0)		
Functional status of relative (based on ECOG score)			
Score 0	1 (2.0)		
Score 1	24 (48.0)		
Score 2	19 (38.0)		
Score 3	2 (4.0)		
Score 4	4 (8.0)		
Relative still able to work/do chores			
Yes	25 (50.0)		
No	25 (50.0)		
Relative capable of self-care			
Yes	44 (88.0)		
No	6 (12.0)		
Shared caregiving			
Yes	43 (86.0)		
No	7 (14.0)		
External support			
Yes	3 (6.0)		
No	47 (94.0)		
Duration as caregiver (months)		14.7 ± 18.16	10.0 (14.0)
Time spent on caregiving in a week (hours)		87.9 ± 57.83	84.0 (113.8)
Number of other family caregivers assisting in caregiving		2.2 ± 1.77	2.0 (2.0)

ECOG, Eastern Cooperative Oncology Group; IqR, Interquartile range; SD, Standard deviation

4.2.3 Reliability and Validity of MZBI Scale

4.2.3.1 Reliability and Internal Consistency of MZBI Scale

The split-half reliability of the MZBI scale was measured using the Spearman-Brown coefficient for equal length-items scale. For split-half of the first 11 items versus the last 11 items, the correlation coefficient was 0.873. As for split-half of the odd items versus the even items, the correlation coefficient was even higher at 0.912, indicating an excellent internal consistency for the MZBI scale.

The high internal consistency of the MZBI scale was further confirmed with a Cronbach's alpha value of 0.898. The highest inter-item correlation coefficient (0.780) was found between item 20 and 21, whereas the lowest (- 0.152) was found between item 12 and item 21. The corrected item-total correlations ranged from 0.228 to 0.760 (Table 4.3).

For item 20 and item 21, the corrected item-total correlation value was 0.261 and 0.228 respectively. These low values (i.e. less than 0.30) indicated weak correlations for these two items with the rest of the items in the MZBI scale. Also, Cronbach's alpha coefficient would increase from 0.898 to 0.900 if item 20 was deleted, or to 0.902 if item 21 was deleted from the scale (Table 4.3). The rest of the items were essential as they had higher corrected item-total correlations, and their removal would result in lower Cronbach's alphas.

Table 4.3: Corrected item-total correlation and Cronbach's alpha if item deleted for MZBI scale (N = 50)

	Corrected Item-Total Correlation	**Squared Multiple Correlation**	**Cronbach's Alpha if Item Deleted**
Item 1	0.411	0.609	0.896
Item 2	0.543	0.756	0.893
Item 3	0.649	0.752	0.890
Item 4	0.486	0.825	0.895
Item 5	0.510	0.673	0.894
Item 6	0.521	0.600	0.894
Item 7	0.492	0.562	0.895
Item 8	0.517	0.763	0.894
Item 9	0.646	0.668	0.891
Item 10	0.760	0.878	0.889
Item 11	0.721	0.784	0.890
Item 12	0.555	0.708	0.893
Item 13	0.508	0.674	0.895
Item 14	0.544	0.732	0.893
Item 15	0.587	0.596	0.892
Item 16	0.542	0.711	0.893
Item 17	0.653	0.797	0.891
Item 18	0.506	0.727	0.894
Item 19	0.503	0.637	0.894
Item 20	**0.261**	0.813	**0.900**
Item 21	**0.228**	0.833	**0.902**
Item 22	0.451	0.605	0.897

*Cronbach's alpha for total MZBI is **0.898***
MZBI, Malay version of the Zarit Burden Interview scale

4.2.3.2 Validity of MZBI Scale

Convergent and criterion validity of MZBI scale was assessed through correlation with MCES-D and EZI scales. The Spearman's correlations between the total MZBI score and MZBI factors with the scores of MCES-D and EZBI were presented in Table 4.4. There was a moderate significant positive correlation between the MZBI and MCES-D (rs = 0.58, p < 0.01), and high significant positive correlation between the MZBI with EZBI (rs = 0.84, $p < 0.01$). These correlations still remained significant when the MZBI scale was divided into three factors. Each of the factors was also significantly correlated to the total MZBI score and with each other (Table 4.4).

Table 4.4: Correlation (Spearman's rho) between the MZBI scores and factors with the EZBI and MCES-D scores (N = 50)

Variable	MZBI Total	MZBI Factor 1[a]	MZBI Factor 2[b]	MZBI Factor 3[c]	EZBI Total	MCES-D Total
MZBI Total	1.00					
MZBI Factor 1[a]	0.91**	1.00				
MZBI Factor 2[b]	0.74**	0.59**	1.00			
MZBI Factor 3[c]	0.69**	0.46**	0.32*	1.00		
EZBI Total	0.84**	0.72**	0.67**	0.62**	1.00	
MCES-D Total	0.58**	0.46**	0.49**	0.45**	0.58**	1.00

Factor distribution was based on a study by Bianchi et al. (2016): [a] Tensions related to the role; [b] Intra-psychic tensions; [c] Competencies and expectations
*EZBI, English version of the Zarit Burden Interview scale; MCES-D, Malay version of the Center for Epidemiologic Studies - Depression scale; MZBI, Malay version of the Zarit Burden Interview scale; ** $p < 0.01$; * $p < 0.05$*

4.2.3.3 Determining Cut-off Score for MZBI Scale

The ROC curve (Figure 4.4) was plotted for the purpose of determining the suitable cut-off score for MZBI scale in local population. This was carried out by comparing the scale with the MCES-D, where the presence of probable depression (based on MCES-D score ≥ 16) was used as the determinant of the cut-offs for caregiver burden. The sensitivity and specificity of the MZBI scores across a range of values were generated as shown in Table 4.5. Generally, the shoulder of the ROC curve would suggest the most likely score range for the cut-off point. The area under the curve (AUC) was 0.786 (95% Confidence Interval: 0.658 – 0.914, p = 0.001). This value indicated that the MZBI scale has fairly good accuracy in differentiating those with significant caregiver burden from those without.

The MZBI score with optimal sensitivity and acceptable specificity was chosen as the cut-off score. At MZBI score of 22, the sensitivity and specificity of the scale were 70.8% and 69.2% respectively (Table 4.5). The positive predictive value and the negative predictive value were 68% and 72% respectively, calculated based on the 2 X 2 contingency table as demonstrated in Table 4.6. These values were reasonable in minimizing both false negative and false positive rates. Therefore, a MZBI score of 22 was determined to be the cut-off score in this study, and would be used in subsequent bivariate and multivariate analyses in Phase II.

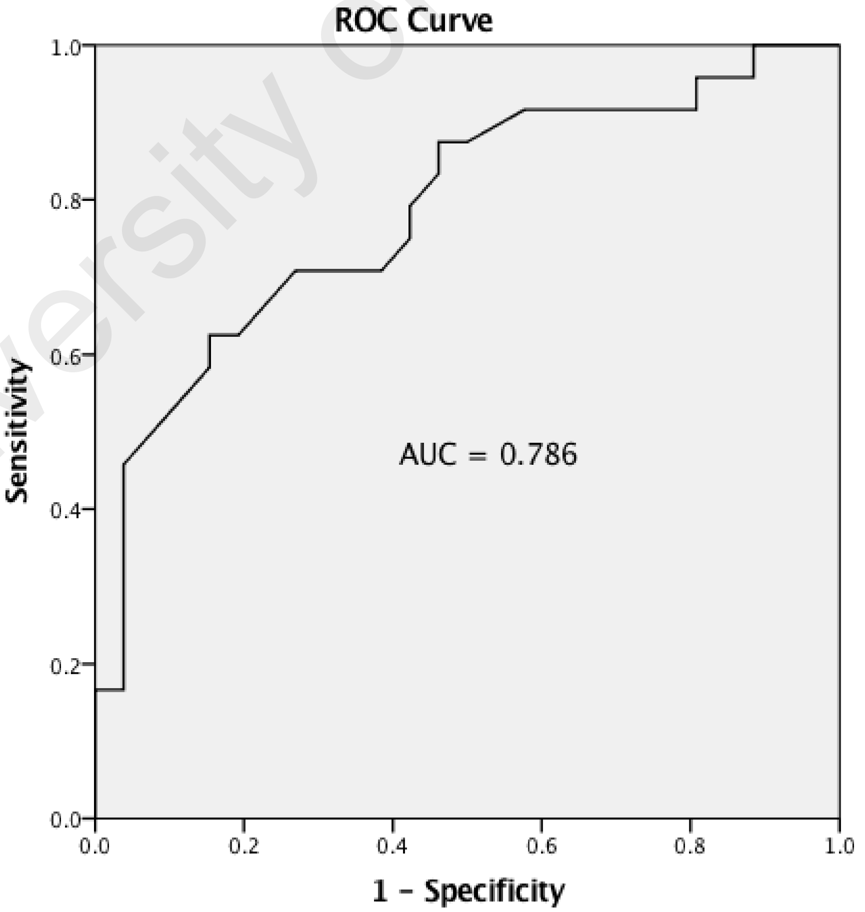


Figure 4.4: ROC plot for diagnostic sensitivity and 1 - specificity of MZBI scale

Table 4.5: Validity characteristics of MZBI scale at different cut-offs (N = 50)

Cut-off Score	**Sensitivity**	**Specificity**
15	0.917	0.423
16	0.875	0.500
17	0.875	0.538
18	0.833	0.538
19	0.792	0.577
20	0.750	0.577
21	0.708	0.615
22	**0.708**	**0.692**
23	0.708	0.731
24	0.667	0.769
25	0.625	0.808
26	0.625	0.846
27	0.583	0.846

Area under the curve, AUC = 0.786 (95% CI: 0.658 – 0.914)
MZBI, Malay version of the Zarit Burden Interview scale

Table 4.6: Assessment of the accuracy of MZBI scale in relation to MCES-D scale using a 2 X 2 contingency table

		Caregiver burden based on MZBI		Total
		No significant burden (score < 22)	Significant burden (score ≥ 22)	
Presence of depression based on MCES-D	Not depressed (score < 16)	18	8	26
	Depressed (score ≥ 16)	7	17	24
Total		25	25	50

MZBI, Malay version of the Zarit Burden Interview scale
MCES-D, Malay version of the Center for Epidemiologic Studies - Depression scale

4.3 RESULTS FOR PHASE II

4.3.1 Sociodemographic Characteristics

The median age of the 127 family caregivers in this study was 42 years old (range 19 – 67 years, IqR = 18 years), whereas the mean age was 41.1 years (SD = 12.27 years). Eighty-six caregivers were female (67.7%), which was about twice the number of the male caregivers. *Bumiputera* Sarawak (56.7%) constituted the majority of the caregivers, followed by Malay (25.2%) and Chinese (15.7%) caregivers. Among the 72 *Bumiputera* Sarawak caregivers, majority were Ibans (n = 39) and Bidayuhs (n = 20). Figure 4.5 depicts the ethnic distribution of the caregivers in Phase II.

The commonest religion was Christianity (55.1%), followed by Islam (34.6%) and Buddhism (7.1%). Three of the caregivers (2.4%) had no religion. Majority of the caregivers were married (80.3%), unemployed (52%), and from low-income group with household income less than RM 3,000 per month (56.7%). Most of them stayed in village houses (43.3%) and terraced houses (22.9%), followed by squatters (18.1%) and semi-detached houses (6.3%).

A substantial portion of the caregivers was well-educated with 63.8% had secondary education and 24.4% were educated up to tertiary level. Only 15 (11.8%) had primary education and none was without formal education. Majority were the spouses of the cancer patients (44.9%), followed by the children or grandchildren (41.0%) and the parents (6.3%). Table 4.7 summarizes the sociodemographic characteristics of the study subjects.

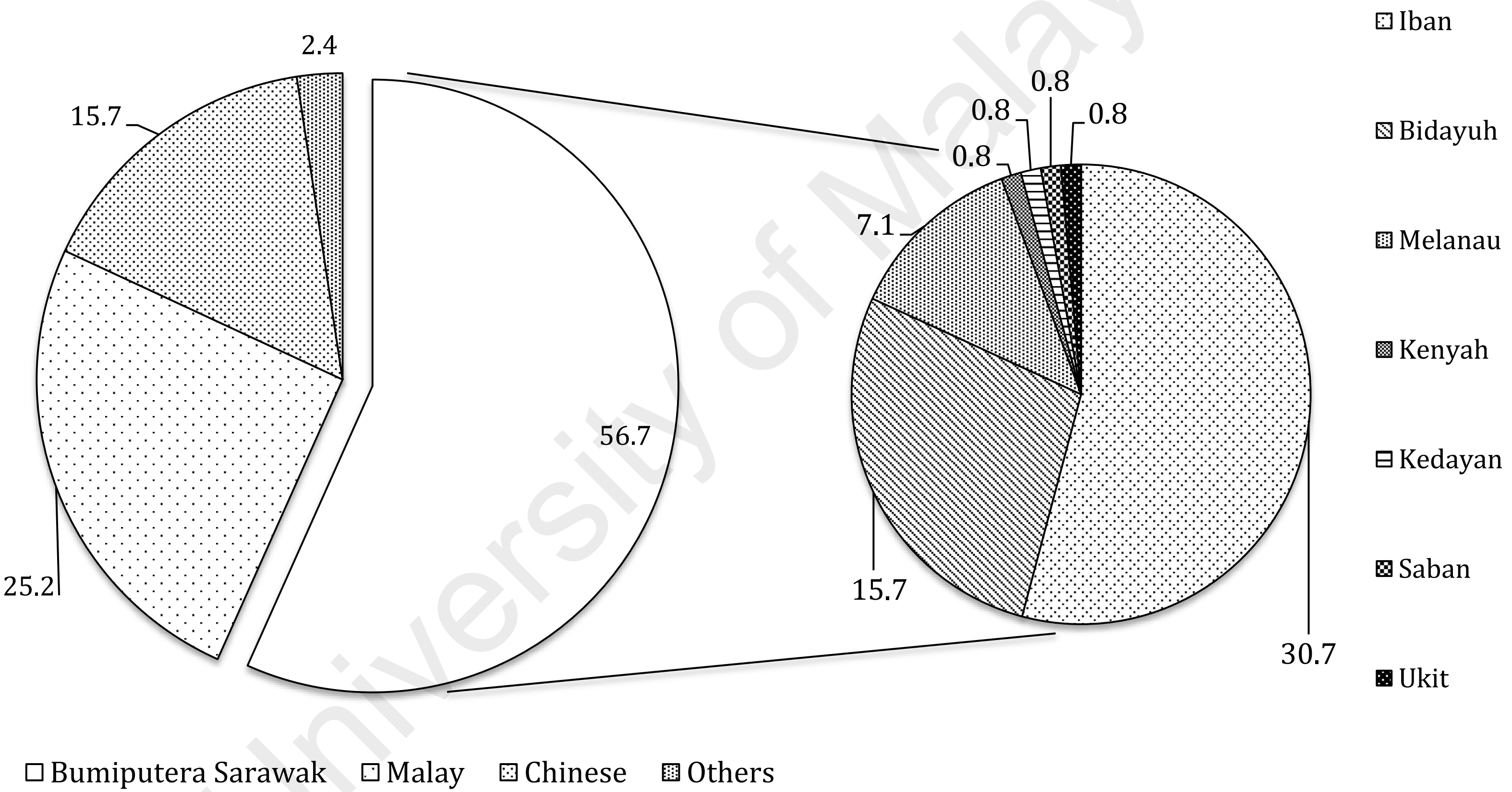


Figure 4.5: Ethnic distribution of the study subjects (N = 127)

Table 4.7: Sociodemographic characteristics of family caregivers (N = 127)

Characteristics	**n (%)**	**Mean ± SD**	**Median (IqR)**
Age (years)		41.1 ± 12.27	42.0 (18.0)
< 42	61 (48.0)		
≥ 42	66 (52.0)		
Gender			
Male	41 (32.3)		
Female	86 (67.7)		
Ethnicity			
Malay	32 (25.2)		
Chinese	20 (15.7)		
Bumiputera Sarawak	72 (56.7)		
Others	3 (2.4)		
Marital status			
Single	25 (19.7)		
Married	102 (80.3)		
Religion			
Muslim	44 (34.6)		
Christian	70 (55.1)		
Buddhist	9 (7.1)		
Others	1 (0.8)		
No religion	3 (2.4)		
Types of dwelling			
Bungalow/Condominium	6 (4.7)		
Semi-detached	8 (6.3)		
Terraced	29 (22.9)		
Flat	6 (4.7)		
Village house	55 (43.3)		
Squatter	23 (18.1)		
Employment			
Yes	61 (48.0)		
No	66 (52.0)		
Household income (per month)			
< RM3,000	72 (56.7)		
Between RM3,000 to RM10,000	41 (32.3)		
≥ RM10,000	14 (11.0)		
Education level			
Tertiary	31 (24.4)		
Secondary	81 (63.8)		
Primary	15 (11.8)		
Relationship to relative with cancer			
Spouses	57 (44.9)		
Children/Grandchildren	52 (41.0)		
Parents	8 (6.3)		
Siblings	6 (4.7)		
Others	4 (3.1)		

IqR, Interquartile range; SD, Standard deviation

4.3.2 Clinical Characteristics

Majority of the caregivers in this study were looking after relatives with solid cancer (92.9%), while the rest were caring for relatives with hematological malignancies. Among the solid cancer group, nasopharyngeal cancer (n = 27) was the commonest cancer suffered by relatives of the caregivers. This was followed by colorectal cancer (n = 23), breast cancer (n = 22) and lung cancer (n = 11). As for those with hematological malignancies (n = 9), five had leukemia, three had lymphoma and one had aplastic anemia. The distribution of types of primary cancer among the cancer patients in Phase II is depicted in Figure 4.6.

In terms of cancer stages or severity in relatives of the caregivers, about 54 (42.5%) were of moderate severity, or in Stage 2 and 3 of their illness. This was followed by severe cancer or Stage 4 (32.3%), and mild cancer or Stage 1 (9.5%). Majority of the relatives were receiving oncology treatment as inpatient (n = 72), and the rest as outpatient (n = 55). Most of the relatives were on active treatment (73.2%), while only ten (7.9%) were on palliative care. Some of the relatives were on neither active nor palliative treatments, as 11.8% of them were still awaiting treatment plan and 7.1% of them already completed their treatments.

As for the functional status of the relatives based on ECOG scoring, most of them scored 1 (43.3%) and 2 (37.8%), whereas the rest scored 3 (10.3%), 4 (4.7%), and 0 (3.9%) respectively. The ECOG scores of 0 and 1 correspond to relatives that were still able to work or perform house chores, whereas a score of 2 or less indicates the relatives were still capable of caring for themselves. In this study, slightly more than half of the relatives of the caregivers were not able to work or do house chores (52.8%), but most were still capable of self-care (85%).

Looking at the caregiving aspects, majority of the caregivers have shared caregiving responsibilities with other family caregivers (78.7%), with average having two other caregivers assisting in the care of their relatives. In contrast, however, only one caregiver (0.8%) has shared caregiving in the form of external support such as housemaids or private nurses. The median duration as caregiver in this study was nine months (range 1 – 156 months, IqR 20 months). As for the total time spent on caregiving in a week, the median time was 128 hours (range 2 - 168 hours, IqR 120 hours). Table 4.8 summarizes the clinical characteristics of the subjects in Phase II.

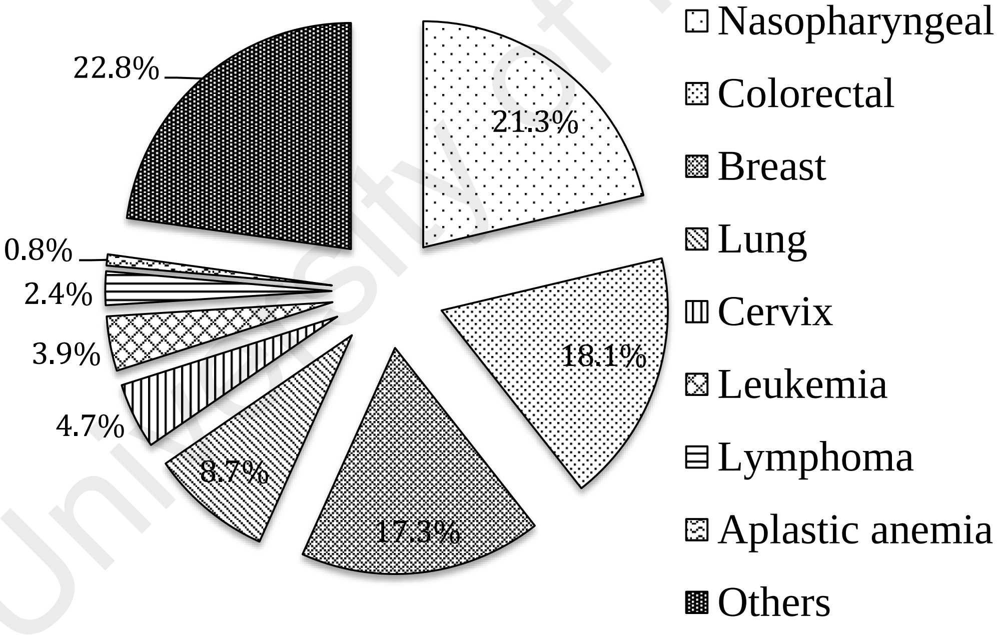


Figure 4.6: Types of primary cancer in relatives of the study subjects (N = 127)

Table 4.8: Clinical characteristics of family caregivers (N = 127)

Characteristics	**n (%)**	**Mean ± SD**	**Median (IqR)**
Types of primary cancer in relative			
Solid	118 (92.9)		
Hemotological	9 (7.1)		
Stages of cancer in relative			
Stage 1/Mild	12 (9.5)		
Stage 2-3/Moderate	54 (42.5)		
Stage 4/Severe	41 (32.3)		
Unsure stage	20 (15.7)		
Treatment setting of relative			
In-patient	72 (56.7)		
Out-patient	55 (43.3)		
Treatment types received by relative			
Active treatment	93 (73.2)		
Palliative treatment	10 (7.9)		
Not yet plan for treatment	15 (11.8)		
Completed treatment	9 (7.1)		
Functional status of relative (based on ECOG score)			
Score 0	5 (3.9)		
Score 1	55 (43.3)		
Score 2	48 (37.8)		
Score 3	13 (10.3)		
Score 4	6 (4.7)		
Relative still able to work/do chores			
Yes	60 (47.2)		
No	67 (52.8)		
Relative capable of self-care			
Yes	108 (85.0)		
No	19 (15.0)		
Shared caregiving			
Yes	100 (78.7)		
No	27 (21.3)		
External support			
Yes	1 (0.8)		
No	126 (99.2)		
Duration as caregiver (months)		17.3 ± 22.60	9.0 (20.0)
Time spent on caregiving in a week (hours)		109.9 ± 60.75	128.0 (120.0)
Number of other family caregivers assisting in caregiving		2.0 ± 1.67	2.0 (2.0)

ECOG, Eastern Cooperative Oncology Group; IqR, Interquartile range; SD, Standard deviation

4.3.3 Descriptive Statistics for MZBI Scores

In the main phase of the current study, the median score for MZBI based on the responses gathered from the subjects was 26.0 (range 0 – 67, interquartile range 20.25), whereas the mean score was 26.5 with standard deviation of 14.44. The mean scores of the individual items in the MZBI ranged from 0.4 to 2.8. All individual item scores were significantly correlated to the total MZBI score through Spearman’s correlation ($p < 0.01$). The descriptive summary for MZBI scores is displayed in Table 4.9. Based on the MZBI cut-off score of 22 determined earlier in the study, majority of the 126 family caregivers (55.6%) were found to have significant caregiver burden (Table 4.11).

4.3.4 Descriptive Statistics for MCES-D, DUREL-M and M-RCOPE Scores

Table 4.10 summarizes the descriptive statistics for MCES-D, DUREL-M and M-RCOPE scales used to assess the level of depression, religiosity and religious coping respectively in this study. The scores for MCES-D ranged from 0 to 47, with a median score of 19 (interquartile range 17), which was very near to the mean score of 19.3 (standard deviation 11.41). Based on the cut-off score of 16 for MCES-D scale, more than half of the 127 caregivers (59.1%) in this study were having probable depression (Table 4.11).

For DUREL-M, the total scores in this study ranged from 7 to 27 with a median score of 23 (interquartile range 5) and a mean score of 22 (standard deviation 4.03). The scale was further described in three separate domains (ORA, NORA, IR) with their respective median and mean scores as shown in Table 4.10. Based on the median score of 23, the study subjects were divided into two groups: those who scored 23 and above the median score (high religiosity), and those who scored below the median score (low religiosity). As shown in Table 4.11, the group with high religiosity (56.7%) constituted the majority over the low religiosity group (43.3%).

The M-RCOPE was interpreted separately for two of its main subscales (PRC and NRC), as the total scoring is not applicable for this scale. For PRC, the median score was 25 (interquartile range 7) and the mean score was 23.6 (standard deviation 4.54) within a range of scores from 7 to 28. Compared to PRC, the median and mean scores for NRC were considerably lower (median 10, interquartile range 5; mean 11.4, standard deviation 4.52) with scores ranged from 7 to 27 (Table 4.10).

Similarly, the study subjects were divided into two separate groups based on the median scores for PRC and NRC respectively: High PRC group (scored 25 and above) versus low PRC group (scored below 25); and high NRC group (scored 10 and above), versus low NRC group (scored below 10). Both high PRC group (53.5%) and high NRC (57.5%) group were more in numbers than the low PRC group (46.5%) and low NRC group (42.5%) respectively (Table 4.11).

Table 4.9: Descriptive statistics for MZBI scores (N = 126)

Items	**Minimum**	**Maximum**	**Mean (SD)**	**Median (IqR)**	**rs**
Factor 1[a]	0	37	11.4 (8.41)	10.0 (13.00)	0.94**
Item 2	0	4	1.4 (1.27)	1.0 (2.00)	0.65**
Item 3	0	4	1.4 (1.24)	2.0 (2.00)	0.67**
Item 8	0	4	1.7 (1.48)	2.0 (3.00)	0.56**
Item 10	0	4	1.0 (1.02)	1.0 (2.00)	0.70**
Item 11	0	4	0.9 (1.09)	1.0 (2.00)	0.74**
Item 12	0	4	0.9 (1.23)	0.0 (2.00)	0.71**
Item 13	0	4	0.4 (0.83)	0.0 (0.00)	0.50**
Item 14	0	4	1.2 (1.46)	0.0 (2.00)	0.65**
Item 17	0	4	0.8 (1.07)	0.0 (1.00)	0.64**
Item 22	0	4	1.8 (1.49)	2.0 (3.00)	0.69**
Factor 2[b]	0	17	4.6 (4.13)	3.0 (5.00)	0.81**
Item 1	0	4	1.3 (1.14)	1.0 (2.00)	0.38**
Item 4	0	4	0.4 (0.73)	0.0 (0.00)	0.48**
Item 5	0	2	0.5 (0.69)	0.0 (1.00)	0.46**
Item 6	0	4	0.4 (0.78)	0.0 (0.00)	0.64**
Item 9	0	4	0.9 (1.06)	0.0 (2.00)	0.67**
Item 16	0	4	0.8 (1.14)	0.0 (1.00)	0.60**
Item 18	0	4	0.6 (0.90)	0.0 (1.00)	0.52**
Factor 3[c]	0	20	10.5 (4.28)	12.0 (5.00)	0.65**
Item 7	0	4	2.3 (1.37)	2.0 (3.00)	0.38**
Item 15	0	4	2.0 (1.40)	2.0 (2.00)	0.52**
Item 19	0	4	1.1 (1.06)	1.0 (2.00)	0.54**
Item 20	0	4	2.4 (1.42)	3.0 (3.00)	0.41**
Item 21	0	4	2.8 (1.33)	3.0 (2.00)	0.28**
Total	0	67	26.5 (14.44)	26.0 (20.25)	

Factor distribution was based on a study by Bianchi et al. (2016): [a] Tensions related to the role; [b] Intra-psychic tensions; [c] Competencies and expectations
MZBI, Malay version of the Zarit Burden Interview scale; IqR, Interquartile range;
rs, Spearman's rho correlation coefficient in relation to the total MZBI score;
SD, Standard deviation; ** $p < 0.01$

Table 4.10: Descriptive statistics for MCES-D, DUREL-M and M-RCOPE scores (N = 127)

Scale		Minimum	Maximum	Mean ± SD	Median (IqR)
MCES-D		0	47	19.3 ± 11.41	19.0 (17.0)
DUREL-M	ORA	1	6	4.3 ± 1.36	5.0 (2.0)
	NORA	1	6	3.9 ± 1.60	4.0 (3.0)
	IR	5	15	13.8 ± 1.97	15.0 (2.0)
	Total	7	27	22.0 ± 4.03	23.0 (5.0)
M-RCOPE	PRC	7	28	23.6 ± 4.54	25.0 (7.0)
	NRC	7	27	11.4 ± 4.52	10.0 (5.0)

DUREL-M, Malay version of the Duke University Religion Index scale; IqR, Interquartile range; IR, Intrinsic religiosity; MCES-D, Malay version of the Center for Epidemiologic Studies - Depression scale; M-RCOPE, Malay version of the Brief RCOPE scale; NORA, Non-organizational religious activity; NRC, Negative religious coping; ORA, Organizational religious activity; PRC, Positive religious coping; SD, Standard deviation

Table 4.11: Descriptive statistics for caregiver burden, caregiver depression, religiosity and religious coping among the study subjects

Variable	n	%
Caregiver burden [a]		
No	56	44.4
Yes	70	55.6
Depression [b]		
No	52	40.9
Yes	75	59.1
Religiosity level [c]		
Low	55	43.3
High	72	56.7
Positive religious coping [d]		
Low	59	46.5
High	68	53.5
Negative religious coping [e]		
Low	54	42.5
High	73	57.5

[a] *Presence of caregiver burden was based on total MZBI score of equal or more than 22*
[b] *Presence of caregiver depression was based on total MCES-D score of equal or more than 16*
[c] *Religiosity level was determined based on total DUREL-M median score of 23*
[d] *Positive religious coping level was determined based on M-RCOPE PRC median score of 25*
[e] *Negative religious coping level was determined based on M-RCOPE NRC median score of 10*

4.3.5 Association between Caregiver Burden and Sociodemographic Characteristics

Bivariate analysis was performed to examine the associations between caregiver burden and caregivers' sociodemographic factors such as age, gender, ethnicity, marital status, employment status, socioeconomic status, household income, education level, religion group, and relationship to cancer patients. Only one sociodemographic factor was found to be significantly associated with caregiver burden: Relationship to relatives with cancer being the children or grandchildren.

In other words, caregivers who were the children or grandchildren of the cancer patients were significantly less likely to have caregiver burden than caregivers who were not (OR 0.46, CI 0.22 – 0.94, p = 0.032). Table 4.12 illustrates the associations between the caregiver burden and the sociodemographic characteristics from bivariate analysis using the Chi-square test.

4.3.6 Association between Caregiver Burden and Clinical Characteristics

Clinical characteristics in relatives of the caregivers such as types of primary cancer, severity of cancer, treatment settings, treatment types, and functional status (ability to work and capacity for self-care); as well as caregiving factors such as presence of shared caregiving, external support, and caregiving duration were examined for associations with the caregiver burden. Two factors in the relatives of the caregivers were found to be significant: Treatment setting and the ability to work.

On bivariate analysis, significant caregiver burden was more likely among family caregivers who cared for cancer patients that were treated as inpatients than those that were treated as outpatients (OR 2.21, CI 1.08 – 4.55, p = 0.03). Also, caregivers who looked after cancer patients that were unable to work experienced significantly more burden than those who cared for relatives that were still able to work (OR 2.43 CI 1.18 – 4.99, p = 0.015). Table 4.13 illustrates the associations between the caregiver burden and the clinical characteristics from bivariate analysis using the Chi-square test.

4.3.7 Association between Caregiver Burden and Depression, Religiosity and Religious Coping

After creating the dummy categorical variables for depression, religiosity, and religious coping (Table 4.11), the associations between these variables and the caregiver burden variable were then tested using Chi-square test. The finding from this bivariate analysis is summarized in Table 4.14.

Significant positive association was found between caregiver burden and caregiver depression (OR 5.20, CI 2.41 – 11.21, p < 0.001). This finding can be interpreted in two possible ways: depressed caregivers are more likely to have significant caregiver burden than non-depressed caregivers, or burdened caregivers are more likely to be depressed than non-burdened caregivers. Caregivers with high negative religious coping (NRC) also experienced significantly more burden than those with low NRC (OR 2.21, CI 1.08 – 4.55, p = 0.03). However, no significant relationship was found between caregiver burden with the religiosity level or positive religious coping pattern of the caregiver.

Table 4.12: Bivariate analysis of the association between caregiver burden with sociodemographic characteristics among the study subjects using Chi-square test (N = 126)

Characteristics	**Caregiver Burden** [a] **No** **n (%)**	 **Yes** **n (%)**	χ^2	**OR**	**95% CI**	***p*-value**
Age (years)						
< 42	31 (51.7)	29 (48.3)	2.420	1.75	0.86 – 3.57	0.120
≥ 42	25 (37.9)	41 (62.1)				
Gender						
Female	43 (50.0)	43 (50.0)	3.386	2.08	0.95 – 4.55	0.066
Male	13 (32.5)	27 (67.5)				
Ethnicity						
Bumiputera	44 (41.9)	61 (58.1)	1.646	0.54	0.21 – 1.40	0.200
Non-Bumiputera	12 (57.1)	9 (42.9)				
Marital status						
Single/Divorced/Widowed	15 (60.0)	10 (40.0)	3.056	2.20	0.90 – 5.36	0.080
Married	41 (40.6)	60 (59.4)				
Employment						
Yes	28 (46.7)	32 (53.3)	0.229	1.19	0.59 – 2.40	0.632
No	28 (42.4)	38 (57.6)				
Household income						
< RM3000 per month	30 (42.3)	41 (57.7)	0.316	0.82	0.40 – 1.66	0.574
≥ RM3000 per month	26 (47.3)	29 (52.7)				
Education level						
Tertiary	13 (41.9)	18 (58.1)	0.105	0.87	0.39 – 1.98	0.746
Primary /Secondary	43 (45.3)	52 (54.7)				

Cont.

Cont.						
Socioeconomic status [b]						
Higher status	22 (51.2)	21 (48.8)	1.193	1.51	0.72 – 3.17	0.275
Lower status	34 (41.0)	49 (59.0)				
Religion						
Christian	31 (44.3)	39 (55.7)	0.002	0.99	0.49 – 2.00	0.968
Non-Christian	25 (44.6)	31 (55.4)				
Religion						
Muslim	18 (41.9)	25 (58.1)	0.177	0.85	0.41 – 1.79	0.674
Non-Muslim	38 (45.8)	45 (54.2)				
Relationship to cancer patient						
Non-spouses	35 (50.0)	35 (50.0)	1.969	1.67	0.82 – 3.41	0.161
Spouses	21 (37.5)	35 (62.5)				
Relationship to cancer patient						
Non-children/grandchildren	27 (36.5)	47 (63.5)	4.599	0.46	0.22 – 0.94	0.032*
Children/grandchildren	29 (55.8)	23 (44.2)				

*χ^2 , Chi-square; OR, Odds ratio; CI, Confidence interval; * Statistically significant ($p < 0.05$)*

[a] *Presence of caregiver burden was based on the total MZBI score of equal or more than 22*

[b] *Socioeconomic status was determined based on types of dwelling: higher status e.g. staying at bungalow, condominium, semi-detached or terraced house; lower status e.g. staying at flat, village house or squatter*

Table 4.13: Bivariate analysis of the association between caregiver burden with clinical characteristics among the study subjects using Chi-square test (N = 126)

Characteristics	Caregiver Burden [a]		χ^2	OR	95% CI	*p*-value
	No n (%)	Yes n (%)				
Types of cancer in relative						
Solid	53 (45.3)	64 (54.7)	0.485	1.66	0.40 – 6.94	0.486
Hematological	3 (33.3)	6 (66.7)				
Severe cancer stage in relative [b]						
No	42 (49.4)	43 (50.6)	2.610	1.88	0.87 – 4.08	0.106
Yes	14 (34.1)	27 (65.9)				
Treatment setting of relative						
Out-patient	30 (55.6)	24 (44.4)	4.725	2.21	1.08 – 4.55	0.030*
In-patient	26 (36.1)	46 (63.9)				
Relative on active treatment						
Yes	41 (44.6)	51 (55.4)	0.002	1.02	0.46 – 2.25	0.964
No	15 (44.1)	19 (55.9)				
Relative on palliative treatment						
Yes	3 (30.0)	7 (70.0)	0.918	0.51	0.13 – 2.07	0.338
No	53 (45.7)	63 (54.3)				
Relative able to work [c]						
Yes	33 (55.9)	26 (44.1)	5.930	2.43	1.18 – 4.99	0.015*
No	23 (34.3)	44 (65.7)				
Relative capable of self-care [d]						
Yes	51 (47.7)	56 (52.3)	2.978	2.55	0.86 – 7.58	0.084
No	5 (26.3)	14 (73.7)				

Cont.

Cont.

Shared caregiving						
No	9 (33.3)	18 (66.7)	1.718	0.55	0.23 – 1.35	0.190
Yes	47 (47.5)	52 (52.5)				
Caregiving duration (months)						
< 9	27 (42.9)	36 (57.1)	0.129	0.88	0.44 – 1.78	0.720
≥ 9	29 (46.0)	34 (54.0)				
Caregiving hours in a week						
< 128	30 (47.6)	33 (52.4)	0.514	1.29	0.64 – 2.62	0.473
≥ 128	26 (41.3)	37 (58.7)				

χ^2 *, Chi-square; OR, Odds ratio; CI, Confidence interval; * Statistically significant (p <0.05)*

[a] *Presence of caregiver burden was based on the total MZBI score of equal or more than 22*

[b] *Severe cancer stage was referring to stage 4 cancer*

[c] *Ability to work was based on the ECOG score of 1 or below*

[d] *Capacity for self-care was based on the ECOG score of 2 or below*

Table 4.14: Bivariate analysis of the association between caregiver burden with depression, religiosity, and religious coping among the study subjects using Chi-square test (N = 126)

Characteristics	Caregiver Burden [a]		χ^2	OR	95% CI	*p*-value
	No n (%)	Yes n (%)				
Depression [b]						
No	35 (67.3)	17 (32.7)	18.744	5.20	2.41 – 11.21	<0.001*
Yes	21 (28.4)	53 (71.6)				
Religiosity level [c]						
Low	25 (45.5)	30 (54.5)	0.040	1.08	0.53 – 2.18	0.841
High	31 (43.7)	40 (56.3)				
Positive religious coping [d]						
Low	24 (40.7)	35 (59.3)	0.637	0.75	0.37 – 1.52	0.425
High	32 (47.8)	35 (52.2)				
Negative religious coping [e]						
Low	30 (55.6)	24 (44.4)	4.725	2.21	1.08 – 4.55	0.030*
High	26 (36.1)	46 (63.9)				

*χ^2, Chi-square; OR, Odds ratio; CI, Confidence interval; * Statistically significant ($p < 0.05$)*

[a] *Presence of caregiver burden was based on the total MZBI score of equal or more than 22*

[b] *Presence of caregiver depression was based on the total MCES-D score of equal or more than 16*

[c] *Religiosity level was determined based on the total DUREL-M cut-off score of 23 (median)*

[d] *Positive religious coping level was determined based on the M-RCOPE PRC cut-off score of 25 (median)*

[e] *Negative religious coping level was determined based on the total M-RCOPE NRC cut-off score of 10 (median)*

4.3.8 Factors Associated with Caregiver Burden: A Multivariate Analysis

Significant factors obtained from the bivariate analyses of the earlier data were included in the multiple logistic regression analysis to determine the associated factor(s) for caregiver burden after controlling for the confounders. The findings from this multivariate analysis were summarized in Table 4.15.

According to this regression model, the caregivers' relationship of being the children or grandchildren of cancer patients (OR 0.41, CI 0.18 – 0.94, $p = 0.035$), as well as the presence of caregiver depression (OR 4.26, CI 1.87 – 9.72, $p = 0.001$) remained significantly associated with caregiver burden after adjusted for other significant associated factors.

In other words, the odds of having significant caregiver burden in caregivers who were the children or grandchildren of cancer patients were 2.44 times less than the odds in non-children or non-grandchildren caregivers in this study. Also, the presence of depression in the caregivers increased the odds of having significant caregiver burden up to four-folds.

With five significant variables, this logistic regression model explained 27.9% (Nagelkerke $R^2 = 0.279$) of the variance on caregiver burden and correctly classified 73% of the caregivers. The model fits well to the data with good calibration, as suggested by the Hosmer-Lemeshow goodness-of-fit test that yielded a $\chi^2(8)$ of 3.599 and was insignificant ($p = 0.891$).

Table 4.15: Multivariate analysis of the factors associated with caregiver burden among the study subjects using multiple logistic regression method (N = 126)

Characteristics	**Crude OR**	**Adjusted OR**	**95% CI (Adjusted OR)**	***p*-value**
Relationship to cancer patient				
Non-children/grandchildren	0.46	0.41	0.18 – 0.94	**0.035**
Children/grandchildren				
Treatment setting of relative				
Out-patient	2.21	1.10	0.46 – 2.66	0.834
In-patient				
Relative able to work [a]				
Yes	2.43	2.02	0.84 – 4.85	0.115
No				
Depression [b]				
No	5.20	4.26	1.87 – 9.72	**0.001**
Yes				
Negative religious coping [c]				
Low	2.21	2.04	0.91 – 4.58	0.085
High				

OR, Odds ratio; CI, Confidence interval

[a] *Ability to work was based on the ECOG score of 1 or below*

[b] *Presence of caregiver depression was based on the MCES-D score of equal or more than 16*

[c] *Negative religious coping level was determined based on the total M-RCOPE NRC cut-off score of 10 (median)*

CHAPTER 5

DISCUSSION

5.1 SOCIODEMOGRAPHIC CHARACTERISTICS OF CANCER CAREGIVERS

The family caregivers of cancer patients in the main phase of the study have a mean age of around 41 years old and a median age of 42 years old, similar to the mean ages reported in most of the caregiver studies conducted in Asia (Mahadevan et al., 2013; Meecharoen, Northouse, Sirapo-ngam, & Monkong, 2013; Lukhmana et al., 2015; Chua et al., 2016). The caregivers in Phase I of the study were much younger with mean and median ages below 40 years old. However, in Western countries, the caregiver’s mean age tends to be older at around 50 to 60 years old (Romito, Goldzweig, Cormio, Hagedoorn, & Andersen, 2013; National Alliance for Caregiving, 2016). This may be due to the increasing number of aging population in developed countries where better healthcare services for elderly citizens are readily available (Baider & Surbone, 2014).

In this study, 60% of the caregivers in Phase I and about two-thirds of the caregivers in Phase II were women. Majority of them were married. Almost all the previous studies on cancer caregiving showed that female caregivers and married caregivers were more in numbers than male caregivers and unmarried caregivers respectively (Kim et al., 2008; Meecharoen et al., 2013; Lukhmana et al., 2015; Chua et al., 2016; National Alliance for Caregiving, 2016). The higher number of female caregivers may be due to the differential survival rates for gender that resulted in more women than men in the general population (Romito et al., 2013).

Another plausible explanation is the difference in basic personality traits between men and women, where women in general tend to be more nurturing, and have a greater sense of responsibility and self-sacrifice (Sharma, Chakrabarti, & Grover, 2016). Traditionally, women are also less likely to be employed outside and more likely to stay at home, which lead to women devoting more time to caregiving than men (Sharma et al., 2016). Correlatively, a substantial amount (53.5%) of the female caregivers in the main phase of the study are homemakers.

The ethnicity of the cancer caregivers in the main phase of the study represents the overall ethnic distribution in Sarawak, where the natives or *Bumiputera* Sarawak are the majority (“State statistics”, 2014). Similarly, Christianity was the commonest religion in the study as majority of the *Bumiputera* Sarawak, especially Ibans and Bidayuhs are Christians. Despite a considerable portion of the caregivers in Phase II of the study were from lower socioeconomic group with total household income less than RM 3,000 per month, and mostly stayed in village houses, none of the caregivers were illiterate. In fact, more than half of them had at least secondary education.

Nevertheless, in Phase I, Chinese caregivers constituted the majority, followed by *Bumiputera* Sarawak. Majority of the caregivers were from middle socioeconomic group with total household income between RM 3,000 to RM 10,000 per month. Most of them were also employed, had tertiary education, and stayed in terraced houses compared to the caregivers in Phase II. The overall younger age group and higher socioeconomic status among the caregivers in Phase I may be due to the inclusion criteria in which the Phase I caregivers were required to be bilingual. English language proficiency is generally more prevalent among the younger generation and those with higher socioeconomic status.

Phase I also reported a great number of caregivers are looking after their elderly parents, followed by the spouses. The reverse was true for Phase II in which spousal caregivers were more common. Similar findings were found in other caregiver studies done previously (Chua et al., 2016; National Alliance for Caregiving, 2016). This finding may be related to the fact that cancer is predominantly a chronic disease affecting older people (Baider & Surbone, 2014). Thus, it makes sense that most of the cancer caregivers were either the children or the spouses of the elderly cancer patients.

5.2 CLINICAL AND CAREGIVING CHARACTERISTICS OF CANCER CAREGIVERS

The commonest cancer in patients cared for by the caregivers in this study was different for Phase I and Phase II. In Phase I, breast cancer was the commonest, followed by colorectal cancer and lung cancer. This data depicted well the cancer trend in Malaysia where breast, colorectal and lung cancers were the top three cancer diagnoses between 2007 and 2011 (Manan et al., 2016). In Phase II, however, nasopharyngeal cancer was the commonest, followed by colorectal and breast cancers. Nasopharyngeal cancer is unique as its rate in Sarawak was twice the rate in Peninsular Malaysia. In fact, nasopharyngeal cancer was the most common cancer type diagnosed among Sarawakian males (Manan et al., 2016).

The cancer stages reported in the present study also followed the national cancer trend in which stage 2 and 3 combined were the most common, followed by stage 4 and stage 1 respectively (Manan et al., 2016). Majority of the cancer patients were on active treatment, especially chemotherapy, due to the study being conducted in a tertiary hospital setting with oncology services. This finding is similar to another hospital-based study by Lukhmana et al. (2015). There were more outpatients than inpatients in Phase I, but the opposite was true in Phase II, presumably due to differences in the sampling process that were based on convenience sampling.

Despite more cancer cases were in moderate to severe stages and needing active chemotherapy, majority of the patients in both phases of the study were still functional and capable of self-care (ECOG score 0 to 2). This finding is comparable to the functional status of cancer patients in another local study that also used the same ECOG scoring (Mahadevan et al., 2013). Nevertheless, there was a slight difference in the number of patients who were still able to work between Phase I and Phase II. In Phase II, cancer patients who could not work were slightly more in numbers than patients who could still work, but the numbers were equal for patients in Phase I.

As for the caregiving characteristics, a great number of the caregivers (86% in Phase I; 78.7% in Phase II) shared their caregiving roles with other caregivers. This seemed to be a universal trend both locally as well as abroad (Jaafar et al., 2014; National Alliance for Caregiving, 2016). On the contrary, only a small number of the local caregivers (6% in Phase I; 0.8% in Phase II) in the present study engaged in the service of housemaids or paid nursing services to look after their relatives, compared to 41% of the caregivers in the United States (National Alliance for Caregiving, 2016). This trend may be explained by the overall lower socioeconomic status of the local caregivers, as majority of them could not afford the cost of formal care services. The lack of such specialized services locally may be another possibility (Yi, 2013).

The median duration of caregiving in this study was almost similar for both phases: ten months in Phase I and nine months in Phase II. These durations are much shorter than the median duration of 24 months in a study conducted in Singapore (Chua et al., 2016), as well as the average duration of 22.8 months in the United States (National Alliance for Caregiving, 2016). The longer duration of caregiving in Singapore and the United States may reflect the longer survival rates of cancer patients owing to the medical advances in these two developed nations. However, this notion needs further examination and review in order to establish more evidence.

Comparing the total time spent on caregiving in a week, there is a marked discrepancy between the results from the present study (median time 84 hours in Phase I and 128 hours in Phase II) and the findings (median time ranged from 10 to 20 plus hours) reported in other studies (Hsu et al., 2014; Jaafar et al., 2014; National Alliance for Caregiving, 2016). In fact, about 37.3% of the total 177 caregivers in the current study reported spending full time on caregiving. This finding should be interpreted with caution as the definition and criteria on caregiving hours might be different from one study to another. Nevertheless, the result suggests that cancer caregiving is a labour-intensive task.

5.3 MZBI SCALE AS A RELIABLE AND VALID TOOL FOR CAREGIVER BURDEN

To the best knowledge of the author, the present study is the first local study to validate the Malay version of Zarit Burden Interview (MZBI) scale, and to determine the cut-off score suitable to the Malaysian norms. Results from this study indicate that the internal consistency of MZBI scale is good with high Cronbach’s alpha coefficient of 0.898 and split-half correlation coefficient of 0.912. The high internal consistency of the scale means the respondents who tended to select high scores for one item, also tended to select high scores for other items, and vice versa. These findings were consistent with the results from other validation studies conducted across a range of populations (Hérbert et al., 2000; Wang et al., 2008; Chattat et al., 2011).

Among the 22 items of the MZBI, two items (item 20 and item 21) were noted to have low corrected item-total correlation values of less than 0.30, indicating weak correlations with all the other items in the scale. It was also noted that the Cronbach's alpha coefficient of the MZBI would increase to 0.900 and 0.902 respectively if item 20 and item 21 were removed from the scale. The weak correlations of both item 20 and item 21 were discovered as well in the Chinese version of ZBI, of which the authors suggested for the two items to be considered for deletion (Lu, Wang, Yang, & Feng, 2009).

Nevertheless, both item 20 and item 21 were still retained in the MZBI scale used in this study for two reasons. Firstly, the Cronbach's alpha value in this study was already satisfactory high and did not increase by a large degree from deleting the two items. Statisticians have suggested in keeping an item in a scale if the alpha value only increases by miniscule amount after dropping the said item (Tolmie, Muijs, & McAteer, 2011). Secondly, the squared multiple correlation values for both item 20 and 21 were fairly acceptable, suggesting that these items were still able to predict some of the variability of the other items. Therefore, there is no strong statistical reason to drop item 20 or item 21 from the MZBI scale, although revision of the wording used in the two items may be considered in the future to further improve the reliability of the scale.

In this study, the MZBI score was positively and significantly correlated to the MCES-D score (rs = 0.58, p < 0.01), which supported the convergent validity of the MZBI. Again, this finding is similar to those found in Hérbert et al. (2000) and Wang et al. (2008), which indicated a strong association between depression and caregiver burden. The high correlation between the MZBI score with EZBI score (rs = 0.84, p < 0.01) further confirmed the validity of the MZBI, as respondents who were bilingual tended to select similar score range for the related items in both scales.

A MZBI cut-off score of 22 derived from this study is suggested for use in local population. This reading is slightly higher than the score 21 recommended in the original scale (Zarit et al., 1985). It is however noteworthy to mention that the score 21 from the original ZBI was not a statistically derived cut-off score, but instead an arbitrary value proposed by the original author (Hérbert et al., 2000). As different populations have unique cultural values and distinct demographic characteristics, it is not unusual to obtain a different cut-off value in this study (Wang et al., 2008).

Higher ZBI cut-off scores ranging from 24 to 26 have previously been identified for different caregiver groups, although the scores were used as predictors for risk of depression rather than caregiver burden in general (Schreiner, Morimoto, Arai, & Zarit, 2006). As caregiver depression has been identified as separate construct from caregiver burden (Given et al., 2004), it is not surprising the cut-off scores used to identify them will be different. Caregiver burden being a multidimensional entity that encompasses various emotional states (Given et al., 2004) will be a wider construct than caregiver depression, thus requiring a much lower range of cut-off scores for identification.

In addition, the use of MZBI scale as a screening tool would mean that a false negative rate (i.e. below the burden cut-off but depressed) is less desired than a false positive rate (i.e. above the burden cut-off but not depressed), thus a cut-off score that results in higher sensitivity rate would be preferred at the expense of specificity (Schreiner et al., 2006). This explains the rationale in choosing a lower cut-off score of 22 in this study, as the value would give a higher sensitivity of 70.8% with a lower but reasonable specificity of 69.2%, compared to higher cut-off values (Table 4.5).

5.4 CAREGIVER BURDEN AND DEPRESSION RATE

Using the MZBI cut-off score of 22, the rate of caregiver burden among family caregivers of cancer patients in SGH was estimated at 55.6%. This rate is lower than the cancer caregiver burden rates (ranged from 67.3 to 75%) reported from previous studies conducted in the United States (Kim & Schulz 2008; Hsu et al., 2014), but much higher than the rate (24.6%) reported in another local study conducted in Kuala Lumpur (Mahadevan et al., 2013).

The difference in rates may be explained by the distinct caregiver demographics from each study site, as well as the use of non-standardized individual caregiver burden assessment tools in these studies. For instance, Depression, Anxiety, Stress Scale (DASS) was used by Mahadevan et al. (2013), while Hsu et al. (2014) employed the Caregiver Strain Index (CSI) to assess the caregiver burden. These scales have different scoring systems from the ZBI scale, thus producing vast difference in the burden rates. There was also no uniform criteria or definition on caregiver burden across the studies. Example is the use of ‘caregiving stress’ instead of ‘caregiver burden’ in Mahadevan et al. (2013).

A more appropriate study for comparison of the caregiver burden rate with the present study is a similar cross-sectional, hospital-based study by Lukhmana et al. (2015). This study was conducted among 200 family caregivers of cancer patients from Delhi, India, using a validated Hindi version of ZBI that follows the same scoring system as the original English version of ZBI. The rate of caregiver burden reported in this study was 43.5%, a much closer value to the rate found in the current study.

As for the rate of caregiver depression, the present study reported a rather high rate of 59.1% among the family caregivers of cancer patients in SGH, using the MCES-D scale with the cut-off score of 16. This rate was very similar to the caregiver burden rate in the present study as reported above. Compared to other studies with documented prevalence rates of depression between 48.6% and 67% (Ambigga et al., 2005; Rhee et al., 2008), the rate reported in the present study may be considered as the average rate for caregiver depression. However, it is important to note the potential variation in rates due to the different scales used across these studies e.g. Hospital Anxiety and Depression Scale (HADS) used by Ambigga et al. (2005), and Beck Depression Inventory (BDI) used by Rhee et al. (2008).

Careful consideration should be exercised when interpreting the high rate of depression among the local cancer caregivers in the present study. It may be best to view the depression identified in this study as probable depression rather than true depression so as to avoid unnecessary psychiatric diagnosis and unwarranted treatment. The lifetime prevalence of true depression in population usually ranged from 4.9% to 17.1% (Ministry of Health Malaysia, 2007). This was revealed in Jaafar et al. (2014), which established only 17.7% of the caregivers of breast cancer patients were diagnosed as having depressive disorders with the Mini International Neuropsychiatric Interview (MINI), compared to the initial 49.2% of caregivers identified through DASS.

As the relatively high rate of caregiver depression in the present study might not reflect the true depression rate, it is worthwhile to explore a broader variable i.e. the distress level of the caregivers. Distress is defined by the National Comprehensive Cancer Network as a multifactorial, unpleasant experience of an emotional, psychological, social or spiritual nature that interferes with one’s ability to cope with a debilitating condition such as cancer (Holland, 2003). It encompasses a broad spectrum of feelings ranging from normal stress, sadness, and fear to psychiatric conditions such as clinical depression and anxiety (Holland, 2003). Thus, it is entirely possible that some of the cancer caregivers might actually be distressed rather than depressed.

Due to the above findings, it can be deduced that MCES-D scale should be regarded as a screening tool rather than used as an isolated diagnostic measure for depression (Vilagut, Forero, Barbaglia, & Alonso, 2016). Nevertheless, the high rate of caregiver depression present in the current study proved that it is worthwhile to screen for depression among all cancer caregivers. Caregivers who screened positive for depressive symptoms should warrant further thorough assessment, preferably by psychiatrists, to identify those with notable depressive disorders that need psychiatric interventions (Rivera, 2009).

In summary, both caregiver burden and depression rates reported in the present study are high, indicating that cancer caregiving is a relatively burdensome and challenging task, and the well-being of the local cancer caregivers is at stake due to the huge care demands placed on them. The high rates found in this study may in part explained by the vulnerabilities faced by the local caregivers, who were mostly of lower socioeconomic status, and were less equipped with the knowledge and support in caregiving compared to the caregivers from developed countries. Furthermore, the local healthcare systems often neglect the needs of the caregivers, and do little to assist them in looking after their own welfares in addition to those of their loved ones (Cheong & Putit, 2011).

5.5 RELIGIOSITY AND RELIGIOUS COPING AMONG CANCER CAREGIVERS

Majority of the cancer caregivers (56.7%) in this study scored high for the three religiosity subscales (ORA, NORA, IR) in DUREL-M. For organizational religiosity, about a third of the caregivers attended religious activities in their religious institutions on a weekly basis (33.9%), followed by those who attended few times in a month (22.8%). For non-organizational religiosity, more than half of the caregivers (62.2%) performed private religious activities, such as prayers and reading religious scriptures, for at least two or more times in a week. As for intrinsic religiosity, more than half of the caregivers (57.5%) selected '*amat benar sekali*' ('definitely true') for all three IR items (score 15), indicating that the caregivers generally have high degree of personal religious commitment and tend to view religion as the ultimate significance compared to their personal needs.

The overall high religiosity of the cancer caregivers in the study was also observed in other studies on caregivers of impaired elderly and Alzheimer's patients (Shah, Snow, & Kunik, 2001; Herrera et al., 2009). The strong culturally influenced religious values, especially among the Sarawak indigenous people who constitute the majority of the caregivers in the main phase of the present study, may be the reason for this observed trend (Sarawak Tourism Federation, 2015).

Similar to the religiosity level, most of the caregivers (53.5%) in the current study demonstrated high positive religious coping (PRC), although high negative religious coping (NRC) was also common (57.5%). Nonetheless, the median score for PRC was notably higher than the score for NRC (25 versus 10), indicating that more caregivers practiced positive coping strategies rather than negative coping strategies when looking after their relatives. This trend was also present among the cancer caregivers in India, and likely conforming to the religious belief systems of the majority of the Indian population (Thombre et al., 2010).

5.6 FACTORS ASSOCIATED WITH CAREGIVER BURDEN

Among the various sociodemographic factors being examined in this study, caregiver's relationship as the children or grandchildren of cancer patients was the only factor found to be significantly associated with caregiver burden. This factor remained significant after controlling for the confounding variables in multivariate analysis (OR 0.41, CI 0.18 – 0.94, p = 0.035). The level of significance was not observed however, when examining the association between spousal caregiving and caregiver burden.

According to Wolff and Kasper (2006), nearly 80% of the informal caregivers who care for an older adult aged 65 or older are spouses or adult children, as being demonstrated in the present study where the spouses and the offspring of the cancer patients constituted 85.9% of the total 177 caregivers in both phases of the study. Spouses are usually the first to provide care (primary caregiver) to an older adult who is sick. Adult children generally function as the secondary caregiver and only step into the main caregiving roles when spouses are not available (Lowenstein & Gilbar, 2000; Revenson et al., 2015).

The influence of the caregiver's relationship to cancer patients has been studied previously and found to be related to the caregiver burden (Lowenstein & Gilbar, 2000; Ferrario, Cardillo, Vicario, Balzarini, & Zotti, 2004; Given et al., 2004; Hagedoorn et al., 2008). Majority of these studies reported that spousal caregivers have greater caregiver burden compared to adult children caregivers. A notable exception is a study done by Given et al. (2004) who reported the opposite where adult children caregivers were found to have high levels of depressive symptoms and feeling of abandonment (a portion of caregiver burden) when caring for patients with cancer at the end of life.

In the present study, it was discovered that offspring caregivers of cancer patients were significantly less likely to experience caregiver burden than non-offspring caregivers, even though spousal caregivers were not found to be significantly experiencing more burden than non-spousal caregivers as reported in the studies mentioned above. The lack of significant association between spousal caregiving and caregiver burden in this study may be due to the relatively small sample size and the use of non-random sampling method.

There are a few possible explanations on why adult children who care for the cancer patients may experience fewer burdens than other caregiver groups. Firstly, as mentioned before, majority of the offspring caregivers are secondary caregivers as compared to the spouses who are the primary caregivers. As the children only involve in assisting the primary caregiver, the caregiving expectations and workloads are understandably lower in the former. Thus, the adult children are generally less vulnerable to the physical and psychological distress of caregiving (Revenson et al., 2015).

Secondly, the nuclearization of families following rapid urbanization of Asian societies might also influence the perceived burden by the adult children caregivers. A nuclear family usually comprises of married couple staying together with or without their dependent children (Sharma, 2013). Relevant to the increasing work requirements, many adult children start to live separately from their parents to form a nuclear family of their own. As a result, they are only able to provide distance caregiving when a parent becomes ill, relying much on the help of other family members or formal nursing services (Mazanec, 2012).

Consequently, distance adult children caregivers with adequate social support may experience less direct burden on caregiving. Lowenstein and Gilbar (2000) demonstrated this whereby the children caregivers that stayed in separate households from the cancer patients were found to experience significantly fewer burden than the spouses who resided together with their ill partners. Nevertheless, distance caregivers or adult offspring caregivers may still expose to psychological distress, especially when they lack social support, as they often have multiple commitments such as child-rearing, domestic chores, full time employment and various financial responsibilities (Gaugler et al., 2005; Mazanec, 2012).

Thirdly, the concept of filial piety, a cultural belief that influences adult children's attitudes and behaviours toward their parents, may play an important role in the buffering of care burden faced by the adult children caregivers. In many Asian cultures, Malaysian included, children are often expected to care for their parents in their aging years, more so when the elderly parents are suffering from chronic medical illnesses (Chan et al., 2012). The practice of filial piety includes showing respect and affection toward parents, fulfilling responsibilities, preserving the family harmony, and making payments and other sacrifices (Sung, 1998, as cited in Lai, 2010).

Various studies have demonstrated the positive effects of filial piety on the caregiving appraisal and subsequently on the caregiver burden (Lai, 2010; Khalaila & Litwin, 2011). According to Lai (2010), filial piety may even serve as protective factor against caregiver burden, which is mediated through other factor such as caregiving appraisal as there was no direct relationship observed between these two variables. Thus, offspring caregivers who identify more with filial piety are more likely to find caregiving tasks to be positive, beneficial and not burdensome (Khalaila & Litwin, 2011). This will help to reduce the subjective care burden as the caregivers have a more positive evaluation and understanding of their roles and responsibilities.

Coming to the clinical and caregiving characteristics, two factors related to the cancer patients were found to be associated with caregiver burden from bivariate analysis: treatment settings (inpatient versus outpatient) and ability to work (able to work versus unable to work). Generally, cancer patients requiring inpatient hospital treatment, often due to more serious presentation or complications, are more dependent and difficult to care for (Girgis et al., 2013; Mahadevan et al., 2013). Thus, it is understandably that their caregivers would experience more burden than the caregivers who care for patients from outpatient setting.

Similarly, cancer patients with good functional status (capable of self-care and still able to work) would be relatively easier to care for compared to patients with low functional abilities, as the latter require more time and assistance in their activities of daily living (Jaafar et al., 2014). Various studies have indicated that cancer patients with poor functional status would predict higher caregiver burden due to the increase in the care demands and the longer caregiving hours needed (Weitzner et al., 1999; Gaugler et al., 2005; Mahadevan et al., 2013; Hsu et al., 2014). Nonetheless, most of the above studies did not examine further which aspects of the patients' functionality would best predict the caregiver burden.

In the present study, it was discovered that the patient's ability to work is more important than the patient's capacity for self-care in terms of association with the caregiver burden. The results from bivariate analyses would suggest that employed cancer patients might be associated with fewer burdens in their caregivers, and vice versa. Employed patients can be an indicator that patients have higher functionality and mobility, thus requiring less physical assistance from the caregivers. This would translate to less restriction in caregivers' ability to socialize and participate in valued activities, which in turn reduce their perceived burden (Cameron, Franche, Cheung, & Stewart, 2002). In addition, working patients could contribute financially to ease the economic strain of their caregivers as well (Ghaswalla & Min, 2016). However, after controlling for the confounders in multivariate analysis, both patient factors (treatment settings and ability to work) were no longer significant in the present study.

Presence of depression in cancer caregivers was another important factor that significantly associated with caregiver burden in this study (OR 4.26, CI 1.87 – 9.72, p = 0.001). The strong association between these two variables was also indicated by the presence of significant correlation between the MZBI score and the MCES-D score in Phase I of the study. Consistent results were found in other caregiver studies, which support the significant relationship between caregiver depression and caregiver burden (Stommel et al., 1990; Butler et al., 2005; Grov et al., 2006; Rivera, 2009).

As mentioned in previous chapter, the significant relationship between caregiver burden and depression can be bi-directional. In general, caregiver depression has been viewed as a reaction or consequence of the caregiving processes (Rhee et al., 2008).

Thus, many researchers established that both subjective and objective caregiver burdens, especially following long-term caregiving, might contribute to depression in the caregivers (Rhee et al., 2008; Rivera, 2009). In other words, caregivers with high burden are more likely to be depressed, and vice versa.

However, Stommel et al. (1990) put forward an interesting perspective that the opposite might be true where caregiver depression can predict the caregiver burden. Simply put, depressed caregivers are more likely to have high caregiver burden. The authors argued that depression, being a rather stable condition, would be a significant influence on the caregivers' perceptions and thus able to explain most of the variation in the perceived burdens (Stommel et al., 1990). This intriguing perspective was confirmed in a study by Lim, Sahadevan, Choo, & Anthony (1999), who concluded that depressed mood in the caregivers of dementia patients was predictive of the caregiver burden and explained about 40% of the variance.

In addition to the direct association, it is possible that caregiver depression may also act as a mediator of indirect influence on the caregiver burden (Grov et al., 2006). One such example is the finding by Utne, Miaskowski, Paul, & Rustøen (2013), which suggested that depression possibly mediates caregiver burden through the feeling of hope, as hopelessness is known to be an important component of and highly correlated with depression. Nevertheless, the causal relationship between caregiver burden and depression was still not established in the present study due to the relatively small sample size and the cross-sectional design of the study (Pirraglia et al., 2005).

To the best understanding of the author, there is yet any local study done on the association between religious factors and caregiver burden. The role of religion in caregiving can be studied in a multiracial and multireligious environment like Malaysia.

Unexpectedly, the current study failed to demonstrate any significant relationship between the religiosity and religious coping strategies with the caregiver burden on a multivariate level, although there was a significant association between the negative religious coping (NRC) with the caregiver burden from bivariate analysis. Similarly, there were no significant associations found between the caregiver burden and each of the religion groups in the study. The results were inconsistent with those of the previous studies reporting the association between these variables (Mickley et al., 1998; Pearce et al., 2006; Herrera et al., 2009; Gholamzadeh et al., 2014).

The present study showed that high NRC use, but not positive religious coping (PRC), was associated with higher caregiver burden on a bivariate level. This finding is in concordance with the results from previous literature supporting the association between the NRC, but not the PRC, with the levels of psychological distress or mental health outcomes (Hebert et al., 2009; Herrera et al., 2009; Nurasikin et al., 2012; Ng et al., 2016). Caregivers who felt that God has abandoned them, questioned God’s power or considered their caregiving responsibilities as a punishment from God were more likely to report less satisfaction and more burden from caregiving (Pearce et al., 2006). It is postulated that individuals who struggle with their religious beliefs may not be able to use their faith as a resource for coping, as they see their faith as distant and weak, thus leading to an existential crisis (Ng et al., 2016). Despite the presence of significant association between the caregiver burden and the NRC in bivariate analysis, the association did not remain significant in multivariate analysis, possibly due to the small sample size in the current study.

The relatively high religiosity level and use of PRC strategies among the cancer caregivers in the present study were found to have little or no significant impact on the caregiver burden and depression rate. These findings may be explained by the presence of multiple concomitant stressors, e.g. lower socioeconomic status, lack of caregiving resources or supports, severity of cancer presentation, etc., which greatly overshadow the buffering effects of religiosity and PRC in the current study. Interestingly, the use of PRC strategies may actually be associated with greater caregiver burden as reported by Pearce et al. (2006). The authors hypothesized that PRC may build up one's burden by increasing the possibility that one takes on more number of or more difficult caregiving tasks out of a feeling of religious duty. Also, it is possible that those who are the most burdened may be more likely to turn to religion as a way to cope and to find sacred meaning (Pearce et al., 2006).

Another plausible explanation is the use of non-random sampling method and cross-sectional design in the present study, which limit the understanding on the multidimensional nature of the religious elements (Stefanek et al., 2005). Furthermore, the religious pluralism in Malaysia may pose a challenge for the effective study of religious factors in this respect (Samian, 2010). Consequently, the current study was not robust enough to detect the complex relationships between the religious variables and the caregiver burden or depression.

In general, the findings from the current study supported that the influence of religiosity and religious coping on caregiver burden is still vague and inconsistent (Hackney & Sanders, 2003; Hebert et al., 2006). However, this does not mean that religious factors have no value or positive role at all in the caregiving process. More local research is needed in this field, preferably using a broad-spectrum and standardized measure, to address the multidimensional qualities of religiosity and religious coping, as well as to take into consideration the religious pluralism in Malaysia.

5.7 LIMITATIONS AND STRENGTHS OF THE STUDY

There are several limitations present in this study. First, it was a cross-sectional study, which did not describe the temporal relationship between the caregiver burden and the various factors examined in the study. Thus, causal inferences could not be made between these variables. A longitudinal prospective study may be a better design for this purpose.

This can be done by recruiting a study cohort consists of the caregivers of cancer patients at the time when the patients receive a diagnosis of cancer. The caregivers are then followed up at specific interval, for example 12-weekly, up to 52 weeks or until patient’s death. Data collection can be done either through face-to-face clinic appointments or through telephone interviews at the time of recruitment and subsequently during each follow-up. Sociodemographic and caregiving-related information is collected and measures of patient symptoms, caregiver burden, depressive symptoms, religiosity level and religious coping patterns are obtained. With this design, life course of an individual caregiver can be recorded and multiple observations or measurements can be made over time.

Second, convenience or non-random sampling techniques used in this study would generate sampling bias, especially when the study was conducted in a single setting based in government hospital. Therefore, the sample chosen might not represent the general population of the cancer caregivers, which also includes caregivers in the community setting as well as those in the private medical centres. Nonetheless, convenience sampling was chosen as the author faced difficulties in terms of costs, manpower, and time spent on performing the study with random samples.

Third, a relatively smaller sample size could have contributed to the study having small effect size and wide confidence intervals, which further restricted the generalization of its findings, and the statistical power necessary to detect the complex relationships between the study variables. A study with a larger sample size of family caregivers is needed to obtain a more robust finding. Fourth, the study also could not run away from information or recall bias, as the information obtained was based solely from the caregivers' account for most part of the data collection.

In addition, the study did not differentiate between the physical and the psychological components of caregiver burden, which may have resulted in different patterns of burden reported among the caregivers (Hsu et al., 2014). Last but not least, potential important information about the cancer caregivers and patients that might influence the caregiver burden was not included in the study questionnaires. Thus, some potential confounders for caregiver burden were not measured in this study. Examples include the presence of medical comorbidities, the exact caregiving tasks performed with stricter criteria on caregiving hours, as well as whether the caregivers are staying together or separately from the patients, etc.

As for the validation process of the Malay version of the Zarit Burden Interview (MZBI), one limitation is that the construct validity of the scale was not assessed using the factor analysis as was being done in previous validation studies by Lu et al. (2009) and Chattat et al. (2011). It will be worthwhile to carry out both exploratory and confirmatory factor analyses in the future to enhance the overall validity of the MZBI scale in the context of cancer caregiver burden.

The use of MCES-D scale to determine the rate of caregiver depression in this study may also lead to overestimation of the findings (Vilagut et al., 2016). Also, as

MCES-D scale was already used to determine the cut-off score for MZBI in Phase I of the study with the assumption that burden is well correlated with depression, the use of the same scales in Phase II to study the association between caregiver burden and depression would not be appropriate, despite the study subjects did not overlap between the two phases of the study.

It is recommended that a different scale for measurement of depression should be used in Phase II to explore the association between caregiver burden and depression in order to avoid bias. Future studies on this aspect should utilize valid diagnostic tool such as the Mini International Neuropsychiatric Interview (MINI) for a more accurate estimation of the prevalence of depression among the caregivers. Addition of distress scale e.g. Distress Thermometer, General Health Questionnaire or Brief Symptom Inventory can also be done to measure the distress level of the caregivers in order to ascertain whether they are truly depressed or just feeling distressed.

On the other hand, the current study demonstrated a few notable strengths as well. Despite being a single-centred study, it was conducted in a tertiary referral centre for oncology services with cancer patients and caregivers originated from various parts of the Sarawak state. This, together with the multiracial background of the study subjects, made up for the diversity of the samples. The cross-sectional design has its fair share of advantages as well, in which it allows the study to measure the prevalence of caregiver burden and depression, and to explore multiple factors and outcomes at the same time. This helps to bring into perspective the resulting effects of cancer caregiving and the caregiving problems relevant to the local Malaysia population in a short period of time.

Based on the available local data to date, this study also prides itself on being the first local study to validate the Malay version of the Zarit Burden Interview for use on the local population. On top of that, the study was the first to examine the context of caregiver burden among the local family caregivers of multiracial background and of various types of cancer patients, not limiting to just a single-race caregivers as studied by Cheong and Putit (2011), or a single type of cancer patients as studied by Mahadevan et al. (2013). The findings from the present study would add to the growing literature on cancer caregiving and caregiver burden in the local setting.

CHAPTER 6

CONCLUSION

6.1 CLINICAL IMPLICATIONS AND RECOMMENDATIONS

In a general context, family caregivers often received little attention from the healthcare providers compared to the cancer patients that they are caring for (Payne et al., 1999). As a result, many of the caregivers have unmet needs, both physical as well as psychosocial needs, which manifested as caregiver burden and/or depression following the untoward effects of the cancer caregiving process (Romito et al., 2013). Therefore, the findings from this study should alert the local healthcare personnel about the importance of addressing the needs and concerns of the caregivers.

Studies found that majority of the family caregivers were not experienced and had no formal training in cancer caregiving (Northouse et al., 2012; Lukhmana et al., 2015; Chua et al., 2016). According to the National Alliance for Caregiving (2016), as many as 84% of the cancer caregivers in the United States have indicated that they need more help and information on at least one caregiving-related subject. The caregivers need to be educated on important topics pertaining to patient's illness features, treatment options, specific care needs, managing own emotional stress, and making end-of-life decisions, etc.

Training on specific caregiving tasks such as transferring patients, feeding with nasogastric tubes, dealing with incontinence, and cleaning of bodily secretions will help to guide the inexperienced caregivers, and also to reduce both the caregiver burden and depression (Butler et al., 2005). In addition, exposure to soft skills training such as effective communication skills, problem-solving skills, self-motivation, and financial management may be beneficial as well (Northouse et al., 2012). Caregivers should also be taught on how to seek help and engage other relatives or outside resources to relieve their burden. In this regard, participation in the caregiver support groups would be very useful and should be encouraged.

The high rate of caregiver depression and its significance in the prediction of caregiver burden in the study point to a need to actively screen and identify those distressed caregivers at risk of developing depression. Unrecognised depression will have a devastating effect on the physical and psychological well-beings of the caregivers (Given et al., 2004). It is not uncommon to find high rates of suicidal ideation and suicide attempts among depressed caregivers of cancer patients (Park et al., 2013). Hence, it is important that psychiatric consultations and mental health services should be made available and easily accessible to the caregivers at any time by the policymakers. Counseling and psychoeducation about caregiver distress, depression, and treatment strategies will help caregivers to better cope with these conditions. If needed, antidepressant medications and/or psychotherapeutic interventions may be provided based on the recommendations by the psychiatrists.

Caregiver's relationship of being the offspring of cancer patients was found to be significantly associated with caregiver burden in this study, with an interesting finding that children or grandchildren caregivers experienced fewer burdens than non-children or grandchildren caregivers. This finding from the present study would highlight the need for the policymakers, researchers, and healthcare providers to devote more attention to the non-offspring caregivers on top of the general focus given to the cancer caregivers as a whole.

Specific caregiver interventions and social policies should be implemented accordingly to address the needs of the non-offspring caregivers and to improve their caregiving experiences without neglecting the well-beings of the offspring caregivers. In particular, more educational programmes that provide information on direct care should be made available to these caregivers with relevance to the finding in the research report by the National Alliance for Caregiving (2016). Healthcare providers should also go beyond their clinical duties by linking the caregivers with outside community services and resources for sustained support (Hoffman & Zucker, 2016).

Another way to help relieve caregiver burden is by providing respite care services to these caregivers, especially to those full-time caregivers who stay together with the patients (Mahadevan et al., 2013; National Alliance for Caregiving, 2016). These services should be made affordable with assistance and subsidies from both the government and non-governmental organizations taking into account the socioeconomic status of the local caregivers. Various respite services or approaches suitable in the cancer context could be explored. Apart from short-term nursing home placement, brief daycare programme that provides temporary relief for the caregivers is another promising option.

Similar to many Asian countries with deep-rooted traditional and religious value systems, adult children in Malaysia often have strong cultural obligations to look after their sick parents as a form of filial duty (Chan et al., 2012). The use of culturally validated tool such as the MZBI would lead to a more appropriate assessment of their caregiving difficulties in future studies. Following that, the relevant policy planners should establish services that provide culturally relevant support systems to the family caregivers (Khalaila & Litwin, 2011). Example is the provision of psychoeducation and counselling in a relevant language catered to the language and cultural background of the caregivers (Lee & Yim, 2013). The cultural influence of filial piety, which possibly explain the fewer burden experienced by the offspring caregivers in the present study, should be encouraged and promoted through the media and academic platforms.

Despite the roles of religion on cancer caregiving are not very clear from this study, the presence of high religiosity and religious coping use among the cancer caregivers in this study should be an encouraging finding that religious faith may still be a valued resource with immense potential waiting to be explored. Future studies to validate the findings from the present study may be helpful and should be designed with an aim to develop more evidence-based strategies to empower the family caregivers and to alleviate their burdens.

6.2 SUMMARY

In conclusion, this study confirmed that cancer caregiving is burdensome. A relatively high rate of caregiver burden and depression was observed among the local family caregivers of cancer patients. Caregivers who were the children or grandchildren of cancer patients were experiencing significantly fewer burdens than the non-offspring caregivers. On the other hand, caregivers who had probable depression were more likely to experience significant caregiver burden. The Malay version of the Zarit Burden Interview (MZBI) is a reliable and valid tool for the assessment of caregiver burden among this group of caregivers. The significant risk factors identified in this study can serve as a stimulus for future intervention strategies to be planned and tailored accordingly so as to target the multiple dimensions of the caregiver burden.

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