POSTTRAUMATIC GROWTH AND PSYCHOSOCIAL, CANCER AND TREATMENT RELATED FACTORS IN HEAD AND NECK CANCER: ASSESSING THEIR ASSOCIATIONS IN A CROSS-SECTIONAL STUDY

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by

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TABLE OF CONTENTS

APPENDICES

LIST OF TABLES

Page

LIST OF FIGURES

Page

LIST OF SYMBOLS

α	Alpha
β	Beta
ϭ	Standard deviation
=	Equal to
<	Less than
>	Greater than
Zα	The standard normal deviate for α
Zβ	The standard normal deviate for β
$Z_{1-\alpha/2}$	The desired confidence interval of 95
Δ	Precision
r	Pearson's correlation coefficient
n	Frequency

LIST OF ABBREVIATION

CI	Confidence interval
CIDI	Composite International Diagnostic Interview
CTSQ	Cancer Treatment Satisfaction Questionnaire
DSM	Diagnostic and Statistical Manual for Mental Disorders
EFA	Exploratory factor analysis
EORTC-QLQ-H&N35	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – Head and Neck 35
ET	Expectation with therapy
FoP-Q-SF	Fear of Progression Questionnaire – Short Form
FSE	Feeling about side effect
HNC	Head and neck
HRQoL	Health related quality of life
ICC	Intraclass correlation coefficient
ICD	International Classification Diseases
IUCN	International Union Against Cancer
IQR	Interquartile range
KMO	Kaiser-Meyer-Olkin
MMSE	Mini Mental State Examination
PTG	Posttraumatic growth
PTGI-SF	Posttraumatic Growth Inventory – Short Form
SCID	Structured Clinical Interview for DSM
SCNS-SF34	Supportive Care Needs Survey – Short Form 34
SE	Standard error
SWT	Satisfaction with therapy

LIST OF APPENDICES

PERKEMBANGAN PASCA TRAUMA DAN FAKTOR-FAKTOR PSIKOSOSIAL DAN YANG BERKAITAN DENGAN KANSER DAN RAWATAN KANSER KEPALA DAN LEHER: PENILAIAN HUBUNGKAIT MEREKA DALAM SATU KAJIAN KERATAN LINTANG

ABSTRAK

Kajian keratan lintang ini bertujuan untuk menterjemahkan dan mengkaji kesahan Soal Selidik Takut akan Perkembangan Kanser-Borang Pendek (FoP-Q-SF) dan Soal Selidik Kepuasan Terapi Kanser (CTSQ) ke Bahasa Melayu (fasa 1 kajian) dan untuk menilai hubungkait diantara keperluan sokongan penjagaan, ketakutan pada perkembangan kanser, kualiti kehidupan yang berkait dengan kesihatan dan kepuasan terhadap terapi kanser dengan perkembangan pasca trauma (PTG) (fasa 2 kajian). Dalam fasa 1 kajian, seramai 200 orang penghidap pelbagai jenis kanser menjawab draf FoP-Q-SF versi Bahasa Melayu (FoP-Q-SF-M) dan draf CTSQ versi Bahasa Melayu (CTSQ-M). Penilaian relibiliti dan kesahan FoP-Q-SF-M dan CTSQ-M dilakukan. Dalam fasa 2 kajian, seramai 200 orang peserta kanser kepala dan leher telah menjawab Inventori Perkembangan Pasca Trauma- Borang Pendek (PTGI-SF), Soal Selidik Kualiti Kehidupan Organisasi Kajian dan Rawatan Kanser Eropah-Modul Kepala dan Leher-35 (EORTC QLQ-H & N35), Soal Selidik Takut akan Perkembangan Kanser-Borang Pendek (FoP-Q-SF), Soal Selidik Kepuasan Terapi Kanser (CTSQ) dan Survei Keperluan Sokongan Penjagaan-Borang Pendek 34 (SCNS-SF34). Hubungkait diantara setiap soal selidik dan perkembangan pasca trauma (PTG) dinilai menggunakan model regresi multivariat umum dengan penyusunan semula sebanyak 2000 replikasi. Dalam fasa 1 kajian, domain-domain CTSQ-M (Cronbach's α dalam lingkungan dari 0.72 ke 0.85) dan skor keseluruhan FoP-Q-SF-M (Cronbach's α = 0.93) menunjukkan konsistensi dalaman dari tahap

memuaskan hingga ke tahap tinggi. Kedua-duanya juga mencapai kesahan permukaan, kandungan, konvergen dan diskriminan yang baik. Analisis faktor eksplorasi menunjukkan bahawa CTSQ-M mumpunyai tiga faktor dan FoP-Q-SF-M mempunyai satu faktor, sama seperti soal selidik versi asal dalam Bahasa Inggeris. Dalam fasa 2 kajian, para peserta menunjukkan skor keseluruhan PTGI-SF yang tinggi (median = 41.0, IQR = 11.0). Model regresi multivariat umum dengan penyusunan semula sebanyak 2000 replikasi mempamerkan hanya satu faktor sahaja yang berkaitan dengan rawatan kanser yang mempunyai hubungkait dengan perkembangan pasca trauma (PTG), iaitu jangkaan terapi rawatan yang lebih positif ($B = 0.075$, 95% CI = 0.009 hingga 0.155, SE = 0.035, p = 0.038). Manakala hanya satu sahaja komponen kualiti kehidupan yang berkaitan dengan kesihatan yang mempunyai hubungkait dengan perkembangan pasca trauma (PTG), iaitu tahap masalah dengan perhubungan sosial (B = -0.874, 95% CI = -1.559 hingga -0.204, SE = 0.398, p = 0.022). Namun, keperluan sokongan penjagaan dan ketakutan terhadap perkembangan kanser tidak berhubungkait dengan perkembangan pasca trauma (PTG) dalam kalangan pesakit kanser kepala dan leher. Keseluruhannya, CTSQ-M dan FoP-Q-SF-M mempunyai ciri-ciri psikometrik yang berpatutan dan sesuai untuk mengukur kepuasan terhadap terapi kanser dan ketakutan terhadap perkembangan kanser dalam kalangan populasi kanser di Malaysia. Disamping itu, intervensi psikososial seharusnya fokus kepada pengurusan masalah perhubungan sosial dan meningkatkan jangkaan terhadap terapi kanser yang lebih positif untuk merangsang perkembangan pasca trauma dalam kalangan pesakit kanser kepala dan leher.

POSTTRAUMATIC GROWTH AND PSYCHOSOCIAL, CANCER AND TREATMENT RELATED FACTORS IN HEAD AND NECK CANCER: ASSESSING THEIR ASSOCIATIONS IN A CROSS-SECTIONAL STUDY

ABSTRACT

This cross-sectional study aimed to translate and validate the Fear of Progression Questionnaire-Short Form (FoP-Q-SF) and Cancer Treatment Satisfaction Questionnaire (CTSQ) into Malay (phase 1 of the study) and to determine the associations between unmet supportive needs, fear of cancer progression, health-related quality of life, expectation and satisfaction with cancer therapy, and posttraumatic growth (PTG) among a group of head and neck cancer (HNC) patients (phase 2 of the study). In phase 1, 200 participants of various types of cancer were administered with the drafted Malay versions of FoP-Q-SF (FoP-Q-SF-M) and CTSQ (CTSQ-M). The reliability and validity for both of them were assessed. In phase 2, 200 HNC participants were administered with the Posttraumatic Growth Inventory-Short Form (PTGI-SF), European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-H&N35 (EORTC QLQ-H & N35), Fear of Progression Questionnaire-Short Form (FoP-Q-SF), Cancer Treatment Satisfaction Questionnaire (CTSQ) and 34-item Supportive Care Needs Survey- Short Form (SCNS-SF34). The associations between each one of them and PTG were determined by general multivariate regression model with bootstrapping with 2000 replications. In phase 1, the domains of CTSQ-M (Cronbach's α ranged from 0.72 to 0.85) and the total score of FoP-Q-SF-M (Cronbach's α = 0.93) exhibited acceptable to excellent internal consistency. They both also achieved face, content, convergent and discriminant validity. The exploratory factor analysis revealed that CTSQ-M had three factors and

FoP-Q-SF-M had a single factor, which were similar to the original English versions of the questionnaires, respectively. In phase 2, the participants registered high total PTGI-SF score (median = 41.0, IQR = 11.0). General multivariate regression model with bootstrapping with 2000 replications pinpointed that the only treatment related factor which was associated with PTG was a more positive expectation of therapy (B = 0.075, 95% CI = 0.009 to 0.155, SE = 0.035, p = 0.038). On the other hand, the only health-related quality of life component associated with PTG was problem with social contact (B = -0.874, 95% CI = -1.559 to -0.204, SE = 0.398, p = 0.022). Conversely, unmet supportive needs and fear of cancer progression did not predict PTG among head and neck cancer survivors. Overall, both CTSQ-M and FoP-Q-SF-M had acceptable psychometric properties and suitable for measuring satisfaction of cancer therapy and fear of cancer progression among Malaysian cancer population. In addition, psychosocial interventions should focus on managing problem with social contact and enhancing positive expectation towards cancer therapy in head and neck cancer patients as these will facilitate the development of PTG.

CHAPTER 1

INTRODUCTION

1.1   Background

Cancer is a disease that occurs when there is an abnormal change in cells which develop into a tumor. There are many types of cancer, depending on the location of the tumor. HNC specifically refers to malignant tumor which develop around the head and neck area, such as around the throat, mouth, nose and ear (National Cancer Institute, 2021). The worldwide incidence of HNC is approximately 900,000 cases annually, while it results in 400,000 deaths annually (Global Cancer Observatory, 2021). The male to female ratio of HNC ranging from 2:1 to 4:1. Several regions which reported high incidence of HNC include France, the Indian subcontinent, Central and Eastern Europe, Spain, Hong Kong, Italy and Brazil. Nasopharyngeal carcinoma is common in Hong Kong and Southeast Asian countries. While mouth and tongue carcinoma are common in the Indian subcontinent (Bray et al., 2013; Lambert et al., 2011). In Malaysia, from year 2007 to 2011, HNC had become the fourth most common cancer where it made up 9.1% of all cancer cases reported (Ching, 2017), and this number is expected to increase each year.

There is substantial degree of impact which a cancer patient could experience, either from the disease itself, or from the side effect one might have after going through cancer treatment. Among the common physical side effects HNC include difficulty in chewing, swallowing and talking. These side effect could be temporary, or in some unfortunate cases, they may become permanent. Apart from the physical effects of cancer, patients' mental state could also be negatively affected by this disease.

This research was conducted to evaluate the psychosocial aspects of HNC patients as they go through all the challenges they may face throughout their recovery journey, and by studying the factors that can affect posttraumatic growth (PTG). To date, the majority of PTG studies in cancer patients focus on breast cancer (Casellas-Grau et al., 2017). Only a few studies have investigated the factors that may be linked to PTG in patients with HNC.

The scope of this study covered the translation and back translation of the Fear of Progression Questionnaire-Short Form (FoP-Q-SF) and the Cancer Therapy Satisfaction Questionnaire (CTSQ) into Malay and validation of the Malay versions of the FoP-Q-SF and CTSQ, as these two questionnaires were used for assessment of subjects in this study but initially, were not translated and validated in the Malay language. In addition, this study assessed relationship between psychosocial factors (unmet supportive needs and fear of cancer progression), cancer and treatment related factors (health-related quality of life and expectation and satisfaction with cancer therapy), and PTG. This study did not cover the assessment of positive psychology (such as hope, optimism and social support) and psychological complications of cancer (such as depression, anxiety, and posttraumatic stress symptoms).

1.2   Research Objectives

1.2.1   General Objectives

1. To describe PTG and health-related quality of life (HRQoL) among HNC patients.

2. To determine the relationship between psychosocial factors and PTG in HNC patients.

1.2.2   Specific Objectives

1. To translate the original English versions of the Fear of Progression Questionnaire- Short Form (FoP-Q-SF) and Cancer Treatment Satisfaction Questionnaire (CTSQ) into Malay, and evaluate the internal consistency, face, content, convergent, discriminant and construct validities of the Malay versions of the FoP-Q-SF and CTSQ.

2. To evaluate the levels of PTG and HRQoL in HNC patients within one year after diagnosis.

3. To determine the associations between fear of cancer progression, satisfaction of cancer treatment, unmet supportive needs of cancer patients, HRQoL, and PTG, while controlling for socio-demographic and clinical factors among HNC patients.

1.3   Research Hypotheses

(a) Null Hypotheses:

1. H_0: The Malay versions of the FoP-Q-SF and CTSQ are not reliable and valid tool for assessment of the degree of fear of cancer progression and satisfaction with cancer therapy, respectively among Malaysian cancer patients.

2. H_0: The degree of posttraumatic growth among HNC patients within one year after diagnosis does not exhibit high degree.

3. H_0: Fear of cancer progression, unmet supportive needs of cancer patients, and satisfaction with cancer treatment are not predictive of PTG among HNC patients.

(b) Alternative hypotheses:

1. **H_A:** The Malay versions of the FoP-Q-SF and CTSQ are reliable and valid tool for assessment of the degree of fear of cancer progression and satisfaction with cancer therapy, respectively among Malaysian cancer patients.

2. **H_A:** The degree of posttraumatic growth is high among HNC patients within one year after diagnosis.

3. **H_A:** Fear of cancer progression, unmet supportive needs of cancer patients, and satisfaction with cancer treatment are predictive of PTG among HNC patients.

CHAPTER 2

LITERATURE REVIEW

2.1   Posttraumatic Growth and Head and Neck Cancer

2.1.1   Posttraumatic Growth and its Components

PTG is the positive psychological changes experienced when a person is struggling with a highly stressful life event or a trauma. The five components of the positive psychological changes may involve better personal strength, having more possibilities in life, improved interpersonal relationship, greater degree of spiritual development and greater appreciation of life. Below are the different components of posttraumatic growth:

i)   Improved relations with others

Living with head and neck cancer might deepen the connections or relationships with family or friends or any close contact of the patient. Adequate support is one of the most valuable emotional resource for those who are living with cancer. It can be easier for head and neck cancer patients to get attached with other cancer patients who experience similar condition in their daily life. It has been observed that people are more attached to others in their life when they are facing a traumatic event such as cancer (Casellas-Grau et al., 2017).

Cancer patients are not only dependent on their family and friends for support, but they also rely on the support of those who provide treatment to them, such as doctors, nurses and other medical practitioners. It was observed in studies that people with head and neck cancers are getting emotionally more attached to their friends and family more frequently upon surviving from cancer (Cormio et al., 2017).

5

ii)   New life experiences

After diagnosis of cancer and surviving from the illness, cancer patients may have a new focus in life and aim to achieve certain new goals in life. They may start to develop new hobbies and aim to achieve what they have newly plan in life. Cancer survivors may also try to accomplish what they failed to do before being diagnosed with cancer, such as change of lifestyle from less ideal to healthier lifestyle (Tedeschi and Calhoun, 2004).

iii)   Greater appreciation of life

Cancer survivors may begin to value their live more than before diagnosis of cancer and the priority in life may change. For example, a cancer survivor may appreciate their life more than ever compared with before cancer diagnosis and change their priority in life and started to focus more on their family or the value of their survivor from cancer (Tedeschi and Calhoun, 2004).

iv)   A sense of personal strength

Cancer survivors may experience improvement in their self-efficacy and gathered more personal strength to live with cancer and endure the complications of its treatment in a more positive manner. Cancer survivors with posttraumatic growth often argued that they never thought that they could be strong enough to endure all the complications of cancer and its treatment to the extent that they survive from having cancer. Hence, with the new personal strength which they acquired, they are confidence that they can overcome all difficulties in life (Tedeschi and Calhoun, 2004).

v)   Spiritual developments

Having survive living with cancer, the cancer survivors would experience increase spirituality and spiritual development. They become closer to God, the Almighty being, and utilized god as an ally to overcome their difficulty of living with cancer and possibility of cancer recurrence in the future. The cancer survivors will also intend to engage in more religious practice and have deeper sense of belonging on their religious faith (Tedeschi and Calhoun, 2004).

2.1.2   Theories Related to PTG

Posttraumatic growth is based on a few theories, such as the organismic valuing theory of growth, the Janus face model, and the affective-cognitive processing model of posttraumatic growth. The organismic valuing theory of growth explains that human being has the innate ability to know what is important to them and the essentials to fulfil life. Hence, people are intrinsically motivated to move towards a growthful direction in life. When trauma occurred, it will be processed in two ways: either the existing worldview assumptions about self, others and the surrounding are confirmed or disconfirmed. If the assumptions are confirmed, the assumptions will continue to exist and remained unshattered. But if the assumptions are disconfirmed (initial worldview assumptions shattered), then it may progress in two ways, that are either assimilation or accommodation will occur. Assimilation is where the trauma-related information is assimilated into the existing worldview assumptions and the assumptions are resumed. Accommodation is where the trauma-related information is incorporated into the existing worldview assumptions for construction of a new worldview assumptions (Joseph and Linley, 2005). Hence, it is the positive

accommodation which will contribute to development of PTG, rather than assimilation. While negative accommodation will lead to posttraumatic depreciation (figure 2.1).

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                    ┌─────────────────────────┐
                    │     Assumptive world     │
                    └────────────┬────────────┘
                                 ↓
                    ┌─────────────────────────┐
                    │  Triggering event (cancer)│
                    └────────────┬────────────┘
                                 ↓
                    ┌─────────────────────────┐
                    │ Cognitive processing of event│
                    └───────┬─────────┬───────┘
                  ┌─────────┘         └─────────┐
        ┌──────────────────┐        ┌──────────────────┐
        │  Conformation of  │        │ Disconformation of│
        │ existing assumptions│      │ existing assumptions│
        └──────────────────┘        └──────┬──────┬────┘
                               ┌────────────┘      └──────┐
                      ┌──────────────┐          ┌──────────────┐
                      │ Accommodation │          │ Assimilation  │
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                    ┌────────┘    └────────┐
              ┌──────────┐          ┌──────────┐
              │ Positive  │          │ Negative  │
              └─────┬────┘          └────┬─────┘
                    └────────┐  ┌────────┘
                       ┌──────────────┐
                       │ New assumptive world│
                       └──────────────┘
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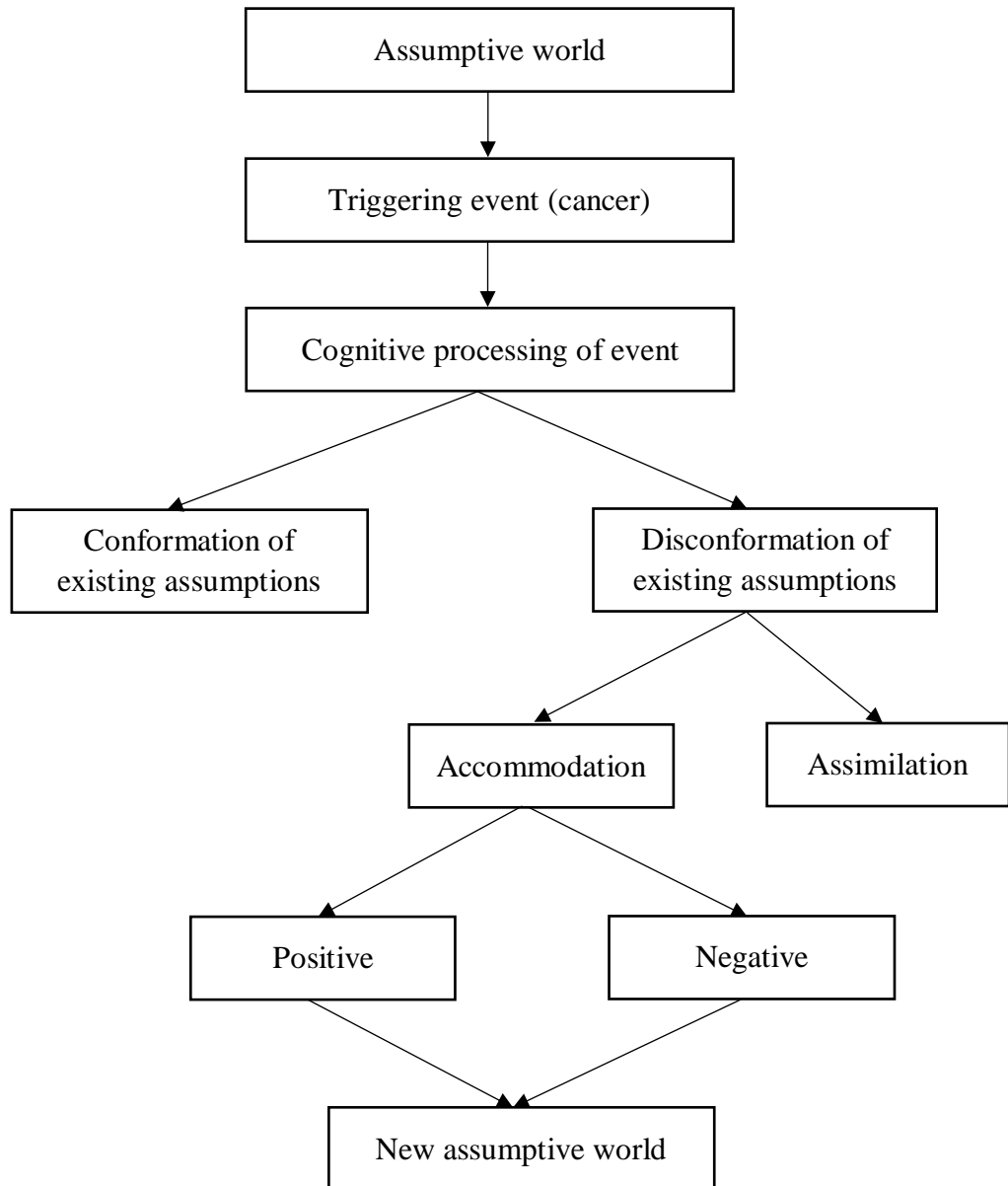
Figure 2.1: Organismic valuing theory of posttraumatic growth

In Janus face model, two components of PTG exists, such as the illusory component and the constructive component. The illusory component which may initially develop when a person is diagnosed with cancer as a result of coping by denial, is distorted positive illusion of posttraumatic growth that protects the subject from cognitive processing of the experience of loss and distress. Hence, the illusory component is not real PTG, but it is helpful to temporary maintain the psychological equilibrium and prevent changes in the assumptive world of the individual (Taylor et al., 2000). While the constructive component which develop later when trauma or extreme stress began to be experienced stated that posttraumatic growth developed from significant changes in identity, personal cognitive schemas and positive adjustment to trauma after successful coping with adverse circumstances (Zoellner and Maercker, 2006).

Traumatic events alone are not sufficient to induce PTG in a cancer survivor. Instead, the individual cancer survivor must also reflect their experiences and seek to find meaning in them such that PTG arises as a result of adaptation to the trauma of cancer diagnosis and its complications and rebuilding one's sense of the world (Tedesche and Calhoun, 2004; Sumalla et al., 2009). According to the affective-cognitive processing model of PTG, when a traumatic experience occurred, it may lead to incompatibility between the existing pre-assumptive view about self, others and the surrounding world and the new trauma-related information. This triggers reappraisal of the traumatic event via cognitive conscious processing which is characterized by either ruminative brooding or reflective pondering. If ruminative brooding follows, then assimilation occurred, and this leads to temporary restoration of the pre-assumptive view. But if cognitive conscious processing of the traumatic event resulting in reflective pondering, accommodation occurred whereby trauma-related information

9

is incorporated into searching for meaning which eventually leads to construction of a new assumptive worldview and development of PTG (Joseph et al., 2012).

2.1.3 The Mechanism Underlying the Development of Posttraumatic Growth in Cancer Patients

PTG may develop if someone experienced a highly stressful life events or a trauma. Hence, by definition, normal stressors or stressors of low degree may not be sufficient to induce PTG. Cognitively, a highly stressful experience or a trauma is necessary to shatter the pre-assumptive worldview of a person about self, others and the surrounding world. Then, if cognitive reappraisal of the highly stressful or traumatic event occurred, searching for meaning out of the traumatic event will take place. If the person is able to incorporate trauma-related information for the reconstruction of the new assumptive worldview about self, others and the surrounding world and successfully search for meaning to the traumatic event, accommodation is said to occurred which will facilitate the development of PTG. This distinguish PTG from coping as PTG resulted in positive psychological changes to progress to a level greater than that prior to the traumatic event. Hence, PTG serve as a transformational process rather than a process to sustain the psychological equilibrium in response to a traumatic event (Tedeschi and Calhoun, 2004). Hence, it is of utmost importance to study PTG in cancer patients as it is inversely correlated to psychological complications of cancer, such as psychological distress and depression, while PTG is positively correlated to cancer patients' health-related quality of life (Shand et al., 2015; Tomich and Helgeson, 2012; Casellas-Grau et al., 2017).

2.1.4 Posttraumatic Growth in Head and Neck Cancer Patients

Cultural differences may contribute to differences in occurrence of PTG in cancer patients and also influence the factors associated with PTG (Cho and Park, 2013). To date, data is still lacking regarding PTG in Asian head and neck cancer patients. There were only two studies investigated PTG in Asian head and neck cancer patients. The first study was conducted in Hong Kong oral cavity cancer patients which demonstrated a mean PTGI score of 51.76 (Ho et al., 2011) while the second study was a prospective study in Malaysian head and neck cancer patients which demonstrated a decrease of the PTGI-SF score across time (Leong Abdullah et al., 2015). PTG exhibited by head and neck patients is relatively lower as compared to other types of cancer (Leong Abdullah et al., 2015). This may be due to physical complications of head and neck cancer and its treatment such as facial disfigurement, problem with speech and swallowing, xerostomia, and trismus which are not seen in other types of cancer. In a recent cross-sectional study on PTG Taiwanese head and neck cancer patients with oncologic emergency revealed that 46.5% reported little-to-no PTG, and 53.5% had moderate-to-high PTG. In addition, PTG my also help to reduce anxiety and overcome fear of cancer recurrence (Chang et al., 2022). Hence, knowing that PTG is associated with mental health well-being of head and neck cancer and predicted higher QoL among cancer patients, it is vital to investigate on psychosocial factors which affect PTG in head and neck cancer patients.

2.1.5 Factors Associated with Posttraumatic Growth in Head and Neck Cancer Patients

Several factors may be associated with PTG in cancer patients which include socio-demographic and clinical factors such as female gender, younger age, minority race, higher level of education, religiosity, tumour size, radiotherapy, endocrine treatment, and mastectomy as well as positive psychology such as hope, optimism, and social support (Helgeson et al., 2006; Zwallen et al., 2010; Kinsinger et al., 2011; Fallah et al., 2012; Hullmann et al., 2014; Yi et al., 2015).

To date, most posttraumatic growth studies in cancer patients were conducted in breast cancer patients (Casellas-Grau et al., 2017). There are only a few studies which investigated on the possible factors associated with posttraumatic growth in head and neck cancer patients. Three studies reported socio-demographic factors and clinical characteristics such as higher income group, married patients, being female, being younger, having cancer-related financial stress, lower tumour stage and better social functioning were associated with higher PTG in head and neck cancer (Ho et al., 2011; Holtmaat et al., 2017; Sharp et al., 2018). Contrastingly, PTG study in Malaysian head and neck cancer patients reported no associations between socio-demographic and clinical factors, and PTG (Leong Abdullah et al., 2015). Hence, the associations of socio-demographic and clinical factors with PTG is still inconclusive. A systematic review of PTG in cancer patients pointed out the importance of investigating the relationship between PTG and health attitudes such as the fear of cancer progression as well as the type, quality, efficacy and satisfaction of patients with cancer treatment received (Casellas-Grau et al., 2016). However, the relationship between these psychosocial and clinical factors and posttraumatic growth have not been investigated in head and neck cancer survivors.

2.2   Health-related Quality of Life and Head and Neck Cancer

Quality of life is the perception of one's position in life in the context of the culture and values of the community one lives in and in relation to standard, goals, concern and expectations (Feelemyer et al., 2014). Quality of life (QoL) is an important measure in the field of psycho-oncology as a health indicator for assessments and treatment outcomes. QoL assessment serves a few purposes in psycho-oncology research, such as an indicator of the therapeutic outcome in the assessment of the efficacy of a treatment for cancer, to assess its association with other variables in the cancer survivors and to be used as a reference tool for the assessment of validity of other instruments for measuring QoL in the cancer patient population (King et al., 2016). Since head and neck cancer is associated with a wide range of illness complications and adverse effects from its treatment which could lead to deterioration in QoL among cancer patients (Holtmaat et al., 2017; Ernst et al., 2017; Sharp et al., 2018), it is pivotal to investigate on whether health related QoL is associated with PTG and vice versa. This will provide important information to device psychosocial interventions which may enhance QoL which in turn would also facilitate PTG development in HNC survivors.

2.3   Unmet Supportive Needs and Head and Neck Cancer

Supportive care of cancer patients covers a wide aspect of services provided by professionals who manage cancer patients, which include the need for information, psychological support, social support, care for physical well-being and daily life, and spiritual needs. Unmet supportive care needs arise when there is a gap between the cancer patient experience of the services received and the actual services desired by

the patient (Mohd Shariff et al., 2021). Unmet supportive care needs are common among head and neck cancer patients. Psychological needs is the most prevalent unmet needs, followed by other unmet needs, such as pain management, worry about treatment results, support for anxiety, change in sexual relationship, and fear of death and dying (Soothill et al., 2001). Deficiency in any of these needs may affect the quality of life, emotional and functional adjustment, and the survival of cancer patients (Mohd Shariff et al., 2021). Contrastingly, fulfillment of unmet needs, particularly informational needs among head and neck cancer patients contributed to less depression and anxiety, and improved health-related quality of life (Husson et al., 2011). Nevertheless, data on how unmet supportive care needs is related to PTG in head and neck cancer patients is lacking.

2.4   Fear of Cancer Progression and Head and Neck Cancer

Fear of cancer progression is defined as the fear, worry, and concern about cancer returning or recurring (Lebel et al., 2016). It is the most prevalent source of psychological distress among cancer survivors (Simonelli et al., 2017). High prevalence of fear of cancer recurrence (52.8% to 64.5%) has been documented even in newly diagnosed head and neck cancer patients. High fear of cancer recurrence is associated with higher odds of developing anxiety and depressive symptoms, and even higher risk of lifetime history of anxiety disorder or major depressive disorder among head and neck cancer patients (Mirosevic et al., 2019; Luo et al., 2020). In essence, PTG acts as a buffering factor in the positive relationship between fear of cancer recurrence and psychological distress in breast cancer patients (Ochoa Arnedo et al.,

2019). Hence, it will be interesting to examine whether fear of cancer progression and recurrence is predictive of PTG in head and neck cancer.

As for the measurement of fear of cancer progression among cancer patients, there are only two instruments available, which are the fear of cancer progression questionnaire (FoP-Q) (Herschbach et al., 2005) and the Fear of Cancer Recurrence Inventory (FCRI) (Simard and Savard, 2009). The FCRI may not be suitable to assess fear of cancer progression as it consists of 42 items which required a relatively longer duration of administration and hence, increase the risk of response bias among cancer patients as cancer subjects may be affected by discomfort due to presence of physical symptoms such as pain, fatigue, dizziness and other symptoms. Consequently, a shorter instrument is more suitable for cancer patient assessment. The FCRI is also available in shorter versions, such as 9-item FCRI, 7-item FCRI, and the 4-item FCRI. However, the 9-item FCRI has low specificity, while the 7-item FCRI and 4-item FCRI are not suitable to measure fear of cancer progression and the latter two instruments are only designed to assess fear of cancer recurrence (Peng et al., 2019; Humphris et al., 2018). The FoP-Q is available in a shorter version called Fear of Cancer Progression Questionnaire-Short Form (FoP-Q-SF) which consists of only 12 items and hence, more suitable to assess fear of cancer progression among cancer patients (Mehnert et al., 2006). The FoP-Q-SF has been translated and validated in Chinese and Dutch (Mahendran et al., 2020; Kwakkenbos et al., 2012). However, the FoP-Q-SF has not been translated to Malay and validated in the Malaysian cancer population.

2.5   Satisfaction of Cancer Therapy and Head and Neck Cancer

Besides, in the management of chronic recurrent illness, such as cancer, where treatment is associated with limited increase in survival of patients and compounded by disturbing adverse effects; information on the expectation, satisfaction, and perception of side effects of cancer treatment are of utmost importance as they allowed treating clinicians to devise plan for management of adverse effects, individualized the course of treatment for cancer patients, and improve adherence of patients to the cancer treatment (Cheung et al., 2016). Moreover, in the context of cancer patients, PTG is reported to significantly predict lower psychological distress only if perceived vulnerability, such as concerns about the side effects of treatment is being controlled (Ochoa Arnedo et al., 2019). Hence, it would be informative to determine whether expectation and satisfaction with cancer therapy as well as perception about its side effects are predictive of the level of PTG among head and neck cancer patients.

Despite the importance of assessing the expectation and satisfaction of cancer therapy, there is only one instrument available to perform the measurement, which is the Cancer Therapy Satisfaction Questionnaire (CTSQ). The validity of the domains of the CTSQ was assessed by comparing the domain scores with appropriate known group validity such as ECOG status of patients, stage of cancer, perceived change in cancer and medication side effects (Trask et al., 2008). The CTSQ was translated and validated in other languages such as Korean and Dutch (Park et al., 2013; Cheung et al., 2016). Despite the importance of the CTSQ for measuring expectation and satisfaction of cancer therapy among cancer patients, the CTSQ has not been translated into Malay and validated in the Malaysian cancer population.

2.6   Rationale of the Study

There were a few rationales behind conducting this study:

1. The importance of assessment of fear of cancer progression and satisfaction of cancer therapy among cancer patients justified our study to translate and validate the FoP-Q-SF and the CTSQ for use in the Malaysian cancer population.

2. Head and neck cancer differ from other types of cancer due to the complication of facial disfigurement which may increase the psychological vulnerability of patients due to the society's emphasis on physical attractiveness. Moreover, a number of devastating complications of the cancer itself and the side effects of its treatment such as fatigue, pain, problem with speech and swallowing, breathing problem, mucositis, xerostomia, and trismus which further exerts detrimental effects on many functions and activities of daily living which causes further psychological distress and decreasing quality of life. Hence, it would be vital to assess health-related quality of life among head and neck cancer patients. In addition, a few psychosocial and treatment related factors may also affect the psychological well-being of head and neck cancer patients, such as unmet supportive needs, fear of cancer progression, and expectation and satisfaction with cancer therapy. These factors should also be measured among head and neck cancer patients.

3. Despite several factors mentioned above which could produce negative impact on head and neck cancer patients, development of posttraumatic growth in response to the traumatic experience of living with cancer could rebalance the mental health status of cancer survivors. To the best of our knowledge, to date

no studies have investigated the degree of health-related quality of life, fear of cancer progression, unmet supportive needs, and satisfaction of cancer therapy among head and neck cancer patients. Data is also lacking on how these factors are related to posttraumatic growth in head and neck cancer patients.

4. Although, occurrence of trauma is an important ingredient for development of PTG, it should be noted that not all patients with trauma related to living with cancer could trigger the development of PTG. If the traumatic experience of living with cancer is too intense, it may lead to failure for cognitive reprocessing of the traumatic event to search for meaning, which will hamper the development of PTG. Hence, it is of outmost significance to study how negative psychological aspects, such as fear of cancer progression, unmet supportive care needs, and poor health-related QoL affects PTG, which remain unexplored in cancer patients. Furthermore, it is also of outmost significance to study whether a positive satisfaction of cancer therapy will enhance PTG. Better understanding of how health-related quality of life, fear of cancer progression, unmet supportive needs, and satisfaction of cancer therapy are related with posttraumatic growth among head and neck cancer patients will serve as a guidance for future studies to investigate on psychosocial interventions which enhances factors that increase PTG and reduce factors that decrease PTG to bring about improved outcome and provide a holistic approach in the management of this group of cancer patients.
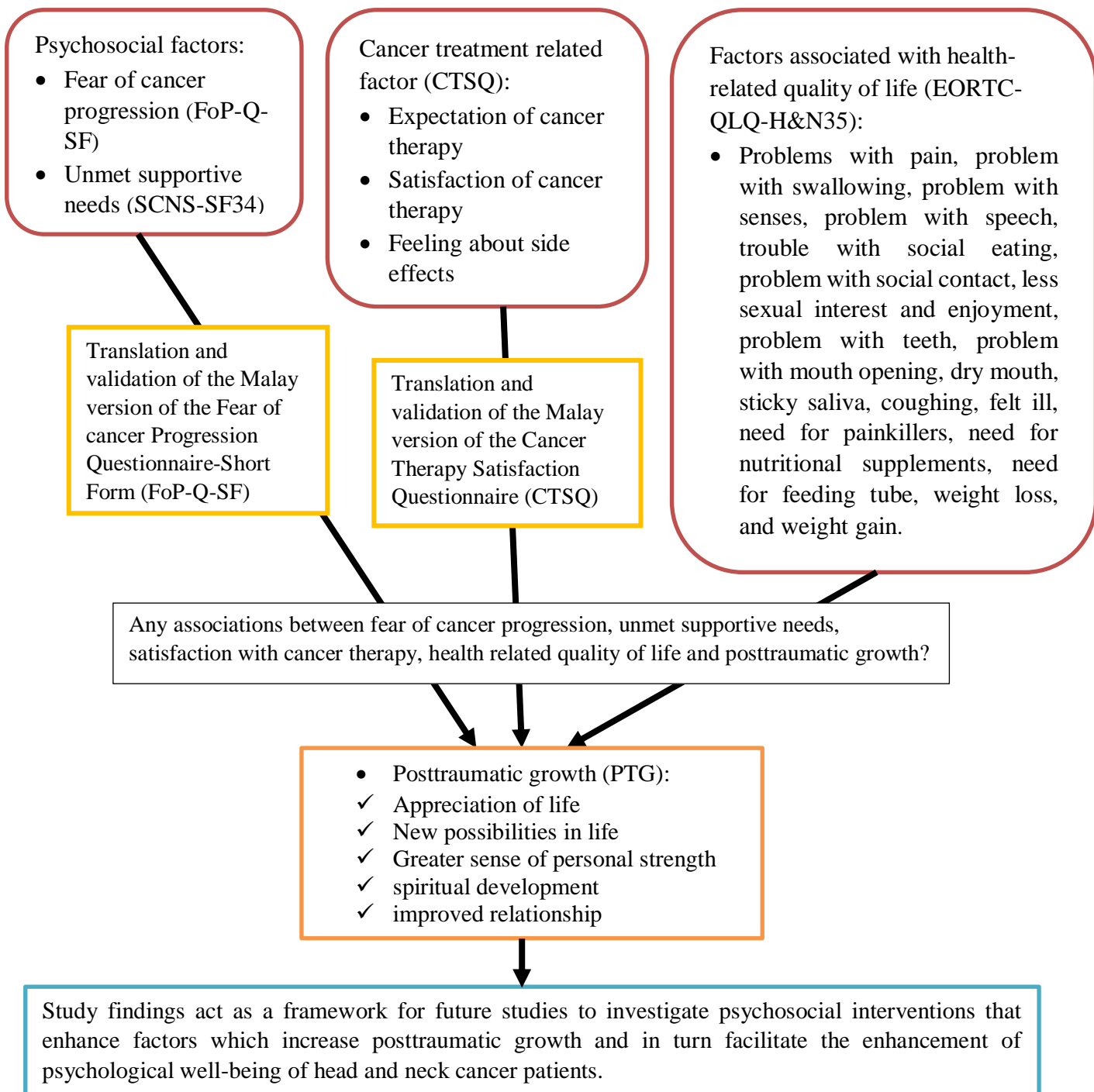
Psychosocial factors:
- Fear of cancer progression (FoP-Q-SF)
- Unmet supportive needs (SCNS-SF34)

Cancer treatment related factor (CTSQ):
- Expectation of cancer therapy
- Satisfaction of cancer therapy
- Feeling about side effects

Factors associated with health-related quality of life (EORTC-QLQ-H&N35):
- Problems with pain, problem with swallowing, problem with senses, problem with speech, trouble with social eating, problem with social contact, less sexual interest and enjoyment, problem with teeth, problem with mouth opening, dry mouth, sticky saliva, coughing, felt ill, need for painkillers, need for nutritional supplements, need for feeding tube, weight loss, and weight gain.

Translation and validation of the Malay version of the Fear of cancer Progression Questionnaire-Short Form (FoP-Q-SF)

Translation and validation of the Malay version of the Cancer Therapy Satisfaction Questionnaire (CTSQ)

Any associations between fear of cancer progression, unmet supportive needs, satisfaction with cancer therapy, health related quality of life and posttraumatic growth?

- Posttraumatic growth (PTG):
  - ✓ Appreciation of life
  - ✓ New possibilities in life
  - ✓ Greater sense of personal strength
  - ✓ spiritual development
  - ✓ improved relationship

Study findings act as a framework for future studies to investigate psychosocial interventions that enhance factors which increase posttraumatic growth and in turn facilitate the enhancement of psychological well-being of head and neck cancer patients.

Figure 2.2: *Conceptual framework of this study which includes psychosocial factors (from FoP-Q-SF and SCNS-SF34), cancer treatment related factor (from CTSQ) and factors associated with health-related quality of life (from EORTC-QLQ-H&N35) to see if there is any associations with PTG. The importance of studying fear of progression and cancer treatment satisfaction were to examine whether they are predictive of PTG in HNC patients. Meanwhile, the study of unmet supportive needs was important because the data on how it is related to PTG in HNC patients is still lacking. Lastly, health-related quality of life was an important study because it could provide crucial information to device psychosocial interventions which may enhance quality of life which in turn would also facilitate PTG development in HNC survivors.*

CHAPTER 3

METHODOLOGY

3.1 Research Setting and Design

This study was conducted from 1st July 2019 to 30th June 2021 for a period of two years. This multicenter cross-sectional study was open to all patients with HNC registered under the Oncology and Otorhinolaryngology units of Advanced Medical and Dental Institute, Universiti Sains Malaysia, and Oncology, Otorhinolaryngology and Oral and Maxillofacial Surgery units of Universiti Kebangsaan Malaysia (UKMMC). The study consists of two phases which were:

- Translation of the original English versions of the Fear of Progression Questionnaire (FPQ-Q-SF) and Cancer Treatment Satisfaction Questionnaire (CTSQ) into Malay, and validation of Malay versions of the FPQ and CTSQ (Phase 1)
- Investigation of posttraumatic growth and its psychosocial predictive factors in head and neck cancer patients (Phase 2).

Two of the questionnaires used in Phase 2 of this study were not translated and validated in Malay. Hence, Phase 1 was conducted to fulfil specific objective (1) of the study.

3.2   Ethical Issues

This study received approval from the Human Research Ethics Committee of Universiti Sains Malaysia (USM/JEPeM/18100483) and the Medical Research Committee of the Faculty of Medicine, Universiti Kebangsaan Malaysia (FF-2019-279). The study was conducted according to the ethical code of the Declaration of Helsinki 1964 and its subsequent amendments.

3.3   Translation of the Original Versions of Fear of Progression Questionnaire (FoP) and Cancer Treatment Satisfaction Questionnaire (CTSQ) into Malay and Validation of Malay Versions of FoP and CTSQ (Phase 1) (to achieve objective 1)

Phase 1 of the study was a cross-sectional study and was open to all cancer patients at the Oncology outpatient clinics, Oncology inpatient ward and Otorhinolaryngology out-patient clinic of Advanced Medical and Dental Institute, Universiti Sains Malaysia (AMDI, USM) as well as the Oncology, Otorhinolaryngology and Oral and Maxillofacial Surgery outpatient clinic and wards, Universiti Kebangsaan Malaysia Medical Center (UKMMC).

3.3.1   Sampling Method

Sampling method employed in Phase 1 of this study was convenient sampling.

3.3.2   Sample Size Estimation

i.   Pilot study of the translated Malay versions of the FoP and CTSQ required 20 cancer patients.

ii. Calculation of sample size for validation of Malay versions of the FPQ and CTSQ:

(a) Calculation of sample size for internal consistency:

From the Statstodo Programme:

Probability of type I error = 0.05

Power = 1 – β = 0.8

Expected Cronbach's α = 0.95 (based on Ramli et al., 2012)

Sample size required for each item = 4 subjects

Total number of items = 28 items

Sample size = 4 x 28

= 112 subjects

(b) Calculation of sample size for convergent and discriminant validity:

To detect a correlation coefficient of 0.23 (based on Lua and Wong, 2012)

Significance level of 5% (α = 0.05)

Power of 80% (β = 0.2)

The standard normal deviate for α (Zα) = 1.96

The standard normal deviate for β (Zβ) = 0.84

C = 0.5 * ln[(1-r)/(1-r)] = 0.24

n = [2.8/0.24]2 + 3

   = 139 subjects

(c) Calculation of sample size for exploratory:

To calculate the sample size of exploratory factor analysis, Rule of 5 (Bryant et al., 1995) was referred, which states that one's sample should be at least five times the number of variables to be studied. Hence, the subjects-to-variables ration should be 5 or greater. The total number of observed variables in the two questionnaires are 28 items. Therefore, sample size needed= 28 x 5 = 140 subjects.

Based on all three calculations, the largest sample size required were 140 subjects. Hence, the estimated sample size needed for the validation of Malay versions of the FoP and CTSQ were 168 subjects (inclusive of 20% of dropout rate).

Finally, the total estimated sample size required to achieve objective 1 was:

168 subjects + 20 subjects (from pilot study)

= 188 subjects

3.3.3 Subject Recruitment

All cancer patients who attended the Oncology outpatient clinics, Oncology inpatient ward and Otorhinolaryngology out-patient clinic of AMDI, USM as well as the Oncology, Otorhinolaryngology and Oral and Maxillofacial Surgery outpatient clinic and wards of UKMMC were approached by the research officer in the research team during working days. The potential subjects were explained regarding the following details:

- ✓ The decision to participate in the study was fully voluntary and if the participants decided to withdraw from the study, they may do so without the need for a valid reason and without loss of any benefit they were entitled for prior to the study.

- ✓ Assurance of anonymity of their personal information.

- ✓ The description of the study, the procedure and how the participants will be assessed in the study.

- ✓ The purposes, benefits, and risks of the study.

- ✓ The use of data for publication purpose and the consent of data use for policy planning.

  Then, the potential subjects were screened for the following inclusion and exclusion criteria:

  i. Inclusion Criteria:

  a. All patients diagnosed with any type of cancer and at any stage of cancer (Stage I to IV) confirmed by histopathological report except those with metastasis to central nervous system.

  b. Patients were able to read and write in Malay.