

QUALITY OF LIFE AMONG LYMPHOMA PATIENTS  
RECEIVING CHEMOTHERAPY IN HOSPITAL USM

by

NURUL SARAH BT FAZILAN

Dissertation submitted in partial fulfillment of the  
requirements for the degree of Bachelor of Nursing  
(Honours)

June 2020

## **CERTIFICATE**

This is to certify that the dissertation entitled “Quality of Life Among Lymphoma Patients Receiving Chemotherapy in Hospital USM” is the bona fide record of research work done by Ms Nurul Sarah Bt Fazilan during the period from September 2019 to August 2020 under my supervision. I have read this dissertation and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation to be submitted in partial fulfillment for the degree of Bachelor of Nursing (Honours).

Main supervisor,

.....

Dr. Zakira binti Mamat @ Mohamed

Senior University Lecturer

School of Health Sciences,

Universiti Sains Malaysia,

Health Campus,

16150 Kubang Kerian,

Kelantan, Malaysia.

Date: .....

## DECLARATION

I hereby declare that this dissertation is the result of my own investigations, except where otherwise stated and duly acknowledged. I also declare that it has not been previously or concurrently submitted as a whole for any other degrees at Universiti Sains Malaysia or other institutions. I grant Universiti Sains Malaysia the right to use the dissertation for teaching, research and promotional purposes.

.....

Nurul Sarah bt Fazilan (MATRICES NO. :134151)

Student of Bachelor Nursing (Honours)

School of Health Sciences

Universiti Sains Malaysia,

16150 Kubang Kerian,

Kelantan, Malaysia.

Date: .....

## **ACKNOWLEDGEMENTS**

First and foremost, I would like to express my greatest gratitude to Allah for giving me the strength and guidance to complete this dissertation successfully in a whole new environment.

I wish to convey my deepest appreciation to my supervisor, Dr. Zakira binti Mamat @ Mohamed, for her full support in guiding, supervising and encouraging me throughout the preparation until completion of this dissertation.

I would also like to extend my acknowledgement to the Dean of the School of Health Sciences who allowed me to carry out this study in this School, to every participant that have been so nice and willing to lend me their valuable time and make this study a reality.

Also a huge gratitude to my friends for their on-going support, guidance and motivation during this challenging and hard times in completing this dissertation especially to Ms Maisarah bt Osman.

Last but not least, I wish to dedicate my dissertation to my beloved family and a special thanks to my parents, Mr. Fazilan Bin Zakaria and Mrs. Haslina Bt Alwi, for their endless love, prayers and encouragement. Not forgetting all my beloved siblings who give me the strongest motivation to complete this dissertation.

# TABLE OF CONTENTS

QUALITY OF LIFE AMONG LYMPHOMA PATIENTS RECEIVING CHEMOTHERAPY IN HOSPITAL USM ..	i
CERTIFICATE .....	ii
DECLARATION .....	iii
ACKNOWLEDGEMENTS .....	iv
TABLE OF CONTENTS.....	v
LIST OF TABLES.....	viii
LIST OF FIGURES .....	ix
ABSTRAK.....	x
ABSTRACT .....	xi
Chapter 1.....	1
1.1 Background of the Study.....	1
1.2 Problem Statement .....	3
1.3 Research Objective.....	5
1.3.1 General Objective.....	5
1.3.2 Specific Objective .....	5
1.4 Research Question .....	5
1.5 Hypothesis.....	5
1.6 Conceptual and Operational Definitions.....	6
1.7 Significance of the Study .....	9
Chapter 2.....	10
2.1 Introduction .....	10
2.2 Review of Literature.....	10
2.2.1 Quality of Life .....	10
2.2.2 Lymphoma.....	11
2.2.3 Chemotherapy.....	12
2.2.4 Association of Socio-Demographic and QOL.....	14
2.2.5 QOL Instrument.....	14
2.2.6 QOL Measurement.....	16
2.3 Theoretical/Conceptual Framework of the Study.....	17
Chapter 3.....	19
3.1 Introduction .....	19
3.2 Research Design .....	19

3.3 Population and Setting.....	19
3.4 Sampling Plan.....	20
3.4.1 Patient Recruitment and Sampling .....	20
3.4.2 Sample.....	21
3.4.2.1 Inclusion Criteria .....	21
3.4.2.2 Exclusion Criteria.....	21
3.4.3 Sampling Method.....	21
3.4.4 Sample Size Estimation .....	22
3.5 Instrumentation .....	23
3.5.1 Instrument.....	23
3.5.2 Translation of Instrument .....	24
3.5.3 Validity and Reliability.....	25
3.6 Variable .....	25
3.6.1 Variable Measurement .....	25
3.6.2 Variable Scoring .....	26
3.7 Ethical Consideration .....	27
3.7.1 Privacy and Confidentiality .....	27
3.7.2 Vulnerability Issue.....	27
3.7.3 Community Sensitivities and Benefits.....	27
3.7.4 Declaration of Interest .....	28
3.8 Data Collection Plan .....	28
3.8.1 Procedure of Data Collection .....	28
3.8.2 Flow Chart of Data Collection .....	30
3.9 Data Analysis .....	31
Chapter 4.....	32
4.1 Introduction .....	32
4.2 Results of the Study .....	32
4.2.1 Socio-demographic .....	32
4.2.2 Level of Domains of QOL among Lymphoma Patients.....	34
4.2.3 Association between the QOL of Lymphoma Patients with Socio-demographic Characteristics.....	34
Chapter 5.....	37
5.1 Introduction .....	37

5.2 Discussion of Result.....	37
5.2.1 Level of Domains of QOL among Lymphoma Patients.....	37
5.2.2 Association between the QOL of Lymphoma Patients with Socio-demographic Characteristics.....	39
5.3 Strength and Limitation of the Study.....	40
5.3.1 Strength of the Study.....	40
5.3.2 Limitation of the Study.....	40
Chapter 6.....	41
6.1 Summary of the Study Findings.....	41
6.2 Implication and Recommendation.....	42
6.2.1 Nursing Practice.....	42
6.2.2 Nursing Education.....	42
6.2.3 Nursing Research.....	43
6.3 Conclusion.....	43
REFERENCES.....	44
APPENDIX A: INSTRUMENT (ENGLISH VERSION).....	48
APPENDIX A: INSTRUMENT (MALAY VERSION).....	52
APPENDIX B: PERMISSION FROM AUTHOR.....	56
APPENDIX C: RESEARCH INFORMATION & INFORM CONSENT (English Version).....	57
APPENDIX C: RESEARCH INFORMATION & INFORM CONSENT (Malay Version).....	62
APPENDIX D: INSTITUTIONAL APPROVAL.....	68
APPENDIX E: ETHICAL APPROVAL.....	71
APPENDIX F: GANTT CHART/PROJECT SCHEDULE.....	73

## LIST OF TABLES

Table 3.1 Independent and Dependent Variables .....	25
Table 4.1 Socio-Demographic Data of Respondents (n=24).....	33
Table 4.2 Descriptive Statistics of Level of Domains QOL (n=24) .....	34
Table 4.3 Association Between the QOL of Lymphoma Patients with Socio-Demographic Characteristics (n=24).....	35

## LIST OF FIGURES

Figure 2.1 Health-Related Quality of Life (HRQoL) Model.....	17
Figure 2.2 Adapted Health-Related Quality of Life (HRQoL) Model .....	18
Figure 3.1 Determination of Sample Size Using Raosoft Calculation Software.....	22
Figure 3.2 Flow Chart of Data Collection Process .....	30

# **KUALITI HIDUP DALAM KALANGAN PESAKIT LIMFOMA DI HOSPITAL USM**

## **ABSTRAK**

Limfoma, sejenis kanser darah, boleh berlaku pada sebarang usia termasuk kanak-kanak dan mungkin kadang-kala boleh menjejaskan kualiti hidup (QOL) seseorang. Salah satu rawatan yang sering disarankan untuk kanser adalah kemoterapi. Kesan sampingan sementara yang berkaitan dengan rawatan kemoterapi juga boleh mempengaruhi Kualiti Hidup Berkaitan Kesihatan (HRQoL) pesakit. Pemahaman yang baik mengenai hubungan antara pemboleh ubah yang menjelaskan kualiti hidup dapat meningkatkan perawatan dan pemulihan pesakit limfoma. Oleh itu, kajian ini bertujuan untuk mengenal pasti kualiti hidup pesakit limfoma yang menerima rawatan kemoterapi dan kaitan antara kualiti hidup dan ciri-ciri sosio-demografi di kalangan pesakit limfoma di Hospital USM. Seramai 24 pesakit limfoma berusia antara 18 hingga 73 tahun telah terlibat dalam kajian ini. Reka bentuk kajian keratan rentas telah digunakan. Data kemudiannya dikumpulkan menggunakan instrumen Fungsi Penilaian Terapi Penyakit Kronik-Limfoma (FACT-LYM) dan kemudian dianalisis menggunakan SPSS versi 26. Ujian Pearson's Chi Square telah diguna untuk menentukan hubungan antara kualiti hidup pesakit limfoma dan ciri-ciri sosio-demografi mereka (umur, jantina, status perkahwinan, status pekerjaan, tahap pendidikan, masa sejak diagnosis dan kitaran kemoterapi semasa). Kajian ini mendapati bahawa majoriti pesakit limfoma yang menerima kemoterapi mempunyai skor kualiti hidup yang sederhana ( $n=24$ , 103.88). Kesemua tujuh faktor sosio-demografi, hanya usia sahaja didapati mempunyai signifikan berkaitan dengan kualiti hidup pesakit limfoma ( $p=0.042$ ). Kajian ini menunjukkan bahawa perawatan yang lebih baik oleh penyedia penjagaan kesihatan diperlukan untuk meningkatkan kualiti hidup pesakit limfoma.

# **QUALITY OF LIFE AMONG LYMPHOMA PATIENTS RECEIVING CHEMOTHERAPY IN HOSPITAL USM**

## **ABSTRACT**

Lymphoma, a type of blood cancer, can occur at any age including children and may occasionally compromise a person's quality of life (QOL). One of the treatment commonly suggested for cancer is chemotherapy. The temporary side effects associated with the chemotherapy treatment may also influence the patients' Health-Related Quality of Life (HRQoL). A better understanding of the relationship between the variables explaining QOL may improve care and rehabilitation of lymphoma patients. Thus, this study aimed to identify the QOL of lymphoma patients receiving chemotherapy and the association between the QOL and socio-demographic characteristics among lymphoma patients in Hospital USM. A total of 24 lymphoma patients aged between 18 to 73 years old were involved in this study. A cross-sectional study design was employed. The data was then collected using the Function Assessment of Chronic Illness Therapy-Lymphoma (FACT-LYM) instrument and then analyzed using SPSS version 26. Pearson's Chi Square test was used to determine the association between the QOL of lymphoma patients and their socio-demographic characteristics (age, gender, marital status, occupational status, educational level, time since diagnosis and current chemotherapy cycle). This study found that majority of the lymphoma patients receiving chemotherapy had moderate score of QOL (n=24, 103.88). Of seven factors of socio-demographic characteristics, only age was found as significantly associated with the QOL of lymphoma patients (p=0.042). These study revealed that a better care by health care providers are required to improve the lymphoma patients' QOL.

# Chapter 1

## INTRODUCTION

### 1.1 Background of the Study

Quality of life (QOL) is a major concern of patients with terminal cancer. Symptoms of cancer can affect their QOL (Malathi et al., 2017). Cancer is a family of complex disease with manifestations that vary according to the body system affected and the type of tumor cells involved (Dewit 1998; LeMone & Burke 1996).

Lymphoma, a type of blood cancer, can occur at any age including children and may occasionally compromise a person's QOL. Lymphoma is the term used to describe cancers that begin in cells of the immune system. There are two main types of lymphoma, that is, Hodgkin lymphoma (HL) and Non-Hodgkin lymphoma (NHL). The favorable choice treatment for common cancer including lymphoma cancer is chemotherapy, as it is a systemic treatment where the drugs will travel throughout the body or system (Wildes & Ades, 2004).

In the International Agency for Research on Cancer in Switzerland (Global Cancer Observatory, 2019), the latest estimates on the global burden of cancer have risen up to 18.1 million new cases and 9.6 million cancer deaths in 2018 for all the cancer sites combined. NHL ranked on the 11<sup>th</sup> place worldwide with estimated people diagnosed is 509,590 and HL on 26<sup>th</sup> place in the world with estimated diagnosed is 79,990 people.

In Asia, the estimated number of new cases in 2018 for NHL and HL of both sexes is (42.4%) and (36.2%) respectively (Global Cancer Observatory, 2019). Asia have the highest estimated number of new cases in 2018 for lymphoma cancer (NHL and HL) compared to other continents which is 243,553 of Asian people.

While in Malaysia, a total of 103,507 new cancer cases were diagnosed for the period of 2007-2011 stated in the Malaysian National Cancer Registry Report 2007-2011 (Azizah et al., 2016). Approximately 5,374 people are diagnosed with lymphoma (NHL and HL) and it is the 4<sup>th</sup> place for most common cancer in all residents in Malaysia for 2007-2011. According to Hamidillah (2019) from Unit Rekod Perubatan, in year 2018, about 21 lymphoma patients were treated with chemotherapy in Hospital Universiti Sains Malaysia (Hospital USM) Oncology Ward (3S & 1TD)

A serious illness and death can be resulted from the untreated cancer. One of the treatment commonly suggested for cancer is chemotherapy. The temporary side effects associated with the chemotherapy treatment may influence the patients' Health Related Quality of Life (HRQoL) during treatment (Eisenbraun et al., 2011). A study done shows patients aged 55-64 years old (55%) were more likely to experience fatigue in their daily basis lasted for a week after completion of their chemotherapy treatment (Gregory et al., 2000). Understanding QOL from the patient's perspective especially in oncology area is a pivotal factor for clinical decisions (Montazeri et al., 2008) and patient preferences (Valderas et al., 2008).

Lymphoma cancer patient will mostly experience a variety of symptoms. Deficient management of cancer symptoms will disrupt a person's daily activities. The treatment of symptoms can help to improve the QOL of an individual and relieve the suffering (Paleri et al., 2005).

## **1.2 Problem Statement**

In the past few decades, lymphoma had become more common. By 2040, the incident cases of HL are expected to increase by +32.4% while NHL is +59.5% globally (Global Cancer Observatory, 2019). Unfortunately, there is still a lack of understanding on the disease especially in terms of common symptoms experienced, the possible side effects of cancer treatments as well as the variables affecting the QOL of lymphoma patients. Besides, in an assessment survey in 2000 showed 40% of cancer patients were not offered with any recommendations to achieve symptomatic relief by the health care professionals (Gregory et al., 2000).

A study found that there is significant depletion of QOL among cancer patients due to common symptoms experienced by them (Knobf, 2014). A research by Gregory et al (2000), after recent chemotherapy treatment, around 30% patients experienced fatigue on a daily basis and 76% said to feel fatigue at least for a few days in each month. The difficulty to perform typical cognitive tasks and engage in social activities are one of the consequences of fatigue. Given the impact of fatigue, treatment options should be routinely considered in the care of cancer patients (Gregory et al, 2000).

Pettengel et al (2007) also shared same results regarding low QOL among lymphoma patients. Those participants receiving chemotherapy that involved in their study were reporting overall to have worse health functioning, depressive symptoms, and activity impairment than those participants who were not having chemotherapy.

In Hospital USM, the highest number of admitted patients in Unit Oncology in 2018 is breast cancer which is 137, with colorectal cancer on second place (95) and lymphoma cancer (82) on third place (Ayuelena, 2019). With an increasing incidence of lymphoma cancer patients throughout the years, this could leave negative effect to health care professions as it leads to low quality of care towards the patients. Depletion in quality of care by health professions can be due to lack of competent and motivated staff, shortage time management by health care due to understaff, burdens with heavy workloads and overwhelmed with large volume of patients (World Health Organization, 2019). Incorporating QOL into standard clinical practice holds great promise for improving communication with health care providers, with a resultant improvement in patient outcomes.

### **1.3 Research Objective**

#### **1.3.1 General Objective**

To identify the QOL of lymphoma patients receiving chemotherapy in Hospital USM.

#### **1.3.2 Specific Objective**

- i) To identify the level of domains of QOL (physical, social, emotional, and functional) among lymphoma patients receiving chemotherapy in Hospital USM.
- ii) To determine the association between the QOL of lymphoma patients with their socio-demographic characteristics (age, gender, marital status, occupational status, educational level, time since diagnosis and current chemotherapy cycle).

### **1.4 Research Question**

- i) What are the level of domains of QOL (physical, social, emotional, and functional) among lymphoma patients receiving chemotherapy in Hospital USM?
- ii) What are the association between the QOL of lymphoma patients with their socio-demographic characteristics (age, gender, marital status, occupational status, educational level, time since diagnosis and current chemotherapy cycle)?

### **1.5 Hypothesis**

1. Null hypothesis ( $H_0$ ): There is no significant association between the QOL of lymphoma patients with their socio-demographic characteristics.

Alternative hypothesis ( $H_a$ ): There is significant association between the QOL of lymphoma patients with their socio-demographic characteristics.

## 1.6 Conceptual and Operational Definitions

Quality of Life (QOL) - Based on a fundamental World Health Organization (WHO) definitions on health, QOL includes the physical, psychological and social condition of an individual. According to general scientific belief, QOL is a multidimensional concept that implicates different influencing factors predicting the individual risk to achieve a “full life potential” (Augustin & Radtke, 2014). Quality of life refers to a subjective evaluation, which is embedded in a cultural, social and environmental context. QOL are also define as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (Billington, R., 1999).

In this study, QOL include the physical, social, functional and emotional well-being of an individual.

Lymphoma - Lymphoma, a cancer that begins in cells of the immune system. There are over 60 different types of lymphoma, which are sorted into groups or subtypes. Lymphoma is a type of blood cancer that develops when white blood cells called lymphocytes grow out of control and do not die when they should. Lymphocytes are part of the immune system which they travel throughout the body in lymphatic system to fight infections. The abnormal

lymphocytes build up usually in lymph nodes in neck, armpits and groin, or other parts of the body (Lymphoma Action, 2019).

In this study, lymphoma patients refer to those who diagnosed with Hodgkin lymphoma or Non-Hodgkin lymphoma.

#### Chemotherapy -

Chemotherapy, a treatment that uses cytotoxic drugs to kill cancer cells. The strong drugs work by stopping cancerous cells from dividing or triggering cancer cells to die. Commonly chemotherapy drugs used are carboplatin, cisplatin, paclitaxel, docetaxel, doxorubicin and others. These medications are given either alone or in combination (American Cancer Society, 2016). In these study, it refers as cancer treatment that use strong drugs to destroy cancer cells.

Chemotherapy in this study also refer to the lymphoma patients who had previously received at least one cycle of similar chemotherapy regimen. This is because, the researcher intended to assess their experiences of chemotherapy side effects that affecting their quality of life.

This study will involve inpatient and outpatient patients with confirmed diagnosed of lymphoma that receiving chemotherapy

in Hospital USM. Inpatient patients refer to those who were admitted to receive repeated cycles of chemotherapy in any of the targeted wards (3 Selatan and 1 Timur Depan), while outpatient patients refer to those who is receiving single-day chemotherapy at Hematology Daycare center.

## **1.7 Significance of the Study**

QOL is one of the important outcomes of cancer treatment. An individual with cancer were more likely to have low QOL due to symptoms they experienced (Malathi, 2017). With the expected increases in NHL incidence rates (Global Cancer Observatory, 2019), the time has come to understand the health and QOL status of those who report active NHL disease. This study is fundamental in order to develop insight to health care professionals to upgrade the treatment and rehabilitation facilities, and advance the palliative care to aid cancer patients for better coping and improve their QOL. A better understanding of the relationships between the variables explaining QOL may improve care and rehabilitation of lymphoma patients.

Hopefully through this study, effective QOL care can be planned, implemented, evaluate and revised during the chemotherapy period by the health care professionals. It gives guideline and awareness for them to be more focused on QOL of patients undergoing chemotherapy and plan specific interventions to meet the needs of patients to optimize patient's QOL.

This study may also contribute the benefits by increasing the realization in our country that the incidence cases of lymphoma cancer are globally increasing by years and thus can create a community that demonstrate positivity and able to provide supportive care for this cancer-fighting groups.

## **Chapter 2**

### **LITERATURE REVIEW**

#### **2.1 Introduction**

This chapter provides a review of a literature on quality of life (QOL), lymphoma, impact of chemotherapy on lymphoma patients by accredited scholars and researchers. Literature was searched through general academic research databases such as Google Scholar and ScienceDirect using key words and terms, which were either used singly or in various combination: chemotherapy, QOL and lymphoma. This chapter also details the conceptual framework, Health-Related Quality of Life model's (HRQOL) guiding this study.

#### **2.2 Review of Literature**

##### **2.2.1 Quality of Life**

QOL is a term that is mainly used in medical studies even though it can also be applied in various disciplines such as politics, religion and economics. QOL term in medical studies measures the effect of illness, disease and its treatment on the patient's welfare by going beyond the physician-dominated indicators of the patient's progress (Camilla-Brennan & Steele 1999). Evaluating QOL of cancer patients is important issues because of the amount of symptoms distressed experience by them will influence their general well-being (Heydarnejad, Hassanpour & Solati, 2011).

QOL assessment is vital for both cancer patients and clinician because the results can guide patients on treatment options and informed decision-making can be made by clinicians. Besides, QOL may help clinicians in making treatment options and determine the best way to support and enhance the QOL of cancer patients during their difficult times of disease and on-going cancer treatments (Yusuf et al., 2013).

In oncology area, several research has shown that further studies on QOL can gradually improve the efficacy of treatments on cancer patients (Harper et al., 2012).

### **2.2.2 Lymphoma**

Lymphoma is the term used to describe cancers that begin in cells of the immune system. There are two categories of lymphoma: Hodgkin (HL) and non-Hodgkin (NHL). There are over 60 different types of lymphoma, which are sorted into groups or subtypes. NHL can be further divided into cancers that have an indolent (slow-growing) course and those that have an aggressive (fast-growing) course. These subtypes behave and respond to treatment differently. Both HL and NHL can occur in children and adults, and prognosis and treatment depend on the stage and the type of cancer.

Follicular lymphoma is typically a slow-growing or indolent form of NHL. This lymphoma subtype accounts for 35% of adult in the United States and 22% worldwide (Ganti et al., 2005). NHL is a heterogeneous group of lymphatic cancer system with an overall 5-year survival rate of 50-60% with statistics vary depending on the cell type, stage of disease at diagnosis and treatment. However, indolent lymphomas generally carry a good prognosis with a median survival of 10 years but a high rate of relapse, and are usually not curable in advanced stages (Smith et al, 2009). By comparison, 30 to 60% of individuals who convert to or present with aggressive forms of NHL can be cured with intensive chemotherapy regimens, but the disease has shorter natural history with greater risk of relapse within 2 years of treatment ends (Smith et al., 2009).

Most patients with NHL present with multiple sites of lymphadenopathy and/or bone marrow disease (advanced-stage disease). This may manifest with disease-related syndrome such as fatigue, loss of weights, fever and night sweats. Restricted movement and pain may

also occur due to enlarged lymph nodes. Treatment generally attempts to control rather than cure the disease, with types of treatment includes periods of watchful waiting, radiation therapy and chemotherapy.

### **2.2.3 Chemotherapy**

Early detection, diagnosis and treatments are key points for cancer recovery. Cancer treatment includes variety of therapies, namely surgery, radiotherapy, chemotherapy, immunotherapy, photodynamic therapy and bone marrow transplantation. According to Wilkes and Ades (2004), chemotherapy is the first choice for treating many cancers and it differs from surgery and radiation for it is always used as a systemic treatment where the drugs travel throughout the whole body or system.

Chemotherapy, the use of cytotoxic drugs to poison cancerous cells and stop them from divide abnormally. The problem with cytotoxic drugs is that they can stop normal healthy cells dividing as well as cancer cells. This is what causes many of the side effects of chemotherapy. The temporary side effects associated with the chemotherapy treatment may influence the patients' Health Related Quality of Life (HRQoL) (Eisenbraun et al., 2011).

Chemotherapy may be given as neoadjuvant therapy (before radiation or surgery) or as adjuvant therapy (after surgery or radiation). Neoadjuvant chemotherapy and adjuvant chemotherapy has been recently emerging as a feasible and safe therapeutic option for cancer patients. Chemotherapy used in the treatment of most non-hematologic and some hematologic cancers is most frequently administered intravenously over the course of a single day.

The aim of the treatment of NHL is to maximize overall survival, maintain health-related quality of life (HRQoL), and minimize treatment-related morbidity. In NHL, the treatment sometimes can have more negative impact than the condition itself. For this reason, it is important to consider the HRQoL of patients to establish the suitability of a treatment. Chemotherapy can result in nausea, vomiting, hair loss and cause skin irritation, sore mouth, dysphagia and gastrointestinal problems depending upon the site treated (Pettengell et al., 2007).

According to American Cancer Society (2019), chemotherapy side effects can be acute, immediate or delayed effects. Acute side effects may begin when treatment is given or very soon after it is finished. At worst the side effects can last 5-6 hours after the chemo which patient commonly will complained of vomiting, nausea and fatigue. However, many side effects go away fairly quickly. The severity of side effects (how bad they are) varies greatly from person to person. Sometimes the side effects can last a lifetime, such as when chemo causes long-term damage to the heart, lungs, kidneys, or reproductive organs. Certain types of chemo sometimes cause delayed effects, such as a second cancer that may show up many years later (American Cancer Society, 2019).

A study done by local researchers in Malaysia, Huan-Keat & Sabrina (2014), revealed some of the chemotherapy-related side effects commonly experienced by local cancer patients. Chemotherapy-induced nausea and vomiting (CINV) have been ranked as two of the most feared and distressing side effects since the last three decades. According to the study, majority of the patients desired to receive as much information about chemotherapy-related side effects and believe it should be provided as soon as they knew they were going to be given chemotherapy.

#### **2.2.4 Association of Socio-Demographic and QOL**

In a study done by Malathi et al. (2017), showed that QOL of majority cancer patients (82.3%) are influenced by their symptoms, which adversely lower the patient's QOL. The poor scored in symptoms are due to financial constraints which reported as major issue causing barrier to symptom management. Farooqui et al. (2013) shared the same findings mentioning that having no medical insurance and being unemployed affect their participants scores on emotional functioning and that it contributed to the poor QOL.

In terms of gender and marital status, better QOL was seen among breast cancer patients who are either single, divorced or widowed compared to married woman in a study by Ganesh et al. (2016). Significant difference was seen in the functioning scale (physical functioning, social functioning, body image, sexual functioning, future perspective) and symptoms scale (systemic therapy side effects and upset by hair loss).

Better QOL was also observed in Ganesh et al. (2016) among breast cancer patients older than 55 years, compared to patients who are 55 years and younger. Significant difference was present in the functioning scales and symptoms scales. In contrary with Gregory et al. (2000), where patients aged 55-64 years old were more likely to have low QOL due to fatigue symptoms they experienced after chemotherapy treatment.

#### **2.2.5 QOL Instrument**

Several hundreds of well-validated cancer-specific instruments have been developed and use to measure QOL across diseases and its treatment (Kaasa et al., 1995). Most of the instruments included physical, functional and symptom control, as well as psychological aspects.

One of the tools used to measure QOL is World Health Organization Quality of Life (WHOQOL-100) by World Health Organization in 1997. This tool can be used in particular cultural settings, but at the same time results are comparable across cultures. It contains 24 facets relating to quality of life that grouped into 6 domains: physical health, psychological, social relationship, and environment (World Health Organization, 2017).

Next is European Organization for Research and Treatment of Cancer quality of life questionnaire (EORTC-QLQ C-30) version 3.0, the current standard version by Quality of Life Unit, EORTC Data Center. The EORTC QLQ is an integrated system for assessing the HRQoL of cancer patients participating in international clinical trials. It contains 30-items compilation of functional scales (15-items), symptoms scales (13-items) and 2-items of global health status/QOL scale (Aaronson et al., 1993).

Another type of tool is Quality of Life Scale (QOLS) by Flanagan, J. (1970). It is a questionnaire that design for use in patients with chronic illness. It contains 16-items from 6 domains: physical well-being, relationship with other people, social, community and civic activities; personal development and fulfillment; recreation; independence (Burchardt, 2003).

Short Form Health Survey (SF-36) that developed by RAND Corporation in 1980 containing 36-items; a set of generic, coherent and easily administered QOL measures. SF-36 was standardized in 1990 as a self-report measure of functional health and well-being. These measures rely upon patient self-reporting and now widely utilized by managed care organizations for routine monitoring and assessment of care outcomes in adult patients (Von Der Heyde, 2007).

Functional Assessment of Cancer Therapy-General (FACT-G) part of the FACIT Measurement System that are owned and copyrighted by David Cella, Ph.D, containing 27-item along with disease-specific subscale fitting the patient's cancer diagnosis. The FACT-G was developed to measure QOL in cancer patients receiving therapy. While the FACT-G is widely used across diverse cancer patient populations, it was not initially developed to monitor QOL of patients over a longer follow-up period or for patients in remission or on observation (Yost et al., 2013). The FACT-G consists of three 7-item subscales, physical well-being, social well-being and functional well-being, and a 6-item subscale emotional well-being.

A standardized structured and self-administered questionnaire, the Function Assessment of Chronic Illness Therapy–Lymphoma (FACT-LYM) comprise of 42-items. It consists of 27-items FACT-G and 15-items lymphoma-specific ‘Additional Concerns’ subscale (LYM).

### **2.2.6 QOL Measurement**

QOL is a subjective experience. The most accurate way to measure the QOL is by letting the patients themselves to rate their own QOL. Clinicians are usually under-assess the level functioning of the patients.

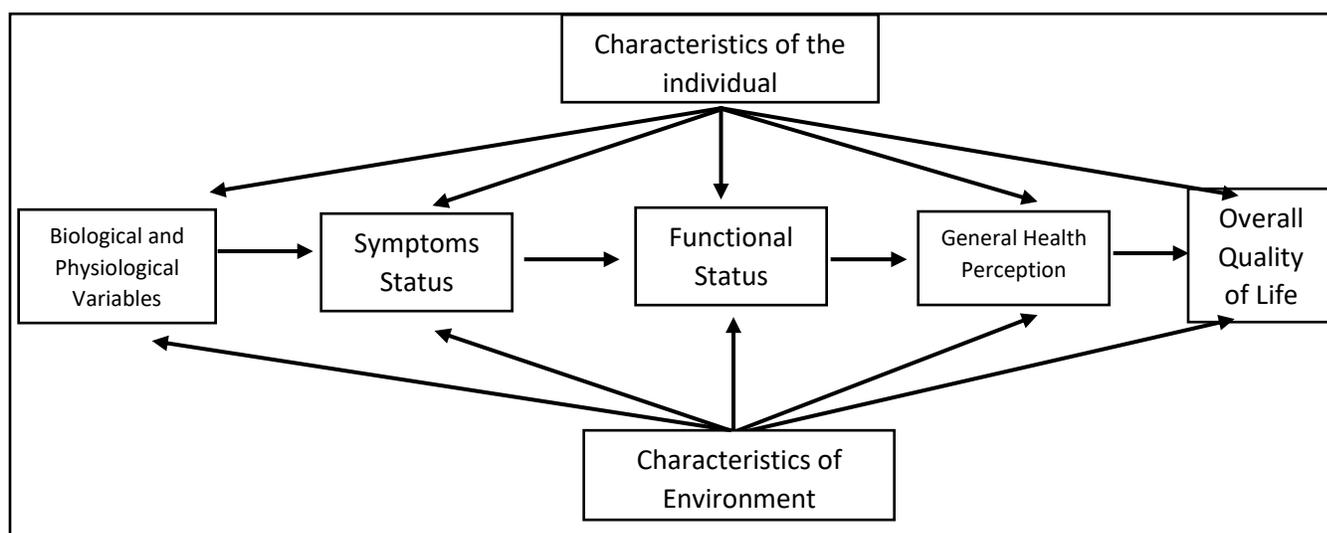
Bottomley (2002), carried out a study to compare 163 cancer patients' QOL with clinical assessment. He found only 54% of physician assessment correlated with patients' assessment. Therefore, the use of patient-reported questionnaire has become a standard practice in the assessment of cancer patients' QOL.

In conclusion, patient's own view and rating on their QOL play vital parts in providing a valid picture of one's own life quality.

### 2.3 Theoretical/Conceptual Framework of the Study

To guide this study, the Health Related Quality of Life (HRQoL) model were used as the conceptual framework. The rationale behind the use of HRQoL was the model were conceived as dynamic, subjective and multidimensional; and the dimension often include physical, social, psychological and spiritual factors (Jones et al., 2006).

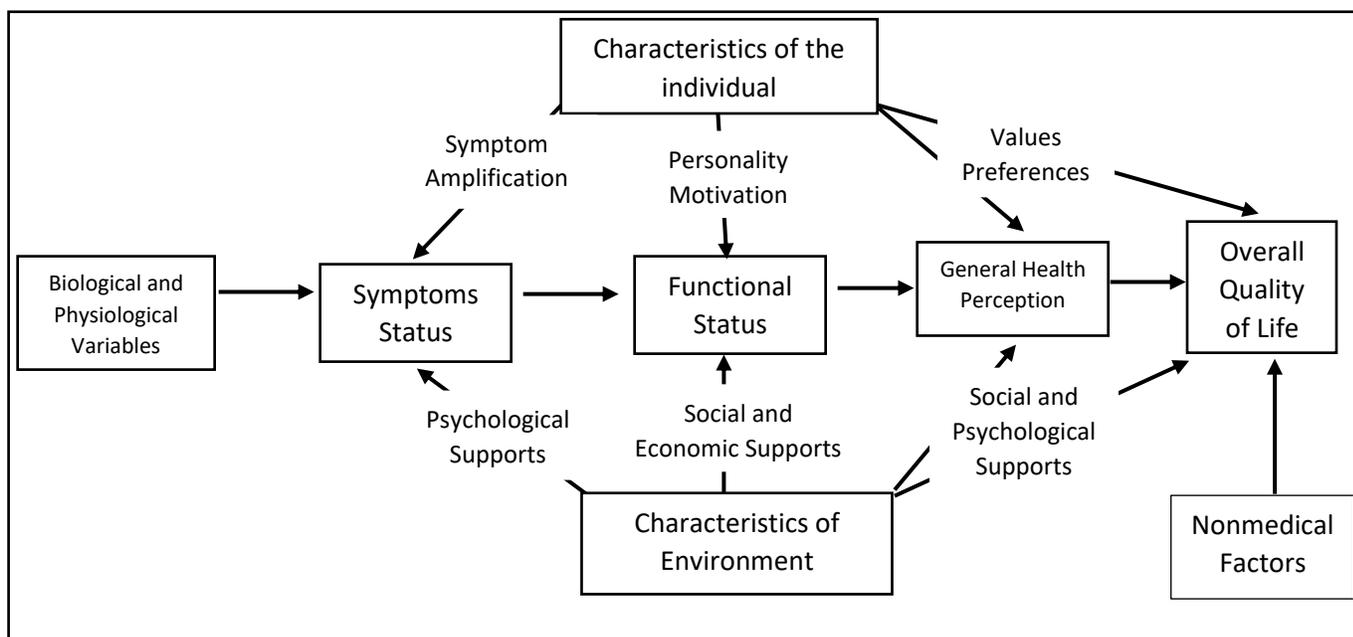
HRQoL is increasingly used as an outcome in clinical trials, effectiveness research, and research on quality of care. Factors that have facilitated this increased usage include the accumulating evidence that measures of HRQoL are valid and reliable (Wilson & Cleary 1995). Wilson and Cleary presented a conceptual model that focused on relationships among aspects of health.



**Figure 2.1** Health-Related Quality of Life (HRQoL) Model

This model linked biological function, symptoms status, functional health status, general health status and overall quality of life. Wilson and Cleary suggested that this HRQoL

conceptual model can be used to unify the pathological processes; and biological, physiological and clinical outcomes. In the model, the evaluation of biological variable centers on cells, organs, and organ systems, while the assessment of symptoms status shift to organism as a whole. Functional health status has been defined as the ability of an individual to perform and adapt in one’s environment. Symptoms status and functional health have been included in many HRQoL outcomes studies. General health perceptions represent an integration of all health concepts previously reviewed (Wilson & Cleary 1995). In this study, the conceptual framework will explain the measurement of QOL among lymphoma patients receiving chemotherapy treatment (Figure 2.2).



**Figure 2.2** Adapted Health-Related Quality of Life (HRQoL) Model

# **Chapter 3**

## **RESEARCH METHODOLOGY**

### **3.1 Introduction**

This chapter outlines the research methodology and methods used in this study aiming to assess the quality of life (QOL) among lymphoma patients receiving chemotherapy in Hospital Universiti Sains Malaysia (Hospital USM). This chapter begins with the rationale of choosing the research design. Followed by details of population and sampling, the participants' selection criteria, the instrument used, ethical consideration, data collection plan and data analysis.

### **3.2 Research Design**

The research design for this study is cross-sectional study. The characteristics of cross-sectional study takes place at a single point of time, allow researchers to look at the prevailing characteristics in a given population and to able provide information about what is happening in a current population. The type of data was primary data, which the data was directly obtain from original resources that is the patients themselves.

### **3.3 Population and Setting**

The population of this study are the lymphoma patients who were receiving chemotherapy and attending oncology ward (3 Selatan and 1 Timur Depan), and Hematology Daycare center in Hospital USM, Kubang Kerian, Kelantan. Hospital USM was chosen as the study setting because Hospital USM is one of the available government oncology hospitals in Malaysia therefore most cancer patients including lymphoma cancer patients referred to Hospital USM.

### **3.4 Sampling Plan**

A sampling plan is a term widely used in research studies that provide an outline on the basis of research conducted. It tells which category is to be surveyed, what should be the sample size and how the respondents should be chosen out of the population. Sampling plan should be designed to allow all questions, as stated in objectives, to be answered.

#### **3.4.1 Patient Recruitment and Sampling**

This study involved inpatient and outpatient patients with confirmed diagnosed of lymphoma who were admitted to receive repeated cycles of chemotherapy in any of the targeted wards (3 Selatan and 1 Timur Depan) or received single-day chemotherapy at Hematology Daycare center. As intended to assess their QOL of experiencing chemotherapy side effects, only those who had previously received at least one cycle of similar chemotherapy regimen were included. No patients were approach during chemotherapy session.

Only those inpatient patients that were admitted to receive repeated cycles of chemotherapy were approached at least 5 days after their last chemotherapy drug given. This is to avoid any acute or immediate side effects of chemotherapy reaction. While for the outpatient patients, those that received single-day chemotherapy at Hematology Daycare center were approached a day before their chemotherapy drug given, which the patients need to come on appointment a day before to get their blood taken for investigation. The researcher obtained the date of appointment at the Hematology Daycare center from the staff nurse.

### **3.4.2 Sample**

When conducting a research study, certain inclusion and exclusion criteria were considered in selecting an eligible sample from the population in Hospital USM, Kubang Kerian, Kelantan.

#### **3.4.2.1 Inclusion Criteria**

Subjects are eligible for inclusion in this study if they are:

- i. Lymphoma cancer patients (diagnosed with Hodgkin lymphoma or Non-Hodgkin lymphoma) that receiving chemotherapy in Hospital USM.
- ii. Being age over 18 and above.
- iii. Able to understand, speak and write in English or Bahasa Malaysia.
- iv. Previously received at least one cycle of similar chemotherapy regimen.
- v. For inpatient patients, had their last chemotherapy session at least 5 days before.
- vi. For outpatient patients, attending appointment a day before single-day chemotherapy session (Hematology Daycare Centre, 2019).

#### **3.4.2.2 Exclusion Criteria**

Subjects are excluded from this study if they:

- i. Receiving radiotherapy in Hospital USM.
- ii. Declined to participate in this study.

### **3.4.3 Sampling Method**

In this research study, respondents were selected by using purposive sampling. Due to limited number of primary data sources who can contribute to the study as a consequence to uncommon type of disease, purposive sampling is the only appropriate method available.

To reduce biasness, the subjects who best meets the needs of the study to represent the population of subject group were selected as a respondent.

### 3.4.4 Sample Size Estimation

February to March 2020 was planned as the two-month data collection period. Number of patients receiving chemotherapy in oncology wards (3 Selatan and 1 Timur Depan) during November and December 2019 was used to estimate the sample size. In total, there were 46 patients admitted for chemotherapy during that period. The sampling size was then determined using the Raosoft sample size calculation software and the projected sample size (n) needed was 42 patients. Based on this formula, a confidence level was set at 95% with a margin error that can be tolerated at 0.05. This is shown in the Figure 3.1 below.

**Sample size calculator**

What margin of error can you accept? <small>5% is a common choice</small>	<input type="text" value="5"/>	%	The margin of error is the amount of error that you can tolerate. If 90% of respondents answer <i>yes</i> , while 10% answer <i>no</i> , you may be able to tolerate a larger amount of error than if the respondents are split 50-50 or 45-55. Lower margin of error requires a larger sample size.
What confidence level do you need? <small>Typical choices are 90%, 95%, or 99%</small>	<input type="text" value="95"/>	%	The confidence level is the amount of uncertainty you can tolerate. Suppose that you have 20 yes-no questions in your survey. With a confidence level of 95%, you would expect that for one of the questions (1 in 20), the percentage of people who answer <i>yes</i> would be more than the margin of error away from the true answer. The true answer is the percentage you would get if you exhaustively interviewed everyone. Higher confidence level requires a larger sample size.
What is the population size? <small>If you don't know, use 20000</small>	<input type="text" value="46"/>		How many people are there to choose your random sample from? The sample size doesn't change much for populations larger than 20,000.
What is the response distribution? <small>Leave this as 50%</small>	<input type="text" value="50"/>	%	For each question, what do you expect the results will be? If the sample is skewed highly one way or the other, the population probably is, too. If you don't know, use 50%, which gives the largest sample size. See below under <b>More information</b> if this is confusing.
Your recommended sample size is	<b>42</b>		This is the minimum recommended size of your survey. If you create a sample of this many people and get responses from everyone, you're more likely to get a correct answer than you would from a large sample where only a small percentage of the sample responds to your survey.

**Online surveys with Vovici have completion rates of 66%!**

**Alternate scenarios**

With a sample size of	<input type="text" value="100"/>	<input type="text" value="200"/>	<input type="text" value="300"/>	With a confidence level of	<input type="text" value="90"/>	<input type="text" value="95"/>	<input type="text" value="99"/>
Your margin of error would be	0.00%	0.00%	0.00%	Your sample size would need to be	40	42	44

**Figure 3.1** Determination of Sample Size Using Raosoft Calculation Software

Then, by considering the possibility of drop out, another 10% is added. Therefore, the sample size (n) needed for this study are:

$$\begin{aligned}n &= 42 + \text{drop out of 10\%} \\ &= 42 + 4.2 \\ &= 46.2 \\ &= 46 \text{ lymphoma patients}\end{aligned}$$

Due to short period for data collection and limited number of primary data sources who can contribute to the study, 46 lymphoma patients as sample size are seem acceptable to avoid limitation of the study.

### **3.5 Instrumentation**

A standardized structured and self-administered questionnaire, the Function Assessment of Chronic Illness Therapy–Lymphoma (FACT-LYM), were used in this study (Appendix A). It consists of Functional Assessment of Cancer Therapy-General (FACT-G) and lymphoma-specific ‘Additional Concerns’ subscale (LYM). It also included the socio-demographic characteristics of the study subjects which developed based on the literature to achieve the study objectives.

#### **3.5.1 Instrument**

The instrument, a self-administered questionnaire used in this study comprised of two parts: Part A and Part B. Some modifications have been made to the original version in order to obtain the purpose of study. Permission to use the questionnaire has been obtained from the author (refer Appendix B).

Part A consists of 7 questions about the socio-demographic characteristics: age, gender, marital status, occupational status, educational level, time since diagnosis and current chemotherapy cycle.

Part B consists of combination of 27-item FACT-G and 15-item lymphoma-specific "Additional Concerns" subscale (LYM) and the symptom indices. The FACT-G consists of three 7-item subscales, physical well-being (PWB) (scored 0–28), social well-being (SWB) (scored 0–28) and functional well-being (FWB) (scored 0–28), and a six-item subscale emotional well-being (EWB) (scored 0–24). The “Additional Concerns” subscale (LYM) consists of 15-items with score range 0-60.

All items response choices are identical to the five-point Likert scale of the FACT-G (0=Not at all; 1= A little bit; 2=Somewhat; 3=Quite a bit; 4=Very Much). The FACT-Lymphoma utilizes a time frame of “*the past seven days,*” consistent with the time frame used in the FACT-G and most other FACIT scales. Seven days was assumed as long enough to allow for a symptom or problem to be experienced, yet short enough to avoid the tendency people can have to respond generally to questions, reflecting their trait or general disposition rather than their true recent experience.

### **3.5.2 Translation of Instrument**

The original version of FACT-LYM is in English. Provisional testing done by Eremenco et al. (2004) showed that FACT-LYM has good internal consistency ( $\alpha = 0.70$ ) across five different languages.

For the Bahasa Malaysia version, it is already available in FACIT Measurement System for the use of registered members.