QUALITY OF LIFE IN CHILDREN WITH BRONCHIAL ASTHMA IN INSTITUT PEDIATRIK HOSPITAL KUALA LUMPUR (IPHKL)

DR MOHAMAD AZLAN BIN HAMDAN

DISSERTATION SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENT FOR THE DEGREE OF MASTER OF MEDICINE (PAEDIATRIC)



UNIVERSITI SAINS MALAYSIA 2017

KUALITI HIDUP PESAKIT KANAK-KANAK ASMA DI INSTITUT PEDIATRIK HOSPITAL KUALA LUMPUR (IPHKL)

DR MOHAMAD AZLAN BIN HAMDAN

TESIS YANG DIKEMUKAKAN UNTUK MEMENUHI SEBAHAGIAN DARIPADA SYARAT MEMPEROLEHI IJAZAH SARJANA PERUBATAN (PEDIATRIK)



UNIVERSITI SAINS MALAYSIA 2017

ACKNOWLEDGEMENTS

Alhamdulillah to Allah The Almighty God, the completion of this thesis work would not have been possible without the contributions of many wonderful people. First, I would like to thank my mother, Puan Hajah Siti Easah binti Mor, for her love and continuous support. I really could not have come this far without her praying and blessing to me.

I would like to especially thank my sister, Siti Khadijah binti Hamdan for spending her time to help me for data calculation. I would like to acknowledge the children and caregivers who were willing to participate in this study. You have taught me so much. In addition, I would like to thank the staffs involved for their assistance with data collection and data analysis.

I am grateful to my both dissertation supervisors; Dr Norzila Mohamed Zainudin, Consultant Paediatrician and Paediatric Chest Physician in Institut Pediatrik Hospital Kuala Lumpur, and Associate Professor Dr Norsarwany Mohamad, Consultant Paediatrician and Head Department of Paediatric, Hospital Universiti Sains Malaysia for their invaluable guidance, encouragement and understanding in helping me throughout the preparation of this thesis. Apart from these two great teachers, I would like to thank to my dissertation co supervisor, Associate Professor Dr Ariffin Nasir, Consultant Paediatrician in Hospital Universiti Sains Malaysia for his continuous inspiration and motivation during the thesis preparation.

In addition, I would also like to thank all the children and their parents, whom I have had the privilege to take care of over the last 9 years since I hold the title of "Doctor". You are the reason I enjoy being as what I am doing till now that will never ending and I am forever grateful.

May Allah bless.

ABSTRACT

Background: Asthma is a public health problem that adversely affects different aspects of quality of life (QoL). Childhood asthma is a common chronic disease affecting children worldwide.

Objective: To measure the quality of life in children with bronchial asthma who were admitted to the ward due to asthma exacerbation and those who attended general paediatric clinic for follow up in Institut Pediatrik Hospital Kuala Lumpur.

Methods: In this cross-sectional observational study, 105 children with physician diagnosed bronchial asthma (57 children attended clinic for follow up and 48 children admitted for asthma exacerbation) were evaluated to measure quality of life and were administered paediatric asthma quality of life questionnaire (PAQLQ).

Results: There were 75 boys and 30 girls, age ranged between 7 to 12 years with mean of 8.9 ± 1.5 years. For asthmatic children that were admitted to the ward for exacerbation, the mean age was 8.4 ± 1.2 years and for the asthmatic children who attended the clinic for follow up, the mean age was 9.4 ± 1.6 years. Asthmatic children that were admitted to the ward for exacerbation had moderate impairment in their quality of life as the overall mean score was only 4.0 ± 0.6 . The mean score of the quality of life in the symptoms, emotional

function and activity limitation domains were 3.7 \pm 0.7, 4.4 \pm 0.8 and 4.0 \pm 0.8

respectively. Children with bronchial asthma who attended the general clinic for

follow up had better overall mean score in their quality of life which was 5.9 ±

1.1. This showed that they only had minimal impairment in their quality of life.

Meanwhile, the mean score of the quality of life in the symptoms, emotional

function and activity limitation domains were 5.8 \pm 1.2, 6.0 \pm 1.0 and 5.8 \pm 1.2.

There was no difference of the quality of life score among children with

bronchial asthma that had the disease less than 3 years duration and for 3

years and more for the both groups of these asthmatic children. Similarly, there

was no difference of the quality of life score among asthmatic children who has

normal BMI with asthmatic children who were overweight to obese.

Conclusion: Childhood asthma had significant adverse effects on the quality of

life of the affected children particularly among asthmatic children that were

admitted for acute exacerbation.

Keywords: quality of life, childhood asthma, clinic follow up, ward admission for

exacerbation

ABSTRAK

Latar Belakang: Penyakit asma adalah masalah kesihatan awam yang menjejaskan pelbagai aspek kualiti hidup (QoL). Penyakit asma ialah penyakit kronik yang melibatkan ramai kanak - kanak di seluruh di dunia.

Objektif: Untuk mengukur kualiti hidup kanak-kanak yang menghidap penyakit asma yang dimasukkan ke wad kerana serangan asma dan mereka yang menghadiri klinik kanak - kanak untuk rawatan susulan di Institut Pediatrik Hospital Kuala Lumpur.

Kaedah: Dalam kajian keratan rentas ini, 105 kanak-kanak yang telah disahkan menghidap penyakit asma (57 daripadanya adalah kanak-kanak yang menghadiri klinik untuk rawatan susulan dan 48 kanak-kanak dimasukkan ke wad kerana serangan asma) telah dinilai untuk mengukur kualiti hidup dan telah diberikan soal selidik kualiti hidup asma pediatrik (PAQLQ).

Keputusan: Terdapat 75 kanak-kanak lelaki dan 30 kanak-kanak perempuan berumur di antara 7 hingga 12 tahun dengan purata umur 8.9 ± 1.5 tahun. Kanak - kanak asma yang dimasukkan ke wad kerana serangan asma mempunyai purata umur 8.4 ± 1.2 tahun dan kanak - kanak asma yang menghadiri rawatan susulan di klinik mempunyai purata umur 9.4 ± 1.6 tahun.

Kanak – kanak asma yang dimasukkan ke wad kerana serangan asma mempunyai skor kualiti hidup yang sederhana terjejas kerana purata skor keseluruhan hanya 4.0 ± 0.6. Purata skor untuk domain simptom, domain fungsi emosi dan domain limitasi aktiviti adalah 3.7 ± 0.7, 4.4 ± 0.8 dan 4.0 ± 0.8. Kanak – kanak asma bronkial yang menghadiri rawatan susulan di klinik mempunyai purata skor kualiti hidup keseluruhan yang lebih baik iaitu 5.9 ± 1.1.Ini menunjukkan mereka hanya mengalami gangguan yang ringan sahaja dalam kualiti hidup mereka. Manakala, purata skor untuk domain simptom, domain fungsi emosi dan domain limitasi aktiviti adalah 5.8 ± 1.2, 6.0 ± 1.0 dan 5.8 ± 1.2. Tiada perbezaan skor kualiti hidup dalam kalangan kanak - kanak yang menghidap penyakit asma bronkial yang menghidap penyakit kurang daripada 3 tahun dan lebih daripada 3 tahun dan ke atas untuk kedua - dua kumpulan kanak - kanak asma. Keputusan yang serupa tidak menunjukkan perbezaan dalam skor kualiti hidup kanak - kanak asma yang mempunyai jisim tubuh yang normal dengan kanak - kanak asma yang mempunyai berat badan berlebihan kepada obes.

Kesimpulan: Penyakit asma boleh memberi kesan buruk ke atas kualiti hidup kanak - kanak yang menghidap penyakit ini terutamanya kanak - kanak asma yang dimasukkan ke wad kerana serangan asma.

Kata kunci: kualiti hidup, kanak-kanak asma, rawatan susulan di klinik, kemasukan wad kerana serangan asma

DEFINITIONS

HRQoL

Health related quality of life - the individual's perception of their position of life in the context of the culture and value systems in which they live and in relation to their goals, expectations and concerns (World Health Organization, 1993).

QoL

Quality of life - general well-being of individuals and societies, outlining negative and positive features of life. It observes life satisfaction, including everything from physical health, family, education, employment, wealth, religious beliefs, finance and the environment

PEFR

Peak expiratory flow rate

BMI

Body mass index (kg/m2)

| LIST OF FIGURES PA | | |
|--------------------|--|-------|
| Figure 5.1: | Distribution of participants | 38 |
| Figure 5.2: | Age distribution of children with bronchial asthma | 41 |
| | | |
| LIST OF T | ABLES | |
| Table 5.1: | Descriptive statistic for demographic characteristic | 39-40 |
| Table 5.2: | Quality of life score in children with bronchial asthma | 42 |
| | in Institut Pediatrik Hospital Kuala Lumpur (IPHKL) | |
| Table 5.3: | Mean score of quality of life in children with bronchial | 43 |
| | asthma that were admitted to the ward for asthma | |
| | exacerbation according to the duration of the disease. | |
| Table 5.4: | Mean score of quality of life in children with bronchial | 45 |
| | asthma who attended general clinic follow up according | |
| | to the duration of the disease. | |
| Table 5.5: | Mean score quality of life in children with bronchial | 47 |
| | asthma who has normal BMI with overweight to obese | |

LIST OF CONTENTS

| CONTENT | ΓS | | | PAGE |
|-------------|-------|-------------|-----------------------------|----------|
| ACKNOWL | EDGE | MENT | | I - II |
| ABSTRACT | - | | | III - IV |
| ABSTRAK | | | | V - VI |
| DEFINITION | NS | | | VII |
| LIST OF FIG | GURES | S AND | TABLES | VIII |
| CHAPTER | 1 | INTR | ODUCTION | 1 - 2 |
| CHAPTER | 2 | LITE | RATURE REVIEW | |
| | | 2.1 | HISTORICAL ASPECT OF ASTHMA | 3 - 5 |
| | | 2.2 | PREVALENCE OF ASTHMA | 6 - 9 |
| | | 2.3 | MANAGEMENT OF ASTHMA | 10 - 15 |
| | | 2.4 | QUALITY OF LIFE IN CHILDREN | 16 - 22 |
| | | | WITH BRONCHIAL ASTHMA | |

| CHAPTER 3 OBJECTIVES | | | | |
|----------------------|---|------|--|---------|
| | | 3.1 | GENERAL OBJECTIVE | 23 |
| | | 3.2 | SPECIFIC OBJECTIVES | 23 |
| | | 3.3 | HYPOTHESES | 24 |
| CHAPTER | 4 | METH | HODOLOGY | |
| | | 4.1 | BACKGROUND | 25 |
| | | 4.2 | STUDY DESIGN | 26 |
| | | 4.3 | SAMPLING METHOD | 26 |
| | | 4.4 | SOURCE OF DATA | 26 - 27 |
| | | 4.5 | INCLUSION CRITERIA | 27 |
| | | 4.6 | EXCLUSION CRITERIA | 27 - 28 |
| | | 4.7 | WITHDRAWAL CRITERIA | 28 |
| | | 4.8 | DATA COLLECTION | 28 |
| | | 4.9 | STUDY INSTRUMENT | 29 - 32 |
| | | 4.10 | ETHICAL APPROVAL | 33 |
| | | 4.11 | SAMPLE SIZE | 33 -35 |
| | | 4.12 | STATISTICAL ANALYSIS | 35 -36 |
| | | 4.13 | FLOW CHART | 37 |
| CHAPTER | 5 | RESL | JLTS | |
| | | 5.1 | DEMOGRAPHIC CHRACTERISTIC | 38 - 41 |
| | | 5.2 | ANALYSIS QUALITY OF LIFE | 42 - 47 |
| CHAPTER | c | DISC | HEELON | |
| CHAPTER | b | | USSION AND | 10 E1 |
| | | 6.1 | BACKGROUND AND | 48 - 54 |
| | | 6.2 | SOCIODEMOGRAPHY OF CHILDREN QUALITY OF LIFE IN CHILDREN | 55 - 69 |
| | | 0.2 | | 55 - 69 |
| | | | WITH BRONCHIAL ASTHMA | |

| CHAPTER 7 | CONCLUSION | 70 - 72 |
|------------|---------------------------------|---------|
| CHAPTER 8 | LIMITATIONS AND RECOMMENDATIONS | 73 - 74 |
| REFERENCES | | 75 - 78 |

APPENDICES

APPENDICE 1: PAEDIATRIC ASTHMA QUALITY

OF LIFE QUESTIONNAIRE

(PAQLQ – MALAY VERSION)

APPENDICE 2: PATIENT'S INFORMATION SHEET

APPENDICE 3: LETTER OF PERMISSION FROM PROF.

ELIZABETH JUNIPER (AUTHOR OF ORIGINAL

QUESTIONNAIRE)

APPENDICE 4: ETHICAL APPROVAL FROM JEPeM USM

APPENDICE 5: ETHICAL APPROVAL FROM MREC MOH

APPENDICE 6: ETHICAL CONSENT FORM

CHAPTER 1

INTRODUCTION

Asthma is a chronic respiratory illness in children. It carries a significant morbidity and a considerable mortality. Signs and symptoms might not be recognized and thus, patients are not properly treated. It was reported by the American Academy of Paediatrics in 1999 that about 1.5 million youngsters around the world suffered from asthma, which includes an estimated of 1.3 million children under the age of 5 years old (American Academy of Paediatrics, 1999). Asthma can be operationally defined as reversible obstruction of large and small airways due to hyperresponsiveness to various immunologic and non-immunologic stimuli manifested by widespread narrowing of airways that changes on severity or because of therapy (Bergman DA, 1994). The diagnosis of asthma is supported by symptoms of wheezing and/ or cough that are episodic, nocturnal or following exercise or after exposure to allergen (Academy of Medicine, Malaysia Ministry of Health 1996).

In any medical condition, there are three basic goals or aims for treating patients which are, to prevent them from dying; to reduce the risk of long term organ damage and to improve their wellbeing i.e quality of life (QoL). In paediatric asthma patient, the conventional clinical outcomes such as forced expiratory volume measured in first second (FEV1), peak expiratory flow rate (PEFR) and symptoms are used to assess asthma control and are primarily used to gauge whether the first two goals are being achieved.

Certainly, children with very severe asthma tend to have worse quality of life than children with milder disease but recent research has shown that not only the quality of life does not correlate closely with asthma control, but it is also a very distinct component of overall asthma health status. Therefore, the impact that asthma has on a child's quality of life cannot be inferred from the clinical indices and it must be measured directly with a standard measurement instruments or properties to assess functional problems that are most troublesome to the patients.

CHAPTER 2

LITERATURE REVIEW

2.1 HISTORICAL ASPECT OF ASTHMA

Asthma has puzzled and confused physician from the time of Hippocrates until the present day. The word "asthma" comes from a Greek word meaning "panting", but references to asthma can also be found in ancient Egyptian, Hebrew and Indian writing (Pearce N et al.,1998). In the second century, a clear evidence of patients experiencing attacks was observed and evidence of disordered lung anatomy was observed in the seventeenth century. Thus, the study of asthma attacks interests many scholars and physicians alike, as many important signs and symptoms of severe attacks of asthma were already recognized as far back as 1800 years ago, and the knowledge of asthma progressed during the ancient and medieval period. During the Renaissance period, two important aspects of asthma were discovered i.e. 1) the role of atopy as a cause of development of asthma but also as an important factor for prevention 2) the role of airways inflammation as the cause of asthma attack (Pearce N et al., 1998). Early in 1883, Churchman had described the existence of spiral mucoid cast in asthmatic sputum and proposed that mucus within airways could cause airflow obstruction. The concept of bronchial hyperactivity, exaggerated bronchoconstrictor response to a wide variety of non-specific and allergic stimuli was later developed in nineteenth century. Further progress in the understanding of asthma was made in the early 1920s, where a series of

post mortem studies demonstrated the presence of widespread inflammation as a prominent feature of death from asthmatic patients. These studies established the importance of airways inflammation in severe asthma, although at that time, clinicians had difficulties relating to the pathological features to clinical and physiological indices of less severe forms of disease. However, in recent years, with the introduction of fibre optic bronchoscopy that helped to obtain mucosal lavage and biopsy, samples have provided evidence for central role of airways inflammation in the pathogenesis of childhood and adult asthma of varying degrees of severity (Beasley et al., 1993).

Mast cell and eosinophil's have been identified as key effector cells of inflammation response, through their capacity to secrete a wide range of preformed and newly-generated mediators that act on airways directly or indirectly through neural mechanism. The T lymphocyte is recognized as a pivotal cell in orchestrating the inflammatory response of cytokines release (Lord and Lamb, 1996). It is clear from the early historical account that the essential clinical features of asthma were observed and described. With the advancement of anatomic pathology, these various factors described above were observed as cumulative factors leading to airway obstruction. It was noted that exogenous factors could induce asthma attacks and the similarities with anaphylaxis prompted consideration of asthma as allergic disease (Pearce N. et al., 1998). This evolution of understanding has been reflected in many attempts to define asthma, and such definition have steadily evolved from clinical description to encompass physiological and pathological features. Nevertheless, the definitions of asthma have continued to be a subject of

controversy until now. One widely accepted definitions of asthma was proposed in 1992 by the International Consensus Report on Diagnosis and Asthma in Bethesda, Maryland USA (2012) that defines asthma as a chronic inflammatory disorder of the airways in which many cells play a role in the pathogenesis of disease. In susceptible individuals, this inflammation causes symptoms which are usually associated with widespread but variable airflow obstruction that is often reversible either spontaneously or with treatment and it also can cause associated airway responsiveness to a variety of stimuli.

The chronic airway inflammation, reversible airflow obstruction and bronchial hyperreactivity are the three main components to the pathophysiological events leading to the symptoms of wheezing, breathless, chest tightness, cough and sputum production by which diagnosis of asthma is made.

2.2 PREVALENCE OF ASTHMA

Asthma is a common chronic disease among children causing considerable morbidity. In the United States, childhood asthma is the most common cause of childhood department visits to either emergency department of district health centre, hospitalization and missing school days. Globally, childhood asthma prevalence varies widely and has shown worldwide consistent pattern in persistence for a rise over the last several decades. The rise in the prevalence for this increasing trend is still poorly understood (Mutius EV, 2000). It is a major global health problem which exerts an increasing burden on family, health care services and community. Furthermore, this illness is cited as the most frequent cause of school absenteeism and hospitalization in children (Werk LN et al., 2000). The American Academy of Paediatrics in 1999 reported that annually children with asthma missed more than 10 million school days which was more than three times of the school absenteeism in non-asthmatic children. Prevalence studies lack consistency possibly due to ill-defined diagnostic criteria that arises from the problem in defining asthma itself. Other clinical respiratory disorders might mimic asthma which lead into confusion. The term wheezy illness or bronchitis has been used to describe children who wheeze in association to viral respiratory infection. Martinez et al (1995) has shown that children with wheezy bronchitis or asthma could not be separated with respect to their natural illness.

The data that was used to investigate the risk factors for the development of wheeze or asthma during infancy was taken from a two-year follow up data from the Longitudinal Study Asthma Centre (LSAC) infant cohort 2009 in Australia. This two-year data found that being male, maternal asthma, young maternal age, maternal smoking during pregnancy, early gestational age, admission to a neonatal intensive care unit (NICU), having older siblings and attending child care were independently associated with a greater risk of developing asthma during infancy. Breastfeeding was associated with a lower incidence of asthma at this age. The result of this large cohort study was consistent and it was welldocumented that boys had a higher prevalence of asthma than girls and this pattern reversed after puberty (Strachan et al., 1985). Boys had smaller airways than girls relative to lung volume which results in greater airway resistance, thus making boys more susceptible to wheezing illness (Doershuk et al., 1974; Mandhane et al., 2005; Pagtakhan et al., 1984 & Xuan et al. 2000). A family history of asthma or atopic disease is a strong predictor of the development of childhood asthma (Duffy et al., 1997). A Finnish study involving children born between 1996 and 2004 who had been diagnosed with asthma by the year 2006 and had purchased inhaled corticosteroids (ICS) or montelukast at least once, found maternal asthma to be the strongest predictor of childhood asthma (Metsala et al., 2008). Similarly, the Children's Health Study conducted in Southern California found that maternal asthma was associated with an increase in the risk of early-onset persistent asthma, early-onset transient asthma and late-onset asthma among the children (London et al., 2001).

There was some evidence that young maternal age might be a predictor of asthma and asthma symptoms in infants. The European Community Respiratory Health Survey found that maternal age of delivery between 13 and 19 years was associated with higher prevalence of wheeze and asthma in their children (Laerum et al., 2007). Apart from that, it was noted that the young maternal age was also associated with low birthweight and pre-term delivery. conditions which had been shown to be linked to reduce lung function (Metsala et al., 2008 & Seidman et al., 1991) and further predisposed to early onset of wheeze during infancy. Maternal smoking during pregnancy was a statistically significant risk factor for the development of wheeze or asthma in infants. The Tucson Children's Study and South Californian Children's Health Study had reported similar findings (Stein et al., 1999). Studies had shown that foetal exposure to maternal smoking during pregnancy adversely affected infant lung function growth, and results in structural and functional changes in the developing lung, which results in smaller airways at birth and an increased propensity to develop wheeze during infancy (Stock & Dezateux 2003). Mallen et al in 2008 found that admission to NICU independently predicted the development of wheeze or asthma during the first three years of life. The most common reasons for admission to NICU are prematurity, low birthweight and the use of instruments such as forceps during the birth process. Each of these reasons for admission to NICU had been shown to have an impact on respiratory health (Chan et al., 1989; Lewis et al., 1995 & Metsala et al., 2008). It is possible that the statistically significant association between admission to NICU and the development of wheeze or asthma observed represents the

aggregated effects of prematurity, mode of delivery and birthweight, which were not found to be significant on their own.

The international study of Asthma and Allergies in Childhood-ISAAC is a large international study of childhood asthma prevalence in 155 centres of 56 countries that found a wide range of asthma prevalence from 1.6% to 36.81%. Prevalence reaches 17 to 30% in the United Kingdom, New Zealand and Australia whereas a low prevalence rate was found in Eastern Europe, China and Indonesia. In Malaysia, Norzila MZ in year 2000 reported a prevalence of 10.3% of children with asthma, in a study carried out among 7 to 12 years old school children of inner city of Kuala Lumpur. Overall prevalence of asthma was noted to be higher in the English-speaking communities but it was still unclear of the large variation of the prevalence gap. It was suggested that greater understanding of the patient regarding the awareness in recognizing symptoms of asthma likely contributed to the reason of higher prevalence among them (Mutius EV, 2000). However, childhood respiratory diseases, dietary changes and socioeconomic influences may also play a role in the variations (Woocock AJ, 1986).

2.3 MANAGEMENT OF ASTHMA

In every child with asthma, the aim of asthma management is to minimize the symptoms, maximize the lung function and maintain it at its best and to identify, thus avoiding the possible triggering factors of asthma exacerbations. These are important to prevent the development of permanently abnormal lung function, to reduce morbidity and mortality from acute attacks and ultimately to achieve the best quality of life for the children with asthma. In children with bronchial asthma or even in any chronic diseases, improving and maintaining quality of life is important for them to enjoy their growing up years. Asthma education is another important aspect in the management of asthma. It offers patients and parents about the knowledge and understanding of the disease and self-management skills that subsequently improve the quality of life in handling asthma exacerbation and further reduce its morbidity and mortality. Seaton et al (1978), in his editorial on asthma care had emphasized from his report that "proper management depends on the education of the patients to understand his condition, to recognize signs of deterioration and to adjust his or her own treatment accordingly". Many studies worldwide showed the importance of asthma education in managing asthmatic patients. Noreen et al (1986) showed that proper asthma education could help parents and children to manage their asthma better and it also helped them to distinguish severe asthma from non-life threatening exacerbation that could be managed at home and therefore, reduce visits to emergency rooms and also minimize health costs. Proactive approach with asthma education is important because the burden of the disease could be shared together with the attending doctor.

The introduction of inhaled corticosteroids during the 1980's had resulted in better disease control and a reduction in asthma exacerbations. Current medications allow children to live "normal" life, including participation in sports and other physical and social activities. A small group of children with problematic severe asthma remain the exception. The goal of asthma therapy in children is to achieve asthma control by optimizing lung function, reducing day and night time symptoms, reducing limitations in daytime activities and the need for reliever treatment, and by reducing asthma exacerbations (Global Initiative for Asthma, GINA report 2009). However, in children, it is important to achieve control with a minimum side effect of medication. Asthma control is assessed by the presence of daytime symptoms, limitation in activities, nocturnal symptoms and awakenings, need for reliever medication, and lung function assessment in children from the age of six. Total control is possible, but optimal effect of medication is often hampered by poor adherence and poor inhalation technique. Apart from these factors, additional conditions such as dysfunctional breathing, allergic rhinitis, obesity, and mental condition may hinder optimal control. Children with uncontrolled asthma despite inhaling a high dose of corticosteroid and controller therapy have a decreased quality of life, consume a high amount of resources, and may die prematurely (Flening L et al., 2007)

In children, improving and maintaining quality of life is important in order for them to enjoy their growing up years. With an accurate diagnosis and assessment of their asthma status, proper management can be instituted to achieve both short and long term improvements. Short term improvement includes abolishing day and night time symptoms with minimal use of β_2

agonist. Other measures of improvement are reduction of long term risk of symptoms that interfere with daily activities and minimize school absences. The child and his family should understand his condition, the triggering factors and how to avoid them and able to manage asthma confidently at home. Ultimately, adverse side effects of treatment must be avoided, particularly in relation to growth and development. Traditionally, the degree of symptoms, airflow limitation, and lung function variability have allowed asthma to be classified by severity (e.g. as intermittent, mild persistent, moderate persistent, or severe persistent). The Global Initiative for Asthma (GINA) classifies asthma severity as intermittent or persistently mild, moderate or severe.

Table 1 - GINA Classification of Asthma severity based on symptoms

| Class | Day | Night Symptoms |
|---------------------|-------------------------|------------------|
| Step 1 | <1 per week | =1 per month</td |
| (Mild Intermittent) | Brief exacerbation | |
| Step 2 | >1 per week | >/=2 per month |
| (Mild persistent) | <1 per day | |
| Step 3 | Daily attacks | >/=1 per week |
| (Moderate) | Attacks affect activity | |
| Step 4 | Continuous | Frequent |
| (Severe persistent) | Limit Physical Activity | |

Source: Global initiative for Asthma 2009

The presence of one of the features of severity is sufficient to place the child in that category. Children with intermittent asthma but have had severe exacerbations should be considered as having moderate persistent asthma. When the child is already on treatment, the classification of severity should be based on the present clinical features and the daily medication regiment steps that the child is currently on.

In order to achieve a good control in asthma, the overall management plan should include:

- Newly diagnosed asthma should be properly evaluated as to their degree
 of asthma severity. The initial medication and dosages depends on the
 severity and the necessity to attain quick control of asthma.
- 2. Treatment plan for asthma includes asthma education, avoiding the triggering factors and strategies to optimize pharmacotherapy. The management plan is individualized because each patient has different triggering factors, asthma phenotypes and different response to treatment.
- Optimizing medication by treating with the least number of medications and using the minimal dose of prophylaxis and reliever medication so as to produce minimal side effect.
- 4. Children with asthma should maintain normal activities including the ability to exercise, attending school as usual, no visits to the emergency department or any hospitalization due to asthma exacerbation, no mortality and no side effects of medication.

- 5. Children and caregivers should be able to recognize the early warning signs of deterioration of asthma control as it is life threatening.
- 6. The individual written action plan is recommended and this should include how to recognize the possible and potential triggering factors, instruction to use the medication during acute attacks and easy accessibility to the nearest health center when dealing with an acute attack.
- 7. Patient and family should be regularly educated and have more reviews to ensure they understand the disease, the rationale for their treatment and how to implement their action plan.

Management is based on Clinical Practice Guidelines for the Management of Childhood Asthma 2014, Academy of Medicine Malaysia Malaysian Thoracic Society.

2.4 QUALITY OF LIFE (QOL) IN CHILDREN WITH BRONCHIAL

ASTHMA

Asthma puts a serious burden on children's health-related quality of life, despite the availability of effective and safe treatment (Dalheim-England et al., 2004; Global Initiative for Asthma, 2010; Masoli el al., 2004 & Mohangoo et al., 2005). The overall goal of asthma management is to achieve optimal disease control and health related quality of life improvements (Bateman et al., 2007 & Pedersen et al., 2011). The World Health Organization has defined the term health related quality of life as the individual's perception of their position of life in the context of the culture and value systems in which they live and in relation to their goals, expectations and concerns (World Health Organization, 1993). Their own perception is important because it emphasises that these are the impairments that patients themselves consider as important. The quality of life for a child with asthma has been defined as the measure of emotions, asthma severity and symptoms, emergency department visits, missing school days, activity limitations, and number of visits to the emergency department (Juniper, 1997). Asthma might have physical, emotional and psychosocial impact on children's lives and subsequently can lead to poor control of asthma despite the proper management that already have been imposed on the children (Grootenhuis et al., 2007; Juniper, 1997; Merikallio et al., 2005 & Sawyer et al., 2004). Breathing difficulty, leading to the sensation of "air hunger", can of course be terribly upsetting. The bigger children especially can experience and understand the fear that they are going to die during an acute asthma episode. The fear of dying can become more general and continue even when they do

not have active symptoms. For most patients, asthma episodes are somewhat unpredictable, and unpredictable events can be more stressful than events that can be anticipated and prepared for. Feeling that another asthma episode could start at any time may cause some children to feel anxious constantly. With this perception of feeling, the quality of life of these children can be significantly affected. Apart from that, the frequency and severity of asthma attacks and effects of asthma management or treatment are associated with children's health-related quality of life. Children with moderate or severe asthma have a worse level of functioning in several domains of their health-related quality of life compared to children with mild asthma.

One of the main goals of asthma management is to achieve good asthma control. Asthma control has been defined as the minimisation of night time and daytime symptoms, activity limitation, rescue bronchodilator use and airway narrowing (Global Initiative for Asthma, 2010). Poorly controlled asthma symptoms impaired health-related quality of life in children (Guilbert et al., 2011). An important issue is whether proper asthma management improves quality of life in asthma patients, and whether poor health related quality of life makes disease management harder. Studies had found that poor health-related quality of life is a predictive of subsequent asthma-related emergency department visits, which implicates poor asthma control (Magid et al., 2004). Pont et al (2004) showed that proper asthma management improved health-related quality of life. In short, children experienced asthma as an interruption to their daily life that affected them physically, emotionally and socially. The frequency and severity of asthma attacks and effects of asthma management or

treatment are associated with children's health related quality of life. There are also other variables in association to health related quality of life in childhood asthma (Annett et al., 2003; Erickson et al., 2002; Mrazek, 1992 & Sawyer et al., 2001) that have shown to influence the child. Hospital admissions, absences from school, limitations of sport and other activities, sleeping problems and fatigue are associated with health-related quality of life in asthmatic children (Mrazek, 1992).

Erickson et al (2002) showed that both asthma morbidity and health-related quality of life were related to socioeconomic status. The household income was most consistently associated with the health-related quality of life of asthmatic children and their caregivers. Sawyer et al (2001) reported the impact of family functioning on health-related quality of life in children with asthma. They had found that the degree to which children are upset by their asthma was related to general functioning of their families, and their symptom levels were associated with several dimensions of family functioning. Children living in families with more clearly defined roles, greater interest and concern for the well-being of each other and clearer rules have been found to be less bothered by their asthma symptoms (Sawyer et al., 2000). A study by Annett et al (2003) did not find an association between health-related quality of life of asthmatic children and family functioning measured by the degree of cohesion among family members. Additional to the increase incidence of asthma, obesity in asthmatic children has also been on the increase causing exacerbation of respiratory symptoms. The prevalence of asthma increased as BMI increased in both males and females.

Majority of studies regarding quality of life and asthma have focused on adults. Many of the adult studies found asthma had mild impact on quality of life except in those subjects who had recently been hospitalized for an acute exacerbation (Gibson, Talbot, Toneguzzi, & Population Medicine Group, 1995). Due to the increasing prevalence of asthma among children, research has now begun to emerge regarding childhood asthma and their quality of life. However, the number of studies conducted on child quality of life and asthma remains scarce.

Asthma is a common medical condition with a prevalence of over 4% in Malaysia. There is lack of accurate data on the epidemiology of asthma in Malaysia although asthma is known to be a common cause of admission to hospital and attendance in hospital accident and emergency departments as well as hospital outpatient's clinics. During the Second National Morbidity and Health Survey carried out by the Ministry of Health Malaysia in 1996, it was found that an estimated prevalence of asthma (self-reported to be medically diagnosed) in Malaysia was 4.2%. Among children at birth to 14 years old, the estimated prevalence was observed to be 4.5%. The Paediatric Asthma Quality of life Questionnaire (PAQLQ) was developed to measure the functional (physical, emotional, occupational and social) problems that are most troublesome to children with asthma (Juniper et al., 1997). The questionnaires are easy to administer, well-accepted by children, have high level of reliability and good correlations with the conventional asthma indices as well as with general quality of life.

There are not many Health Related Quality of Life (HRQoL) studies on children with chronic illness such as bronchial asthma. Apart from that, there had been no study on quality of life in children with bronchial asthma that have been conducted in Malaysia. However, a close recent study which was a survey on the quality of life in patients with bronchial asthma in an outpatient clinic in Malaysia, focusing on patient aged 18 years and above found that, 60 out of the 250 patients had severe impairment in the quality of life. The assessment of quality of life in children especially those with chronic illness such as bronchial asthma are particularly important. If they survived the illness, they also have longer lives to lead compared to adults, but they are less able to voice their concerns and are more vulnerable than adults. Therefore, by conducting this study, it helps to promote better health among children.

Quality of life assessment is increasingly recognized as an important health outcome measure in asthma. The measurement of health-related quality of life is based on the growing recognition that healthcare should not only focus on the patient's survival or quantity of life, but also on the quality of the extended life. In patients with chronic disorders, which are not curable but only treatable, quality-of-life assessment may be even more relevant, as achievement of the best possible quality of life becomes the major goal of patient management. There are three asthma-related quality of life instruments available for paediatric study population which are Child Health Survey for Asthma - Child version (CHSA -C) developed by the American Academy of Paediatrics in 2000, The Paediatric Asthma Quality of Life Questionnaire (PAQLQ) developed by E.F.

Juniper in mid 1990s and The Paediatric Quality of Life (PedsQL) Inventory 3.0 Asthma Module developed by J.W. Varni in 2004 (Sandra et al., 2012).

The Child Health Survey for Asthma-Child Version (CHSA-C) is an asthma specific QoL that is only available in English language. It can be administered to the children aged 7 to 16 years and has 25 items that consist of three major domains which are physical health, child activities and emotional health. The text answers are accompanied by visual cues in the form of graduated circles. For each question, the child looks at the card and responds by verbalizing his or her answer or pointing to corresponding circle. The questionnaire need longer administration time and there was only one study which had been published in English language since year 2000 (Sandra et al., 2012).

The Paediatric Quality of Life (PedsQL) Inventory 3.0 Asthma Module is also only available in English language. The asthma module is designed for children and adolescents aged 2 to 18 years and has 28 items with answers that focus more on assessment of asthma symptoms and problems than on general QOL (Sandra et al., 2012).

The Paediatric Asthma Quality of Life Questionnaire developed by E.F. Juniper in mid 1990's is a child-reported instrument of the problems (ie; physical, emotional, and social) that are most troublesome for children with asthma. The PAQLQ is a relatively short instrument designed for children aged 7 to 17 years to report on their own experiences. The instrument includes symptoms of

asthma, as well as the child's emotional reactions to the symptoms and limitations caused by asthma. The questions contain the day to day problems and limitations that the majority of children with asthma find most troublesome. It is also able to identify and recognize small differences between children of different levels of impairment and able to detect small but clinically important changes that children experience as a result of treatment or natural fluctuation in their asthma (Sandra et al., 2012).

An overall PAQLQ score is calculated as 3 domain subscales which are symptoms (10 items), activity limitations (5 items), and emotional function (8 items) and the individual domain scores are the means of the items in each domain. The responses are scored on a seven-point Likert scale with a score of 1 indicating maximum impairment or poor QoL and 7 indicating no impairment or good QoL. Since it started in 1996, it has been translated into other languages from countries worldwide including Malaysia in 2001 and it has been validated. There were 44 studies including 14 clinical trials that had been published worldwide by using this questionnaire (Sandra et al., 2012). Therefore, with the establishment of the questionnaire and its strengths to specifically measure the quality of life in children with bronchial asthma apart from the only available questionnaire in Malay language, the questionnaire was chosen to be used in the current study. Thus, by conducting this study, it helps to promote better health among children with bronchial asthma.

CHAPTER 3

OBJECTIVES

3.1 GENERAL OBJECTIVE

To measure the quality of life (QoL) in children with bronchial asthma admitted to the ward due to asthma exacerbation and those who attended the general paediatric clinic for follow up.

3.2 SPECIFIC OBJECTIVES

- To determine the quality of life (QoL) score among children with bronchial asthma that were admitted to the ward for exacerbation and those who attended the general paediatric clinic for follow up.
- 2. To compare the mean difference of QoL of the children with bronchial asthma with disease duration <3 years and with disease duration of ≥ 3 years independently for asthmatic children that were admitted to the ward for exacerbation and those who attended general paediatric clinic for follow up.</p>
- 3. To compare the mean difference of QoL among children with bronchial asthma who has normal BMI with overweight to obese.

3.3 HYPOTHESES

- 1. There is a difference in quality of life score among children with bronchial asthma that were admitted to the ward for asthma exacerbation and those who attended the general paediatric clinic for follow up.
- 2. There is a significant difference in quality of life score among children with bronchial asthma with disease duration of < 3 years and with disease duration of \geq 3 years independently for asthmatic children that were admitted to the ward for exacerbation and those who attended the general paediatric clinic follow up.
- 3. There is a significant difference of quality of life score among children with bronchial asthma who has normal BMI with overweight to obese.

CHAPTER 4

METHODOLOGY

4.1 BACKGROUND

The study was conducted in Institut Pediatrik Hospital Kuala Lumpur (IPHKL) located in the urban area of Kuala Lumpur. It is a nationwide tertiary and referral centre that covers wide varieties of paediatric cases from different subspecialties to provide core services in general paediatrics and neonates. The IPHKL also serves as a tertiary referral centre for Paediatric Surgery, Orthopaedics, Child Psychiatry and Paediatric Intensive Care. The IPHKL has three general paediatric wards namely ward KK1, ward KK2 and ward KK6. Each ward has its own general clinic day for children who come for follow up. The clinics were conducted twice per week for each ward on different days and run either in the morning or afternoon session. The venue was chosen for the study primarily because of the investigator-designated post graduate posting at the centre and secondly it covers most paediatric population that enables investigator to have sufficient samples for the study. The study proposal has been presented to the Department of Paediatric Hospital Universiti Sains Malaysia (HUSM) for approval.