CHILDHOOD ATOPIC ECZEMA: CHILDREN'S QUALITY OF LIFE AND FAMILY IMPACT

by

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In The Name Of God, Most Gracious, Most Merciful.

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P value	Level of significance
DFI	Dermatology family Impact
GLR	General Linear regression
HRPZ II	Hospital Raja Perempuan Zainab II
HRQOL	Health-Related Quality of Life
IQR	Interquartile Range
SCORAD	Scoring Atopic Eczema
SIGN	Scottish Intercollegiate Guidelines Network
SLR	Single Linear Regression
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ABSTRAK

Pengenalan : Penyakit atopik eksema merangkumi 40% daripada kes-kes yang dirujuk kepada pakar dematologi pediatrik di Malaysia. Semasa perawatan dilakukan, isu yang menjadi topic perbincangan di kalangan pesakit, waris dan perawat adalah berkaitan kualiti pesakit atopik eksema. Di dalam istilah perubatan, terminologi yang digunakan dalam penentuan kualiti hidup pesakit dikenali sebagai kualiti kehidupan berkaitan kesihatan (HRQoL). Umumnya, konsep ini adalah luas dan merangkumi kesan serta impak penyakit atopik eksema terhadap kehidupan penghidap dan ahli keluarga secara keseluruhannya.

Objektif : Untuk menentukan kualiti hidup dikalangan kanak-kanak yang menghidap penyakit atopik eksema dan impak terhadap keluarga terdekat serta faktor-faktor yang berkait rapat dengan penyakit tersebut.

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Hasil kajian : Kesemua 110 subjek telah terlibat dalam kajian ini menjadikan kadar respon adalah 100%. Mengikut pecahan, tahap keseriusan peringkat minima 30.9%, sederhana 62.7% dan tahap paling serius 6.4%. Skor median (IQR) kualiti kehidupan kanak-kanak atopik eksema dan impak terhadap keluarga masing-masing adalah 8.0(8.0) dan 7.0(9.0). Tahap keseriusan pesakit merupakan faktor berkaitan dengan kualiti kehidupan. Analisis regresi linear memberikan persamaan garisan lurus di mana tahap keseriusan subjek menyumbang sebanyak 15% daripada seluruh variasi kualiti kehidupan mereka.

Kesimpulan : Secara keseluruhannya, kajian ini merumuskan bahawa kualiti kehidupan penghidap atopik eksema tidak terganggu. Atopik eksema juga tidakmemberikan impak terhadap keluarga subjek di dalam kajian ini. Walaubagaimanapun, terdapat hubungan secara langsung di antara tahap keseriusan pesakit dan kualiti kehidupan mereka. Hubungan secara langsung ini terjadi berdasarkan penilaian tahap keseriusan pesakit secara objektif.

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Introduction: Childhood atopic eczema accounted 40% of the referral to pediatric dermatology clinic in Malaysia. One of the most important issues that should be discussed during outpatient hospital based clinic is health related quality of life (HRQOL). HRQOL was defined as a broad multidimensional concept that usually includes self-reported measures of physical and mental health.

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Results: A total of 110 participants with 100% response rate entered this study. Majority of subjects suffered mild to moderate disease which comprised of 30.9% and 62.7%, respectively. Only 6.4% had severe atopic eczema. The median (IQR) for quality of life and family impact score was 8.0 (8.0) and 7.0 (9.0), respectively. Disease severity was the significant associated factor for quality of life in childhood atopic eczema. Regression analyses showed that 15% of the variance in quality of life score could be explained by disease severity score.

Conclusion: In the present study, the overall children's quality of life was not impaired because not all the items in the children's quality of life were equally affected. Childhood atopic eczema also had no impact on family life as majority of parents perceived the disease was not severe. The only significant associated factor for children's quality of life was disease severity. Measurement of HRQOL among childhood atopic eczema should be done along with objective disease severity assessment.

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CHAPTER ONE

INTRODUCTION

1.1 Definition of Childhood Atopic Eczema

Childhood atopic eczema is defined as a chronic relapsing inflammatory skin disease characterized by intense itching, dry skin, inflammation and exudation (Hussain Imam Muhammad Ismail *et al.*, 2008; Williams *et al.*, 2008). Atopic eczema is a distinct clinical entity that is different from other type of endogenous eczema. Atopic eczema is the first manifestation of the atopic march i.e. eczema, allergic rhinitis and asthma. The onset of atopic eczema occurs during infancy in about 50 % of the sufferers (Hussain Imam Muhammad Ismail *et al.*, 2008). Approximately 50% of infants with atopic eczema will develop asthma and allergic rhinitis (Spergel and Paller, 2003). Thus, atopic child will grow together with the illness and march from one condition towards another (Spergel and Paller, 2003).

1.2 Clinical phases according to age

Hill and Sulzberger in 1935 described three clinical phases of atopic eczema, in which both the site and morphology of the skin lesions change with age (Spergel and Paller, 2003). As the children grow the lesions tend to be localized to flexural area causing thickening of the skin and relapsed inflammation with a period of remission in between. Three phases may overlap with each other or be separated by a period of remission (Spergel and Paller, 2003). The infantile phase occurs in the first two years of age, the childhood phase from age 2 years old to 10 years old or puberty, and the adolescent phase from 11 years old until adulthood (Spergel and Paller, 2003).

1.3 Natural history and Prognosis

Many children affected with atopic eczema will outgrow their illness. It is typically a chronic illness with estimated one third of patients having persisting disease into adulthood (Hussain Imam Muhammad Ismail *et al.*, 2008). There are numerous factors that influence the persistence of atopic eczema; the severity of atopic eczema eruption, early onset in the first six months of life, association with other atopic diseases, high serum immunoglobulin E level, acute food allergies and disease persisting after five years of age. In one study, it is estimated around 80% of severe childhood atopic eczema persists into adulthood (Ben-Gashir *et al.*, 2004).

1.4 Diagnosis

The standardized criteria for the diagnosis of atopic eczema were established for the first time by Hanifin and Rajka in 1980 (Hanifin and Rajka, 1980). The authors had divided atopic eczema into major and minor criteria with the major criteria weighted in favour of diagnosis. The criteria were useful in primary care out patient clinic and for epidemiological studies but unfortunately many features did not present at one time during children visit to their primary care doctor. Furthermore, a few of the minor criteria was not validated (Williams *et al.*, 2008). Thus, more universally acceptable criteria were developed by Williams and colleagues in 1994. These criteria were more practical for diagnosis and useful for the epidemiological studies (Williams, 2005). The criteria were a refinement of that of Hanifin and Rajka and known as United Kingdom Working Party's criteria with a sensitivity of 80% and specificity of 97% (Chan *et al.*, 2006). The criteria were easy to use in everyday practice and have been validated for use in both clinical setting and epidemiological studies (Chan *et al.*, 2006).

In clinical practice, there were some physicians who regarded attempts at defining atopic eczema as an imposition to their practice. They simply did not follow recommended criteria. In these particular cases, Williams *et al.,* agreed with the diagnosis made by those physicians based on their clinical competency and recognition was entirely appropriate when dealing with their regular patients. However in clinical studies, if the researcher wants to determine the difference between groups then the UK Working Group criteria were more preferable (Williams, 2005). The authors also emphasized that there was no reason why the preferred above standardized criteria could not be used in a study targeting at representative populations of atopic eczema subjects such as in a hospital setting studies.

In a study on knowledge, attitude and practices among South East Asian dermatologists, Chan, YC *et al.,* proposed established criteria for diagnosis of atopic eczema in this region. They recommended the use of UK Working Party's criteria as the preferable diagnostic tool in the daily practice and research (Chan *et al.*, 2006).

1.5 Burden of Atopic Eczema

It has been estimated that patient with atopic eczema account for 30% of dermatology consultations in primary care and up to 20% of all referrals to dermatologists (Anja *et al.*, 2004). Estimating the prevalence of atopic eczema is important for several reasons including monitoring disease burden, documentation in changing trends of the disease prevalence and for provision of health care in the European country (Fennessy *et al.*, 2000).

Atopic eczema is associated with increased disease burden on patients, families and community at large (Carrol *et al.*, 2005). Children affected with atopic eczema are facing significant psychosocial and financial burden ahead of them. In addition to dealing with the physical appearance of the disease, children and their primary care givers have to cope with the disease. Individuals and family members are burdened with time-consuming treatment regimens for the disease, as well as dietary and household changes. Financial pressures were rated as relatively unimportant for the majority of families because health care cost is subsidized for school children in Malaysia (Institute for Public Health, 2008).

In general, the burden of childhood atopic eczema can be divided into the impact of the disease to patient, family and community. The prevalence of atopic eczema is high and along with other atopic diseases, they become one of the most important groups of all chronic childhood diseases (Fennessy *et al.*, 2000). Identification of both the financial and psychosocial burden to individuals and community will enable primary health care providers to request for the appropriate necessary resources for disease management in the future (Lewis-Jones, 2005).

1.6 Justification of the study

As many studies in the world have found the increasing trend in the prevalence of the disease, the quality of life of children with atopic eczema is expected to be tremendous in future. Atopic Eczema was also known to cause misery to the sufferer, psychosocial problems, reduced quality of life, and disruption to family life (Hawkins, 2005). The disease affected the school going children worldwide. Much of the burden of atopic eczema is managed in the primary care setting where treatment is often commenced at providing symptomatic relief (Carrol *et al.*, 2005). To date, studies that were published focused on the epidemiology of Asthma in Kelantan (Quah *et al.*, 1997; Quah *et al.*, 2005). Nothing much was known on how atopic eczema affected children's quality of life and how their families were impacted. Atopic eczema was included as part of the study outcome because the questionnaire-based study was part of the International Study of Asthma and Allergies in Childhood (ISAAC) (Quah *et al.*, 2005).

The results of the study could be extrapolated into primary care practice because majority of the subjects in out patient hospital based clinics were having mild to moderate disease severity. Thus the major proportion of these patients can actually be managed in primary care setting. The available clinical practice guideline in United Kingdom has stated that majority of atopic eczema cases were most appropriately managed within primary care (Fennessy *et al.*, 2000; SIGN Guideline Development Group, 2007). The Children Dermatology Life Quality Index (CDLQI), Dermatology Family Impact (DFI) Questionnaire along with Scoring Atopic Dermatitis (SCORAD) Score had been used in various dermatology research studies (SIGN Guideline Development Group, 2007). The inclusion of these instruments in clinical practice could help medical professionals with a more holistic assessment of the child and family.

CHAPTER TWO

LITERATURE REVIEW

2.1. Prevalence of childhood atopic eczema

Atopic eczema is a chronic relapsing skin disease occurring in the children where majority of the disease occurring in those below 5 years of age (Williams, 2005). Atopic eczema is common in the developing countries like Malaysia. The geographical location and weather had an important role in the epidemiology for the occurrence of Atopic Dermatitis (Jaafar and Pettit, 1993).

In Malaysia, the prevalence of atopic eczema among patients who attended dermatology clinic of National University of Malaysia in Kuala Lumpur was 3.7% in 1993 (Jaafar and Pettit, 1993). The prevalence of eczema in the 5 to 7 year age group among Kelantanese school children was 13.7% whereas that of the 12 to 14 year age group was 9.9% in 1995 (Quah *et al.*, 1997) . The same author repeated the study using the similar questionnaire-based methodology. The prevalence rate of eczema symptoms among primary school children was 17.6% and 13% among secondary school in Kota Bharu in 2001 (Quah *et al.*, 2005). In that study, the prevalence rate among primary school children, aged 6 to 7 years old ranged from 14% to 17.6% as compared to 12% to 13% among secondary school children, aged 13 to 14 years old (Quah *et al.*, 2005). These prevalence rates were comparable with previous reports in Malaysian children, but were considerably lower than those reported for most developed countries (Quah *et al.*, 2005).

The largest population based study that estimated the prevalence of eczema symptoms in children and adolescents were the phase three International Study of Asthma and Allergies in Childhood (ISAAC) undertaken from 1999 to 2004. ISAAC was designed to survey respondents' self-reported symptoms to determine the prevalence rate and comparisons of asthma, rhinitis, and atopic eczema between populations in different countries using the standardized epidemiologic tools (Torres-Borego *et al.*, 2008).

In one of a population based study, the lifetime prevalence of childhood atopic eczema in United Kingdom was 20% in children aged 3 to 11 years old (Williams, 2005). Williams and colleagues reported that the disease prevalence varied between 0.3% and 20% of the children worldwide (Williams, 2005). In general, the prevalence of childhood atopic eczema was between 16% and 20% once in their life or other, and the estimate had been increasing in most countries with a western style of environment over the last few decades (Williams *et al.*, 1995; Williams *et al.*, 2008).

2.2. Measurement of disease severity

There was no standardized method to measure the outcome in clinical trials involving atopic eczema children (Lewis-Jones, 2006). Serological markers have not been shown to consistently correlate with disease severity (Hon and Leung, 2010). Another option was to objectively measure atopic eczema severity in clinical practice and for research purposes. Some of the scoring systems are complex and there are a few which is too simple (Lewis-Jones, 2006).

There were thirteen named scales for assessing disease severity in childhood atopic eczema (SIGN Guideline Development Group, 2007). Among them were Skin Intensity Scale (SIS), Atopic Dermatitis Severity Index (ADASI), Rajka and Langeland's Scoring

System, Nottingham Eczema Severity Score (NESS) and Scoring Atopic Dermatitis Score (SCORAD) (SIGN Guideline Development Group, 2007).

The SCORAD system was developed by the European Task Force on Atopic Dermatitis (ETFAD) (Oranje *et al.*, 2007). ETFAD consisted of a group of more than 20 dermatologists with special interest and much expertise in paediatric dermatology. SCORAD systems were further classified as SCORAD Index. Based on the training sessions by ETFAD, the SCORAD index is translated into objective SCORAD (Oranje *et al.*, 2007). The objective SCORAD comprised of the extent and intensity items and excluded the subjective assessment (Oranje *et al.*, 2007). Until now, the SCORAD system has become the most widely used scoring system for disease severity in Europe (SIGN Guideline Development Group, 2007). Of those various scoring systems only three had good validity and SCORAD is definitely one of those recommended (Schmitt *et al.*, 2007).

2.3. Health Related Quality of Life (HRQol)

Health Related Quality of Life was defined as subjective perception of the impact of health status, including disease and treatment, on physical, psychological and social functioning well-being (Centers for Disease Control and Prevention, 2011). It was a broad multidimensional concept that usually includes self-reported measures of physical and mental health (Centers for Disease Control and Prevention, 2011). Quality of life encompassed both objective and subjective perspectives in each domain. Quality of life had been used as an outcome measure in most of clinical studies of incurable and chronic illnesses since the last decade. The utilization of Health Related Quality of Life measure rendered examination of the impact of the disease on children's life and their family members. Health Related Quality of Life measures has revealed wide variety of ways in which atopic eczema affect children and their families across all aspects of life from physical, social and psychological perspectives (Lewis-Jones, 2006).

2.4. Measurement of Quality of Life

HRQoL was relatively new concept to paediatric dermatology but few standard quality of life questionnaires that were used extensively in dermatology research mainly for atopic eczema (Lewis-Jones, 2006). The quality of life indices are designed to measure such variables as schooling, sleep disturbances, degree of pruritus, relationship, leisure activities and self-esteem. Ideally the chosen measurement scale should be a valid, reliable and had good repeatability (Lewis-Jones, 2006).

The sensitivity and responsiveness of the scale were important in clinical and outcomes trials. Sensitivity was the ability of the scale to detect differences between groups of patients with mild and severe disease (Fayers and Machin, 2007). Responsiveness was the ability of the scale to detect relevant changes in a person's condition (Fayers and Machin, 2007). The sensitivity can be assessed by a cross sectional survey but responsiveness is evaluated by longitudinal assessment of patients in whom a change is expected to occur. A sensitive measure was usually but not necessarily responsive to detect relevant changes in a person (Fayers and Machin, 2007).

Dr Sue Lewis-Jones in her review article on childhood atopic eczema and children's quality of life stated that there should always be a balance between the number of items included and ease of use of the particular HRQoL scale (Lewis-Jones, 2006). She argued the short questionnaires were of greater benefit in a clinical setting or trial whereas the longer ones were impractical. However, in a research setting, scales containing a more comprehensive set of items may provide additional information to the researchers.

2.5. Impact of atopic eczema to the child

Daud, LR *et al.*, reported that 23% of the pre-school children with severe AD had a significant increase in behavioural symptoms compared with 5% of matched control groups (Daud *et al.*, 1993). Atopic eczema did not only disrupt child's behaviour during daytime. It had been reported that sleep pattern is markedly altered due to nocturnal awakening and scratching (Lewis-Jones and Finlay, 1995; Lawson *et al.*, 1998). The cardinal symptoms of itching and sleep loss contributed as the most important factors of their diseases (Beattie and Lewis-Jones, 2006). For the older child in addition to itching and sleep disturbance, their social and school activities may be affected (Lewis-Jones and Finlay, 1995; Hawkins, 2005). All of these factors have negative implications on their education and lead to school avoidance. Coping ability plays a large part in the perceived impact of the disease so that although there may be an overall trend for severe and widespread disease to cause the greatest impairment in health related quality of life, in an individual person this is not necessarily the case (Lewis-Jones, 2006). Severely affected patients can cope well with the physical appearance and minimally affected their lives, while others with relatively mild objective evidence of the disease may have significantly impaired health related quality of life. There was also some evidence to suggest that parts of body such as hands and feet may be more disturbing than the disease extent itself in causing an adverse effect on Health Related Quality of Life (Lewis-Jones, 2006). The involvement of disease in the face rendered the sufferer to isolate or avoid social meeting or activities confronting other people (Fennessy *et al.*, 2000).

2.6. Impact of atopic eczema on the family

The family impact could be evaluated using the specific tool. There were many potential ways in which atopic eczema might disrupt families' social life. The ranges of the problems described may reflect the health of the child. Practical problems of every day care include increased laundry, house cleaning, food preparation, sleep disturbances, parental anxiety, financial limitations and skin treatment difficulties. In a review, majority of parents report feeling of frustration, hopelessness, anxiety and guilty (Hawkins, 2005).

Research has revealed that families of children with atopic eczema often report lower quality of life than families of healthy children (Carrol *et al.*, 2005). Not surprisingly, the family impact of the disease has been positively correlated with AD severity, with more severe cases associated with increased family disruption (Carrol *et al.*, 2005). Lawson *et al.,* stated though financial issues were not seen as the most important problems they were having during the child eczematous experiences, for a minority of the families the impact may be severe (Lawson *et al.*, 1998). The 2004 International Study on Living with Atopic Eczema (ISOLATE) conducted in European counties reported that parent felt that coping with child's eczema was one of the most important aspects to them, particularly when the eczema was severe (SIGN Guideline Development Group, 2007).

In another study among children with atopic eczema aged below 13 years old, mothers were the majority of primary caregivers, experienced greater stress than father or other family members (SIGN Guideline Development Group, 2007). There appeared to be a direct relationship between parentally observed eczema severity and levels of psychological distress (Arnold *et al.*, 2007). A major stress-causing factor that most families deal with is sleeplessness as a result of itching in a child with atopic eczema (Lawson *et al.*, 1998; Chamlin *et al.*, 2005; Joanne, 2007). Sleep deprivation can affect all family members, including siblings. Lawson *et al.*, found that 68 % of parents of children with atopic eczema rated loss of sleep as a significant problem (Lawson *et al.*, 1998).

2.7. Associated factors for quality of life

The importance of examining the relationship between clinical and psychological factors in atopic eczema was highlighted in clinical samples (Anja *et al.*, 2004). There are a number of factors influencing quality of life measurement. These include age, gender, social class, ethnicity, education, life experience, disease severity and family functioning (Annet *et al.*, 2001)

2.7.1 Age factor

Age was important demographic factors in Quality of life issues. A Hong Kong study in children with atopic eczema using the Children's Dermatology Life Quality Index (CDLQI) found no significant differences between two group of children of more and less than 10 years old (Hon *et al.*, 2008). The authors found that itch and sleep disturbances were generally more marked among young children aged less than 10 years old the Cantonese translated version of CDLQI. Significant itch and sleep disturbance affected both genders equally but were generally more marked in children with atopic eczema aged between 5 to 10 years old compared to those aged 11 to 16 years old (63% vs 43% for itch and 61% vs 40% for sleep disturbance) (Hon *et al.*, 2008).

2.7.2. Gender Factor

Girls were found to have more problems than boys concerning clothes and shoes (Hon *et al.*, 2008). On the other hand, they had shown stigma, disease severity, and depression as strong predictors for Quality of life in adult with atopic eczema (Hon *et al.*, 2008). In a more recent study of atopic eczema children aged less than 4 years, the impact of atopic eczema on children's quality of life was more severe among girls. The relationship between child and parent progressively worsened with the girls' age (Chernyshov, 2012).

The proportion of boys studied in phase three ISAAC (Torres-Borego *et al.*, 2008) varied among the centres from 38.2% to 66.1%, and the proportion of girls varied from 33.9% to 61.8%. When the data for all centres were combined, there was no clear pattern observed for the main outcome measures. There was a little difference in prevalence between boys and girls for symptoms of severe eczema and a slightly higher prevalence for boys for lifetime reported atopic eczema.

Nevertheless, a clear pattern for lower prevalence among boys was seen in 13 to 14 year age group. The proportion of boys in that age group ranged from 18.7% to 71.4% and that of girls varied from 28.6% to 81.3%. Given that, it is not surprising male adolescents showed a lower prevalence of current symptoms of eczema (6.2% for boys and 8.3% for girls respectively (Torres-Borego *et al.*, 2008).

2.7.3. Psychological factors

These were definitely an important aspect of atopic eczema. There were evidences to support atopic eczema as causing considerable distress for children and their parents (SIGN Guideline Development Group, 2007). Preschool children with atopic eczema had high rates of behavioural difficulties and show greater fearfulness and dependency on their parents. For schoolchildren, problems include time away from school, impaired performance because of sleep deprivation, social restrictions, teasing and bullying. Psychological problems have been found to be twice those of normal schoolchildren among children attending out patient dermatology clinics with moderate or severe eczema (SIGN Guideline Development Group, 2007).

Absolon *et al.,* conducted a case-control study evaluating the degree of psychological difficulties among children with atopic eczema, mentally distressed mother, and family support system (Absolon *et al.*, 1997). The study reported the rate of psychological disturbances measured by abnormal child behaviour were twice as likely as the controls. The psychological effects, ie depression and poor self-esteem were significantly different in a moderate to severe atopic eczema (p=0.018) (Absolon *et al.*, 1997).

Anja Wittkowski *et al.,* studied the relationship of demographic variables such as age, age at onset, duration along with psychological factors such as past psychiatric illness, anxiety and quality of life in adults with atopic eczema (Anja *et al.*, 2004). They found the demographic variables did not significantly contribute to the variance in Dermatitis Life Quality Index (DLQI) score. However, in that study, stigmatization and depression score significantly contributed to the variances of quality of life (Anja *et al.*, 2004). Of note, DLQI was the original quality of life measure that leads to the development of CDLQI. Similar structure and domains of quality of life were used in both questionnaires (Lewis-Jones and Finlay, 1995).

CHAPTER THREE

OBJECTIVES AND HYPOTHESIS

3.1. Objectives

General

To determine the quality of life and its associated factors among children with atopic eczema and its impact on the family.

Specific

i. To determine the quality of life among children with atopic eczema.
ii. To determine the impact of atopic eczema on the family.
iii. To determine the associated factors for quality of life in children with atopic eczema.

3.2. Research hypothesis

Disease severity and socio-demographic factors such as age, age of onset, duration of illness, gender, patient and parental educational status, personal and family history of atopy are significant associated factors for quality of life in children with atopic eczema.

3.3. Operational definition

i. Parent or caregiver was defined as someone living in the same household as the patient, spends most of the time with the patient and feeling most responsible for patient (Salleh, 1994).

ii. Childhood atopic eczema was defined as children aged between 5 to 18 years old diagnosed as atopic eczema by consultant dermatologist in Hospital Raja Perempuan Zainab II.

iii. Children's quality of life was defined as a reflection of the way that patients or parent perceive and react to their child's health status and other non-medical aspects of their life, which includes family relationship, friendship and social life (Aziah *et al.*, 2002).

iv. Family impact was defined as aspects of family life most affected and perceived by parent or primary caregiver as important. They were categorized as practical care issues, psychological pressure, sleep disturbance, school and social life, relationship with partner, financial, practical supports, and holidays (Lewis-Jones and Finlay, 1995).

CHAPTER FOUR

METHODOLOGY

4.1. STUDY DESIGN

This was a cross sectional study.

4.2. POPULATION AND SAMPLE

4.2.1 Reference population

Children with atopic eczema in Kota Bharu, Kelantan

4.2.2. Source population

Children with atopic eczema attending dermatology clinic, Hospital Raja Perempuan Zainab II, Kota Bharu, Kelantan.

4.2.3. Study population

4.3. CRITERIA OF CHILDREN

Inclusion Criteria

- i. Aged 5 to 18 years old

Exclusion Criteria

- i. Concomitant serious medical illness such as leukemia, cerebral palsy, alopecia totalis, epilepsy, Attention Deficit and Hyperactive Disorder or autism.
- ii. Children who were not accompanied by parents / care giver.
- iii. Newly diagnosed patient who was naïve to specific treatment of atopic eczema.

4.4. CRITERIA OF PARENT / CAREGIVER

Inclusion Criteria

i. Staying together with the atopic eczematous child

Exclusion Criteria for parent/ caregiver

i. Cannot understand Malay language.

4.5. SAMPLE SIZE ESTIMATION

4.5.1 The sample size calculation was done for each objective. However, only the one that yielded the biggest sample size was taken as the study sample.

For Objective 1, sample size calculation to determine the quality of life of children with atopic eczema was done using single mean formula.

$n = (z\sigma)^2 / \Delta^2$

n = sample size

Z = 1.96; standard normal distribution at 95% confidence interval

σ = standard deviation for CDLQI score = 7.8 (Aziah *et al.*, 2002)

Δ = precision = 2

Based on the previous study by Aziah *et al.*, (Aziah *et al.*, 2002) the SD for CDLQI score was 7.8. Taking the precision of 2 with 95% confidence, the minimum sample size required was 58. However, after considering the non-response rate of 10%, the sample size calculated was 64.

For Objective 2, sample size calculation to determine the impact of the disease on the family was done using single mean formula.

$n = (z\sigma)^2 / \Delta^2$

n = sample size

Z = 1.96; standard normal distribution at 95% confidence interval

σ = standard deviation for family impact score by DFI = 5.2 (Aziah *et al.*, 2002)

Δ = precision = 2

Based on the previous study by Aziah *et al.,* (Aziah *et al.*, 2002) the SD for DFI score was 5.2. Taking the precision of 2 with 95% confidence, the minimum sample size required was 26. However, after considering the non-response rate of 10%, the sample size calculated was 29.

For Objective 3, sample size calculation to determine the associated factors for quality of life in children with atopic eczema was done using Power and Sample Size Calculation software (version 1.0.13) (Dupont and Plummer, Copyright 1990-2000) for comparing two means. The associated factor that yielded the biggest sample size for this objective was for the variable age. The parameters were as follows:

α = 0.05

Power = 80%

m = Ratio of children less than 10 years to older than 10 years old = 3:1 = 3

σ = Standard deviation for quality of life score among children aged older than 10 years old = 6.1 (Chinn *et al.*, 2002)

δ = Detectable difference in population mean = 2

A detectable difference of 2 was decided after considering its clinical importance and feasibility of the study. Taking the alpha of 0.05 and power of 80%, the minimum required sample size was 100. However, after considering the non-response rate of 10%, the sample size calculated was 110.

From the above calculations, the biggest sample size was from Objective 3 (n = 110) and was taken as sample size for this study.

4.5.2. Sampling method

Systematic random sampling in the ratio of 2 in 1 was applied based on the registry record for any given appointment date.

4.6. RESEARCH TOOL

i. Case report form
ii. CDLQI
iii. DFI
iv. SCORAD objective score
v. Medical Record Review

4.6.1. The Case Report Form

This consisted of subjects' self-reported form that included socio demographic data, self-reported medical illness, personal and first degree relative with history of asthma, allergic rhinitis or atopic eczema.

4.6.2. The Children's Dermatology Life Quality Index (CDLQI)

The CDLQI was the first validated specialty-specific dermatology scale for school-age children. It has been shown to demonstrate good repeatability and sensitivity to clinical change. CDLQI was available in almost 20 different languages and one of which was the translated Malay version. Aziah *et al.,* reported the Kappa analysis from CDLQI showed an average of moderate agreement between the two interviews within two weeks intervals (Aziah *et al.*, 2002). The Cronbach alpha for CDLQI questionnaire was 0.92. The questions asked were pertaining to the events that happen in the last week to allow for accurate recall. In this particular study, we decided to use childhood dermatitis quality of life index (CDLQI) because of self explanatory and face validity.

The questionnaire contained 10 items covering the symptoms ie, itchiness and soreness, emotions, friendship, clothing, leisure activities, sports, school/holiday, relationships, sleep loss and treatment difficulties over the last one week. The time span was chosen as such for a better recall of the events in their life. For each question there will be a four-part Likert scale options, which corresponded to scores of 0, 1, 2, or 3 respectively. If subject answered "Not relevant", the item was scored with a zero.

The overall score was calculated by summation of each question, which yielded a result between 0 and 30. The higher the score means the greater impact on children's quality of life. Although this happen infrequently, items that were left blank (missing data) were processed as follows: if one or two questions were left unanswered it was assumed that the respondent considered those questions were not relevant to them and, therefore they were each scored 0 out of 3. There was no percentage rounding-up based on the answers to the correctly answered questions. If more than 2 items were left blank, the questionnaire was rejected (Lewis-Jones and Finlay, 1995).

4.6.3. Dermatitis Family Impact (DFI) score

A commonly used scale to measure the impact on the family is the Dermatology Family Impact (DFI) score. The original study design for this scale comprised in-depth ethnographic interviews of families with children with atopic eczema from all social classes (Lawson *et al.*, 1998). The translated Malay version of DFI was used in our sample because of majority of parent respondents were Malays. Aziah *et al.,* reported the Kappa analysis from DFI showed an average of moderate agreement between the two interviews within two weeks intervals. The Cronbach alpha for DFI questionnaire was 0.85 (Aziah *et al.*, 2002).

DFI consisted of 10 items regarding the effects of children with atopic eczema had on parent's housework, meal preparation, sleep, family activities, shopping time, expenditure, exhaustion, emotional disturbances and relationship between family members. For each item there will be a four-part Likert scale options, which corresponded to scores of 0, 1, 2, or 3 respectively. If subject answered "Not relevant", the item was scored with a zero. An arbitrary cut-off point of 1.0 was considered as mostly affected item in the sub analysis of each respective item as described in the previous two studies in Kuala Lumpur and Singapore (Lawson *et al.*, 1998; Aziah *et al.*, 2002).

The overall score was calculated by summation of each question, which yielded a result between 0 and 30. The higher the score means the greater impact on children's quality of life. Although this happens infrequently, items that were left blank (missing data) were processed as follows: if one or two questions were left unanswered it was assumed that the participant considered those questions were not relevant to them and, therefore they were each scored 0 out of 3. There was no percentage rounding-up based on the answers to the correctly answered questions. If more than 2 items were left blank, the questionnaire was rejected (Lawson *et al.*, 1998).

4.6.4. Scoring Atopic Dermatitis (SCORAD) score

SCORAD is an acronym for Scoring Atopic Dermatitis. It is a clinical score that is widely used in Europe for the assessment of atopic eczema severity. The score was determined on the 2 criteria, i.e. the extent the eczema and the intensity of the most representative lesions. This was performed using rule of nine charts (Oranje *et al.*, 2007). SCORAD was a weighted index, with more emphasis on the intensity (multiplying by a factor of 3.5) but less weight on the extent (multiplying by a factor of 0.2) (Hon *et al.*, 2008). The assessment was done using objective SCORAD (maximum score of 83) for each children participant during their visit to dermatology clinic. There was no inter-observer variability because all the subjects were recruited by the researcher via face to face interview. Subjects were further categorized as having mild (total score < 15), moderate (15-40) and severe (score > 40) according to objective (extent and intensity of the lesions) SCORAD results. As SCORAD varied with the stage of a treatment course, all patients were assessed during a course of treatment. So a new patient who was naïve of specific treatment of atopic eczema will not be included in this study. Patients who suffered from disease flare-ups and superimposed skin infection were treated accordingly.

4.6.5. Medical Record Review

Medical record review was an additional tool in this study. It would provide information on the subject's medication, past experience of atopic eczema and skin condition during previous follow-up.

4.7. DATA COLLECTION METHOD

Data collections were done from January 2010 till January 2011. Both children and respective parent or caregiver were invited to participate. They were fully informed regarding protocol. The confidentiality was maintained as stated in the consent form. All collected data were examined before the participants left the Dermatology Clinic, HRPZ II. They were asked to counter check before leaving the clinic. All data were then transformed into electronic databases for further analysis.

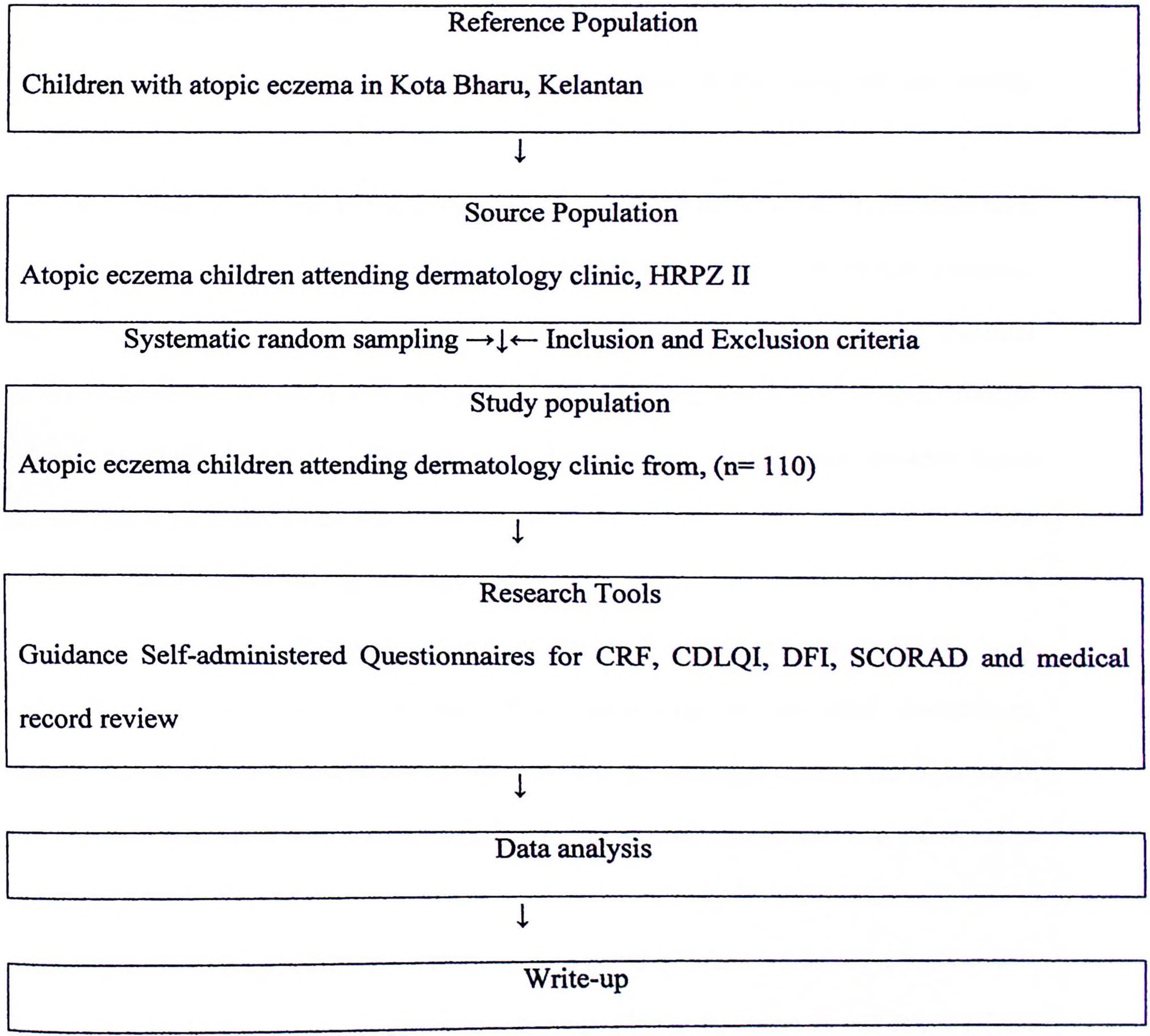

Figure 1: Flow Chart of the study