

**UNIVERSITI SAINS MALAYSIA**



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**THE UTILIZATION OF OUTPATIENT  
REHABILITATION SERVICES AND QUALITY OF  
LIFE IN CHILDREN WITH CEREBRAL PALSY IN  
HOSPITAL UNIVERSITI SAINS MALAYSIA  
(HUSM)**

by

**LIM CHIA SHING**

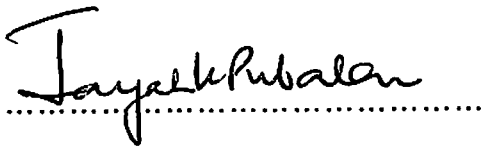
**Dissertation submitted in partial fulfillment of  
the requirements for the degree of  
Bachelor of Health Sciences (Nursing)**

**April 2008**

## CERTIFICATE

This is to certify that the dissertation entitled The Utilization of Outpatient Rehabilitation Services and Quality of Life in Children with Cerebral Palsy in Hospital Universiti Sains Malaysia (HUSM) is the bonafide record of research work done by Lim Chia Shing 81532 during the period of July 2007 to April 2008 under my supervision. This dissertation submitted in partial fulfillment for the degree of Bachelor of Health Sciences (Nursing). Research work and collection of data belong to Universiti Sains Malaysia.

Supervisor



Puan Jayah K. Pubalan

Lecturer,

Universiti Sains Malaysia, Kampus

Kesihatan, 16150, Kota Bharu,

Kelantan

Date: 30/4/2008

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# CONTENTS

|  | Page |
|--|------|
| <b>CERTIFICATE</b> .....   | i    |
| <b>ACKNOWLEDGEMENT</b> .....   | ii   |
| <b>CONTENTS</b> .....  | iii  |
| <b>LIST OF TABLES</b> .....  | vi   |
| <b>LIST OF FIGURES</b> .....   | vii  |
| <b>LIST OF ABBREVIATION</b> .....  | viii |
| <b>ABSTRACT</b> .....  | ix   |
| <b>ABSTRAK</b> .....   | x    |
| <br>   |      |
| <b>CHAPTER 1: INTRODUCTION</b>   |      |
| 1.1 Background of The Study.....   | 1    |
| 1.2 Problem Statement.....   | 2    |
| 1.3 Objectives of The Study.....   | 5    |
| 1.3.1 Specific Objectives.....   | 5    |
| 1.4 Research Questions.....  | 6    |
| 1.5 Hypothesis.....  | 6    |
| 1.6 Definition of Terms (Conceptual/ Operational) .....                      | 6    |
| 1.7 Significance of The Study.....   | 7    |
| <br>   |      |
| <b>CHAPTER 2: LITERATURE REVIEW</b>  |      |
| 2.1 Introduction.....  | 9    |
| 2.2 Quality of Life.....   | 11   |
| 2.2.1 Background of the quality of life of children with cerebral palsy..... | 11   |
| 2.2.2 The domains in measuring quality of life.....                          | 12   |
| 2.2.3 Quality of life after receiving rehabilitation services.....           | 13   |
| 2.3 Conceptual Framework/ Theory.....  | 15   |

# CONTENTS

|  | <b>Page</b> |
|--|-------------|
| <b>CHAPTER 3: RESEARCH METHODOLOGY</b>   |             |
| 3.1 Research Design.....   | 18          |
| 3.2 Population and Setting.....  | 18          |
| 3.3 Sample.....  | 18          |
| 3.3.1 Sample Size.....   | 18          |
| 3.3.2 Sampling Design.....   | 18          |
| 3.3.3 Inclusion and Exclusion Criteria.....  | 19          |
| 3.4 Instrumentation.....   | 20          |
| 3.4.1 Instrument.....  | 20          |
| 3.4.2 Measurement of Variables.....  | 22          |
| 3.4.3 Translation of Instrument.....   | 22          |
| 3.4.4 Validity and Reliability.....  | 22          |
| 3.5 Ethical Considerations.....  | 23          |
| 3.6 Data Collection Methods.....   | 23          |
| 3.6.1 Flow Chart of Data Collection.....   | 24          |
| 3.7 Data Analysis.....   | 24          |
| <b>CHAPTER 4: RESULTS</b>  |             |
| 4.1 Sociodemographic data.....   | 26          |
| 4.2 Types of outpatient rehabilitation services.....                                 | 27          |
| 4.3 The utilization of the outpatient rehabilitation services...                     | 27          |
| 4.4 Quality of life in children with cerebral palsy.....                             | 27          |
| 4.5 Relationship between the utilization of the services and<br>quality of life..... | 28          |
| <b>CHAPTER 5: DISCUSSIONS</b>  |             |
| 5.1 Types of outpatient rehabilitation services provided.....                        | 30          |
| 5.2 The utilization of the outpatient rehabilitation services...                     | 31          |
| 5.3 Quality of life in children with cerebral palsy.....                             | 31          |

# CONTENTS

|   | <b>Page</b> |
|---|-------------|
| 5.4 Relationship between the utilization of the services and quality of life..... | 33          |
| <br><b>CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS</b>                             |             |
| 6.1 Summary of The Study Findings.....  | 34          |
| 6.2 Strengths and Limitations.....  | 34          |
| 6.3 Implications and Recommendations.....   | 35          |
| 6.3.1 Nursing Practice.....   | 35          |
| 6.3.2 Nursing Education.....  | 35          |
| 6.3.2 Nursing Research.....   | 35          |
| 6.3.4 Conceptual Framework/ Theory.....   | 36          |
| <br><b>REFERENCES</b>   | <br>37      |
| <b>APPENDIX</b>   |             |
| Appendix A: Consent Form.....   | 41          |
| Appendix B: Questionnaire .....   | 49          |
| Appendix C: Tables.....   | 63          |
| Table C1: Risk factors associated with cerebral palsy.....                        | 63          |
| Table C2: Gross Motor Function Classification System (GMFCS).....                 | 64          |
| Table C3: Table of determining sample size Krejcie and Morgan (1970).....         | 65          |
| Appendix D: Ethical Approval Letter.....  | 66          |
| Appendix E: Hospital Approval Letter.....   | 69          |

## LIST OF TABLES

|                  |  | <b>Page</b> |
|------------------|--|-------------|
| <b>Table 4.1</b> | <b>Sociodemographic data of the respondents<br/>(n = 10).....</b>                                  | <b>26</b>   |
| <b>Table 4.2</b> | <b>Sociodemographic data of the child (n = 10).....</b>  | <b>27</b>   |
| <b>Table 4.3</b> | <b>Types of Outpatient Rehabilitation Services<br/>(n = 10).....</b>                               | <b>27</b>   |
| <b>Table 4.4</b> | <b>Mean score of Quality of Life Questionnaire for<br/>Children (n = 10).....</b>                  | <b>28</b>   |
| <b>Table 4.5</b> | <b>Pearson correlations between the utilization (total<br/>hours) of the services and QOL.....</b> | <b>28</b>   |

## LIST OF FIGURES

|                |   | <b>Page</b> |
|----------------|---|-------------|
| <b>Fig 2.1</b> | <b>World Health Organization model of the international classification of functioning, disability, and health (2001).....</b> | <b>16</b>   |
| <b>Fig 4.1</b> | <b>Simple Scatterplot of Utilization of the Services (total hours) and Score of Quality of Life.....</b>                      | <b>29</b>   |



## **LIST OF ABBREVIATION**

|                     |   |
|---------------------|---|
| <b>CHQ</b>          | <b>Child Health Questionnaire</b>   |
| <b>CP</b>           | <b>Cerebral Palsy</b>   |
| <b>CP QOL-Child</b> | <b>Cerebral Palsy Quality of Life Questionnaire for Children</b>          |
| <b>GMFCS</b>        | <b>Gross Motor Function Classification System</b>                         |
| <b>HUSM</b>         | <b>Hospital Universiti Sains Malaysia</b>                                 |
| <b>ICF</b>          | <b>International Classification of Functioning, Disability and Health</b> |
| <b>ICT</b>          | <b>Information and Communication Technology</b>                           |
| <b>IQR</b>          | <b>Interquartile range</b>  |
| <b>QOL</b>          | <b>Quality of Life</b>  |
| <b>SD</b>           | <b>Standard deviation</b>   |
| <b>SPSS</b>         | <b>Statistical Package Social Sciences</b>                                |
| <b>WHO</b>          | <b>World Health Organization</b>  |

**THE UTILIZATION OF OUTPATIENT REHABILITATION SERVICES AND  
QUALITY OF LIFE IN CHILDREN WITH CEREBRAL PALSY IN HOSPITAL  
UNIVERSITI SAINS MALAYSIA (HUSM)**

**ABSTRACT**

Cerebral palsy (CP) is one of the major developmental disability affecting function in children. The therapy, education, and technology can help those CP children by improving functional abilities and quality of life (QOL). The general objective of the study was to determine the relationship between the utilization of outpatient rehabilitation services and quality of life (QOL) in children with cerebral palsy (CP) in HUSM. The Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL-Child) Parent-proxy version has been used to assess QOL in children with CP via quantitative approach. This was a quantitative correlational study using a survey design and purposive sampling. There were 10 respondents in this study ( $n = 10$ ). The mean (SD) age of the respondents in this study was 40 (5.48) years old. The median (IQR) of total hours using the rehabilitation services was 43.5 (43.3) hours. The mean (SD) score of quality of life in the study was 64.68 (7.55). From the Pearson correlation test results, there was no significant relationship between the utilization of the services (total hours) and QOL in children with CP with  $p = 0.316$  ( $p > 0.05$ ). In conclusion, quality of life was not influenced by a single factor, i.e. the utilization of the rehabilitation services.

**PENGGUNAAN PERKHIDMATAN PEMULIHAN PESAKIT LUAR DAN  
KUALITI HIDUP KANAK-KANAK DENGAN PALSI SEREBRUM DI  
HOSPITAL UNIVERSITI SAINS MALAYSIA (HUSM)**

**ABSTRAK**

Palsi serebrum (CP) merupakan salah satu masalah ketidakupayaan perkembangan yang utama yang akan menjejaskan fungsi normal dalam kalangan kanak-kanak. Terapi, pendidikan dan teknologi mampu membantu kanak-kanak palsi serebrum dengan meningkatkan tahap keupayaan fungsi kanak-kanak tersebut dan seterusnya meningkatkan kualiti hidup mereka. Objektif umum bagi kajian ini adalah mengenalpasti hubungan antara penggunaan perkhidmatan pemulihan pesakit luar dan kualiti hidup kanak-kanak dengan palsi serebrum di HUSM. Borang soal selidik Kualiti Hidup Kanak-kanak dengan Palsi Serebrum Versi Penjaga Utama telah digunakan untuk menilai kualiti hidup golongan tersebut dengan pendekatan kuantitatif. Reka bentuk kajian ini menggunakan pendekatan tinjauan dan persampelan bertujuan. Seramai 10 peserta telah mengambil bahagian dalam kajian ini ( $n = 10$ ). Min umur peserta dalam kajian ini adalah 40 (5.48) tahun. Median jumlah jam penggunaan perkhidmatan pemulihan adalah 43.5 (43.3) jam. Min kualiti hidup adalah 64.68 (7.55). Keputusan daripada korelasi *Pearson* menunjukkan tiada korelasi antara penggunaan perkhidmatan pemulihan pesakit luar dan kualiti hidup kanak-kanak dengan palsi serebrum di HUSM dengan nilai  $p = 0.316$  ( $p > 0.05$ ). Kesimpulannya, kualiti hidup tidak hanya dipengaruhi oleh faktor tunggal iaitu penggunaan perkhidmatan pemulihan.

# CHAPTER 1

## INTRODUCTION

### 1.1 Background of The Study

Raising a child is not an easy task for the parents. Child rising will become more difficult when the child is experiencing difficulties during his/ her developing years and requires access to and utilization of extensive health care resources over time. According to Jones, Morgan, Shelton & Thorogood (2007), cerebral palsy (CP) is one of the major developmental disability affecting function in children. The current estimated prevalence of CP in the United States, as well as internationally, is 1.5 to 2.0 cases per 1000 births (Jones et al., 2007). Statistics shown by the Department of Social Welfare, Malaysia, noted that 14,154 people have been registered as Persons with Disabilities in year 2005 and there are 632 people who suffer from CP (Orang Kurang Upaya, 2007).

CP is a group of non-progressive, non-contagious neurological disorders of posture and movement caused by an imperfection or insult to the central nervous system (Cerebral palsy – Wikipedia, the free encyclopedia, 2007). Sometimes, the condition of the children with CP may appear to worsen, but it is actually the result of the deficits becoming more obvious as the child grows and matures over time as accounted by Nelson and Ellenberg (1982) (cited in Jones et al., 2007).

Since there is no cure for this life time condition, proper management of children with CP will be more beneficial than treatment (Colledge, 2002).

Although the condition is not progressive, neither worsen nor cured, the therapy, education, and technology can change the effects of CP over time by improving functional abilities and quality of life (QOL) (Jones et al., 2007). The rehabilitation services which include therapy, education and technology are available in the hospital and most of the CP children are treated as outpatient. Thus, these children will receive the outpatient rehabilitation services according to the schedule (e.g. once in a month or twice in a month). Attending the services can help them improve their functional abilities and in turn enhance their QOL.

## **1.2 Problem Statement**

Improvement to access for rehabilitation services has been emphasized in the Eighth Malaysia Plan (2001-2005). The basic rehabilitation services are made available in all Governmental health clinics (Current Situation of Persons with Disabilities, n.d).

Since year 2003, the government of Malaysia has been planned to provide support to the disabled via various approaches and it was reported in the 2004 Budget Speech (The 2004 Budget Speech, n.d) in September 2003. These approaches include financial assistances, job opportunities, and home purchasing discount, reduce the cost of transport and provide Information and Communication Technology (ICT) training.

In the Ninth Malaysia Plan (2006-2010), the Government continued to provide care and support for disabled people. Efforts to integrate the disabled into the mainstream activities of society were intensified through the community-based rehabilitation program (Ninth Malaysia Plan (2006-2010), 2006). The

community-based rehabilitation program involved the family of the disabled and communities and supported by relevant agencies such as health, education and social welfare. Ninth Malaysia Plan (2006) accounted that throughout the plan period, 313 community-based rehabilitation centers were established benefiting 8,453 people with disabilities. This showed that the Government is concern about the disabled and the rehabilitation services provided in Malaysia.

Currently, there are 72 health clinics providing rehabilitation services for children with special needs and 180 clinics providing rehabilitation services for the elderly throughout the country (Current Situation of Persons with Disabilities, n.d). The aim of the rehabilitation services is to aid the disabled to be independent and subsequently assist them to accomplish their maximum potential in all aspects of their lives within their abilities (Md. Rashid, 2003). The rehabilitation services are provided through field and institutional services. For field services, they include:

- Registration of the disabled;
- Identification card for easy access to services and public amenities;
- Artificial aids for the needy disabled;
- Allowance for disabled workers to encourage the disabled to work and as financial aid to help in the expenses of daily living;
- Launching grant scheme to help the disabled who possess knowledge and skill to operate small businesses which they are unable to carry out due to lack of capital and equipment;
- Job placement to assist job placement for disabled in Government Agencies/ factories/ private sectors as well as in special programs such as sheltered workshops and land schemes;

- Financial assistance for children;
- Financial assistance for elderly;
- Public assistance;
- Natural disaster assistance;

The institutional services provided consist of:

- Care, protection and rehabilitation;
- Facilities to fulfill physical, social and spiritual needs;
- Health and safety;
- Education, guidance and vocational training;
- Readjustment in the society;
- Production activities and others related to local community.

Every year, Malaysia Government has spent a large amount of money to improve the rehabilitation services for the disabled and hopes that persons with disabled will be benefited from the services provided. The 2008 Budget Speech (Komitmen memakmurkan Negara, 2007) announced that RM13 billions was allocated to improve the quality of service in hospital, medicine and health amenities. One of the main projects in year 2008 is to build-up the Hospital Rehabilitasi Cheras. However, there is little known about QOL in children with CP after receiving the rehabilitation services. This is because the researcher could hardly find any similar research which had been conducted in Malaysia.

Thus, a research was conducted to explore the relationship between the utilization of outpatient rehabilitation services and QOL in children with CP in Hospital Universiti Sains Malaysia (HUSM). The result from the research can help to improve the rehabilitation services that have been provided in HUSM, to justify further budget in the services and raising the awareness among the

parents/ caregiver to help their children by using the rehabilitation services. These in turn will help to improve the QOL in the children with CP.

The relationship between disability, rehabilitation services and QOL among the disabled can be explained by using the World Health Organization (WHO) model of the international classification of functioning, disability, and health (Figure 2.1). This is an important framework to guide modern thinking about treatment for children with CP (Rosenbaum, 2003). This model accounted that disability is not merely due to the physical impairment but it is an outcome of interactions between health conditions (diseases, disorders and injuries) and contextual factors (environmental factors and personal factors). Thus, both medical and social approach should be taking into account in the rehabilitation services provided to children with CP in order to enhance the QOL in children with CP.

### **1.3 Objectives of The Study**

**General objective:** to determine the relationship between the utilization of outpatient rehabilitation services and quality of life (QOL) in children with cerebral palsy (CP) in HUSM.

#### **1.3.1 Specific Objectives**

- To determine the types of outpatient rehabilitation services provided to children with CP in HUSM.
- To determine the utilization of the services that provided in HUSM.
- To explore the QOL in children with CP after receiving the services.
- To determine the relationship between the utilization of the services provided and the QOL in children with CP.



## 1.4 Research Questions

1. What are the types of rehabilitation services provided to the children with CP in HUSM?
2. What is the utilization of the services that provided in HUSM?
3. How the QOL in children with CP is after receiving the services?
4. Is there a relationship between the utilization of the services provided and the QOL of children with CP?

## 1.5 Hypothesis

The utilization of the outpatient rehabilitation will influence the QOL in children with CP in HUSM.

$H_0$  – There is no relationship between the utilization of the rehabilitation services provided and QOL in children with CP ( $\alpha = 0.05$ )

$H_A$  – There is a relationship between the utilization of the rehabilitation services provided and QOL in children with CP ( $\alpha = 0.05$ )

Independent variable – utilization of the services.

Dependent variable – QOL of children with CP.

## 1.6 Definition of Terms (Conceptual/ Operational)

**Utilization** is defined as 'the state of having been made use of' (Utilization – definition of utilization by the Free Online Dictionary, Thesaurus and Encyclopedia, n.d).

**Outpatient** is defined as 'a patient who is not an inpatient (not hospitalized) but instead is cared for elsewhere, as in a doctor's office, clinic, or day surgery

center' (Outpatient definition - Medical Dictionary definitions of popular medical terms, n.d).

**Rehabilitation** is defined as 'the restoration of the ill or injured patient to optimal functional level in all areas of activity' (Dorland's Pocket Medical Dictionary, 2001).

**Quality of life (QOL)** is defined by World Health Organization (cited in Dickinson, Parkinson, Ravens-Sieberer, Schirripa, Thyen, Arnaud, Beckung, Fauconnier, McManus, Michelsen, Parkes & Colver, 2007) 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.

**Child** is defined as every human being aged 4-12 years (Waters, Davis, Boyd, Reddihough, Mackinnon, Graham, Lo, Wolfe, Stevenson, Bjornson, Blair & Ravens-Sieberer, 2006).

**Cerebral palsy (CP)** is defined as 'a disorder of movement and/ or posture as a result of non-progressive but permanent damage to the developing brain, which may occur before, during, or immediately after delivery' (Dictionary of Nursing, 2005).

## **1.7 Significance of The Study**

The significance of this study is to reveal the relationship between the utilization of outpatient rehabilitation services and QOL in children with CP in HUSM. The result of the research may raise the awareness of parents/ caregiver regarding using the rehabilitation services. The result also can be used to justify the budget for improving the services. Besides that, this research

can be used as a preliminary research in the particular field since there is little known about QOL in children with CP after receiving the rehabilitation services in Malaysia.

In addition, QOL of children with CP will be disclosed to the public and gain more attention and effort to improve their QOL. It is important because children with CP have normal life-expectancy as any other healthy children (Colledge, 2002; Rosenbaum, 2003) and they will grow up as adults with CP. Good QOL of these children will make them able to participate in the mainstream of development when they are grown up. They should be as independent as possible. Despite they are disabled, they still can be productive. They can contribute to our country rather than to become a burden for our country. Hence, the services provided should improve the QOL of the children with CP to help them function at the optimum level which in turn will benefit our country.

## CHAPTER 2

### LITERATURE REVIEW

#### 2.1 Introduction

Cerebral palsy (CP) is an umbrella term that used to describe a group of neurological disorders that cause physical disability in human development, specifically the movement and the posture (Cerebral Palsy – Wikipedia, the free encyclopedia, 2007). It is important to know that CP is non-progressive, non-contagious, not hereditary and not life-threatening but not unchanging disorder (About Cerebral Palsy, n.d; Rosenbaum, 2003). Rosenbaum (2003) and Jones et al. (2007) stated that therapy, education, and technology can maximize each child's potential by improving their functional abilities, participation and quality of life (QOL).

The cause of most cases of CP remain unknown (Cerebral Palsy: a Guide for Care, n.d) but it is resulting from brain injuries that occurs before cerebral development is complete (Kriger, 2006). Because brain development continues during the first two years of life (Kriger, 2006), the risk factors associated with CP can be broken down into three time periods, i.e. prenatal, perinatal, or postnatal (Appendix C, Table C1) (Jones et al., 2007).

CP is characterized by inability to control motor functions and in turn has the potential lead to a negative effect on the overall development of a child by affecting the child's ability to explore, speak, learn, and become independent (Jones et al., 2007). As consequences, child will be facing some associated

problems such as difficulties in feeding, poor bladder and bowel control, breathing problems, and pressure sores (About Cerebral Palsy, n.d). These associated problems are the main reason for the parents/ caregiver to seek for service and treatment for the children with CP.

The physical impairment due to CP can vary considerably and no two people with CP are affected in exactly the same way (Rosenbaum, 2003). Every person who has CP is unique (Colledge, 2002). It is important for the health care providers to know how to classify those children with CP in order to plan and to treat according to their needs. This will made the treatment plan as individualized as possible. Rosenbaum (2003) stated that plan of management for children with CP should be individualized and should always occur in the context of family needs, values, and abilities.

Although every person with CP is a unique individual, it is likely to be classified by number of limbs affected; movement disorder; and functional status. For the classification by number of limbs involved, CP can be classified as quadriplegia, diplegia, hemiplegia, triplegia and monoplegia (Colledge, 2002). If movement disorder used to classify CP, it can be classified as spastic (bilateral or unilateral), ataxic, dyskinetic, dystonic and choreoathetotic CP (Cans, 2000). There are five level of classification CP by the functional status, which known as gross motor function classification system (GMFCS). However, the GMFCS only suitable for children aged between 6 and 12 years (Palisano, Rosenbaum, Walter, Russell, Wood, & Galuppi, 1997).

## **2.2 Quality Of Life (QOL)**

### **2.2.1 Background of the QOL of children with CP**

There are only a few researches (Wake, Salmon & Reddihough 2003; Vargus-Adams, 2005; Aran, Shalev, Biran, & Gross-Tsur, 2007) have been conducted on QOL of children with CP, reported that they have lower QOL if compared to normal or healthy children. Wake, Salmon and Reddihough (2003) revealed that children with CP had markedly poorer health on every Child Health Questionnaire (CHQ) scale than those normal children. In addition, the physical health status was directly proportional to the severity of the CP; while the psychosocial health was similar for mild and severe CP. It showed that psychosocial health was not affected by the severity of the physical impairment.

Another research done by Vargus-Adams (2005) showed that in the physical function domain, most children with CP scored lower than children in normative sample. This suggested that physical function can be one of the factors that affect QOL of children with CP. Apart from that, QOL was also compared to children with CP and their healthy siblings. As expected, health of children with CP was poorer for every subscale of the CHQ than their siblings. Aran et al. (2007) reported that the physical summary score and the psychosocial summary score of children with CP were lower than their healthy siblings.

Recently, there is an article denied that the QOL of the children with CP was lower than other children. A research conducted by Colver et al. (cited in ScienceDaily, 2007) found that most children aged 8-12 years with CP will have similar QOL to other children. The researchers also accounted that children with poorer walking ability had poorer physical wellbeing; children with intellectual

impairment had lower moods and emotions and less autonomy; and children with speech difficulty had poorer relationships with their parents. Although these specific domains of QOL with CP are associated with specific impairments, QOL on most aspects of life is not associated with impairments. Therefore, the researchers suggested that the QOL is likely to be determined largely by social and environmental factors.

### **2.2.2 The domains in measuring QOL**

Quality of life (QOL) is a subjective term used by people to describe their overall status of well-being. As defined by World Health Organization (cited in Dickinson et al., 2007), QOL is an individual's perception of their position in life. However, SHIA/ WHO (2002) described that QOL as an aggregate of different, interrelated aspects of life and these aspects can be organized into domains. These domains will be used to measure QOL in quantitative approach.

There are seven domains that were assessed by the Child Health Questionnaire (CHQ) which consist of physical functioning, bodily pain, self esteem, mental health, behavior, role/ social limitations and lastly, family activities and cohesion (Williams, MoCrindle, Cullen-Dean, Cai, Culbert & Ashbum, 2001). The definition of each domain in CHQ is explained as below (Williams et al., 2001):

#### **Physical Functioning Domain**

It measures the presence and extent of physical limitations due to health-related problem. Besides that, it also captures three dimensions of physically ability, i.e. self-care, mobility, and activities of varying difficulty.

#### **Bodily Pain Domain**

This domain measures the intensity and frequency of general pain.

### **Self Esteem Domain**

It captures the following dimensions of self-esteem along a continuum: satisfaction with school and athletic ability, appearance, ability to get along with others and family and life overall.

### **Mental Health Domain**

This scale measures the frequency of both positive and negative states (anxiety and depression).

### **Behavior Domain**

It measures overt behavior, such as the frequency of behavior problems and ability to get along with others. It also captures the four dimensions of behavior that are shown to discriminate among children. These include aggression, delinquency, hyperactivity and social withdrawal.

### **Role/ Social Limitations Domain**

This scale reflects the importance that society has placed on children's ability socialize and get along with others. The scale elicits limitations in the kind, amount and performance of school work and activities with friends due to physical limitations, emotional or behavioral difficulties.

### **Family Activities & Cohesion Domain**

It assesses the degree of limitation experienced by the family due to their child's health and well-being as well as the cohesiveness of the family unit.

#### **2.2.3 QOL after receiving rehabilitation services**

According to Utter & Al Helo (1995) (cited in Nordholm & Lundgren-Lindquist, 1999), rehabilitation aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and/ or social functional levels, thus providing them with tools to change their lives