# UNIVERSITI TEKNOLOGI MARA

# QUALITY OF LIFE (QOL) AMONG CAREGIVERS OF CHILDREN WITH DISABILITIES IN COMMUNITY-BASED REHABILITATION, SELANGOR

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# TABLE OF CONTENTS

CONTENTS	PAGE
AUTHOR'S DECLARATION	ii
INTELLECTUAL PROPERTIES	iv
ACKNOWLEDGEMENT	vii
LIST OF CONTENTS	viii
LIST OF TABLES	xiv
LIST OF APPENDICES	xv
ABSTRACT	xvi
CHAPTER ONE: INTRODUCTION	
1.1 Introduction	1
1.2 Problem statement	8
1.3 Significant of study	13
1.3.1 Nursing	13
1.3.2 Family	14
1.3.3 Policy	14
1.4 Research objectives	15
1.4.1 General objective	15
1.4.2 Specific objective	15
1.5 Operational definition	15
1.5.1 Quality of Life (QOL)	15
1.5.2 Caregiver	16
1.5.3 Sources of stress	17
1.5.4 Disabilities	17

## **ABSTRACT**

**Background:** The limitation in the functioning of children with disabilities can result in requirements for long-term care from their caregiver. Caregivers of children with disabilities seem to display a higher burden and impaired QOL therefore, caregiving and its related burden is an important aspect in determining the quality of life among caregivers. These finding must be taken into account in policy making to provide better and more specific supports and interventions for the children with disabilities. Thus, the aim of the study is to evaluate QOL and sources of stress among caregivers of children with disabilities in CBR, Selangor.

**Method:** Cross sectional study design was used in the study. The sample consists of 82 caregivers of children with disabilities that registered in CBR, Selangor were calculated using Yamane Formula. The WHOQOL-BREF questionnaire (English and Malay version) is used to assess the QOL.

Result: The results found that the mean score in each domain of WHOQOL-BREF of the caregivers as the following: physical capacity (PC) was 22.10±3.96, physical well-being (PW) was 20.22±3.22, social relationship (SR) was 10.16±2.35 and environment (EN) was 26.99±5.16. These mean score shown that EN was higher compared to other domain. It revealed that the caregivers have excellent functioning in environment (EN) domain of QOL. Insufficient financial support (12.2%), children's behavioral problem (20.7%), children's health problem (36.6%), children's interaction with people (11.0%) and other stress were found significantly correlated with the PW (p=0.01) and SR domain (p=0.02). Meanwhile, the study highlights that race and household income were significantly correlated to all four domain, while age was significantly correlated with PC, PW, and EN. Only marital status and caregiver's relationship with children were significantly correlated to SR.

Conclusion: Majority of caregivers rated their QOL as good and excellent functioning in EN domain of QOL. Despite that, these finding must be taken into account in policy making to provide better and more specific supports and interventions for the caregivers of children with disabilities.

# **CHAPTER ONE**

# INTRODUCTION

### 1.1 Introduction

The term disabilities by World Health Organisation (WHO) are the impairment, activity restrictions, and participation limitations, referring to the negative aspects of the interaction between an individual with a health condition and that individual's contextual factors such as environmental and personal factors (WHO, 2013).

While, according to Azaula, Msall, Buck et al. (2000) and Leonard, Johnson and Brust (1993), the Developmental Disabilities Assistance and Bill of Rights Act of 1991, Public Law 98-527, USA defined the children with developmental disabilities as "severe chronic disability of a person attributable to a mental or physical impairment or a combination of both, manifested before the age of 22 years". This impairment was possible to continue indefinitely and result in substantial limitations of function in three or more in the areas of self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and financial self-sufficiency as cited by Yuen Shan Leung and Wai Ping Li-Tsang (2003).

In article 'Disability in the South-East Asia Region' by WHO (2013) discovered the world's population of people with disabilities (PWD) were about 1 billion (15%) of people. Whereas, the prevalence rate of moderate disability in South-East Asia Region place the second highest with 16% and the prevalence rate of severe disability place the third highest with 12.9%.