

Quality of Life of School Age Children Suffering from Cerebral Palsy

Thesis

*Submitted For Partial Fulfillment of the Requirements of
Master Degree in Pediatric Nursing*

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2019

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2019

Acknowledgement

First of all, all gratitude is due to **Allah** almighty for blessing this work, until it has reached its end, as a part of his generous help, throughout my life.

I would like to express my deepest gratitude and appreciation to **Assist. Prof. Dr. Safaa Fouad Draz** Assistant Professor of Pediatric Nursing, Faculty of Nursing, Ain Shams University, for her generous support and guidance to help me to put this work in its best form and for being an ideal model to follow. It was indeed an honor to work under her supervision. No words of gratitude can equal her help and support.

It is my pleasure to express my unlimited gratitude and deepest thanks to **Assist. Prof. Dr. Hyam Refaat Tantawi**, Assistant Professor of Pediatric Nursing, Faculty of Nursing – Ain Shams University, for her kind assistance, faithful supervision, precious help, valuable advice and guidance, she offer me to complete this study. No words of gratitude can equal her help and support.

Special thanks to all mothers and their accompanying children who participated in this study wishing for Allah good health and welfare.

Finally I would like to thank my professors, my colleges, all nurses and everyone who directly or indirectly helped me to accomplish this study.

Hanaa Abd-elrhman Abd-elaziz

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Abb.	Full term
AAC	: Augmentative and Alternative Communication
AACN	: American Association of Colleges of Nursing
AAP	: American Academy of Pediatric
ACA	: Affordable Care Act
ADCP	: Athetoid or Dyskinetic Cerebral Palsy
ADL	: Activities of Daily Living
AFOs	: Ankle-Foot Orthoses
CIMT	: Constraint Induced Movement Therapy
CNA	: Certified Nursing Assistant
CNS	: Central Nervous System
CP	: Cerebral Palsy
CRC	: Convention of the Rights of the Child
CT	: Computed Tomographic
DMSS	: Dysphagia Management Staging Scale
HBOT	: Hyperbaric Oxygen Therapy
HHHHHMM	: Hurt, Hunger, Hydration, Happiness, Mobility and More good days than bad
ICFDH	: International Classification of Functioning, Disability and Health goals
ICRC	: International Committee of Red Cross
ID	: Intellectual Disability
IEP	: Individualized Education Program
LMICs	: Low and Middle Income countries
MRI	: Magnetic Resonance Imaging
NDT	: Neuro-Developmental Treatment
NGOs	: Non-Governmental Organizations
NHS	: National information and technology partner to the Health and Social care system
PCAs	: Personal Care Assistants
QoL	: Quality of Life
SENs	: Special Educational Needs
SNDP	: Set out in the Nurse Development Program's
UNICEF	: United Nations Children's Fund
WHO	: World Health Organization
WHO QoL	: World Health Organization Quality of Life assessment group

Quality of Life of School Age Children Suffering from Cerebral Palsy

Abstract

Back ground: Quality of life describes an individual's subjective perception of their position in life as evidenced by their physical, psychological and social functioning. Cerebral palsy incorporates a comparable overall impact on quality of life. **The aim** of this study was to assess the effect of cerebral palsy on child's quality of life and the relation between the mothers' knowledge, practices and the quality of life of their children with cerebral palsy. **Research design:** A descriptive study design was used. **Setting:** Specialty Neurology Outpatient Clinic of Pediatric Hospital affiliated to Ain Shams University. **Sample:** Purposive sample was selected which include (100) cerebral palsy children in school age and their mothers. **Tools for data collection:** **A structured interviewing questionnaire tool includes 5 main categories:** Demographic characteristic of children and their mothers, mother's knowledge regarding cerebral palsy, assess child's body functions and associated problems, mother's reported practice regarding care for their children, and the quality of life scale. **Results:** Most of the cerebral palsy children included in the study had unaccepted quality of life. In addition there was high statistically significant difference between mothers' demographic characteristic and their knowledge and reported practice. **Conclusion:** Most of cerebral palsy children included in the study had unaccepted total quality of life; there was positive correlation between mothers' knowledge and total reported practices and their children's quality of life related to cerebral palsy. **Recommendations:** Further studies should be conducted to improve mothers' knowledge and practices for proper dealing with their children with cerebral palsy because mothers play an important role in the maintenance of health and improve quality of life for their children.

Keywords: Cerebral palsy, quality of life, Mother's knowledge, practice, School age children



Introduction

Introduction

Schooling is the experience that, most children worldwide have in common and the most common means by which societies prepare their young for the future. On any given day, more than a billion children are in primary school. They are in permanent or temporary buildings, in tents or under trees sharing the experience of learning, developing their potential and enriching their lives (*Abdazi, 2017*).

But schooling is not always a positive experience for children. It can mean shivering in cold, unheated buildings or sweltering in hot, airless ones. It can mean being forced to stand in unfurnished classrooms, being hungry, thirsty or unwell; it can also mean being frightened by the threat of punishment, humiliation, bullying or even violence at the hands of teachers and fellow pupils (*Kim, 2015*).

School readiness is a framework for assessing profiles of strengths and vulnerabilities of the school child. It considers a child's readiness to learn within five major skill areas: health and physical development; emotional well-being and social competence; approaches to learning; communication skills; cognitive skills and general knowledge. School readiness is a widely used phrase that

generally describes a child's readiness to commence formal schooling (*Roberts, et al., 2011*).

Cerebral palsy (CP) is the most common neurologic disorder in pediatric and defined as non-progressive central motor disorder. The core problem of CP is the abnormal movement and posture which manifests very early in the development. The nature of functional impairments may change as the child develops. Various neurological patterns of dysfunction which characterized by abnormal motor and posture control and can involve communication difficulties (*Tuzun, et al., 2015*).

Cerebral palsy is the most common motor disability of childhood. Population-based registries of cerebral palsy, largely in Australia and Europe have found cerebral palsy prevalence ranging from 1.5 to 2.5 per 1,000 live births. However, recent studies in the United States, Taiwan and Egypt have found prevalence rates above 3 per 1,000 live births. The increased survival of very premature infants has contributed to a modest increase in the prevalence of cerebral palsy in developed countries over the final quarter of the twentieth century (*El-Tallawy, 2014*).

These challenges are compounded when children with disabilities are raised in a family with able-bodied members who do not share their challenges. However, family members can mentor or support the child in dealing with these challenges (*Sigrid-Ostensjo, et al., 2017*).

Despite of development in modern medicine and sciences, the incidence of CP was not decreased in western countries. As a result, CP is the most common disability in childhood with prevalence unchanged. Similar to the unchanged incidence and prevalence, the management of CP also didn't make a breakthrough so far. Fortunately, new treatment regimens with evidence have been continuously introduced and debates for the effects of interventions are ongoing (*Butler and Darrah, 2011*).

The cornerstone to treat the children with CP is the conventional rehabilitation program based on neurodevelopmental approach that has been done for decades. Various translational researches has emerged and focused on changing the therapeutic paradigm using high technologic equipment such as computer or robotic-approach, botulinum toxin or stem cell use with potential therapeutic effect. Many other trials using newly developed

devices or combination of old and new therapies are ongoing however obstacles still remain (*Bandholm, et al., 2012*).

Quality of life (QoL) is multidimensional and influenced by personal and environmental factors and their interactions; it has the same basic composition for all people both subjective and objective and is enhanced by self-determination, resources, purpose in life and a sense of belonging. On the other hand medicine and nursing science define QoL as the ones involving health and functional ability that refer to people's subjective evaluation of influences on their current health level that allows them to pursue valued life goals and is reflected in their general appearance and well-being (*Caci, et al., 2015*).

QoL is a broad concept encompassing many components of overall health and well-being including physical, psychosocial, economic and cultural components. QOL is influenced by the context of the culture and value systems in which the individual lives and relates to the individual's goals, expectations, standards and concerns. Children with cerebral palsy have limitations in Activities of Daily Living (ADLs) and participation restrictions may lead