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

Prepared by

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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

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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 un-changed 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