



QUALITY OF LIFE AMONG MOTHERS OF CHILDREN WITH NORMAL DEVELOPMENT AND MOTHERS OF CHILDREN WITH FALIJ- E-DIMAGH (CEREBRAL PALSY)

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Abstract

Cerebral palsy (Falij e Dimagh) is a non-progressive neurological disorder of childhood and the prevalence is 2 cases per 1000 live births. Among the large variety of childhood developmental disabilities, cerebral palsy (CP) is considered to be the major physical disability affecting the functional development of children. Presence of child with Cerebral Palsy in a family generates profound emotional stress and feeling of unhappiness. The present study was designed to assess and compare the Quality of Life among mothers of children with cerebral palsy and mothers of children with normal development in physical, psychological, social and environmental domains. Two sample groups were chosen from a total of 60 mothers to response the questionnaire WHOQoL. The first group included 30 mothers of children with cerebral palsy who were attended to the Out Patient Department of Borella Ayurveda Teaching Hospital. The second group consisted of 30 mothers of children with Normal Development living in Colombo. T-tests by SPSS were used for statistical analysis. There were significant differences in three domains of QOL between mothers of healthy children and mothers of children with cerebral palsy ($p < 0.005$). The results of this study revealed that, the quality of life of mothers of children with Cerebral Palsy was significantly different in physical, psychological and environmental domains compared to mothers of healthy children. Therefore, appropriate rehabilitation programs for children with Cerebral Palsy and the proper Psychological support for mothers should be provided to improve their quality of life in different domains.

Key words: Quality of Life, Cerebral Palsy, Falij e Dimagh

Introduction

Parenting is a highly stressful job, as normal children progress from one developmental stage to the next; their parents observe them with pride, anxiety and alarm. Parents have expectations of them based on social, family and experimental standards. When the children's behaviour deviates from the established standards, family crisis may develop.

The stress factors accompanying the birth of a normal child are intensified when the child is disabled. The marital relationship may suffer unduly from the added stresses of blame, guilt and anxiety. A child's disability attacks the fabric of marriage in different ways. It excites powerful emotions in both parents but especially mothers. It reshapes the organization of the family. It creates a fertile ground for conflict.

Cerebral palsy is a group of non-progressive disorders of movement and posture caused by abnormal development of or damage to motor control centers of the brain and are often accompanied by neurological and physical abnormalities. Functional deficits developing due to physical, cognitive, emotional, and social disorders prevent children with Cerebral Palsy from performing their roles in society.

Quality of life is defined by the World Health Organization (WHO) as an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards, and concerns.

Mothers are usually the primary caregivers of these children because most of them remain in the family environment during their treatment and they appear to carry the larger burden of care and they may feel a need to be with their child at all times so they experience stress related to coping with the heavy load of care giving (Thompson, 2000).

However, despite the strains related to a disability, caring for a child with special needs is not primarily a story of gloom. Some mothers perceive their life as difficult and more negative, and seem to grieve openly and deeply for years. Others appear to cope well with added demands, without apparent disruption in their ability to function at work or in close relationships. These mothers seem to move on to new challenges with apparent ease or even report high satisfaction and enjoyment of their role as mothers (Bonnano, 2004). But some mothers remain relatively resilient, while others have difficulty in managing the situation related to the rearing process of their child with CP. So far, little is known about the process of adaptation of parents of young children with CP. As a result, professionals working with these parents are not yet fully able to comprehend the impact of a disability on a family.

Objectives of the study

The objectives of the present study are: To investigate the level of Quality of life among Mothers of children with Normal Development and Mothers of children with Cerebral palsy and to identify whether there is a significant difference between the Quality of life among Mothers of children with Normal Development and Mothers of children with Cerebral palsy in all four domains of Life (Physical, Psychological, Social and Environmental)

Methodology

The study was performed in the Borella Ayurveda Teaching Hospital, between April 2015 and August 2015, and 30 mothers with Cerebral Palsy children and 30 with children of normal development were included into the study. Those accepted to participate were informed, and written consents were obtained. Demographic, medical, and developmental histories of children with Cerebral Palsy were taken from families, and age, gender, clinical type, and body involvement of children were defined. Socio-demographic data of mothers in both groups were determined. Quality of Life of mothers was assessed with WHO Quality of Life BREF (WHO QoLBREF) questionnaire.

Inclusion criteria of mothers composed of having a child with Cerebral Palsy, living with the child, not having any chronic disorder, not having a rheumatologic, orthopaedic, and neurologic problem that will markedly affect Quality of Life, not being pregnant, having no history of psychological disorders, not using antidepressant and anxiolytic drugs, and not having another patient or disabled individual along with the Cerebral Palsy child. On the other hand, inclusion criteria of the other group consisted of having a child with normal development and living together, not living with another patient or disabled individual, lacking a history of psychological disorders, not using of antidepressant and anxiolytic drugs, without chronic disorders, not using assisted device, not having pregnant and not having a rheumatologic, orthopedic and neurologic problem that will markedly affect Quality of Life.

Data Collection Measures

In order to assess Quality of Life, both the English and Sinhala version of the WHOQoL-BREF were used. The WHOQoL-BREF, an abbreviated version of the WHOQoL-100, is a self-administered questionnaire. It comprises of 26 items categorized into four broad domains: physical health, psychological well-being, social relationships and environment. The items are rated on a 5-point scale.

Statistical Analysis of the Results

According to the instruction given in the user manual of WHOQoL (BREF) questionnaire, the programmed spreadsheet was launched and the scores were entered onto it, in the order given by default. The programmed spreadsheet automatically showed the calculated averages of the scores.

The level of Quality of Life of mothers of children with Cerebral Palsy and mothers of children with Normal Development (Objective 1)

The level of Quality of Life of both groups of mothers is explained in terms in physical, psychological, social and environmental domains of WHOQoL (BREF) scale. In this research, the level of Quality of Life of each group is measured by calculating the mean values of each domain in the questionnaire.

Table 1 show that the mean of Quality of Life of the mothers of children with Cerebral palsy is 63.7333 and the mean value of Quality of Life of the mothers of children with Normal development is 95.3000. These points out that the mothers of Normal children have improved Quality of life compared to mothers of cerebral palsied children and are performing better.

Mean of the two groups

Table 1: One-Sample Statistics

	N	Mean	Std. Deviation	Std. Error Mean
ts1	30	63.7333	13.79389	2.51841
ts2	30	95.3000	9.92089	1.81130

Comparison of the levels of Quality of Life in physical, psychological, social and environmental domains among mothers of children with Cerebral Palsy and mothers of children with Normal Development. (Objective -2)

In order to find out whether there is a significant difference in the levels of Quality of Life among mothers of children with Cerebral palsy and mothers of children with Normal Development an independent sample t- Test was conducted. There was a statistically significant difference in the scores of physical, psychological, social and environmental domains of life.

P – physical ,Psy –psychological ,S – Social ,E – Environmental

Cp – cerebral palsy = ts1, Nc – normal children = ts2

Table 2: Group Statistics

	group	N	Mean	Std. Deviation	Std. Error Mean
p	cp	30	55.6000	15.96462	2.91473
	nc	30	73.6000	15.70767	2.86782
psy	cp	30	48.7000	15.16837	2.76935
	nc	30	72.5333	13.61220	2.48524
s	cp	30	62.3667	21.28377	3.88587
	nc	30	73.5667	16.52518	3.01707
e	cp	30	44.8667	20.83223	3.80343
	nc	30	75.9000	10.02187	1.82974

Table 3 : Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
p	Equal variances assumed	.242	.625	-4.402	58	.000	-18.0000	4.08901	-26.18504	-9.81496
	Equal variances not assumed			-4.402	57.985	.000	-18.0000	4.08901	-26.18509	-9.81491
psy	Equal variances assumed	.007	.934	-6.405	58	.000	-23.8333	3.72098	-31.28169	-16.38498
	Equal variances not assumed			-6.405	57.333	.000	-23.8333	3.72098	-31.28353	-16.38313
s	Equal variances assumed	1.539	.220	-2.277	58	.027	-11.2000	4.91962	-21.04769	-1.35231
	Equal variances not assumed			-2.277	54.645	.027	-11.2000	4.91962	-21.06058	-1.33942
e	Equal variances assumed	10.759	.002	-7.353	58	.000	-31.0333	4.22066	-39.48191	-22.58476
	Equal variances not assumed			-7.353	41.741	.000	-31.0333	4.22066	-39.55254	-22.51413

**p < 0.05

In the physical domain, there was a statistically significant difference in the scores mothers of children with Cerebral palsy (M= 55.6000, SD = 15.96462) and mothers of children with Normal Development. (M=73.6000, SD=15.70767); t (58) = 4.402, significant two-tailed = .000, p< 0.05

In the psychological domain, there was a statistically significant difference in the scores mothers of children with Cerebral palsy (M= 48.7000, SD = 15.16837) and mothers of children with Normal Development. (M=72.5333, SD=13.61220); t (58) = 6.405, significant two-tailed = .000, p< 0.05

In the environmental domain, there was a statistically significant difference in the scores mothers of children with Cerebral palsy (M= 44.8667, SD = 20.83223) and mothers of children with Normal Development. (M=75.9000, SD=10.02187); t (58) = 7.353, significant two-tailed = .000, p< 0.05

As well as in the social domain, there was a statistically significant difference in the scores mothers of children with Cerebral palsy (M= 62.3667, SD = 21.28377) and mothers of children with Normal Development. (M=73.5667, SD=16.52518); t (58) = 2.277, significant two-tailed = .027, p< 0.05

These results suggest that there is significance evidence to support the alternative or research hypothesis proposed in this study and the null hypothesis of this study can be rejected. Therefore, it can be concluded that there is a significant difference between mothers of children with Cerebral palsy and mothers of children with Normal Development.

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