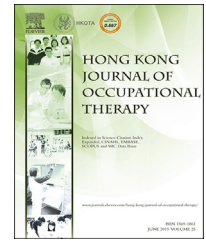




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ORIGINAL ARTICLE

Factors Associated with Quality of Life in Mothers of Children with Cerebral Palsy in Iran



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Summary *Objective/Background:* Children with cerebral palsy (CP) need more attention and care, especially from their mothers. This can affect the mothers' quality of life (QOL) adversely. This study aimed to assess the QOL of Iranian mothers who have a child with CP, compared with mothers with a healthy child, focusing on some individual and social underlying factors.

Methods: Using a cluster-sampling approach, two groups of eligible mothers having children aged 4–12 years, with and without CP, from Tehran's randomly selected clinics, were chosen in a convenient way and enrolled in a cross-sectional study. A group of mothers with healthy children whose demographics closely matched with the group of mothers having children with CP were selected and recruited in the study. The group with mothers with children with CP was selected randomly from a convenience sample in 14 rehabilitation and occupational therapy clinics in Tehran, Iran. To collect data on characteristics of interest, mothers were interviewed, and the SF-36 Questionnaire was used to measure their QOL. The relationship between each characteristic and the mothers' level of QOL was assessed, and the crude odds ratios (ORs) and adjusted ORs were measured by logistic regression.

Results: Sixty mothers with CP children, and 60 mothers with healthy children participated in this study. Their mean (\pm standard deviation) age was 33.79 (\pm 6.02) years, and their children's mean age was 7.11 (\pm 2.71). The two groups were significantly different in QOL mean score (57.35 ± 18.39 vs. 71.7 ± 13.58 ; $p \leq .001$). It was shown that having a child with CP with

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intellectual disability is significantly related to a worse level of QOL of mothers (adjusted OR = 5.4, $p \leq .001$), whereas having full-time jobs is reversely associated with it (adjusted OR = 0.2, $p = .02$).

Conclusion: Two important factors that lead to a worse QOL of mothers with a CP child are the unemployment of mothers and having a CP child with concurrent intellectual disabilities. To diminish the adverse effects of having a CP child on QOL of mothers, unemployed women who have a CP child with concurrent intellectual disabilities need more psychological support and help.

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Introduction

Quality of life (QOL) is widely used in health and medical studies to measure health status (Habashneh, Khader, & Salameh, 2012). Identifying the factors affecting QOL can enhance treatment, care, and rehabilitation programs (Soh et al., 2013). One of the major goals of all countries is to improve people's QOL and well-being (Prudente, Barbosa, & Porto, 2010). QOL is a subjective concept that encompasses all conditions and aspects of human life (Nesterko, Braehler, Grande, & Glaesmer, 2013). According to the World Health Organization, QOL is defined as the individual's perception of his/her position in life in the context of his/her culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards, and concerns (Susniene & Jurkauskas, 2009).

Cerebral palsy (CP) is the most common cause of motor dysfunction in children; it involves a group of permanent disorders in the development of movement and posture causing activity limitation, which is attributed to nonprogressive disorders occurring in the development of the foetus or the infant's brain (Raina et al., 2005). Although impaired motor dysfunction is a hallmark of CP, many of these children, in addition to speaking, understanding, and learning disabilities, may also experience intellectual and emotional problems. Consequently, these constraints may lead to dysfunction in self-care and make these children dependent on others for their activities of daily living (Davis et al., 2010; Kaya et al., 2010).

Disability not only affects children themselves but also their family members (Gardiner & Iarocci, 2012; Terra et al., 2011). Disabled children require more care, and their parents suffer more stress in taking care of them (Karande & Kulkarni, 2009). In most cultures of the world, women have more responsibility in raising children, and the primary caregivers of children with disabilities are often mothers (Ones, Yilmaz, Cetinkaya, & Caglar, 2005). In confronting the problems of children, mothers are more affected than fathers (Oh & Lee, 2009; Ones et al.). Taking care of these children, especially those who require special and long-term support, results in physical and mental stress for mothers (Kaya et al., 2010). There is much evidence to show that mothers who take care of disabled children suffer from more severe physical and psychological complications than mothers with healthy children (Laurvick et al., 2006). Mahani, Rostami, and Nejad (2013) found that the socioeconomic status, marital satisfaction, and subtypes of pervasive developmental disorders have a

significant influence on the QOL of mothers of children with pervasive developmental disorders in Iran. There is no doubt that these conditions can affect the QOL of mothers who have children with CP (Gorter, Ketelaar, Rosenbaum, Helders, & Palisano, 2009).

It naturally follows that taking care of a disabled child has a profound impact on the QOL and health of mothers who are in charge of caregiving; however, its different dimensions and scales must be reviewed in each region or country based on those lifestyles (Davis et al., 2010). As has been reported in multicultural comparative studies, underlying social factors, such as race, sex, religion, and the socioeconomic status of families with disabled children are among the critical factors that can cause problems while caring for these children (Oh & Lee, 2009). The present study concentrates on several individual and social factors to compare the QOL of mothers who have a child with CP and mothers with a healthy child in Iran.

Methods

This was a cross-sectional study in which a sample of mothers, living in Tehran, who had children aged 4–12 years participated. They were selected in two groups: those with one or more healthy children and those with a CP child. They were studied and compared over a 2-month period in 2011. The mothers of children with CP were selected from among those people referred to 14 rehabilitation and occupational therapy clinics, and the mothers of healthy children were selected from among those who took their children to one of 20 selected medical clinics in Tehran, the capital of Iran, for outpatient therapy. The inclusion criterion for mothers with a CP child was having only one child aged 4–12 years with CP, whereas for the mothers with a healthy child, the criterion was having a healthy child in the same age range. It was essential that both mother and child lived together, and that the mother is the main caregiver for the child. The exclusion criteria for both groups were as follows: (a) not being able to read and write, (b) having any sort of medical problems or acute or chronic psychological disorders, so that it prevents the mother from taking care of her child alone. Furthermore, mothers who smoked or used any drugs, pregnant women, and those who took care of other elderly or mentally or physically disabled persons were also excluded. We also excluded mothers when their children showed symptoms of puberty.

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