

Quality of life of disabled children's mother: a comparative study

Asghar Dadkhah, PhD.¹; Robabeh Ghaffar Tabrizi, PhD.; Sahel Hemmati, MD.
University of social welfare and rehabilitation sciences, Tehran, Iran

Objectives: Quality of life for disabled children often has been assessed based on functional status or parental perceptions rather than direct reports from the children. The objective of this study was evaluating the quality of life of mothers with disabled children.

Method: There is widespread acceptance of the need for disabled children to be fully integrated into society but there needs to be further attitudinal change. Totally forty mothers with a cerebral palsy child and forty mothers with health problems participated in a study. Health Survey was used to assess a mother's quality of life

Results: The mean scores on Health Survey were significantly lower in mothers of children with disabled child than those of the other group. The quality of life scores also was correlated with the severity of disability. Coping strategies were clear correlates of health related quality of life when socio-demographic, disability related and social support variables were studied. The relationship between coping strategies and quality of life was the more reevaluation of life values.

Conclusion: The results suggest that greater focus needs to be directed to coping strategies and to ways of facilitating adaptive outcomes in rehabilitation. Different coping strategies and psychosocial programmes must be designed and implemented to decrease the burden of care.

Keywords: quality of life; disabled children's mother; parental perceptions

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Introduction

Diseases and their treatment may have an impact not only on quantity of life, but also on the well-being of the individual. Effort is now being made to gauge these consequences. Quality of life is a multidimensional dynamic concept that has developed from the need to estimate the impact of diseases, which includes economic welfare, characteristics of community and environment, and health status. The term quality of life has become a bandwagon concept for all those human needs, which are often neglected in a society dominated by technology. As a rule, the term quality of life is used in medical research for characterizing an individual's quality of life from his own subjective perspective, as contrasted with the professionals' objective evaluation of the health status of the individual (1). There is a need to distinguish between global well-being and health

related well being although health is one of the strongest determinants of global quality of life. Key dimensions of health related quality of life are physical functions, sensations, self-care, cognition, pain, discomfort and emotional psychological well-being. The most serious diseases confronting children in the developed world are chronic and disabling conditions. The cerebral palsies are such a condition. A growing number of parents have begun searching for ways to raise their children with cerebral palsies at home. Families of children with disabilities have to cope with greater financial stress, more frequent disruption of family routine and reduced social activities outside the family (2,3). Health-related quality of life is often considered the primary endpoint in research, clinical medicine and health promotion when impairments are incurable or insufficiently understood (4).

1- All correspondences to: Dr. Asghar Dadkhah , E-mail: asgaredu@uswr.ac.ir

Some studies suggested the relation between quality of life and well-being in disabled children's mother. The quality of life and well-being of mothers of children with familial fever were slightly impaired (5). Likewise, a study conducted on the mothers of children with chronic arthritis showed the quality of life of these mothers was lower than those who had healthy children (6). Hedov et al. indicated that the presence of a child with Down's syndrome in a family might have a negative impact on maternal quality of life (7).

In this study the quality of life and consequent burden of care, on mothers who look after their disabled children with cerebral palsy and the quality of life of other mothers will be compared. The research wants to know if there is a relation between quality of life of disabled mothers and the severity of their child disability.

Method

There is widespread consensus about the necessity of disabled children's intergration to society but it needs further attitudinal changes. In a comparative study, totally forty mothers with a cerebral palsy child and forty mothers with health problems participated in a study. The data were collected at the University of social welfare and rehabilitation clinics.

The Inclusion criteria for mothers with a cerebral palsy child were having a child with cerebral palsy, not having a severe medical condition; absence of a history of severe or chronic psychological disorder, and absence of an indication to an inpatient or outpatient clinic for any kind of medical services. The control group consisted of forty mothers who had a child with minor health problem.

Health Survey was used to assess a mother's quality of life. The SF-36 Health Survey is a generic outcome measure designed to examine a person's perceived health status. As a Self-report Questionnaire Health Survey includes one multi-item scale measuring each of the following eight health concepts:

(1) physical functioning; (2) role limitations because of physical health problems; (3) bodily pain; (4) social functioning; (5) general mental health (psychological distress and psychological wellbeing); (6) role limitations because of emotional problems; (7) vitality (energy/fatigue); and (8) general health perceptions (8).

The SF-36 also includes a single-item measure of health transition or change (9). The SF-36 can also be divided into two aggregate summary measures

the Physical Component Summary (PCS) and the Mental Component Summary (MCS) (10). The Farsi version of the Medical Outcomes 36-Item Short Form Health Survey (SF-36) was used to assess the quality of life of mothers. Mehraban, Naderi, et al developed the Farsi version of the short form 36-item (SF-36) questionnaire related to quality of life. It was translated into Farsi and modified by adding 25 specific items related to renal replacement therapy. The modified questionnaire was tested on 10 transplant patients within 6-12 months after operation. The test to retest time interval was three weeks. The answers to the questionnaire were obtained during a direct interview. The total reliability coefficient (RC) was 0.70. Deletion of items 20, 49 and 52 increased the RC to 0.75 (11). Medical and developmental history of the children was obtained from their parents. The children were examined with respect to disability, deformity, and motor and sensory deficits. Muscle strength, tone, motor development, involuntary movements, primitive reflexes, senses, cerebellar system, and posture-gait were evaluated. The functional level has been determined based on the Gross Motor Function Classification System (GMFCS). GMFCS is a classification system specifically devised for children with CP in which children younger than 12 years of age are classified into 5 groups according to gross motor movements such as spontaneously initiated movements, sitting, and gait (12). Validation of Farsi model of gross motor function was done by Dehghan, et al (13).

After interview and gathering data, statistical analyses were carried out using the Statistical Package for the Social Sciences (SPSS) for Windows. To examine the differences between groups, Mann – Whitney U and chi-square tests were used. Pearson's correlation coefficients were calculated to assess the linear association between scores on the SF-36 and a number of continuous variables.

Results:

Coping strategies were clear correlates of health related quality of life when socio-demographic, disability related and social support variables were studied. The relationship between coping strategies and quality of life was: the more reevaluation of life values and acceptance and the fewer tendencies towards dependent behavior the better the health-related quality of life.

The statistical analyses verified that with the exception of the SF-36 physical functioning subscale, the mean

scores on the SF-36 subscales were significantly lower in mothers of children with cerebral palsy than those in the comparison group. SF-36 subscales were correlated with GMFCS in a negative direction. GMFCS was strongly correlated with the RP subscale of SF-36 ($p < 0.01$); moderately with RE and MH subscales ($p < 0.05$); and weakly with P and GH subscales ($p > 0.05$). The subgroup analyses, highlighted that there were statistically significant correlations between some of the subscales of the SF-36 and socio-demographic variables. The results were very similar to Levent and Emine's study (14).

Conclusion:

The results suggest that greater focus needs to be directed to coping strategies and to ways of facilitating adaptive outcomes in rehabilitation. Different coping strategies and psychosocial programmes must be designed and implemented to decrease the burden of care. Mothers of children with leukemia requiring hospital care have poor health related quality of life, particularly with regard to mental health and social

functioning, and are at a greater risk for depression. These results suggest that the current system for treating leukemic diseases of children in Japan should also include close monitoring of mothers' mental health, and provision of appropriate treatment and psycho-social support (15). The social functioning subscale identifies the extent to which physical health or emotional problems interfere with normal social activities. Caring for a child with physical disability throughout a whole day may interfere with the mother's social functioning. Lower Emotional role and mental health subscales may be a result of depression, anxiety, and behavioral –emotional control. It is generally argued that those who provide care on a regular basis often experience greater levels of depression and anxiety and are more likely to experience psychiatric and physical health problems (16). John Bowlby in 1980 predicted a relation between depressive disorder in adulthood and the quality of the earlier bond between the child and their adult caregiver (17) which confirm our result.

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