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INVESTIGATION OF THE LIFE QUALITY OF FAMILIES WITH DISABLED CHILDREN

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ABSTRACT

The purpose of this study is to examine the quality of life of families with children with disabilities. It was carried out in a relational screening model. Data were obtained by conducting a related field study. In the analysis of the data obtained, it was found that the gender of the parents made a difference, and the high number of children and low-income status negatively affected the family's quality of life.

Key Words: Children with disabilities, family / parents, quality of life

INTRODUCTION

The child, with whom the family waits with great excitement, is born with a disability or a serious illness means that the child is in need of constant care. Disability is a long process that affects both the individual in need of care and their relatives spiritually, physically, emotionally and socially. Although it is not desired, there is a disabled person in the family.

The birth of a child with disabilities in the family is a condition that negatively affects the lives, feelings and behaviors of family members. In addition, families experience the feelings of shock, rejection, extreme sadness, guilt, and inadmissibility, trying to adapt to the differences in their child and seek solutions for the situation (Akıncı, 1999).

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There are also some difficulties encountered during the care and education of children with disabilities. Increasing economic needs, not having enough information about the child's condition, changing roles of family members due to disabled children, deterioration of marital relations, not being able to participate in social activities resulting from both time limitation and lack of time for them, against individuals with disabilities and their families their attitudes increase the problems of the family (Wallender, JL, Varni, JW, Babani, L., Dehan, CB & Banis, KT (1989).

In addition to the stress that families experience with having a disabled child, they also experience emotional strain. The fact that children with disabilities cannot get enough information about their condition, difficulties in explaining their child's condition to their family or other people in the community, not getting enough information about their behavior and health problems, treatment and education in individuals with disabilities, efforts to find a suitable educational institution for their children, more time, energy and the need for money is the source of tension in families (Kavak, 2007). The tension of the family negatively affects their quality of life. The World Health Organization has defined the quality of life as follows; Quality of life (Quality of life, QOL); It is defined as the person's perception of his stance in life in relation to his goals, expectations, standards and interests within the framework of his own culture and value systems.

Today, private and official non-governmental organizations are established for individuals in need of care in almost every country, and many of these institutions undertake significant works. The quality and quality of practices for individuals in need of care

It is one of the most important factors showing the level of development. The main reason for this is the awareness of society, which has become quite common today. At the core of this consciousness is the idea that the care of these individuals belongs not only to the first and second degree relatives of the individual, but also to the whole society. Therefore, the problem of an individual with a physical or mental disability should not only concern his family, but actually

concern the whole society. Because the basic rule of having national consciousness as a whole is to be conscious of the common past and the desire to live in the future (Gökalp, 2010).

TARTIŞMA

When the studies are analyzed, it is determined that there is a difference in the quality of life of families with disabled children according to their gender, and that women experience more quality of life loss than men.

It is claimed that motherhood role is always a priority in maintaining the health of the family and especially in protecting the health of children. In other words, community ideology and gender roles entrust child and family health to women. Research shows that when a child has chronic illness, mothers take responsibility for family health in situations that concern general family health (Shore, Austin, Dunn, 2004).

In the study related to the quality of life, it was found that factors such as gender, poor economic situation negatively affect the quality of life. (Eser, Eser, Ozyurt, Fidaner, 2005).

Considering the findings of the research about income level, it was seen that families with low income levels suffered more from the families with medium and high income levels in terms of quality of life.

While these diseases cause physical and mental difficulties in the child, they affect all members of the family both economically and mentally. There may be serious adjustment problems and mental disorders in family members (Toros, Tot, Düzovalı, 2002).

In the study conducted to determine the effect of the characteristics of children and their families on their quality of life, it was found that families with low income levels had lower quality of life (Chia-Ling, 2003). The decrease in the quality of life of one of the family members, especially the mother, affects the quality of life

of the whole family. The family functions of families with mentally handicapped children were examined in terms of some variables, and it showed that the family functions of mothers with mentally handicapped children showed a significant difference according to the income level of the family, the number of children that the mother had and their variables (Günsel, 2010). In the study, it was determined that, as the number of children of mothers increased, they had difficulty in fulfilling their family responsibilities and thus showed more unhealthy functions in family functions. The high number of children in the family with mentally insufficient children increases the responsibilities and roles taken by the mother. The mothers' attempts to adapt to living with a mentally deficient child, the father's inability to take care of the child, the increase of economic problems, the mothers' inability to meet the needs of the family members, the mother's fatigue due to the efforts to show the same attention to each family member and to maintain the order in the family. It can also be said that the burden of mothers has increased as the increase in the number of children can increase the quarrels and jealousy among siblings. This is another factor that will affect the family's quality of life (Sarıhan, 2007).

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