

Research Paper: The Quality of Life of Siblings of Children With Severe Developmental Disabilities Children



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ABSTRACT

Objectives: Having a disabled child can have profound effects on the living conditions and the mental health of their family. Siblings of the children with disabilities have an important role in supporting them. Their physical, mental and emotional health may be at risk, therefore, their condition and living should be concerned and improved. The current study aimed to investigate the quality of life of these siblings in comparison with the siblings of normal children.

Methods: This cross-sectional comparative study was carried out on 33 people who had one sibling with severe developmental disabilities aged 13 to 18 years. The control group consisted of 32 siblings of healthy children who were geographically and economically identical with the test group. The quality of life was measured by the Pediatric Quality of Life Inventory Version 4.0 (PedsQL4). The data were analyzed by the Independent t test and Mann-Whitney test.

Results: The Mean±SD age of the siblings with severe developmental disabilities was 15.64±2.06 years and the same score for the normal group was 15.30±2.23 years. The results showed that the siblings of children with developmental disabilities significantly have a poorer quality of life compared to the siblings of the healthy group (P<0.05). This significant difference was also found in the academic, emotional and physical scores of the quality of life scale, but no significant differences were found between the two groups in respect with the social function (P>0.05).

Discussion: The current study showed that the quality of life of siblings of children with developmental disabilities is decreased. These results suggest the necessity to provide supportive and therapeutic programs for maintaining and improving the quality of life of these siblings and the whole family.

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Highlights

- Siblings of children with developmental disabilities significantly have a lower quality of life compared to the siblings of the healthy group.
- While the academic, emotional and physical scores of the quality of life are different between two groups, their social function is the same.

Plain Language Summary

Presence of a child with disabilities in a family can have unpleasant effects on the whole family. Caring a disabled child imposes a lot of financial and spiritual costs to the family. These conditions can create problems for other healthy children of the family and affect their quality of lives. Therefore, we decided to investigate the quality of life of healthy siblings of disabled children. As expected, the quality of life of these children is affected by the presence of a disabled child and is significantly lower than that of peer adolescents. A total of 33 healthy adolescents who had one sibling with severe developmental disabilities aged 13 to 18 years were participated in this study. In addition, 32 siblings of healthy children who were geographically and economically matched with this test group were selected as the control group. The quality of life of these two groups was measured by the Pediatric Quality of Life Inventory Version 4.0 (PedsQL4) and the obtained data of two groups were compared with analytic statistics. The findings showed that the quality of life of siblings of children with developmental disabilities is lower. These results calls for providing supportive and therapeutic programs for maintaining and improving the quality of life of these siblings and the whole family.

1. Introduction

Children with chronic diseases requires more healthcare compared to others. Each year 16% of children with chronic illness or disabilities are admitted to hospital. The need for long-term care to improve baby's health affects family function [1]. Once recognizing their child's disability, families may experience different responses such as shock, confusion, anger, depression, disappointment and guilt, and their relationships change either negatively or positively [2-4]. The effect of such incidents can be very deep. Also, caregiving, educational, medical and financial problems impose more stress on the families. This issue can affect the family dynamics, family members' mental health, and quality of life [2].

Family members must adapt to the changed roles and activities and reset the family goals and values which may harmfully affect siblings' psychosocial health [5]. The disabled child can adversely affect his/her siblings [6]. Siblings feel ignored, when parents pay more attention to the special needs of their disabled child [7]. Normal siblings of disabled children are 0.6-1.2 times more likely to experience emotional and behavioral problems compared to the siblings in a normal family [1]. Many studies show that families with a disabled child are subjected to mental problems such as depression and anxiety

which can affect their quality of life [2-4, 8, 9]. The "quality of life" has many definitions [10].

According to the World Health Organization, the quality of life includes individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns [11]. Quality of life is a broad biopsychosocial health concept [12]. Numerous researchers investigated the quality of life and its different aspects and the rate of articles on health-related quality of life have increased from 21% in 1985 to 76% in 1995 [13]. Health has different aspects which influence quality of life and make individuals pay attention to their health status. In addition, social issues can lead to sanitation problems which affect quality of life [14].

Quality of Life is considered as an indicator of sanitation and happiness. Therefore, researchers attempted to recognize and evaluate key indicators of quality of life [15]. Quality of Life includes physical well-being (health, nutrition, mobility and daily activities), emotional well-being (happiness, satisfaction, lack of stress, self-concept and religious ideas), social welfare (intimacy, friendship, social activities, events and roles), productive welfare (progress in education or work, leisure time amusements, autonomy and individual competence), mental well-being (ownership, financial security, housing and socio-economic conditions), and urban prosper-

ity (privacy, voting, availability, citizenship responsibilities and protection rules) [16].

Siblings of a disabled person tend to limit the family relationships [17]. They are at risk for developing anxiety, depression, aggression, social withdrawal, isolation and confusion [18]. One major human relationship is siblings' close interactions which may change over time. There is only a little satisfaction about sibling interactions with other siblings in most societies [19]. Family's mental health directly impact the society, thus, studying the effective factors on quality of life is very important. Family's serious problems may affect their quality of life and mental health.

As mentioned, a disabled child in the family is among such serious problems. In the family, siblings have a crucial role to protect the disabled brother or sister which may threaten their physical, mental and emotional health. Therefore, paying attention to disabled persons quality of life is very important and useful for parents and professionals and all healthcare providers for families. The prevalence of disability is 1.4% in Iran [20]. No research has been conducted on the health status of healthy siblings of children with disabilities and it is not clear what kind of support system should be considered for them. Therefore, the present study aimed to evaluate the quality of life of healthy siblings of children with developmental disabilities.

2. Methods

This was a cross-sectional study carried out in Semnan, Iran in 2013. The sample group was selected by studying records in the rehabilitation centers of Semnan and children with developmental disabilities with 13-18 years old sibling were selected. Then, 35 siblings were selected after considering the income level of the family and parent's educational level. The control group samples were randomly selected from the four regions of the city, considering the educational region. Next, some 13-18 years old children with a younger healthy sibling were selected as the control group. The parents of the control group were matched with the experimental group with respect to education and income status.

The Persian version of Pediatric Quality of Life Inventory 4.0 (PedsQL) was used for measuring health-related quality of life in children and adolescents aged 2-18 years [19, 20]. The validity and reliability of this questionnaire is consistently high [21]. It consists of 23 items that assesses factors in four domains: physical, emotional, social and school functioning [21]. The va-

lidity and reliability of the Persian version of PedsQL has been reported previously [22].

The obtained data were analyzed by SPSS V. 16. Normal distribution of the data was evaluated by the Kolmogorov-Smirnov test. The Independent t test was used for between-group comparison. By using descriptive and analytical statistics (K-S square, mean, paired-T and independent T).

3. Results

The Mean±SD age of the siblings in the experimental group and the control group were 15.64±2.56 years and 15.30±2.23 years, respectively. The Kolmogorov-Smirnov test was used to investigate the normality of sample distribution, and to determine the method of the analytical statistics. According to Table 1, there is no difference in the scores of social function between the healthy children siblings and the siblings of children with developmental disabilities. However, the mean score difference in emotional, educational, physical, and the quality of life of healthy children siblings is significant ($P>0.05$).

4. Discussion

According to the results, children with developmental disorders do not negatively affect the social relationship quality of their siblings. Although it is assumed that adolescents, who live in families with disabled children, have social problems, the results showed that these adolescents are no different from other adolescent in social relationships. Such difference can be due to the limitations in the statistical population of this research. It can also be due to the expansion of social relationships in adolescents (from the family level to the level of community) and their less dependency on the family. Benson and Karlof concluded that the siblings of children with autism have the same social function as the siblings of the healthy group, if not suffering from mental disorders [23].

Seltzer and Shattuck showed that there may be social damages in siblings of a child with autism, but these are not progressive and their social relationship will develop by improving their relationship with the child with autism [24]. Children with developmental disabilities have negative effects on their sibling's emotional quality. This can be the result of adaptive problems in these children. In case of proper admission, the disability of the affected sister will be reduced to emotional damage. Also, it can result from emotional and behavioral problems of their

Table 1. The Mean±SD scores for the PedsQL scales in two groups

Dimensions of QOL	Groups				Mean Differences	P
	Control		Experimental			
	Mean	SD	Mean	SD		
Social function	78.65	13.01	83.63	15.6	-2.66	0.026
Emotional function	73.28	18.07	61.81	21.50	-2.07	0.023
Physical function	83.20	13.85	71.93	20.06	-1.84	0.023
School function	85.15	13.82	77.42	14.69	-2.66	0.027
Quality of life	82.32	11.38	73.69	13.13	-8.66	0.018

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parents which have a negative effect on emotional quality of these adolescents. Also, the negative feeling of having a disabled brother or sister increases as a result of extended social networks, during adolescence. They may receive less attention from their parents that leads to emotional problems [1]. According to Benson and Karlof, siblings of children with autism have increased level of mental pathology [23].

The findings showed that children with developmental disabilities negatively affect the physical quality of their siblings. This can be due to family limitations to leave the house and limited physical rest for such teenagers since childhood. Also considering that in this study healthy children are older than disabled ones, weakness in physical quality can be due to the healthy children's assistance in daily activities of their disabled sibling and its resulted physical pressures.

Mulroy and Roberson indicated that events participation was difficult for families with children with special needs [6]. Hashemi and Shekarpour indicated that cancer diagnosis in a child causes severe anxiety for parents and since a child with cancer needs more care, parents' attention to other siblings decreases that leads to behavioral, social and physical problems [24]. There are no sufficient studies available to discuss this issue further. Most studies showed limitations in the general function of these adolescents but no explanation was presented for physical problems.

Considering the findings, it seems that children with developmental disabilities have a negative effect on their sibling's educational quality. This can be explained by adolescent's limited time to study and their so much time spent to protect the disabled child. Also, parents may spend time teaching and treating their disabled child and

ignore their other children's educational functions. Furthermore, emotional conditions of these adolescents can influence their education. Sharp and Roeyers showed that humiliation as a result of parents ignorance, does not simply appear in the form of aggressive and risky behaviors in the disabled child, and it is rather expressed in other aspects such as educational issues. Since these adolescents devote most of their time to their disabled sibling, they miss the time for educational activities [24].

Skotko and Levine declared that children with a brother or sister with Down syndrome, experience more educational problems than others and factors such as children training, their age difference and the biologic conditions of the disabled child and the family size are effective in this matter [25]. Generally, it seems that children with developmental disabilities have a negative effect on their sibling's quality of life. Considering the results about weakness in physical, educational and emotional quality of these adolescents, decreased quality of life is expected which can be justified by the above-mentioned causes, such as adaptive problems and parent's ignorance.

Wood and Sherman studies about siblings of children with seizures show that their quality of life is to some extent related to the behavioral disorders in suffered sibling [26]. Comprehensive behavioral problems require parent's persistent participation which may limit parent's time for their healthy children. Thus, healthy children may feel that a lot of protection duties are imposed to their parents and this decreases their quality of life.

5. Conclusion

Previous studies show that the siblings of children with developmental disabilities who are dependent to others

for their daily activities, are more affected than those with less dependency [26]. The present study showed that educational, emotional and physical quality and in general the quality of life of siblings of children with severe developmental disorders are lower than the healthy group. Therefore, it is essential to mention these children's problems to their parents. Therefore these parents try their best ways to treat their healthy and disabled children, to improve their mental health and to increase their quality of life. Future research can investigate further problems of these children, such as anxiety, fear, and stress.

Ethical Considerations

Compliance with ethical guidelines

All participants were informed about study objectives and those agreeing to participate signed the informed consent forms.

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Conflict of interest

The authors certify that they have no affiliation with or involvement in any organization or entity with any financial, or non-financial interest in the subject matter or materials dismissed in this manuscript.

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