



Desire to have other children in families with a chronically disabled child and its effect on the relationship of the parents

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Abstract

Aim: The aim of this study was to examine the desire of the parents who had a chronically disabled child to have other children and to investigate the effect of having a disabled child on the relationship of the parents.

Material and Methods: The families of 145 chronically disabled children were included in the study. After the sociodemographic information belonging to the child and family were obtained, the prepared questionnaire form was used to interrogate if the parents lived together, the number of children in the family, if they wished to have other children and the relation of the disabled child with the household. Ethics committee approval was obtained from Dokuz Eylül University (date: 18.10.2012, decision number, 2012/34-13). The data obtained in the study were expressed as figures and percentages.

Results: While 91.7% of the parents continued their relationship, 2.8% were divorced and 1.4% were left by their spouses. The rate of the parents who did not wish to have (or did not have) other children after a disabled child was found to be 65.2%. The major reason for the families not to wish to have other children was found to be the fact that they thought they could not spare enough time for their disabled child. While 35.1% of the parents stated that clamped together more tightly, 35.2% stated that their concerns about the future increased further. Fifty eight percent of the parents stated that social relations and community involvements were not affected, whereas others stated that they were affected in different ways.

Conclusions: Although the relationship between the parents was not affected to a great extent in families who had chronically disabled children, it was found that parents intensively experienced concern for the future. It was found that this also affected the desire of the parents who had a chronically disabled child to have other children with the concern that the child will be disabled. (Türk Pediatri Ars 2015; 50: 163-9)

Keywords: Impact on family, caregiver, sibling, chronically disabled children

Introduction

Learning that they will have a disabled child while waiting excitedly to have a healthy child like every family leads to devastating outcomes in the parents of disabled children. Studies have shown that parents who have disabled children are under stress with a higher rate and experience psychological disorders including depression and anxiety with a higher rate compared to parents who have healthy children (1-3). With the additional stress brought by the disabled child into the familial life, intra-family relationships and social relations are disrupted and the economical status of the family is affected negatively. Many parents experience an in-

creasing level of anxiety, depression and hopelessness, their marriage relationships are disrupted and personal adaptations are decreased (4, 5). Florian et al. (6) reported that the levels of self-confidence and marital adjustment were lower in the mothers who had children with cerebral palsy compared to the healthy control group.

The financial and moral burden in caregivers of chronically disabled children increases, such that care of disabled children may become a burden which can not be overcome by the families who experience economical problems in cases where one of the parents is not working (7). In studies conducted with siblings of disabled children in recent years, it has been found that

children with a disabled sibling are also more stressful (8). Siblings of disabled children had psychopathological problems such as stressful life, adaptation problems, increase in the feeling of inadequacy and internal and external behavioral problems and unrealistic responsibilities at home (9, 10). Siblings of disabled children reported that their responsibility to take care of their siblings when their parents were not at home was "a very big responsibility" (11, 12).

In the literature, there are studies examining the relationship between the mother and father and how marriage relations are affected, but there is no study how this condition affects the thoughts of having another child. Some studies reported that parents who had disabled children were less satisfied with their marriages compared to parents who had healthy children. Other studies reported that parents who had disabled children were satisfied with their marriages, but the quality of their marriages were affected negatively (13-15). This study was planned to examine the desire of the parents who had chronically disabled children to have another child and investigate the effect of having a disabled child on the relationship of the mother and father.

Material and Methods

One hundred forty-five families whose children were diagnosed with chronic disability, received rehabilitation in private education centers in Düzce and Karadeniz Ereğli and accepted to participate in the study were included.

The study inclusion criteria were specified as having a chronically disabled child and volunteering to participate in the study. The families of the children who did not wish to participate in the study and who had difficulty in understanding or replying the questions were excluded from the study.

The consent form in which the method and objective of the study were described was signed by the families who participated in the study. The study was evaluated by Dokuz Eylül University Ethics Committee for Non-interventional Studies and was approved in terms of ethics (decision date: 10.18.2012, decision number: 2012/34-13).

In the scope of the study, the sociodemographic information related with the children and parents were obtained and the data collection process was completed using the prepared questionnaire form which questioned the number of children in the family, if they had other children after their disabled child (or if they

wished to have other children) and their reasons, who directly cared for the disabled child, the relation of the disabled child with siblings and peers, if any financial support was received for the care of the disabled child and the family's intended purpose for this financial assistance, if any change occurred in the relationship of the parents after having a disabled child, domestic and non-domestic relations and social participation of the parents. Face-to-face interview was used as the data collection method.

Statistical analysis

The data obtained were evaluated using SPSS (Statistical Package for the Social Sciences version 20, Chicago, IL, USA) 20 package program. The numerical variables of the study were expressed as mean±standard deviation (Mean±SD), number and percentage (n, %).

Results

The demographic properties and diagnoses of the children included in the study are shown in Table 1.

The demographic properties, education and occupa-

Table 1. Sociodemographic properties of the disabled children

	Mean±SD	
Age (years)	9.56±7.23	
Height (cm)	118.31±25.32	
Weight (kg)	26.84±15.44	
Gender	n (%)	
Female	57 (39.3)	
Male	88 (60.7)	
Diagnosis	n (%)	Cumulative %
Cerebral palsy	63 (43.4)	43.4
Spina bifida	16 (11)	54.4
Mental retardation	15 (10.3)	64.7
Epilepsy	10 (6.9)	71.6
Muscle disease	9 (6.3)	77.9
Down syndrome	9 (6.2)	84.1
Autism-attention deficit hyperactivity	8 (5.5)	89.6
Developmental retardation	5 (3.4)	93
Brachial plexus palsy	3 (2.1)	95.1
Learning difficulty	3 (2.1)	97.2
Hearing defect	1 (0.7)	97.9
Speech disorder	1 (0.7)	98.6
Congenital hip dislocation	1 (0.7)	99.3
Congenital phocomelia	1 (0.7)	100

Cumulative %: cumulative frequency value; Mean±SD: mean±standard deviation

Table 2. Sociodemographic properties of the parents

	Mean ± SD
Age of the mother (years)	36.02±8.44
Age of the father (years)	39.37±7.85
	n (%)
Total monthly income of the family	
0-699 TL (very low)	46 (31.7)
700-1 499 TL (low)	59 (40.7)
1 500-2 500 TL (moderate)	31 (21.4)
2 500 and above (high)	9 (6.2)
Maternal education	
Illiterate	39 (26.9)
Primary school	61 (42.1)
Secondary school	23 (15.8)
High-school	19 (13.1)
University	3 (2.1)
Paternal education level	
Illiterate	25 (17.3)
Primary school	47 (32.4)
Secondary school	36 (24.8)
High-school	29 (20)
University	8 (5.5)
Maternal occupation	
Housewife	139 (95.9)
Officer	6 (4.2)
Paternal occupation	
Self-employment (driver, cook, waiter, farmer, carpenter)	57 (39.3)
Employee	51 (35.2)
Officer	15 (10.4)
Retired	9 (6.2)
Unemployed	8 (5.5)
Tradesman	3 (2.1)
Private	2 (1.4)
Togetherness of the mother and father	
The mother and father are living together	133 (91.7)
Death	6 (4.1)
Divorced	4 (2.8)
Deserted	2 (1.4)
Was the reason of divorce the disabled child?	
Yes	2 (1.4)
No	143 (98.6)

mean±SD: mean ± standard deviation

tional states of the parents included in the study and the distribution of total monthly family income are shown in Table 2.

While 91.7% of the parents were continuing their togetherness, 2.8% were divorced and 1.4% were left by their spouses (Table 2).

The individual responsible of the care of the disabled child was the mother in 97.9% of the participants, the father in 2% and grandmother in 0.7% (Table 3). The median value for the number of children per family was found to be 2 (lower quartile/upper quartile:2/4).

The question "would you wish to have another child after your disabled child (or do you have another child)" was answered as "yes" by 33,8% of the parents and as "no" by 66.2%. The reasons for not wishing to have another child were found to be the thought that they could not spare enough time for their disabled child (31.3%), the fear of having another disabled child (18.8%), lack of financial strength to take care of another child (15.8%) and other reasons (34.3%). The reasons of the parents who wished to have another child (or who had another child) included the thought that a sibling would support the development of the disabled child (a sibling for spending time and playing together) (30.7%), the fact that they had a child from an unplanned pregnancy (24.4%) and the desire to have a crowded and multi-child family (20.4%), respectively.

The question "how is the relationship of your disabled child with his/her siblings?" was answered as "they do not get along very well" by 24 (16.7%) of the parents, as "they get along very well" by 87 (60%), as "my healthy child does not want to take care of his/her sibling" by 6 (4.1%) and as "their relationship is not too bad" by 28 (19.3%) (Table 3).

The question "How is the relation of your child with his/her peers?" was answered as "likes to play with peers" by 98 (67.6%) of the parents, as "feels uneasy and troubled while playing with peers" by 13 (9%), as "be-ware of going to peers" by 15 (10.3%) and "keeps away from other children because he/she can not adapt to their plays" by 19 (13.1%) (Table 3).

The question "How did your child's disease affect your relationship with your spouse and your perspective on the future?" was answered as "my anxiety about the future increased further" by 51 (35.2%) of the parents, as "we started to fight more" by 25 (17.2%), as "my spouse started to be distant from me and home" by 20 (13.9%),

Table 3. The desire of the parents to have another child and the social relations of the disabled child

Questions	n (%)
Do you have another child?	
Yes	115 (79.3)
No	30 (20.7)
The number of children in the family	
1	31 (21.4)
2	65 (44.8)
3	30 (20.7)
4	11 (7.6)
5	6 (4.1)
7	2 (1.4)
Would you like to have another child after your disabled child (or do you have another child?)	
Yes	49 (33.8)
No	96 (66.2)
The reasons of of the parents who did not wish to have another child:	
I fear that my other child will also be disabled	18 (18.8)
We do not have the financial status to afford another child	15 (15.8)
I think that the time I will spare for my disabled child will be reduced.	30 (31.3)
Other	33 (34.3)
The reasons of the parents who wished to have another child after their disabled child (or who had another child):	
I want a crowded family	10 (20.4)
I want my other child to help me in caring for my disabled child	12 (24.4)
I think that it will be a significant factor in recovery of my disabled child	15 (30.7)
We did not wish to have another child. but we did	12 (24.4)
Who takes care of your disabled child?	
Mother	142 (97.9)
Father	2 (1.4)
Grandmother	1 (0.7)
How is the relationship of your disabled child with his/her siblings?	
He/she can not get along well with his/her siblings	24 (16.6)
He/she gets along well with his/her siblings.	87 (60)
My healthy child does not want to take care of my disabled child.	6 (4.1)
Their relationship is not too bad	28 (19.3)
How is your disabled child's relationship with the parents?	
Good	143 (98.6)
Bad	2 (1.4)
How your disabled child's relationship with his/her peers	
He/she likes to play with them.	98 (67.6)
He/she becomes irritable and feels sorry while playing with them.	13 (9)
He/she bewares of going to them	15 (10.3)
He/she keeps away from them because he/she can not adapt to their plays.	19 (13.1)

Table 4. The support given to the parents for their disabled child and the affection of their social relations

	n (%)
Do you receive any financial support for your disabled child from the government or any institution/foundation	
Yes	77 (53.1)
No	68 (46.9)
If the answer is yes what is the amount?	
0-600 TL	74 (96.1)
670-750 TL	3 (3.9)
For what purpose do you use this financial support?	
To meet the disabled child's healthcare. school and other personal requirements	39 (%50.7)
To meet other requirements in addition to the disabled child's requirements	38 (49.3)
- Basic needs of the other siblings	13 (16.9)
- Needs of the house	25 (32.4)
How did your child's disease affect your relationship with your spouse and your perspective on the future?	
My concerns about the future increased	51 (35.3)
We started to fight more and domestic problems increased	25 (17.3)
My spouse started to to be distant from me and home	20 (13.9)
My spouse left home after the child	2 (1.4)
We attached to each other more strongly	46 (31.8)
How did your child's disease affect your relations with your social circle, friends and relatives?	
They do not call me for their meetings any more	8 (5.5)
Even if they call me for their meetings, I can not attend their meetings, because my child gets restless	36 (24.8)
Even if they call me for their meetings, I do not attend their meetings because of their point of view about my child and their behaviors	17 (11.8)
I do not have any difficulty and there is no change in my social relations	84 (58)

as "my spouse left home after the child" by 2 (1.4%) and as "they were attached to each other more strongly" by 51 (35.1%) (Table 4).

The question "How did your child's disease affect your relationship with your social circle, friends and relative?" was answered as "they do not call me for their meetings any more" by 8 (5.5%) of the parents, as "even if they call me for their meetings, I can not attend their meetings, because my child gets restless" by 36 (24.8%), as "even if they call me for their meetings, I do not attend their meetings because of their point of view about my child and their behaviors" by 17 (11.8%) and as "I do not have any difficulty and there is no change in my social relations" by 84 (58%) (Table 4).

The question "Do you receive any financial support from the government of any institution or organization?" was answered as "yes" by 77 individuals (53.1%) and as "no" by 68 individuals (46.9%). Thirty nine (50.7%) of the families who were receiving financial support stated that they were spending this financial support for the child's healthcare, school and other personal requirements, whereas the others (49.3%) stated that they were spending this financial support for the basic needs of the other children in addition to the disabled child's requirements and for the requirements of the house (especially for kitchen expenses) (Table 4).

Discussion

A diagnosis made at the time of birth or during the postnatal period which would affect the well-being of the child may be the onset of a substantially difficult and troublesome life both for the family and the child.

In studies related with families who have chronically disabled children, it has been found that parents experience negativities to a greater extent compared to families who have healthy children. It has been found that these parents experience problems resulting in chronic sorrow, stress, inadequate self-confidence, depression, social isolation, various emotional stresses, increased marriage problems, decreased rates of employment or decreased rates of starting a new job (16-23). It has been reported that the problems experienced increase as the socio-cultural and economical level of the family decreases (24, 25). A significant portion of the families included in our study were in the low and very low income group and 69% of the parents were illiterate or graduates of primary school. The rate of employment was substantially low in the mothers who were responsible of taking care of the disabled child. In studies, it has been found that families with disabled children experience social isolation because of experiencing financial problems, inability to spare time for themselves, narrowing in the social circle and being stigmatized and this affects their psychological health negatively (24, 25). It has been reported that parents have decreased satisfaction with their marriage as a result of affection of their psychological health (6, 26, 27). It has been shown that the stress created by the problems experienced by the parents who have a disabled child while coping with difficulties leads to increased rates of divorce or separation compared to the parents with healthy children (17, 26, 27). Although problems with marital adjustment are experienced after a disabled child, there are also studies reporting that posi-

tive changes occur in the areas of love, hope and happiness (28, 29). In some studies, it was found that the parents who had a disabled child were attached to each other more strongly and supported each other more to cope with the problems brought along by the disabled child (30, 31). In our study, the rate of divorce or being abandoned in the parents who had a disabled child was found to be substantially low. Although there were parents who reported that they experienced anxiety about the future with the birth of the disabled child (or after the diagnosis was made after delivery), a great portion of the participants reported that they were clumped together more tightly. In our study, 13.9% of the participants reported that their spouses drifted apart from themselves and from home. In the study of Özekes et al. (32), it was reported that women experienced adaptation problems with their husbands after the birth of the disabled child and they stated that their husbands cared about home and family members to a lesser extent. However, detailed investigation revealed that this problem arised from the fact that the activities the partners performed together (visiting friends, going together to have a good time, etc.) decreased after the birth of the disabled child, rather than the negative behaviors of the husbands. It was also found that the fact that the fathers spared more time for work was the major reason for them to appear as uninterested (32). In our study, 58% of the families reported that there was no change in their social participations compared to the past, while the others reported that their social participations were disrupted due to various factors arising from themselves (11.8%), from their disabled children (24.8%) or their social circles (5.5%).

Not only parents but also other family members and especially siblings, if present, may be affected in different aspects with presence of a disabled child. In studies, it has been found that siblings of disabled children have a more stressful life compared to healthy peers, experience adaptation problems, take care of their disabled sibling when their mothers are not at home and thus mature earlier and take greater responsibility. In addition, it has been found that children who have a disabled sibling are more emotional, compassionate and helpful compared to peers who have healthy siblings (33, 34). In our study, it was found that 60% of the disabled children could get along well with their siblings, though not questioned in detail, but 4.1% of the healthy siblings did not wish to take care of/play with the disabled child and 16.6% could not get along well with their disabled sibling. According to the information obtained from the parents it was understood that some parents gave their healthy children the responsibility

of caring for and supporting their disabled siblings. In the families who have another child after their disabled child, it is observed that the siblings are given the responsibility of helping in caring for and supporting the disabled child.

To our knowledge there is no report in literature studying the desire for another child birth in parents who have a chronically disabled child. It has been stated that especially the mother is affected negatively and may experience various psychiatric and emotional problems (anxiety, stress, depression, reduced quality of life) (35, 36). The above-mentioned problems and socio-economical problems may lead to different point of views related with the desire to have another child. Hence, parents who have a child with health problems may be observed to experience concerns about the possibility that the other child will also have health problems. The results obtained in our study also support this observation. Sixty-six percent of the parents had no other children except for the disabled child (or they did not think of having another child). Thirty-one percent of the parents stated that the reason for this was that the time they would spare for the disabled child would be shortened. A great portion of the families included in our study were experiencing economical problems and regarded the donation given for the child as the source of income for the family. Sixteen percent of the families stated that they did not wish to have another child because of the economical problems they experienced and because they could not afford caring for another child. Twenty-four percent of the parents who thought of having another child regarded a healthy child as a family member who would take care for the disabled child. All these results show that family members in families who have a disabled child need education and support to a great extent. Providing the necessary support to these families is important in terms of increasing the quality of life of all family members.

The results of this study showed that a significant portion of the parents who had a chronically disabled child experienced economical problems, did not have serious problems in continuing their relationship after having a disabled child, had a reduction in thoughts of having another child and the parents who thought of having another child aimed to use the healthy child as an assistant for supporting the development of the disabled child and for taking care of him/her. Further studies with larger sample groups comparing the domestic states of families who have chronically disabled children, with families who have healthy children are needed.

Ethics Committee Approval: Ethics committee approval was received for this study from the ethics committee of Dokuz Eylül University (date: 18.10.2012, decision number, 2012/34-13).

Informed Consent: Verbal informed consent was obtained from parents who participated in this study.

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