

## Sibling Relationship in Families Raising a Child with Chronic Illness as Perceived by Family Caregiver

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### Abstract:

**Background:** Most of the children with chronic illness live in their home, and their presence impacts family members. Siblings may be especially affected because of the common cultural milieu and egalitarian nature of their relationships. **The aim** of the study was to assess caregiver perception of sibling relationships in families raising a child with chronic illness. **Setting:** It was conducted at the outpatient clinic of Zagazig University hospital and Altarbia Alfezeria school at Zagazig city. **Subjects:** The respondents were composed of caregivers of 108 families who have a child with chronic condition. **Tool:** One tool was used to collect the necessary data. It composed of two parts an interview questionnaire sheet and the Sibling Inventory Behavior (SIB) were used for data collection. The tools consisted of two parts; the first part was used to assess the socio-demographic characteristics of children and their families, the second part used to assess sibling relationships in families with a handicapped child. **Results:** the result of the study showed that, companionship, empathy, teaching/managing has high percentage among sibling of children with diabetes than those with Down syndrome and Autism as rated by the caregivers. The study also showed that caregivers perceived that there was more companionship behavior among the older siblings than the younger ones, while younger siblings had avoidant behavior towards a child with a chronic condition than the older siblings. **Conclusion,** this study showed some differences in perception of sibling relationships according to type of chronic condition. It is **recommended** that, Observational methods might be used in future research to assess sibling relationships.

**Key words:** caregiver perception, children with chronic illness, Sibling relationships, Down syndrome, Autism, Diabetes.

### Introduction:

Chronic illness are defined as physical or mental conditions, that affect the daily functioning of individuals for intervals longer than three months a year, or for a duration of hospitalization longer than one month. Disabilities occur in all ages and racial, ethnic, and socioeconomic groups, and a large number of households have a member with a disability needing care.<sup>(1)</sup> These disabilities or chronic conditions/illnesses may affect the child's intellectual development (e.g., Down syndrome [DS] and developmental delay), emotional development (e.g., autism and bipolar disorder), or

physical development (e.g., arthritis and other orthopedic conditions [OC].<sup>(2)</sup>

Most of the children with chronic illness live at home, and their presence impacts family members even though the specific disabilities/chronic conditions may vary. Sibling relationships provide physical and emotional contact at critical life stages. These stages help children learn social skills, and are usually the first, most intense, and longest peer relation that an individual will have.<sup>(3)</sup> However, when a child suffers a chronic illness, sibling relationships may be altered Strained because a chronically ill child

is perceived as needing more protection and attention in order to survive.<sup>(4)</sup>

The psychological growth of the healthy sibling may be affected if a chronic illness brings stress to the sibling relationship. These siblings are at a higher risk to develop depression, anxiety, and a low self-esteem. Moreover, they are more likely to experience psychosomatic symptoms such as: difficulties with social isolation, poor communication with parents, and a sense of responsibility and resentment toward their ill sibling.<sup>(5)</sup> In the same line, Ellenwood and Jenkins<sup>(6)</sup> note that healthy siblings may feel abandoned by their parent, become resentful, and pick fights with peers and/or other siblings. In another study, researchers displayed that siblings could identify and describe one or more personal strengths that developed as a result of coping with the challenges of having a sibling with a chronic illness. Many of these strengths included: enhanced coping skills, increased personal competence, greater appreciation of the sibling's life and well-being, and a strengthening of family bonds. Further, the healthy sibling became more sensitive to people with disabilities, made new friends, and had a greater appreciation for a person's inner strengths.<sup>(7)</sup>

There is also literature discussing the effects that gender and age have on sibling relationships in families raising a child with a disability. For example, when looking at gender, Houtzager et al.<sup>(8)</sup> displayed that sisters of children with cancer displayed more loneliness, anxiety, and insecurity than did brothers. In addition, Silver and Frohlinger-Graham<sup>(9)</sup> found that sisters of children with disabilities often have more psychological distress than do sisters of typically developing children. Regarding the age of the sibling, mothers perceived older

siblings as more avoidant than younger siblings especially if the child with disabilities (autism, mental retardation, disabilities, or arthritis) behavior is embarrassing or destructive<sup>(10-12)</sup> or if the siblings are teased or lose status in their peer groups.<sup>(13)</sup>

Due to longevity and shared growing experiences, sibling relationships are usually the strongest of all family bonds. Siblings often share their thoughts, feelings and secrets with each other, and this can lead to a supportive relationship in which they can mature. Even competition between siblings can be useful by teaching children about conflict resolution and interaction. Not surprisingly then, that sibling relationship has been shown to have a considerable effect on the development and social adjustment of children.<sup>(14)</sup> As Nurses provide family centered care, nurses can help these needy families develop the necessary coping skills by providing effective interventions that will help them meet the strenuous demands placed on them when there is a chronically ill child to care for within their family.<sup>(15)</sup>

#### **Significance of the study:**

Children's initial social interactions are usually with their siblings. Because of these interactions, they become each other's instructors, role models, counselors and mediators. Siblings usually spend twice as much time interacting together as they do with their mother or father. In addition, the lifespan of the siblings usually extends beyond that of their parents.<sup>(14)</sup> For these reasons, siblings significantly influence one another while growing up and into adulthood.

#### **Aim of the study:**

The aim of current study was to determine sibling relationships in families raising a child with chronic illness as perceived by caregiver.

**Research Question:**

How family caregivers perceive sibling relationships in families raising a child with chronic illness?

**Subjects and methods:****Research design:**

A descriptive exploratory design was utilized

**Setting:**

The current study conducted at the outpatient clinics of Zagazige University Hospital and Altrabia Alfekeria School at Zagazig City. Altrabia Alfekeria School is one of the largest schools providing free care for patients with developmental disabilities. The school accepts repeated 150 children/ adolescents per day. It introduces many services for them such as; learning, physiotherapy, treatment, and care. The school serves a variety of urban and rural area at El Sharkia Governorate.

**Subjects:**

A convenience sample consisting of 108 Caregivers of families having children with chronic condition were recruited. The eligibility criteria was having an adult family caregiver (over the age of 18 years), of a child 4-14 years old with chronic conditions and the age of sibling ranges from 3-18 years, both gender included. The following chronic conditions were represented in the sample: autism ( $n = 20$ , 18.5%); DS ( $n = 36$ , 33.3%); and diabetes ( $n = 52$ , 48.2%).

**Tools of data collection:**

One tool was used to collect the necessary data. It composed of two parts:

- **Part (I): An interview questionnaire sheet:** used to determine the socio-demographic characteristics of the father & mother (age, education, income, and job), child (age, gender, educational grade, birth order,

residence, and diagnosis), and siblings (age & gender).

- **Part (II): Sibling Inventory Behavior (SIB):** The SIB was originally developed by Schaefer and Edgerton<sup>(16)</sup> to assess sibling relationships in families with and without a handicapped child. The SIB was revised again by Hetherington and her colleagues.<sup>(17)</sup> The SIB consisted of 6-subcales,: (a) empathy/concern (5 items), (b) companionship/involvement (6-items), (c) rivalry (6-items), (d) conflict/aggression (5-items); (e) avoidance subscale (5-items), and (f) teach/directiveness (4-items). Alphas across scales were acceptable for empathy (median  $\alpha = .88$ ), rivalry (median  $\alpha = .77$ ), aggression (median  $\alpha = .80$ ), avoidance (median  $\alpha = .85$ ), teaching/directiveness (median  $\alpha = .67$ ) and companionship/involvement (median  $\alpha = .88$ ). Total score and subscale scores were used for the statistical analyses in this study. Caregivers rated relationships between the typically developing sibling and the child with chronic condition on a Likert Scale of 1 (*never*) to 5 (*always*).

**Content validity:**

The instrument was translated into Arabic language using the translation-back-translation method to ensure its validity. Validity was established for face and content validity by five experts from nursing faculty who revised the tools for clarity, relevance, applicability, comprehensiveness, understanding and ease for implementation and according to their opinion minor modification were applied.

**Pilot Study:**

A pilot study was carried out before performing the actual study on 10% of the sample in order to test

clarity of the scale items as well as to estimate the time needed for data collection. Necessary modifications were done. The tool was finalized according to the results of the pilot, and these participants were excluded from the sample.

**Fieldwork:**

The investigator met with individual family caregivers eligible for inclusion and invited them to participate after explaining to them the purpose and procedures of the study. Those who agreed to participate were interviewed individually by the researcher using the data collection tool. Each interview lasted for about 30 minutes. Data collection lasted for 6 months which started from September 2013 to February 2014.

**Administrative and ethical considerations:**

An official permission to carry out the study was secured through an official letter to the administrators of Zagazig University hospital and Altrabia Alfezeria School explaining the purpose of the research to get the permission for data collection. The researcher met with each family caregiver to explain the purpose of the study and to obtain verbal consent to participate after informing them about the rights to refuse or withdraw from the study with no untoward consequences. Participants were reassured about the confidentiality of the information collected, and that it would be used only for the purpose of scientific research. No harmful maneuvers were performed or used, and no foreseen hazards were anticipated from conducting the study.

**Statistical design:**

Data entry and statistical analysis were done using SPSS 16.0 statistical software package. Data were presented using descriptive statistics in the form of frequencies and percentages for qualitative variables, and means and

standard deviation for quantitative variables. We used analysis of variance (F-test) for comparison of mean scores of variables. Correlation analysis was done by Pearson correlation coefficients. Statistical significance was considered at  $P\text{-value} < 0.05$ .

**Results:**

**Table (1):** Display that the age of the children ranged from 4 to 14 years with a mean age of  $10.0 \pm 3.7$  years. More than half of the studied children were male (51.9%), living in urban area (58.3%). More than two third of the studied children (78.7%) have lower birth rank, while (43.5%) of them were primary school grader. Diagnosis was diabetes in (48.1%), Down Syndrome in (33.3%) and Autism in (18.5%) of the studied children.

**Table (2):** Demonstrates that mothers' age ranged from 22 to 57 years, with a mean age of  $37 \pm 7.8$  years, while father age ranged from 23 to 65 years with a mean age of  $43.8 \pm 8.3$  years. About one third of mothers and fathers had intermediate education, 36.1% and 32.4% respectively. About half of fathers (50.9%) were Employees, while more than three fourths of mothers (79.6%) were housewife. Income status was insufficient in more than half of the sample (63%). Brother age in more than half of the sample was between 13 to 18 years (57.4 %).

**Table (3):** Displays that the highest mean scores were empathy, followed by companionship  $19.38 \pm 4.8$  and  $19.25 \pm 5.1$  respectively. Mean while the lowest mean score was for Avoidance  $9 \pm 5.4$ .

**Table (4):** Indicates that the mean scores of empathy, avoidance, and teach/manage according to diagnosis had a high significant difference among diabetes, Down Syndrome and Autism. However, according to age of the sibling it did

not show a significant difference among 3-8 years, 8-13 years, and 13-18 years. Also, according to gender of the sibling it didn't show significant difference between male and female. Rivalry and aggression according to diagnosis, age, and gender of the sibling did not also show significant difference among diabetes, DS and autism. As observed in table (4), companionship according to diagnosis highly statistically significantly differed among diabetes, Down syndrome and autism. However it didn't show significance difference in accordance to the age and gender of the sibling.

**Table (5):** Indicates that the strongest significant positive correlation was between empathy and teach/manage followed by the relationship between aggression / conflict and rivalry ( $r= 0.71$  and  $0.61$ ) respectively at  $p < 0.001$ . It can also be noted that Companionship has strong significant positive correlation between Empathy and Teach/Manage ( $r=0.55$  and  $0.54$ ) respectively at  $p < 0.001$ . While the strongest significant negative correlation was between avoidance and teach/manage, empathy and companionship ( $r= -0.48$ ,  $-0.44$ , and  $-0.37$ ) respectively at  $p < 0.001$ .

#### **Discussion:**

Sibling relationships are a critical part of child development and adaptation<sup>(18, 19)</sup>. However, there are mixed findings in previous studies as to whether these relationships are negative or positive in families raising a child with a disability or chronic condition, and minimal information is available regarding differences in these relationships by the type of chronic condition or characteristics of the parent or sibling. To address this gap in previous literature, care giver perceptions of sibling relationships in families raising a child with a chronic condition was investigated.

Differences in caregivers' perceptions of sibling relationships were examined according to the type of chronic condition (autism, DS, and diabetes) and the age and gender of the sibling.

The present study showed differences in perception of sibling relationships according to type of chronic condition. Caregivers rated sibling of children with diabetes as a significant companionship, empathy and teach/ manage than children with Down syndrome and autism. This finding is contradicted with the finding of Benderix and Sivberg<sup>(10)</sup> who found that sibling of children with autism were empathic toward their brothers or sisters with autism. The literature also indicates that siblings of children with autism or DS have kinder and more positive interactions than did siblings of typically developing children<sup>(20)</sup>, and living with a child with DS may be growth promoting and positive, displayed as kind behaviors toward the child with DS.<sup>(21)</sup>

Results of the current study revealed that, avoidance was significantly higher in autism and Down syndrome followed by diabetes. This may be related to autism and Down syndrome embarrassing or destructive, sibling might be teased or lose status in their peer groups as a result of the behavior of the child with a chronic condition. Caregivers were inaccurate in interpreting child's feelings of avoidance. This may be less overtly expressed than unkind or hurtful action but may nevertheless influence relationship. This result goes on line with the findings of Waite-Jones and Madill<sup>(13)</sup> who found that avoidant behavior toward the child with autism may be a natural outcome.

The current study also showed that caregiver perceived older siblings as having more companionship behavior than younger siblings while youngest siblings had avoidant

behavior toward a child with a chronic condition than the oldest siblings. This finding contradicted with the finding of Lobato et al. <sup>(12)</sup> and Waite-Jones and Madill <sup>(13)</sup> who stated that avoidant behavior toward the child with a chronic condition may be a natural outcome as older siblings seeks acceptance from peers and associates. Older siblings may also have the desires to spend time outside the home with friends and peers, and responsibilities related to the care of the child with a chronic condition may limit their opportunities.

The result of the present study indicated that there is no statistically significant differences by sibling gender were found for caregiver perceptions of sibling relationships. This finding agreed with Cuskelly and Gunn <sup>(22)</sup> and in contrast to previous research Nielsen et al. <sup>(2)</sup> who mentioned that male siblings rated higher on kindness and involvement than the female siblings. Perhaps, a relationship exists between the stereotypes of male and female roles and the ratings of kindness and involvement. Females may be expected to be kind, involved, and nurturing, whereas males may not have this expectation. <sup>(23,24)</sup>

The current study indicated that, there were multiple positive and negative significant correlations between sibling relationship subscales. The strongest significant positive correlation was between empathy and teach/manage followed by relationship between aggression / conflict and rivalry. It can also be noted that Companionship has strong significant positive correlation between Empathy and Teach/Manage. While the strongest significant negative correlation was between avoidance and teach/manage, empathy and companionship. This result concurrent with the results of Nielsen et al. <sup>(2)</sup>

while contradicted with the result of Cuskelly and Gunn <sup>(23)</sup> who found that avoidance was not associated with either positive or negative sibling interaction. Whereas, they found there was a negative association between avoidance and activities that involved sibling care giving.

#### **Conclusion:**

The current study showed some differences in perception of sibling relationships according to type of chronic condition. Caregivers rated sibling of children with diabetes as companionship, empathy and teach/manage than children with Down syndrome and autism. Also, caregiver perceived older siblings as having more companionship behavior than younger siblings while youngest siblings had avoidant behavior toward a child with a chronic condition than the oldest siblings. No statistically significant differences by sibling gender were found for caregiver perceptions of sibling relationships.

#### **Recommendation:**

The present research used a caregiver report instrument to measure sibling relationships. Observational methods might be used in future research to assess sibling relationships because caregiver reports may underestimate or overestimate the kinds of interactions that siblings have with each other, and observational methods may capture a variety of relationships beyond those examined. Observational research could also enhance understanding by examining actual behavior between siblings as opposed to parental perception of sibling behavior.

**Table (1): Distribution of the studied children according to demographic and clinical characteristics (n=108)**

Items	Frequency	Percent %
<b>Age (years):</b>		
▪ Range		4-14
▪ Mean $\pm$ SD		10.0 $\pm$ 3.7
<b>Gender:</b>		
▪ Male	56	51.9
▪ Female	52	48.1
<b>Education:</b>		
▪ Nursery :	30	27.8
▪ Primary school:	47	43.5
▪ Preparatory school:	21	19.5
▪ Secondary school:	10	9.2
<b>Birth order:</b>		
▪ $\leq 3$	85	78.7
▪ $>3$	23	21.3
<b>Residence:</b>		
▪ Urban	63	58.3
▪ Rural	45	41.7
<b>Diagnosis:</b>		
▪ diabetes	52	48.2
▪ Down syndrome	36	33.3
▪ Autism	20	18.5

**Table (2): Distribution of the studied children's parents according to demographic characteristics**

<b>Mother</b>	<b>Frequency</b>	<b>Percent %</b>
<b>Mother Age (years):</b>		
▪ Range		22-57
▪ Mean $\pm$ SD		37 $\pm$ 7.8
<b>Mother Education:</b>		
▪ Illiterate	28	25.9
▪ Basic	19	17.6
▪ intermediate	39	36.1
▪ High	22	20.4
<b>Mother job:</b>		
▪ Working	22	20.4
▪ Housewife	86	79.6
<b>Father Age (years):</b>		
▪ Range		23-65
▪ Mean $\pm$ SD		43.8 $\pm$ 8.3
<b>Father Education:</b>		
▪ Illiterate	25	23.1
▪ Basic	18	16.7
▪ intermediate	35	32.4
▪ High	30	27.8
<b>Father job:</b>		
▪ worker	53	49.1
▪ Employee	55	50.9
<b>Income status:</b>		
▪ Sufficient	40	37.0
▪ Insufficient	68	63.0
<b>*Brother Age:</b>		
▪ 3-8	38	35.1
▪ 8-13	56	51.8
▪ 13-18	62	57.4

*\*Numbers are mutually exclusive*

**Table (3): Sibling relationship as perceived by caregivers (n=108)**

<b>Items</b>	<b>Total score</b>	<b>Mean <math>\pm</math>SD</b>	<b>Range</b>
▪ Companionship	30	19.25 $\pm$ 5.1	9-30
▪ Empathy	25	19.38 $\pm$ 4.8	5-25
▪ Teach/Manage	20	12.1 $\pm$ 4.5	4-20
▪ Rivalry	35	18.9 $\pm$ 5.7	7-35
▪ Aggression / Conflict	25	12.3 $\pm$ 3.8	5-24
▪ Avoidance	25	9 $\pm$ 5.4	5-25



**Table (4): Mean scores of companionship, empathy, teach/manage, rivalry, aggression /conflict, and avoidance according to diagnosis, age of sibling, and gender of sibling**

Items	Diagnosis			F	Age of the sibling			F	Gender of sibling			F
	Diabetes N= 52	Down syndrome N=36	Autism N=20		3-8 years	8-13 years	13-18 years		Male N=19	Female N=36	Both male and female (N=53)	
<b>Companionship</b>												
Mean±SD	21.3±4.5	19.1±4.8	14.1±2.87	20.2**	17.9±5.1	19.2±4.9	21.1±4.8	3.32*	20.1±5.5	18.8±5.8	19.2±4.4	
Range	9-30	11-30	10-23		11-28	10-30	9-30		(13-30)	(9-30)	(10-30)	0.42
<b>Empathy</b>												
Mean±SD	21.2±4.5	18.8±4.36	15.6±4.2	11.8**	19±4.8	18.7±4.7	20.9±4.7	1.92	19.8±4	18.6±5.5	19.7±4.5	0.69
Range	6-25	11-25	5-23		5-25	6-25	12-25		(12-25)	(5-25)	(11-25)	
<b>Teach/Manage</b>												
Mean±SD	13±4.1	12.8±4.5	8.2±3.6	10.8**	12.5±5	11.8±4.3	11.8±4.2	0.29	12.3±4.1	11.1±5	12.6±4.2	1.15
Range	4-20	4-20	4-15		4-20	4-19	4-20		(4-20)	(4-20)	(4-20)	
<b>Rivalry</b>												
Mean±SD	18±6.2	19±4.97	21.0±4.96	2.06	20±6.2	17.8±4.6	19.2±6.4	1.72	20.3±6.2	19.8±5.8	17.8±5.2	2.06
Range	7-29	9-13	13-35		7-35	8-28	8-29		(7-31)	(11-35)	(8-28)	
<b>Aggression / conflict</b>												
Mean ±SD	11.6±4.3	12.3±3.4	13.9±2.4	2.77	12.8±3.9	12.0±3.5	12.1±4.2	0.57	12.7±3.5	13.1±3.8	11.6±3.9	1.82
Range	5-24	5-19	10-20		5-20	5-20	5-24		(5-17)	(6-24)	(5-20)	
<b>Avoidance</b>												
Mean±SD	6±2.3	9.2±3.5	16.3±6.8	50.6**	10.3±6.8	8.7±4.5	7.7±4.4	1.84	8.6±5.2	9.4±5.97	9.0±5.3	0.15
Range	5-16	5-17	5-25		5-25	5-22	5-21		(5-25)	(5-25)	(5-23)	

(\*) statistically significant at  $p < 0.05$  levels(\*\*) statistically significant at  $p < 0.01$  level

**Table (5): Correlation matrix among scores of sibling relationship domains (n=108)**

Items	Companionship		Empathy		Teach/Manage		Rivalry		Aggression / Conflict	
	R	P	R	P	R	P	R	P	r	P
Avoidance	-0.37	<0.001**	-0.44	<0.001**	-0.48	0.001**	0.31	<0.001**	0.4	<0.001**
Aggression / Conflict	-0.26	<0.01*	-0.22	<0.05*	-0.29	<0.01*	0.61	<0.001**		
Rivalry	-0.06	>0.05	-0.09	>0.05	-0.15	>0.05				
Teach/Manage	0.54	<0.001**	0.71	<0.001**						
Empathy	0.55	<0.001**								

(\*) statistically significant at  $p < 0.05$  levels    (\*\*) statistically significant at  $p < 0.01$  levels    (-) negative correlation

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