THE PSYCHOSOCIAL IMPACT OF HANDICAPPED CHILDREN ON THEIR SIBLINGS: A COMPARATIVE STUDY

Irma Roca de Torres, Ph.D.
University of Puerto Rico

The psychosocial impact that a group of mentally retarded (MR) children had on their siblings was evaluated. The impact was assessed through the following instruments: Piers-Harris Children's Self-Concept Scale (PH), Child Behavior Checklist (CBCL) and the Roca's Siblings' Relationships' Scales (RSRS). The sample included 44 children of both sexes, ages 11-16, with intact families from middle/upper-middle class, who were older siblings to either an MR child (experimental group) or a nonretarded child (comparison group). No significant differences were found between the groups on the PH or on the Behavior Problems and Social Competence scales of the CBCL. Siblings of MR children were significantly closer to their MR sibling than controls as measured by the RSRS. It was concluded that siblings of MR children in the sample were not adversely affected by their respective MR brother or sister.

In the last several decades the number of handicapped children in the world has increased, probably because medical technology has saved the lives of children who in less advantageous circumstances would have died. Society, through its value and laws, is finally recognizing that handicapped children have the same human rights of nonhandicapped children. Public law 94-142 (1975) has established the right to a free comprehensive appropriate public education for all handicapped children. As the number of handicapped children in the schools increases, the necessity to prepare teachers and family members to understand the impact of these handicaps is augmented.

The adjustment of the handicapped child has been related, in part, to the attitudes of his or her parents about the handicap (Grossman, 1972; Darling, 1979; Tew & Laurence, 1973). Several authors (Gordon, 1980; Lobato, 1983; Poznanski, 1973; Seligman, 1983a) have stressed the importance of studying the impact that the handicapped child has on his or her family in order to be able to comprehend the individual dynamics.
Within the family dynamics' literature, several researchers have attempted to study the impact handicapped children have on their siblings. After all, siblings have been discussed as an essential part of family functioning (Bank & Kahn, 1975). The siblings' sub-system might have powerful influences on the adjustment of the handicapped child. Moreover, the siblings themselves have been described as children at risk (Lobato, 1983; McKeever, 1983; Seligman, 1983a, 1983b; Travis, 1976; Trevino, 1979).

The above authors have suggested that siblings of handicapped children have more probability of developing emotional disturbances, school difficulties, and maladjustment problems in general.

A review of the studies done on the impact handicapped children have on their siblings reveals contradictory results and variability in research methodology. Some studies (Graliker, Fisher & Koch, 1962; Miller, 1974) report observations or interviews of just a few siblings of handicapped children, while others involve more complex assessment of larger samples, including the assessment of control children (Grossman, 1972; Breslau, Weitzman & Messenger, 1981). Siblings of children with various handicapping conditions have been studied: mental retardation (Adams, 1965; Farber, 1959, 1960; Fowle, 1969; Gath, 1972, 1973, 1974, 1978; Grossman, 1972; San Martino & Newman, 1974); physical handicaps like Spina Bifida, Cerebral Palsy, orthopedic handicaps and Cystic Fibrosis (Breslau et al., 1981; Bolstad, 1975; Harvey & Greenway, 1984; Lobato, Barbour, Hall & Miller, 1986; Tew & Laurence, 1973); Cleft-lip/Cleft-palate (Gath, 1972, 1973, 1974); Diabetes (Carandag, 1978); and sensory deprivation (Schwirian, 1976).

Almost half the studies reviewed concluded that having a handicapped sibling has a negative impact on the "healthy" child. Poznansky (1973) indicates that psychiatrists see more siblings of handicapped children than handicapped children themselves. Harvey and Greenway (1984) found the self-concept score of handicapped children and their siblings significantly lower when compared to the score of normal controls. Tew and Laurence (1973), studying siblings of children with Spina Bifida, through teachers' ratings, found them four times as likely as controls to manifest psychological disturbance in school.

In two related studies, Gath (1972, 1973) compared the psychological adjustment of siblings of children with Down Syndrome and siblings of children with a cleft-lip/cleft-palate condition with siblings of nonhandicapped children through mothers' and teachers' ratings. Despite the similar methodology of both studies, their results were contradictory. No differences were found among the children in the 1972 study, while the 1973 investigation found siblings of Down Syndrome children to be twice as likely as controls to be rated as deviant by their mothers and their teachers.

Despite all these studies suggesting that handicapped children will adversely affect the adjustment of their siblings, the results are inconclusive. Some researchers (Grossman, 1972; Powell and Ogle, 1985) have found that the experience of growing up with a handicapped child brought the family closer together and made the siblings more sensitive towards humanity and more interested in service-oriented professions. No adverse effects were also reported by several researchers (Adams, 1965; Bolstad, 1975; Cleveland & Miller, 1977; Gath, 1973, 1978; Graliker, et al., 1972; Schwirian, 1976), who studied siblings of mentally retarded, orthopedically handicapped and hearing impaired children or adults.

Thomas (1980), Zucman (1982) and Powell and Ogle (1985), in reviews of the literature, concluded that: (1) some children might be negatively affected by the stress of having a
handicapped sibling in the home, (2) others might not be affected at all, (3) still others will be benefited by the experience of growing with a retarded brother or sister.

The contradictory findings of the research reviewed suggest that the impact handicapped children have on their siblings is multifaceted. It depends on the interaction of many ecological variables: socioeconomic status, sex, number of siblings, ordinal position of siblings, severity of handicap, visibility of handicap, religion or philosophical background of parents, their views toward child rearing and their expectations for their children. The majority of the studies reviewed depended on ratings of the siblings by teachers or mothers, or the mother’s opinion on how her normal child or adolescent was affected. Very few interviewed the siblings themselves (Cleveland & Miller, 1977; Graliker et al., 1972; Grossman, 1972). Lack of methodological sophistication as reflected in inadequate or no control groups characterizes some of the research reviewed. Until more coordination is developed among researchers interested in this area, the impact handicapped children have on their siblings will not be clearly understood, especially when considering the effect of it in different cultural settings as in the present study.

The purpose of this study was to examine the psychosocial functioning of siblings of mentally retarded (MR) children in comparison to a matched group of siblings of nonretarded children, who lived in the metropolitan area of San Juan, Puerto Rico.

Method

Sample

The sample consisted of 44 children of both sexes, between the ages 11-16, who were older siblings to either an MR child or a nonretarded child. They were divided in two groups: the “experimental” group included the children who had an MR brother or sister (experimental index subject) and the “control” group consisted of those children whose sibling (control index subject) was not mentally retarded. MR children were selected by their availability according to the following criteria: (1) attending a self-contained private or public school for the MR children; (2) 7 to 13 years old; (3) IQ 25-60 on an individual test of intelligences; (4) intact family with both parents living at home; (5) one to four siblings, with at least one older than the MR child, but not older than 16 years; (6) middle or upper middle class as measured by Hollingshead’s Four Factor Socioeconomic Class Index (Hollingshead, 1975).

Control index children were selected from those attending either a private or public regular school, to match the previously chosen MR index children on the applicable aforementioned criteria. One sibling of each of the control index children was selected to participate in the study matching him or her to the previously selected sibling of an MR child. Table 1 illustrates the characteristics of the sample as it was finally constituted.

Instrument

1. Piers-Harris Children’s Self-Concept Scale (PH): The Spanish translation of the Piers-Harris Children’s Self-Concept Scale (Piers, 1969, 1984), was used as the measure of self-concept for all the children. The Scale was translated and adapted to Puerto Rican children of 8-16 years by Roca de Torres and Rodríguez-Aponte (1985), who reported the following reliability coefficients for their sample: Alpha, r=.9041; Guttman Split-Half, \( r = .9083 \) and Spearman-Brown, \( r = .9045 \). This instrument was selected for the present study because the investigator wanted an objective simple measure of the siblings’ appraisal of themselves, a subjective measure often ignored in previous studies.
Table 1
Descriptive Characteristics of the Sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>Experimental</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 22</td>
<td>n = 22</td>
</tr>
<tr>
<td>Age range</td>
<td>11-16 years</td>
<td>11-16 years</td>
</tr>
<tr>
<td>mean age</td>
<td>13.95 years</td>
<td>13.91 years</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>male</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>female</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Grade range</td>
<td>6-11</td>
<td>6-11</td>
</tr>
<tr>
<td>mean grade</td>
<td>8.95</td>
<td>8.90</td>
</tr>
<tr>
<td>SES*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(middle, high middle class)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>range</td>
<td>31.5 - 54.5</td>
<td>32 - 54</td>
</tr>
<tr>
<td>mean</td>
<td>41.98 (high middle)</td>
<td>44.39 (high middle)</td>
</tr>
<tr>
<td>Children in family</td>
<td>2 - 5</td>
<td>2 - 5</td>
</tr>
<tr>
<td>mean</td>
<td>3.18</td>
<td>3.18</td>
</tr>
<tr>
<td>Index sibling</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>with MR</td>
<td>without MR</td>
</tr>
<tr>
<td>male</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>female</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>Age range</td>
<td>7 - 13</td>
<td>7 - 13</td>
</tr>
<tr>
<td>mean</td>
<td>10.41</td>
<td>10.45</td>
</tr>
<tr>
<td>School</td>
<td></td>
<td></td>
</tr>
<tr>
<td>private</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>public</td>
<td>11</td>
<td>11</td>
</tr>
</tbody>
</table>

*According to Hollingshead Four Factor SES Index (1975).
2. Child Behavior Checklist (CBCL)- The Child Behavior Checklist (Achenbach & Edelbrock, 1979), parents form, was used to assess the social competence and frequency of behavior problems in the both samples of children. This instrument has been translated to Spanish and calibrated for its reliability and current validity (Bird, Canino, Gould et al., 1987). Bird, Canino, Rubio-Stipec and Ribera (1987), have reported a test-retest reliability coefficient of .76 for the Behavior Problems scale and .74 for the Social Competence scale. The CBCL was found to be a good predictor of children referred for psychiatric evaluation, identifying adequately 96% of the “cases” of this study (Bird, Canino, Gould et al., 1987). When measured against alternative definitions of cases like DSM-III, referral or non-referral, Children’s Global Assessment Scale (CGAS) and a diagnosis plus CGAS, the CBCL yielded adequate levels of agreement as measured by the Kappa statistic (Bird, Canino, Rubio-Stipec et al., 1987). The CBCL was judged by Bird, Canino, Gould et al., 1987 to be an index of concurrent validity for the CGAS.

3. Roca’s Siblings’ Relationships Scale (RSRS)- This scale was developed to assess the relationship between the siblings, the attitudes the subjects have towards their siblings, their social relationships, their vocational aspirations, their knowledge about mental retardation, and their assessment of the impact their siblings has had on them. This questionnaire consists of 38 Liker-type questions and 5 open-ended questions. Five additional questions about what, when and how the subjects learned about their siblings’ retardation and with whom they discuss their siblings’ disability were included only for the group of children with retarded siblings.

The RSRS was reviewed by two psychologists and a sociologist to assess its content validity and it was judged to be adequate. These three judges were also asked to classify blindly the questions according to whether they tapped seven sub-areas specified by the investigator. These judges agreed an average of 98% with the classification of the investigator. This high level of agreement is an index of the inter-judge reliability of the scale and in this case also indicates its content validity. Internal consistency of the scale (Total Score) and a subscale of siblings’ relationships’ (SIBREL) were computed for the present sample (44 subjects) and the following indexes of reliability were found: (1) SIBREL-Alpha=.9178, Spearman-Brown=.9180; (2) Total Score-Alpha=.8613, Spearman-Brown=.8198. The SIBREL subscale included the 27 items that had higher item-total correlations and it was this subscale which was used for comparisons between the groups in the present study.

Procedure

All known private special schools in the San Juan metropolitan area and three public ones were visited by the researcher who explained to their directors the extent of the project and the cooperation needed from the school. Several regular private and public schools were also visited to select the control index subjects. All index subjects were chosen by appropriate school officers according to the aforementioned criteria for the experimental index subject or by matching for the control index subjects. An older sibling of each of the index subjects was randomly selected as subject for this study. Parents were first contacted by letter and phone and then a home visit was arranged for the administration of the instruments. Two trained interviewers visited the home, one interviewed the mother, the other the child.

Data Analyses

One-way ANOVAS or ANOVAS with post-hoc blocking were used to evaluate the differences on the mean scores of the Piers-Harris
(PH), social competence (SC), behavior problems (BP) and siblings' relationships. Frequencies and percentages were used for the descriptive analyses of the open-ended questions. Data was processed in an IBM-CMS computer using the program for SPSS-X.

Results

No statistically significant differences were found on the mean scores of the PH, BP or SC measures between siblings of MR children and siblings of nonretarded children. Siblings of MR children were not significantly different that controls on their self-concept as measured by the Piers-Harris (PH) or on their social competence (SC) and behavior problems (BP) as rated by their mothers' on the Child Behavior Checklist (CBCL). Table 2 depicts group means and standard deviations on the measures of PH, SC, BP and SIBREL. T-scores derived from the test's manual, are also available for the BP and SC measures.

Highly significant differences were found on the mean score of the SIBREL subscale between siblings of MR children and siblings of nonretarded children. Siblings of MR children in the sample, scored higher on the SIBREL subscale than siblings of nonretarded children. A higher score on this scale implies a closer relationship between siblings.

Results About the Open-ended Questions of the RSRS

A descriptive analysis was made of the subjects’ answer to the ten open-ended questions of the RSRS. Siblings of MR children rated the impact their respective index brother or sister had made on them as more positive (95%) than siblings of nonretarded children (78%). Siblings of MR children mentioned that by growing up with an MR brother or sister they had developed “better values”, “more responsibility, patience, and perseverance”, and had “learned to accept others as they are”. Moreover, these children, in their responses, showed a very deep involvement with their respective MR brother or sister. Siblings of nonretarded children (56%) mentioned “affect and company” as the main advantage of having this selected brother or sister, but also listed disadvantages like “jealousy”, “lack
of privacy” and “having to be an example”.

Siblings of MR children as compared to control subjects offered more complete definitions of mental retardation. Their responses included twice as many ideas as the ones offered by siblings of nonretarded children. Etiology, educational implications, types of mental retardation, specific characteristics and the importance of pre-natal care, were some of the concepts discussed by siblings of MR children on their definitions. More than half (61%) of the control subjects in the sample defined mental retardation as “an abnormal child who mentally is not well developed” or “somebody with learning difficulties”.

Siblings of MR children in the sample tended to think they would react more positively (55%) to the possibility of having a retarded offspring in the future than those who had a nonretarded brother or sister (27%). In general, siblings of MR children reported that this experience with their respective retarded brother or sister had prepared them for that possibility and had taught them what could be done to rehabilitate a retarded child. Siblings of nonretarded children in the sample seemed astonished by the question and talked about feelings of sorrowness, worry and resignation.

No difference was found between the two groups of siblings on the attributes they liked or disliked about their respective brother or sister, or in their career plans. Both groups of children seemed more inclined toward non-service oriented careers.

Five additional questions were only asked to siblings of MR children about what, when, and by whom they have been explained about their siblings problems and with whom they discussed this issue. Fifty percent of the subjects knew about the diagnosis and some characteristics of their retarded brother or sister. One third of those in the sample (36%) were informed about the diagnosis, etiology and educational needs of their respective sibling’s condition. All this information had been explained by their respective mother (45%) or by both parents (45%). Almost all the subjects in this study share with their friends everything they know about their respective brother’s or sister’s handicap. They also tell their friends about the positive attributes of this sibling and stress the concept that this retarded child be seen as a human being who needs and feels like an ordinary person.

Discussion

Results of the present study indicated only one statistically significant difference in the psychosocial functioning of siblings of MR children as compared to siblings of nonretarded children. Having a mentally retarded brother or sister was not associated with differences between children on measures of their perceived self-concept (PH) or on the ratings their mothers’ made of their social competence (SC) and their behavior problems (BP).

Significant differences between the groups were uncovered only on the SIBREL subscale of the Roca’s Siblings’ Relationship Scale. Siblings of MR children in the sample had a significantly closer relationship with their retarded brother or sister as measured by their SIBREL score than controls with their nonretarded sibling. This close relationship between MR children and their siblings has been reported previously in the literature by Miller (1974) and by Bolstad (1975).

Absence of significant differences between siblings of MR children and control subjects might be explained by several factors. First, a factor that has often been ignored by previous research is the marital status of the parents. Very few studies about the impact handicapped children have on their siblings have controlled this
variable, although several studies have found that the divorce of the parents lowers the self-concept of children (Luepnitz, 1982), increases their behavior problems and lowers their social competence (Hetherington, Cox and Cox, 1985). Adams (1965) Lobato and her collaborators (1986) and the present researcher controlled the “divorce” variable and their results demonstrated that handicapped children did not adversely affect the siblings in their samples. Second, this research used only older siblings of retarded children, while recent research has found that younger siblings are more affected (Grossman, 1972; Simeonsson & Bailey, 1986). Third, the accurate knowledge the siblings had about their respective retarded brother or sister indicates the easiness with which mental retardation was discussed within the family. Fourth, the middle/upper-middle class background of the subjects in the sample might also explain the negative results, since siblings of handicapped children from lower class have been found to be more affected by their handicapped brother or sister than siblings from higher socioeconomic backgrounds (Grossman, 1972). Most of all, the Puerto Rican socio-cultural background of these families might explain the siblings’ apparent adjustment toward their respective retarded brother or sister. Puerto Rican families, in general, are characterized by the strong family structure, their generosity, and their helpful paternalistic attitude toward the younger, the older and the disabled (Lucca-Irizarry, 1981).

In summary, it is concluded that siblings of retarded children in the sample are not adversely affected by being brothers or sisters to an MR child. Moreover, the majority of these siblings show a very close relationship with their respective retarded brother or sister and consider that they have benefited from the experience. They think their respective retarded brother or sister has made them improve as human beings by making them more responsible, patient and perseverant, and by making them accept and respect others as they are. It could be speculated that this adjustment was the result of their parents’ adaptation to the retarded child. Although no data are available on the parents’ adjustment, the easiness with which they discussed their MR child’s condition with the rest of the children and the stability of their marriage, reflects their adequate adjustment to this stressful situation.

The results of this study are limited by the small size of the sample and the lack of randomness in its selection. However, these results point out certain factors that must be considered in future studies.

It seems important to design a future research project that would study the impact retarded children have on their families in general. The adaptive reactions observed in the siblings on the present study might have been influenced by the reactions and attitudes of their parents.

Since siblings of retarded children in the sample were not adversely affected by their retarded brothers or sisters, but showed a closer relationship to them, a future study should be designed to identify those factors in particular that facilitated the siblings’ adaptation to their brothers’ or sisters’ condition. A research project that compares the adaptation of siblings whose parents are divorced and those whose non-divorced parents are living together at home might answer some of the questions raised by the present research project.

References


Bird, H.R., Canino, G., Gould, M.S., Ribera, J.,


Hollingshead, A. B. (1975). Four factor index of social status. (Available from A. B. Hollingshead P.O. Box 1965 Yale Station, New Haven, CT, 06520).


