Parents Reactions Toward the Maladaptive Problems of their Mentally Disabled Children

NEHAD H. MOHAMED, D.N.Sc. and HANAN E. ABD EL-AZIZ, D.N.Sc.
The Department of Psychiatric & Mental Health Nursing, Faculty of Nursing, Cairo University

Abstract
The study aimed to identify parents reactions toward the maladaptive problems of their mentally disabled children.

Design: A descriptive exploratory design was utilized in this study.

Setting: Psychiatric Out-Patient clinics, Pediatric hospital at Cairo University.

Sample: A purposeful sample of 100 parents having mentally disabled children and their children who are attending at the Psychiatric Out-Patient clinics, Pediatric Hospital at Cairo University.

Tools for Data Collection: Socio-demographic data of parents as age, level of education, occupation and family income. Socio-demographic data of children as age, sex, birth order, level of child education, IQ level and degree of disability. Questions about the effects of child disability on the parents, parent reactions, interaction toward their child's needs.

Findings: Two-thirds of the sample (69%) felt sad when they discovered the child's disability, while 86% of them, their current feelings changed to acceptance and for 14% it changed to rejection. The main reason for acceptance was believing in destiny (70.9%), while the main reason for rejection was lack of acceptance by society followed by severity of disability (64.3% and 42.9% respectively).

Conclusion: There was a highly significant relation between present acceptance of child disability and problems related to child disability (X=8.40, p<0.001). Recommendation, providing parents educational programs regularly, which help in dealing with child accurately and prevent or manage behavioral problems.

Key Words: Parents reactions – Maladaptive problems – Mentally disabled children.

Introduction

DISABILITIES in children are not only problems for the affected children but in a real sense they are family diseases. The maximum impact of a child's disability is on his/her parents, who have to cope with the various special needs and demands of these children. Parents play a pivotal role in providing daily care, arranging for special services and ensuring compliance with treatment. Stress faced by them would affect their functioning and hence the management of their child [1].

In Egypt, disability is a problem of particular importance where the handicapped make up from 1.2 to 4.5% of population [2]. The rate of infantile handicap in Egypt varies between 5 and 10%. The presence of a mentally disabled child within a family represents to both parents a state of severe disappointment expressed by a feeling of sadness or guilt and deep despair, besides grieving for the loss of a perfect child. The majority of disabled children receive long term care from their natural parents within the family home, so a family with a disabled child becomes “a disabled family” [3].

A mentally or physically disabled child should enjoy a full and decent life in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community (Convention on the Rights of the Child, 1989, Article 23). Egypt was one of the first twenty countries to ratify this convention by considering the year, 1989-1999, the decade of Egyptian child [4].

The National Information Center for Children and Youth with Disability [5] defined mental disability as a term used when a person has certain limitation in mental functioning and in skills such as communication taking care of him or herself, and social skills. These limitations will cause a child to learn and develop more slowly than typical child. Children with mental disability may take longer to learn, to speak, walk and take care of their personal needs such as dressing or eating. They are likely to have trouble learning in school they will learn, but it will take them longer.
Parental reaction to the birth of a disabled child is controversial. No typical or single reaction can be identified as mature good or bad. Reactions are a result of many feelings such as ambivalence, denial, guilt, shame, self-pity, sorrow, depression, disappointment, and a wish for the child's death. Denial is a common reaction particularly during the initial stages of adjustment providing a form of self-protection against painful realities. Following the shock of finding out about their child's disability, parents will probably deny the existence or seriousness of the condition and may isolate themselves from others to avoid confronting reality [1].

Furthermore, when the parents are informed that their child has a disability, the loss of the fantasized child and the discrepancy between these expectations and reality precipitate a crisis reaction typified by feelings of grief and loss. The grief reaction may be reactivated during later transitions in the life of the child and the family [6]. El-Kashef, [7] explained that the psychosocial process of parental reaction to the onset of a disabling condition of their child includes a series of stages that may last for a relatively long period of time: Denial, guilt or anger, withdrawal, and acceptance.

The next stage is the parents search for a cause; blame placing is an outcome at this point. No one likes to feel that the child's condition may result from a fault on his or her side of the family. In some cases the cause is seen as a punishment from God. Parents are motivated in this search by one or a combination of the following devises: (a) To prevent their future children from being disabled; (b) To find a way to minimize their anxiety concern or self imposed guilt for having a disabled child. After the search has ended in identification of a cause or discovers that no cause exists, the search for a cure is undertaken. This stage in many instances lasts for the child's entire life time. The parent must begin to accept the child's limitation. It is only in the final stage, that of acceptance, that the parents act as if the condition does not exist, (4) denial, in which the parents act as if the condition does not exist, (4) gradual acceptance, in which the parents place realistic and necessary limitations on the child, foster reasonable social and physical activities, and promote self-care [10].

Acceptance of the child is a major and critical step in the healing and growing process. The step implies recognition of the value of the child, his feelings, needs and that he is a person and a very real and important person. The process of self acceptance is long and difficult filled with pain and frustration. In spite of all the hurts, the parents can emerge from it with a firm conviction that they are parents of a very special child and that he is an individual worthy of respect from others and themselves [11].

The health team members have an important role not only in preventing disability but also in helping to meet the special needs of disabled children and their families. One of the psychiatric nurse's first responsibilities is guiding the parents through decision-making processes; the nurse must be familiar with the resources of the community so that she can direct the parent to them. The nurse presents reality to parents through helping them to deal with one issue at a time and one day at a time. Resources for each need can be found as will the consequences of each major decision about the child, and the other family members [12].

Significance of the study:
The presence of a mentally disabled child within a family represents to both parents a state of severe disappointment expressed by a feeling of sadness or guilt and deep despair, besides grieving for the loss of a perfect child. The majority of disabled children receive long term care from their natural parents within the family home, so a family [13], with a disabled child becomes "a disabled family". Although many families with disabled children manage their lives as effectively as other families, some such families may require counseling or therapy to Bindu [14] facilitate the integration of the disabled child into the family.

Furthermore, a study was done by Awadalla, [15] to determine maternal adaptation to mentally disabled children in El-Minia, Egypt, indicated that 35.0% of the mothers adapted positively to their child's condition; 62.9% of those had female children. Negatively adapted mothers were slightly
older than positively adapted mothers and had more children. Also, Knowledge of mothers about their child's condition significantly affected adaptation as well as the dependency of children in eating, drinking and sleeping.

Parents of mentally disabled children usually feel that they are alone with their problems. Most of researches are directed toward mentally disabled children, their needs and care required to be provided to them. No available studies were conducted on parents of mentally disabled children, about their reactions and psychosocial problems.

So the aim of the present study was to identify parents reactions toward the maladaptive problems of their mentally disabled children.

**Subjects and Methods**

The study was aimed to identify parent's reactions toward the maladaptive problems of their mentally disabled children.

**Research design:**
A descriptive exploratory design was utilized in this study.

**Research questions:**
- What are the parent's reactions toward the maladaptive problems of their mentally disabled children?
- What are the problems affecting family due to their child disability?
- Is there a relation between problems affecting family and characteristics of their children?

**Setting:**
The study was conducted at Psychiatric Out-Patient clinics, Pediatric hospital, Cairo University.

**Sample:**
A purposeful sample of 100 parents having mentally disabled children and their children who are attending at Psychiatric Out-Patient clinics Pediatric hospital, Cairo University.

**The inclusion criteria are:**
- Children with different degrees of mental disabilities (mild, moderate, severe, and profound).
- Both sexes of children were included in this study.
- Their age not more than ten years.
- Their parents agreed to participate in the study.

**Tools for data collection:**
Tools used for data collection were consisted of two parts:

**The first part includes:**
- Socio-demographic data of parents was developed by the researchers for collecting data related to age, level of education, occupation and family income... ect.
- Socio-demographic data of children was developed by the researchers for collecting data related to age, sex, birth order, and level of child education, IQ level and degree of disability. When the parent discovered the child condition and what the cause of it, from their opinion was the cause of it, from their opinion.

**The second part includes:**
Questions about the effects of child disability on the parents, parent reactions, interaction toward their child's needs, parent's problems that facing them during caring of their child and effect of child disability on parents decision making to have another child.

It consisted of 14 items, closed direct questions with multiple answers to obtain the information from parents. The content validity of the questionnaire was assessed by a panel of 8 experts who have worked with mentally disabled for at least 2 years. They were asked to judge the relevancy of each item in the questionnaire. 100% agreement of the questionnaire would be achieved.

**Pilot study:**
A pilot study was carried out before performing the actual study. It was conducted on 10 parents at the Psychiatric Out-Patient clinics, Pediatric hospital, Cairo University to test the applicability, feasibility, and practicability of the tools, to identify the proper method for collecting data, and to identify the obstacles that would be faced in data collection.

**Fieldwork:**
Once official permission from the director of Psychiatric Out-Patient clinics Pediatric hospital, Cairo University granted to proceed in this study, the psychologist working at this clinics gave us great support by providing special room to carry out interview, facilitate reaching to necessary data from the patient files, the researchers contacted the participated parents to introduce themselves and to explain the purpose and clarify the items of the different questions used in data collection in the light of their grasping. They were assured about anonymity of answers and that the information
will be used for scientific research only and will be strictly confidential. Also, they informed that their participation was voluntary and refusal to participate will not affect any health services provided to them. The data of the study were collected throughout six month from May to August 2010 at the time of their follow-up in the Psychiatric Out-Patient clinics Pediatric hospital at Cairo University. The children and their parents were interviewed individually for approximately 30-45 minutes two days per week to fill the study questionnaires since the patients’ responses were rated by the researchers.

Ethical consideration:

An official permission to conduct the current study was obtained from the head of Psychiatric Out-Patient clinics Pediatric hospital at Cairo University. Informed consent was obtained from their parent to participate in the current study. Confidentiality of each subject was protected by allocation of the code instead of using subject’s name.

Statistical analysis:

Data were analyzed using statistical package for the social science (SPSS) version 11.5. Numerical data were expressed as means and standard deviations. Qualitative data were expressed as frequency and percentage. ANOVA test was used for comparing successive readings of numerical variables followed by pair-wise comparisons. Relation between different numerical variables was tested using Pearson correlation \((r) \geq 0.05\) was considered good correlation. Probability of error \((p\text{-value}) <0.05\) was considered significant.

Results

Table (1) showed that (56%) the mothers’ age was between 30 years to less than 40 years, less than quarter of mothers’ age was either above 40 years or less than 30 years, (21% & 23% respectively), with mean ± SD (34.5±6.3), while most of the fathers age (49%) was above 40 years and less than half of them their age was between 30 to 40 years and a minority of them were less than 30 years, with mean ± SD (40.6±7.4). Forty five percent of mothers were illiterates compared to 37% of the fathers. The table showed also that highly educated mothers and fathers were only 3% & 6% respectively. Most of the available sample of mothers was housewives (91%) and the minority (9%) was workers. While most of fathers (76%) were workers followed by 21% employees and 3% have no job (jobless). Regarding to per capita income, the same table revealed that 46% of parents have monthly income between 50-100 LE., compared to nearly one third (32%) of parents have less than 50 LE./month, with mean ± SD (67.1±33.2), while less than quarter (22%) of them have more than 100 LE./month.

As regards the interviewed parents, 69% of the study subjects were mothers compared to 31% of parents were fathers.

Table (2) revealed that 46% of the children’s age was 10 years and more and two fifth of them were more than 5 years (40%), while the minority (14%) were less than 5 years with a mean ± SD = 8.9±3.6. The majority of children were males (75%), while quarter of them were females (25%). Regarding the birth order of the children the table showed that most of the children were middlest child (44%) compared to 37% of them were the first child. A relatively high percent of the children (44%) had 1-2 siblings, while more than one third of them had no sibling at all (38%). Only 27% of children were attending intellectual development schools and nurseries, while the majority of them (73%) didn’t attend school and stay at home.

<table>
<thead>
<tr>
<th>Item</th>
<th>Mother No. / %</th>
<th>Father No. / %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;30</td>
<td>23</td>
<td>10</td>
</tr>
<tr>
<td>30-</td>
<td>56</td>
<td>41</td>
</tr>
<tr>
<td>40+</td>
<td>21</td>
<td>49</td>
</tr>
<tr>
<td><strong>Mean ± SD</strong></td>
<td>34.5±6.3</td>
<td>40.6±7.4</td>
</tr>
<tr>
<td><strong>Education:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illiterate</td>
<td>45</td>
<td>37</td>
</tr>
<tr>
<td>Read/write</td>
<td>3</td>
<td>31</td>
</tr>
<tr>
<td>Basic</td>
<td>25</td>
<td>17</td>
</tr>
<tr>
<td>Secondary</td>
<td>24</td>
<td>27</td>
</tr>
<tr>
<td>High</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td><strong>Job:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Housewife</td>
<td>91</td>
<td>–</td>
</tr>
<tr>
<td>Worker</td>
<td>9</td>
<td>76</td>
</tr>
<tr>
<td>Employee</td>
<td>–</td>
<td>21</td>
</tr>
<tr>
<td>Jobless</td>
<td>–</td>
<td>3</td>
</tr>
<tr>
<td><strong>Monthly per capita:</strong></td>
<td>46</td>
<td></td>
</tr>
<tr>
<td>In come (LE.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;50</td>
<td>22</td>
<td>67.1±33.2</td>
</tr>
<tr>
<td>50-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>100+</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mean ± SD</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent interviewed</td>
<td>69</td>
<td>31</td>
</tr>
</tbody>
</table>
Table (2): Socio-demographic characteristics of the children of the studied parents (n=100).

<table>
<thead>
<tr>
<th>Item</th>
<th>No. / %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age:</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;5</td>
<td>14</td>
</tr>
<tr>
<td>5-</td>
<td>40</td>
</tr>
<tr>
<td>10+</td>
<td>46</td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>8.9±3.6</td>
</tr>
<tr>
<td><strong>Gender:</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>75</td>
</tr>
<tr>
<td>Female</td>
<td>25</td>
</tr>
<tr>
<td><strong>Birth order:</strong></td>
<td></td>
</tr>
<tr>
<td>First</td>
<td>37</td>
</tr>
<tr>
<td>Middle</td>
<td>44</td>
</tr>
<tr>
<td>Last</td>
<td>19</td>
</tr>
<tr>
<td><strong>Number of sibling:</strong></td>
<td></td>
</tr>
<tr>
<td>No siblings</td>
<td>38</td>
</tr>
<tr>
<td>1-2</td>
<td>44</td>
</tr>
<tr>
<td>3 or more</td>
<td>18</td>
</tr>
<tr>
<td><strong>School attendance:</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>27</td>
</tr>
<tr>
<td>No</td>
<td>73</td>
</tr>
</tbody>
</table>

Table (3) indicated that the majority of children were having mild degree of mental retardation (71%), while 16% of them had moderate degree and the minority (13%) had severe degree of retardation. IQ, mean was 56.1±1.7. More than half of mentally retarded children of the study subjects (51%) were discovered after the first year of child's life, while 38% of them were discovered at the first year of their life and only 11% were discovered at birth, with a mean ± SD = 4.5±3.6.

Table (3): Degree and causes of disability among children of the studied parents (n=100).

<table>
<thead>
<tr>
<th>Item</th>
<th>No. / %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Degree of disability:</strong></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>71</td>
</tr>
<tr>
<td>Moderate</td>
<td>16</td>
</tr>
<tr>
<td>Severe</td>
<td>13</td>
</tr>
<tr>
<td><strong>IQ:</strong></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>20-70</td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>56.1±1.7</td>
</tr>
<tr>
<td><strong>Disability discovered at:</strong></td>
<td></td>
</tr>
<tr>
<td>Birth</td>
<td>11</td>
</tr>
<tr>
<td>First year</td>
<td>38</td>
</tr>
<tr>
<td>Later</td>
<td>51</td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>4.5±3.6 years</td>
</tr>
<tr>
<td><strong>Causes of disability:</strong></td>
<td></td>
</tr>
<tr>
<td>Illness during pregnancy</td>
<td>4</td>
</tr>
<tr>
<td>Medications during pregnancy</td>
<td>5</td>
</tr>
<tr>
<td>Consanguinity</td>
<td>16</td>
</tr>
<tr>
<td>Child illness</td>
<td>25</td>
</tr>
<tr>
<td>Unknown</td>
<td>50</td>
</tr>
</tbody>
</table>

As regards the causes of mental retardation, 50% of it was with unknown causes and 25% was due to child's illness, followed by 16% for consanguinity and the minority was for illness of the mother or medications taken during pregnancy (4% & 5% respectively).

Table (4) showed that more than half of children were fully dependent on their parents in daily life activities. Most of caregivers were mothers alone (72%) compared to 28% were mothers with another family member.

Table (4): Degree of dependence of disabled children on caregivers (n=100).

<table>
<thead>
<tr>
<th>Item</th>
<th>No. / %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dependency in daily life activities:</strong></td>
<td></td>
</tr>
<tr>
<td>Full dependence</td>
<td>61</td>
</tr>
<tr>
<td>Partial dependence</td>
<td>39</td>
</tr>
<tr>
<td><strong>Caregiver:</strong></td>
<td></td>
</tr>
<tr>
<td>Mother alone</td>
<td>72</td>
</tr>
<tr>
<td>Mother + another family member</td>
<td>28</td>
</tr>
</tbody>
</table>

Table (5) revealed that (69%) of parents felt sad when they discovered the child's disability, while 86% of them, their current feelings changed to acceptance and for 14% it changed to rejection. The main reason for acceptance believed in destiny (70.9%), while the main reason for rejection was lack of acceptance by society followed by severity of disability (64.3% and 42.9% respectively).

Table (5): Parents feeling on discovery and current feeling of child disability (n=100).

<table>
<thead>
<tr>
<th>Item</th>
<th>No. / %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Feeling on discovery of disability (n=100):</strong></td>
<td></td>
</tr>
<tr>
<td>Sadness</td>
<td>69</td>
</tr>
<tr>
<td>Denial</td>
<td>13</td>
</tr>
<tr>
<td>Guilt</td>
<td>11</td>
</tr>
<tr>
<td>Anger</td>
<td>7</td>
</tr>
<tr>
<td><strong>Current feeling of parents (n=100):</strong></td>
<td></td>
</tr>
<tr>
<td>Acceptance</td>
<td>86</td>
</tr>
<tr>
<td>Rejection</td>
<td>7</td>
</tr>
<tr>
<td>Isolation</td>
<td>5</td>
</tr>
<tr>
<td>Depression</td>
<td>2</td>
</tr>
<tr>
<td><strong>Reasons for acceptance (#) (n=86):</strong></td>
<td></td>
</tr>
<tr>
<td>Destiny</td>
<td>61</td>
</tr>
<tr>
<td>Acceptance by family</td>
<td>9</td>
</tr>
<tr>
<td>Acceptance by society</td>
<td>2</td>
</tr>
<tr>
<td>Child joining specialized institution</td>
<td>4</td>
</tr>
<tr>
<td>Mixed causes</td>
<td>8</td>
</tr>
<tr>
<td><strong>Reasons for rejection (#) (n=14):</strong></td>
<td></td>
</tr>
<tr>
<td>Lack of acceptance by society</td>
<td>9</td>
</tr>
<tr>
<td>Severe degree of disability</td>
<td>6</td>
</tr>
<tr>
<td>Lack of acceptance by family</td>
<td>4</td>
</tr>
<tr>
<td>Lack of specialized institutions</td>
<td>4</td>
</tr>
<tr>
<td>No specific reason</td>
<td>3</td>
</tr>
<tr>
<td>(#) Non-mutually exclusive.</td>
<td></td>
</tr>
</tbody>
</table>
Table (6) indicated that the highest percentages of parents decided not to have other children to be able to care for the disabled child (59%), while less than one third (29%) of them preferred wide pregnancy spacing, and the minority of them have enough number of children (11.5%).

Table (6): Effect of child disability on parents decision making to have another child (n=26).

<table>
<thead>
<tr>
<th>Item</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No time for more children</td>
<td>16</td>
<td>59</td>
</tr>
<tr>
<td>Wide pregnancy spacing</td>
<td>8</td>
<td>29</td>
</tr>
<tr>
<td>Current number of children is enough</td>
<td>2</td>
<td>11.5</td>
</tr>
</tbody>
</table>

Table (7) showed that the cost of medication (to some extent) and the cost of transportation to hospital or school were the main causes of financial problems (55% & 50% respectively). Unacceptance of child behavior, unacceptance of child by society and shame feelings from child disability were the most reasons for familial problems (51%, 50%, & 31% respectively). Parents' psychological problems due to child disability (48%) were the main reasons of health problems related to child disability.

Table (7): Problems affecting family due to child disability (n=100).

<table>
<thead>
<tr>
<th>Item</th>
<th>No.</th>
<th>%</th>
<th>To some extent</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial (n=39):</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cost of joining private institution</td>
<td>96</td>
<td>3</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Lower income</td>
<td>58</td>
<td>37</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Cost of medication</td>
<td>7</td>
<td>55</td>
<td>38</td>
<td></td>
</tr>
<tr>
<td>Cost of transportation to hospital/school</td>
<td>23</td>
<td>27</td>
<td>50</td>
<td></td>
</tr>
<tr>
<td>Familial/Social family isolation due to (n=35):</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shame feelings</td>
<td>18</td>
<td>51</td>
<td>31</td>
<td></td>
</tr>
<tr>
<td>Unacceptance by society</td>
<td>19</td>
<td>31</td>
<td>50</td>
<td></td>
</tr>
<tr>
<td>Unacceptance of child behavior</td>
<td>20</td>
<td>29</td>
<td>51</td>
<td></td>
</tr>
<tr>
<td>Unacceptance by siblings</td>
<td>56</td>
<td>28</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Divorce</td>
<td>96</td>
<td>1</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Neglect ion by father/mother</td>
<td>66</td>
<td>9</td>
<td>25</td>
<td></td>
</tr>
<tr>
<td>Health related problems (n=26):</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents illness due to child</td>
<td>83</td>
<td>15</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Parents psychological problems</td>
<td>43</td>
<td>48</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Siblings psychological problems</td>
<td>92</td>
<td>7</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

Table (8) showed that no statistically significant difference was found between parent's age, level of education, job, percapita income and problems affecting family due to child disability. p-Value 0.31, 0.40, 0.89, 0.70, 1.00, 0.81, 0.35 and 0.31 respectively).

Table (8): Relation between problems affecting family due to child disability and characteristics of studied parents.

<table>
<thead>
<tr>
<th>Item</th>
<th>Problems due to child disability</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother age (yrs):</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;30</td>
<td>36</td>
<td>83.7</td>
<td>43</td>
<td>75.4</td>
</tr>
<tr>
<td>30+</td>
<td>7</td>
<td>16.3</td>
<td>14</td>
<td>24.6</td>
</tr>
<tr>
<td>Father age (yrs):</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;40</td>
<td>19</td>
<td>44.2</td>
<td>30</td>
<td>52.6</td>
</tr>
<tr>
<td>40+</td>
<td>24</td>
<td>55.8</td>
<td>27</td>
<td>47.4</td>
</tr>
<tr>
<td>Mother education:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illiterate</td>
<td>19</td>
<td>44.2</td>
<td>26</td>
<td>45.6</td>
</tr>
<tr>
<td>Educated</td>
<td>24</td>
<td>55.8</td>
<td>31</td>
<td>54.4</td>
</tr>
<tr>
<td>Father education:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illiterate</td>
<td>15</td>
<td>34.9</td>
<td>22</td>
<td>38.6</td>
</tr>
<tr>
<td>Educated</td>
<td>28</td>
<td>65.1</td>
<td>35</td>
<td>61.4</td>
</tr>
<tr>
<td>Mother job:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Housewife</td>
<td>39</td>
<td>90.7</td>
<td>52</td>
<td>91.2</td>
</tr>
<tr>
<td>Working</td>
<td>4</td>
<td>9.3</td>
<td>5</td>
<td>8.8</td>
</tr>
<tr>
<td>Father job:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>1</td>
<td>2.3</td>
<td>2</td>
<td>3.5</td>
</tr>
<tr>
<td>Working</td>
<td>34</td>
<td>79.1</td>
<td>42</td>
<td>73.7</td>
</tr>
<tr>
<td>Employee</td>
<td>8</td>
<td>18.6</td>
<td>13</td>
<td>22.8</td>
</tr>
<tr>
<td>Percapita income:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;50</td>
<td>13</td>
<td>30.2</td>
<td>19</td>
<td>33.3</td>
</tr>
<tr>
<td>50-</td>
<td>23</td>
<td>53.5</td>
<td>23</td>
<td>40.4</td>
</tr>
<tr>
<td>100+</td>
<td>7</td>
<td>16.3</td>
<td>15</td>
<td>26.3</td>
</tr>
<tr>
<td>Parent interviewed:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>32</td>
<td>74.4</td>
<td>37</td>
<td>64.9</td>
</tr>
<tr>
<td>Father</td>
<td>11</td>
<td>25.6</td>
<td>20</td>
<td>35.1</td>
</tr>
</tbody>
</table>

Fig. (1) illustrated that the financial problems were the main problems affecting family related to child disability (39%), then familial and social problems (35%), finally health related problems (26%).
Table (9) showed no significant differences regarding to child age, gender, rank order, siblings number, or school attendance in relation to child’s disability problems. Also, there were no significant relation between degree of disability and child dependence, and problems affecting the parents due to child disability.

Table (9): Relation between problems affecting family due to child disability and characteristics of studied children.

<table>
<thead>
<tr>
<th>Item</th>
<th>Problems due to child disability</th>
<th>X</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-2</td>
<td>No siblings</td>
<td>17</td>
<td>39.5</td>
</tr>
<tr>
<td>3 or more</td>
<td>No siblings</td>
<td>7</td>
<td>16.3</td>
</tr>
<tr>
<td>Sex</td>
<td>Male</td>
<td>36</td>
<td>83.7</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>7</td>
<td>16.3</td>
</tr>
<tr>
<td>Rank order</td>
<td>First</td>
<td>19</td>
<td>44.2</td>
</tr>
<tr>
<td></td>
<td>Middle</td>
<td>16</td>
<td>37.2</td>
</tr>
<tr>
<td></td>
<td>Last</td>
<td>8</td>
<td>18.6</td>
</tr>
<tr>
<td>Number of siblings</td>
<td>No siblings</td>
<td>17</td>
<td>39.5</td>
</tr>
<tr>
<td></td>
<td>1-2</td>
<td>19</td>
<td>44.5</td>
</tr>
<tr>
<td></td>
<td>3 or more</td>
<td>7</td>
<td>16.3</td>
</tr>
<tr>
<td>School attendance</td>
<td>Yes</td>
<td>14</td>
<td>32.6</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>29</td>
<td>67.4</td>
</tr>
<tr>
<td>Degree of disability</td>
<td>Mild</td>
<td>31</td>
<td>72.1</td>
</tr>
<tr>
<td></td>
<td>Moderate</td>
<td>4</td>
<td>9.3</td>
</tr>
<tr>
<td></td>
<td>Severe</td>
<td>8</td>
<td>18.6</td>
</tr>
<tr>
<td>Child dependence</td>
<td>Full</td>
<td>26</td>
<td>60.5</td>
</tr>
<tr>
<td></td>
<td>Partial</td>
<td>17</td>
<td>39.5</td>
</tr>
</tbody>
</table>

Table (10) revealed that there was a highly significant relation between parents’ acceptance of child disability and problems related to him. \((X=8.40, p<0.001)\).

Table (10): Relation between problems affecting family due to child’s disability and the parent’s acceptance.

<table>
<thead>
<tr>
<th>Item</th>
<th>Problems due to child disability</th>
<th>X</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Present acceptance</td>
<td>Yes</td>
<td>32</td>
<td>74.4</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>11</td>
<td>25.6</td>
</tr>
</tbody>
</table>

\[X=8.40, p<0.001\]

A- Socio-demographic characteristics of the parents:

As regards the level of education, the results showed that majority of mothers and also more than one third of fathers were illiterates. This high percentage of non-educated parents might be one of the causes of disability as lack of parent’s awareness about disability and how to detect it. The Egyptian Demographic and Health Survey Bradley (2002) revealed a significant inverse relation between pregnancy outcome and educational level of parents. This result is supported by Olsen, & Fuller [16]. Study, where 48% of mothers and 38% of fathers of mentally retarded children were illiterates. A study done by Bristol and Gallagher [17]. Revealed that, the majority of mothers of disabled children were illiterates (83%). Almost the same result was detected by Golding [18]. Where 71.7% of mothers of disabled children were illiterates. Every parent with a special child has to become more educated and empowered; has to learn how to love unconditionally and redefine perfection and disability; understand fully the sacred and tremendous responsibility of being a child’s parent.

Concerning parent’s job, the results of the present study showed that the majority of mothers were housewives. This result may reflect that the mother of a disabled child prefers to stay at home because she takes part in the daily life of the child, while most of the fathers were workers with unstable income. This result could be related to the lower educational level of parents. The current study revealed that more than half of the mothers’ age ranged between 30-40 years old, while most of the fathers were above 40 years. This high percentage of non-educated parents might be one of the causes of disability as lack of parents awareness about disability and how to detect it. The Egyptian Demographic and Health Survey Bradley (2002) revealed a significant inverse relation between pregnancy outcome and educational level of parents. This result agreed with that of Baroff [19]. Where two thirds of mothers of mentally retarded children and most of fathers’ age were above 35 years old to 45 years old.

As regards per capita income, the study result revealed that, most of parents have less than 100 LE. Monthly per capita income. This result indicated their types of work with low income and lower educational level. El-Yafaee [20]. Conducted a study to estimate disability among children in USA, he reported that the disabled group had more children in the lowest income category. In the same...
context, Bradley (2002) stated that high economic status families afford their children an array of services, good parental actions and social connections that potentially return to the benefit of children and a concern that many low socio-economic status children lack access to those same resources and experiences thus putting them at risk for developmental problems.

B- Socio-demographic characteristics of child:

The results of the present study revealed that the middle child is the most disabled child. This result was supported by El-Sherif [21]. Who studied the epidemiology of disabilities among children (2-15y) in Mansheyt Naser, Cairo City, where 46.5% of children were the middle child. Regarding school attendance more than two thirds of children did not attend school. This result might indicate the burden that parents may have as a result of a mentally retarded child who stays at home all time. Abd El-Ghafar [22] reported that the educational services in Egypt serve only 20% from all mentally retarded children.

The results of the present study showed that the highest percent of children.

Were mild mentally retarded. This result agreed with American Psychiatric Association, (2000), about 85% of retarded children fall into this category. In relation to time where the disability was discovered the current results revealed that half of disability was discovered at later age of children. This result reflected the nature of non-educated families with low income where neglection beside lack of immediate and continuous follow-up for child development could predispose the children to a greater risk.

As regards dependence of children in daily life activities, this study results showed that, two thirds of them are completely dependent on parents in daily life activities. This result indicated that parents need assistance from family member's friends, and community services to provide care for their children, and to teach them how to be independent in care. Tourk (2002) stated that, children with disabilities need ample opportunities to solve problems for themselves and to develop a greater sense of independence rather than dependence and a wide variety of movement activities designed to break down the artificial limitations are that often build up around their disabilities.

As regards parents feelings on discovery of child disability, the majority of the sample felt sadness most of them felt it till the present time and the majority of their partners had the same feelings James, Ashwill & Droske [23]. Mentioned that parental reaction to the birth of a retarded child is a resultant of many feelings such as ambivalence denial, guilt, shame, self-pity, sorrow, depression disappointment, and a wish for the child's death.

The current study revealed that three quarters of parents accepted their child disability; the main reason for acceptance was destiny, which is related to religious beliefs. This result was supported by Vidhya & Raju [24]. Who studied the parent's reactions to mental retardation? She stated that, in Egypt, the religious beliefs play an important role in the acceptance of the mentally retarded child. In addition, it is well known that the low socioeconomic class usually adheres more to religious principles and values and these families place great value on physical attributes and physical disabilities than mental retardation.

The highest percent of parents reported lack of acceptance by society as the main reason for rejection of child disability, this study result agreed with McDiarmid, Melanie, Bagner & Daniel [25] who reported that the problem of disability is that society is not always tolerant of people who are different. They added that when society takes a negative attitude toward the disabled child, the capacity of the disabled to communicate with it and be integrated into it is diminished. Another reason for rejection of child disability is severity of disability. But this result contradicted with that of Otong [26]. Who found that there were no significant differences between the parental attitudes of different categories of MR, while Baroff [19]. emphasized that factors such as the characteristics of the disability and the perception of it play a role in the utilization of health resources, as the type and degree of disability affect the belief system around its causes, amenability to cure or rehabilitation, which in turn interacts to influence the seeking behavior of the disabled children and their families.

In relation to problems affecting family due to child disability, the results of the current study showed that financial problems were the most affecting problems in regard to cost of transportation to hospital or school. This result agreed with Jackson [27]. Who reported that the characteristics of the health services, such as accessibility, quality, communication with personnel and cost; all play a role in the use of services for the disabled child. He added that in case of transportation how it plays an important role in the third world countries in particular as a hindering factor for people to utilize services.
Similarly a study was done by Batshaw [28] showed that the familial and the social problems were related to unacceptance of child by society. Health-related problems as psychological problem was the final problem related to child disability. This result is in consistence with that of Lundy & Janes [29]. Who studied psychosocial problems with disabled children, the finding indicated that families of disabled children perceive a multidimensional stress. There is increased financial burden, and an adverse effect on family routine, leisure and interaction. There is also, a perceived ill-effect on the physical and mental health of family members, and mothers of disabled children have increased minor psychiatric disorders and marital harmony is also adversely affected.

The current study revealed no significant relations between problems affecting family due to child disability and parent's socio-demographic characteristics. These results contradicted with Fathey [10] who reported that parents who are more educated, belong to higher social class and have fewer children, accept their child's retardation better and tend to cope with emerging difficulties by approaching external helping sources.

In the same context, no significant relations between degrees of disabilities, time when disability was discovered, child dependence and problems affecting family due to child disability. The result found that the high percent was for mild degree of disability, which may be related to high percent of mild degree disabled children in the current study, also disability discovered later causes family problems more than other earlier age. The results also revealed that the completely dependant child causes psychosocial problems more than the partial by dependent child.

Similarly, the current study revealed no significant relations between problems affecting family due to child disability and parent's socio-demographic characteristics. These results contradicted with Bindu [14]. Who reported that parents, who are more educated, belong to higher social class and have fewer children, accept their child's retardation better and tend to cope with emerging difficulties by approaching external helping sources.

Furthermore, a significant relation between parents acceptance of child disability and problems affecting family. More than three quarters of parents who accepted their child disability have no psychosocial problems. This result might be attributed to their religious beliefs and believing in destiny as reported in a study done by Youssef [11] that the handicapped is looked upon as a “Sheikh” (man of God), it must be borne in mind that he receives divine benediction and added that as illness is willed by God, so his handicap, it is an act of fate.

Moreover, parents need a clear future plan for their child, financial support and vocational training to help disabled child in his life. These opinions are supported by Hall (1996) study which stated that the greatest need identified by parents was in the area of information to plan for their child's future (55%). Lundy & Janes [29]. Reported that disabled child future, schooling and vocational training, and residential care were stresses of families with a child with special needs. The American Academy of Pediatrics (2000) revealed that as children grow older, their education can be directed toward vocational training that prepares them for as independent lifestyle as possible within their scope of abilities.

Raising a child with a mental challenge may be more expensive than raising a typical child. These expenses can arise from medical equipment and supplies, medical care, care giving expenses, private education, tutoring, adaptive learning equipment or specialized transportation. The care of the child may last a lifetime instead of 18 years. Parents may have to set aside money in a trust fund for the child's care when they pass away [30].

In the same context, parents feelings on discover of disability and their current feeling majority of them experience denial and rejection as a reaction in discovery due to lack of acceptance from society this results are congruent with Naseef [31]. Denial provides a form of self-protection against the painful realities. Parents may minimize the degree of handicap or simply deny that any problem exists. They close their minds to their child's limitations or may attribute the limitations to the child's laziness, indifference, or lack of motivation. Denial is both useless and destructive. It is useless because the refusal to accept the reality of the handicap will not make the problem disappear. It is destructive because it impedes the child's own acceptance of the limitations and may prevent the necessary training and support. When the parents (sometimes only one parent) refuse to recognize the conditions for what they really are, treatment is frequently delayed and sometimes never receives proper attention.

Parents of a retarded child may unfortunately withdraw from friends, relatives, professional workers or from activities that may facilitate the healing process. The withdrawn parent can construct a protective barrier or space and silence against outside pain, even if not against the hurt
inside, raising a child who is mentally challenged requires emotional strength and flexibility. The child has special needs in addition to the regular needs of all children, and parents can find themselves overwhelmed by various medical, care giving and educational responsibilities. Whether the special needs of the child are minimal or complex, the parents are inevitably affected. Support from family, friends, the community or paid caregivers is critical to maintaining balance in the home [30].

As indicated by Bindu [14]. The entire process of reaching self-acceptance is a long and difficult one for the parents. It is filled with pain, frustration, self-doubt, and ego-shattering experiences. They further pointed out that somehow, in spite of the hurts and debilitating experiences, the parents can emerge with the firm conviction that they are parents of a very special child; they are individuals worthy of respect from others and from themselves.

From the researcher point of view, Parents of mentally challenged children commonly experience a gamut of emotions over the years. They often struggle with guilt. One or both parents may feel as though they somehow caused the child to be disabled, whether from genetics, alcohol use, stress, or other logical or illogical reasons. This guilt can harm the parent’s emotional health if it is not dealt with. Some parents struggle with “why” and experience a spiritual crisis or blame the other parent. Most parents have aspirations for their child from the time of her birth and can experience severe disappointment that she will not be president, a physician, an actor or whatever they had in mind.

Conclusion:

The most mentally retarded children were boys with mild degree of retardation. The majority of parents were illiterate with low socioeconomic standard. Financial problem was the main problems related to child disability. Parent acceptance of mentally retarded child had a significant relation with problems related to disability. The study results showed that the most facing problem to the parent related to child’s disability was financial problem (39%), psychological problems (69%). There was a high significant relation between present acceptance of child disability and problems related to child disability ($X^2$=8.40, $p<0.00$ 1).

Recommendations:

In light of the previous findings of the current study, the following are recommended:

• Establishing a specialized clinic for disabilities, especially in governorates which have a high percentage of disabilities.

• Providing training for doctors, nurses, social workers in dealing with and counseling for parents with mentally retarded children.

• Guidance and counseling should be provided to parents including financial counseling, information on community resources, transportation and recreational opportunities.

• Providing both parents or one of them educational programs regularly, which help in dealing with child accurately and prevent or manage behavioral problems.

• Provide a list of NGOs, in health centers and pediatric hospitals which include phone number, address and their services.

• Including mentally retarded children in health insurance services.

• Develop programs and strategies to “educate” parents of the mentally retarded children, and the public at large to understand and be aware of mental “retardation” (e.g. radio, leaflets, newspapers, television etc.).

References


10- FATHEY N.: Assessment of parental perception of support needed to care for their mentally retarded children, Un-
published Master Thesis. Faculty of Nursing, Cairo University, 2004.


14- BINDU C.M.: Prominent psychosocial difficulties that parents of young children with severe disabilities may cope with during their child’s early years. Touro College, Graduate School of Education, New York, 2009.


