A comparative study of quality of life between parents of children with Down syndrome and parents of normal children

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ABSTRACT: The aim of this research was comparing the quality of life of parents of children with Down syndrome and parents of normal children in Hashtrud. So, 35 parents of children with Down syndrome and 35 parents of the normal children in Hashtrud kindergartens were selected using cluster sampling. The data were collected by performing the quality of life questionnaire (SF36) and the demographic questionnaire. Data were analyzed using t test and analysis of variance test. Results showed that parents of normal children have a higher quality of life. According to these results, quality of life of the fathers and mothers of children with Down syndrome had no difference, and it was the same for parents of normal children. There was no correlation between the quality of life of parents of normal children with their level of education and economic status and there was no correlation between the quality of life of parents of children with Down syndrome and their economic status but there was a correlation between the quality of life of parents of children with Down syndrome and their level of education, normally the parents with higher level of education had higher quality of life.

Keywords: Down syndrome, quality of life, parents, normal children

INTRODUCTION

People always have been looking for a good life. But what is good life? For centuries, many scientists tried to define good life and their works created a new concept: “Quality of Life” (Fatah Moghadam, Falahi Khoshknab, Rahgooy, Karimloo, 2005).

Quality of life includes all experiences that help people to perceive environment. It is a powerful tool for improvement of health in different societies (World Health Organization, 1998). Many researchers believe that quality of life is a complex issue and has different dimensions. Quality of life is perception of a person in relation to combination of physical, mental and social welfare (Molavi Nojoomi & Anbari, 2008). Quality of life consists of physical, social, familial, emotional, cognitive welfare. Quality of life is feeling of life satisfaction or dissatisfaction and has different facets (World Health Organization, 2005; Frisch, 2006).

Quality of life is a mental factor and is a person’s perception of his/her place in the world in relation to goals, standards and wishes (Ventegodt, Andersen & Merrick, 2003). During past decades many studies have been done about quality of life. These studies primarily focused on normal people and then studies focused on quality of life of children with disabilities (Molavi Nojoomi & Anbari, 2008).

Researchers have studied quality of life of exceptional children and their families. Children develop in families and bonding between family members is very important for children development. Recently, children with mental retardation and developmental disabilities have been studied in their families (Bradly, 1995). Down syndrome is a genetic syndrome that may result in mental retardation (Nadel, 2003).

Child with intellectual disability has a negative effect on presents (Ainge, 1995). Parents of children with Down syndrome encounter great challenges in childrearing. These parents experience more stress because caring a child with intellectual disability is not easy (Hedove , Annerech, & Wikbland, 2002; Roach, Orsmond, & Baratt, 1999). However, some studies show that parents of children with Down syndrome experience less stress than parents of children with other intellectual disabilities because children with Down syndrome have positive characteristics and less behavior problems (Ricci, & Hodapp, 2003) so, parents of children with Down
syndrome can accept child with Down syndrome more easily (Flaherty, & Larine, 2000) and a few parents of children with Down syndrome need help to adapt with the situation (Hornby, 1995).

This study aimed to compare quality of life among parents of children with Down syndrome and parents of normal children. So, 5 hypotheses proposed:

1- Quality of life of parents of children with Down syndrome differs from parents of normal children.
2- There is a correlation between quality of life and economic status in parents of children with Down syndrome.
3- There is a correlation between quality of life and economic status in parents of normal children.
4- There is a correlation between quality of life and education level in parents of children with Down syndrome.
5- There is a correlation between quality of life and education level in parents of normal children.

**METHODS**

Participants were 70 parents of children with Down syndrome (35 fathers and 35 mothers) and 70 parents of normal children (35 fathers and 35 mothers). Participants selected using cluster sampling among parents of children with Down syndrome and parents of normal children lived in Hashtrud, Iran.

**Measures**

To measure quality of life, Iranian version of the SF-36 questionnaire was used. This questionnaire had been translated to Persian and validated for Iranian population by Montazeri et al(Montazeri, Goshtasebi, Vahdaninia & Grandek, 2005). The Short Form (36) Health Survey is a survey of patient health. The SF-36 is commonly used in health economics as a variable in the quality-adjusted life year calculation to determine the cost-effectiveness of a health treatment. The SF-36 consists of eight scaled scores, which are the weighted sums of the questions in their section. Each scale is directly transformed into a 0-100 scale on the assumption that each question carries equal weight. The eight sections are:

- vitality
- physical functioning
- bodily pain
- general health perceptions
- physical role functioning
- emotional role functioning
- social role functioning
- mental health

**Results**

**Hypothesis 1:** Quality of life of parents of children with Down syndrome differs from parents of normal children.

<table>
<thead>
<tr>
<th>Dependent variable</th>
<th>group</th>
<th>N</th>
<th>Std deviation</th>
<th>Mean</th>
<th>N</th>
<th>t</th>
<th>Df</th>
<th>Sig</th>
</tr>
</thead>
<tbody>
<tr>
<td>QoL</td>
<td>DS</td>
<td>70</td>
<td>11.747</td>
<td>60.80</td>
<td>70</td>
<td>-6.961</td>
<td>138</td>
<td>.001</td>
</tr>
<tr>
<td></td>
<td>Normal</td>
<td>70</td>
<td>6.953</td>
<td>72.16</td>
<td>70</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Based on table 1, the null hypothesis is rejected and research hypothesis is accepted. So, quality of life of parents of children with Down syndrome differs from parents of normal children. Results showed that parents of children with Down syndrome had lower quality of life.

**Hypothesis 2:** There is a correlation between quality of life and economic status in parents of children with Down syndrome.
Table 2. ANOVA to compare quality of life of parents of children with Down syndrome in terms of economic status (high, average, low)

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>Mean of squares</th>
<th>Df</th>
<th>F</th>
<th>Sig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between groups</td>
<td>156.125</td>
<td>78.063</td>
<td>2</td>
<td>.558</td>
<td>.575</td>
</tr>
<tr>
<td>Within groups</td>
<td>9365.075</td>
<td>139.777</td>
<td>67</td>
<td></td>
<td></td>
</tr>
<tr>
<td>total</td>
<td>156.125</td>
<td>78.063</td>
<td>2</td>
<td>.558</td>
<td>.575</td>
</tr>
</tbody>
</table>

Based on table 2, the null hypothesis cannot be rejected. So, there is no significant difference between quality of life of parents of children with Down syndrome in terms of economic status.

Hypothesis 3: There is a correlation between quality of life and economic status in parents of normal children

Table 3. ANOVA to compare quality of life of parents of normal children in terms of economic status (high, average, low)

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>Mean of squares</th>
<th>Df</th>
<th>F</th>
<th>Sig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between groups</td>
<td>269.545</td>
<td>134.773</td>
<td>2</td>
<td>2.945</td>
<td>.059</td>
</tr>
<tr>
<td>Within groups</td>
<td>3065.726</td>
<td>45/755</td>
<td>67</td>
<td></td>
<td></td>
</tr>
<tr>
<td>total</td>
<td>156.125</td>
<td>78.063</td>
<td>2</td>
<td>.558</td>
<td>.575</td>
</tr>
</tbody>
</table>

Based on table 3, the null hypothesis cannot be rejected. So, there is no significant difference between quality of life of parents of normal children in terms of economic status.

Hypothesis 4: There is a correlation between quality of life and education level in parents of children with Down syndrome

Table 4. ANOVA to compare quality of life of parents of children with Down syndrome in terms of education level

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>Mean of squares</th>
<th>Df</th>
<th>F</th>
<th>Sig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between groups</td>
<td>1587.569</td>
<td>317.514</td>
<td>5</td>
<td>2.561</td>
<td>.036</td>
</tr>
<tr>
<td>Within groups</td>
<td>7933.631</td>
<td>123.963</td>
<td>64</td>
<td></td>
<td></td>
</tr>
<tr>
<td>total</td>
<td>9521.200</td>
<td>69</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Based on table 4, the null hypothesis is rejected and research hypothesis is accepted. So, there is difference between quality of life of parents of children with Down syndrome who have different levels of education. Tukey's HSD Post Hoc Test Results showed that parents with higher education had higher quality of life.

Hypothesis 5: There is a correlation between quality of life and education level in parents of normal children
Table 5. ANOVA to compare quality of life of parents of normal children in terms of education level

<table>
<thead>
<tr>
<th>Source of variation</th>
<th>Sum of squares</th>
<th>Mean of squares</th>
<th>Df</th>
<th>F</th>
<th>Sig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between groups</td>
<td>451.796</td>
<td>75.299</td>
<td>6</td>
<td>1.645</td>
<td>.150</td>
</tr>
<tr>
<td>Within groups</td>
<td>2883.476</td>
<td>45.769</td>
<td>63</td>
<td></td>
<td></td>
</tr>
<tr>
<td>total</td>
<td>3335.276</td>
<td></td>
<td>69</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Based on Table 5, the null hypothesis cannot be rejected. So, there is no significant difference between quality of life of parents of normal children in terms of education level.

**DISCUSSION**

Hypothesis 1 stated that quality of life of parents of children with Down syndrome differ from parents of normal children. Results showed that parents of normal children have higher quality of life. Many researches support this finding, for example (Hedove, Annereh, & Wikbland, 2000; Emerson, Hatton, Llewellyn, Blacker & Graham, 2006; Roach, Orsmond, & Baratt, 1999; Ainge, 1995; Mahani, 2009; Amiri majd, 2007; Ainge, 1995) showed that children with intellectual disabilities have a negative effect on present. Hedove, Annereh, & Wikbland, 2002; Orsmond & Baratt, 1999 showed that parents of children with Down syndrome encounter great challenges in childrearing. These parents experience more stress because caring a child with intellectual disability is not easy. Mahani, 2009 in a study found that quality of life of parents of children with CP and parents of children with mental retardation was lower than parents of normal children but there was no difference between quality of life of parents of children with CP and parents of children with mental retardation. Amiri majd, 2007 found that child's anxiety, depression and maladjustment predicted mother's mental health problems and anxiety and sleep problems of mother predicted total behavior problems, ADHD, and aggressiveness in children. Emerson, Hatton, Llewellyn, Blacker, Graham (2006) found that it is more likely that mothers of children with mental retardation experience mental disorders. Kazak and Marvin (1984, quoted in Abrag, Bertrand, Mort, Staphylococcus Vagstuf, 1999) in their study showed that mothers of children with mental retardation experience more stress than fathers because mothers often have main responsibility for care of disabled children, while fathers usually have a supportive role. Scott, Atkinson, Minton & Bowman, 1997 in their study showed that mothers of children with Down syndrome compared with mothers of normal children showed higher depression. Van Riper, Reef, Pridham (1992) in their study showed that parents of children with Down syndrome had lower adaptive functioning compared to parents of normal children.

Second and third hypothesis stated that: 1- Quality of life of parents of children with Down syndrome differs in terms of economic status. Results showed that there was no difference in quality of life among parents of children with Down syndrome based on economic status. 2- Quality of life of parents of normal children differs in terms of economic status. Results showed that there was no difference in quality of life among parents of normal children based on economic status. Studies showed that several demographic factors related to behavioral problems in children and maternal mental health. Socioeconomic status is an important factor related to children's behavioral problems. Temporary living environment also affects everyday life and roles and responsibilities of parents (Hallpern, 1993). However, in this research no relationship between family socioeconomic status and child's behavior problems and maternal mental health was observed, probably because of the lack of appropriate jobs classification in Iran and because one of the important elements to determine socio-economic status. Also, most families had moderate and low socio-economic status. Although some studies show that families who have low socio-economic status can better adapt with having a child with mental retardation (Denmark, 1994).

Fourth and fifth hypotheses stated that: 1- quality of life of parents of children with Down syndrome differs according to education level. Results showed that there was difference in quality of life among parents of children with Down syndrome who had different education levels. People with higher education had better quality of life than people with lower education levels. 2- Quality of life of parents of normal children differs according to education level. Results showed that there was no difference between quality of life among parents of normal children based on educational levels. Hedove, Annereh, & Wikbland (2000) studied Perceived health of parents of children with Down syndrome. Results showed significant differences between the health of
mothers and fathers of children with Down syndrome. Mothers of children with Down syndrome had lower scores in wellbeing area. The mothers of children with Down syndrome had lower mental health than mothers with normal children. Fathers of children with Down syndrome in the "wellbeing" and "mental health" areas obtained lower scores than fathers of normal children.

Based on the results, it is suggested that government provide all necessary facilities for parents of children with Down syndrome so quality of life of these families may improve.

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REFERENCES


