OBJECTIVE

The purpose of this study was to investigate the social and demographic features and quality of life of parents that have children with Down syndrome, and to verify the influence that the care of these children has on the quality of life of their parents.

METHODS

This was an investigative and descriptive study that included a sample of 30 parents that have children with Down syndrome who were registered in the APAE Sao Paulo and APAE Barueri. A questionnaire elaborated by the authors and the Quality of Life Scale (WHOQOL-BREF) questionnaire were applied.

RESULTS

In the sample of 30 parents of children with Down syndrome, 80% were female. The age ranged from 28 to 49 years, mean of 37 years. The quality of life was described as “good” by 60% of the sample. The following WHOQOL-BREF scores were found: social (80.72); physical (73.36); environmental (69.74); and psychological (60.28). There were 12 responses about the influence of the care of Down syndrome children on quality of life, of which 58.3% reported major involvement with the education and care of the children, which resulted in satisfaction.

CONCLUSIONS

Observation of the psychological domain had the lowest score in the quality of life evaluation, suggesting that parents need to be offered psychological support.

Keywords: Down syndrome; Quality of life; Child; Parents; Questionnaires

INTRODUCTION

Down syndrome is the most common chromosomal disorder in human beings. It was first described by Edwar Seguin and later by John Langdon Haydon Down between 1846 and 1866. The condition is characterized by moderate to severe mental impairment (1-3).

In 1959, the French scientists Lejeune, Turpin and Gautier demonstrated the genetic cause of this syndrome by characterizing it as a trisomy of a small telocentric chromosome; the condition was then named chromosome 21 trisomy (1,3).

Its phenotype results in clinical manifestations that are present in about 60 to 90% of Down syndrome children, namely: upslanting palpebral fissures, strabismus, brachycephalia, plantar tibial groove, midfacial hypoplasia, brachydactyly of the hands and fifth-finger clinodactyly, a single transverse palmar crease, epicanthic folds, a larger than normal space between the first and second toes, vertebral alterations, poor muscle tone, a high and narrow palate and macroglossia(1).
Following birth and definition of the genetic condition, a dialogue is started to convey this information. Parents initially tend to remain silent, a so-called “silent thunder”, during which feelings such as anger, sadness, discomfort and others may arise in response to this new imposed reality (4-5).

After the diagnosis is defined, the syndrome needs to be clarified to provide relevant basic healthcare for the child, but most of all, to overcome barriers and bring parents closer to their child (4).

Among the factors that affect the physical and mental development of the child, the most important is the stimulation from close contact between mother and child; this becomes extremely relevant when dealing with Down syndrome children (3).

Down syndrome children develop slower; parents, therefore, need to dedicate themselves significantly to foster their development. These children require increased stimulus and attention in their daily activities (6).

Such level of care on the part of parents of Down syndrome children alters daily routines. Thus, functional, structural and emotional changes occur in all family members, particularly in parents relative to their quality of life (6).

The World Health Organization (WHO) defines “quality of life” as the perception that individuals have of their position in life within their cultural and value systems, their objectives, expectations and concerns (7).

These changes in the quality of life of parents are directly related to diverse factors, such as acceptance of their child’s deficiency, how they received the news, lack of access to information and changes in daily routines (6).

OBJECTIVES

General objective

• To assess the opinions of parents of children with Down syndrome about the effect that taking care of these children has on their (parents) quality of life.

Specific objectives

• To characterize parents of Down syndrome children from the social and demographic perspective;
• To verify the influence of taking care of Down syndrome children on the quality of life of their parents.

METHODS

This was a quantitative, exploratory and descriptive level I study.

Study design

A cross-sectional study was made with parents of Down syndrome children who were registered at the Association of Parents and Friends of the Handicapped (APAE; acronym in Portuguese). Parents answered the World Health Organization Quality of Life assessment tool (WHOOOL-BREF) and a questionnaire prepared by the authors of the study.

Subjects

The study sample consisted of 30 parents of children with Down syndrome who were registered at the APAE; the study was carried out from August 1st to October 30, 2007.

The inclusion criteria were:
• to be literate;
• to be a parent of a child with Down syndrome;
• the child should be registered in APAE;
• willingness and consent to participate in the study.

INSTRUMENT

WHOQOL-BREF

The World Health Organization Quality of Life is the original questionnaire developed by the WHO and contains one hundred questions. The assessment tool used in the present study was the summarized Portuguese version (7) of the WHOQOL-BREF (Appendix 1).

The summarized version of the WHOQOL-BREF comprises 26 questions assessing four domains: the physical, psychological, social and environmental domains (6).

Questionnaire

The questionnaire was written by the authors of the present study and contained multiple-choice questions and a dissertation question (Appendix 2).

PROCEDURES

Data collection

Data was collected following approval of the study design by the Research Ethics Committees of the Nursing School (Hospital Israelita Albert Einstein) and of the Hospital Israelita Albert Einstein. Parents of Down syndrome children were then invited to participate; those that accepted were asked to sign an informed consent form before answering two questionnaires – the WHOQOL-BREF and the questionnaire written by the authors.

Data was used only for this study; confidentiality about the identity of subjects was maintained.
throughout the study, as defined in the Researcher Terms and Conditions.

Data analysis

Descriptive statistics (mean, standard deviation, median and percentages) were used to analyze the data, which is presented in absolute numbers and as percentages in charts and tables.

In the WHOQOL-BREF, the 24 answers provided by parents (out of 26) were grouped into four domains; results were summarized by using equations to obtain raw scores (RS) and transformed scores (TS). The TS had no variation of possible values; the TS 4-20 remained within 4 and 20 for all domains, and the TS 0-100 remained between 0 and 100. Assessment of results was done using the means in the RS, the TS 4-20, and the TS 0-100; thus, the interval between individual assessments was not taken into account.

RESULTS

Social and demographic features

In the group of 30 parents of Down syndrome children, 80% were female. Their age ranged from 28 to 49 years (mean of 37 years). Investigation of the marital status showed that 66.67% were married; 60% of parents had two children. A little over half of the sample (56.67%) practiced some religion; 56% were catholic (Table 1).

In the sample, 80% resided in flats or houses with their families; most parents (60%) reported owning their houses. Most of the parents (60%) had an income below one minimum salary per month; 66.67% used public transport (buses) as their means of transportation. And 70% of parents reported not having a regular paid job (Table 1).

Quality of life of parents with Down syndrome children

The quality of life of 30 parents of Down syndrome children was reported as “very good” (10%), “good” (60%) and “neither good nor bad” (30%).

The social domain had the highest score, while the psychological domain had the lowest score, as shown on Table 2.

Concerning the parents’ opinion about whether caring for their Down syndrome children affected their quality of life, 56.67% answered yes (Table 3).

The reason given for this by 58.3% of parents (out of 12 answers) was the need for major involvement in caring and educating their Down syndrome children, which brought satisfaction to the parents. (Table 4)
DISCUSSION

According to Carswell and Borsatto the age of parents with Down syndrome children ranged from 24 to 47 years, and most parents are aged over 30 years\(^{(1,3)}\) as in the present study.

The majority of parents in our sample evaluated their quality of life as “good”. This finding agrees with a study by Fávero (2005), in which 70% of mothers considered their lives “good”\(^{(9)}\).

For the parents that considered the quality of their lives as “neither good nor bad” this fact may be result of the following reasons: altered family routines, difficulty in accepting their child’s impairment, and difficulty in accessing the necessary support\(^{(10)}\).

Among the quality of life assessment domains in the present study, the social domain had the highest score, while the psychological domain had the lowest score. When comparing these results with those reported in a study of mothers with autistic children, we find that in this case the physical domain had the highest score (69.4) and the environmental score had the lowest score (60.8)\(^{(9)}\).

A low score in the psychological domain of the parent’s quality of life confirms the conclusions of Carswell and Grossi. They state that the birth of a child with Down syndrome may result in psychological pain for their parents\(^{(3,11)}\). This psychological impact is responsible for generating confused feelings that may persist throughout life\(^{(11)}\).

Further aspects possibly related with lower scores in the psychological domain in the quality of life assessment of parents are: social, psychological and financial overburden and the need for taking care of the child, which may cause feelings of anxiety and uncertainty in parents. There are also feelings of insecurity about the survival, development and long-term care of the child, as well as the effect of such care on the parent’s personal lives\(^{(12-13)}\).

For the majority of the sample, caring for their Down syndrome child affected their quality of life. There were some explanations given for this, of which the majority reported the existence of major involvement with their child’s education and care which brought satisfaction to the parents themselves, however. Furthermore, a few parents said: “I need to share certain spaces with them. Caring for them requires special attention and more monitoring of their routines.”

According to Carswell, the need for special attention requires that parents involve themselves in every activity and care of their Down syndrome child\(^{(3)}\). Other studies reported the increased responsibility and workload that these parents have in caring for Down syndrome children\(^{(12)}\).

This level of involvement in the care and in the activities of Down syndrome children requires more time from parents, as reported by Parazzi and Dupas\(^{(14)}\), Saraiva and Nobrega\(^{(15)}\), Grossi\(^{(11)}\), Barnett and Boyce\(^{(16)}\), among others, however, stated that time for involvement is the main difficulty parents face daily\(^{(12,17)}\).

The results of this study suggest that most parents feel pleased with their involvement in caring for their Down syndrome child. Parazzi and Dupas\(^{(14)}\) suggested that in caring for a child with developmental problems, parents become able to change possibly negative issues into gains, notwithstanding their difficulties. They learn to know their children better and to notice his or her smartness, which brings them feelings of joy\(^{(14)}\).

Although parents might have initially experienced negative feelings, their role as caretakers is not left aside, and they engage themselves significantly in the new routine. They do it with satisfaction and place high expectations on the development of their child\(^{(12,13,18-19)}\).

CONCLUSIONS

In our sample of 30 parents of Down syndrome children, 80% were female. Age ranged from 28 to 49 years (mean of 37 years). Most parents of these children reported that their quality of life was “good”. The social domain had the highest score, whereas the psychological domain had the lowest score. It suggests that there is a need to offer psychological support to these parents.

The majority of parents in our sample stated that caring for their children affected their quality of life; they reported significant involvement with the education and care of their children as something that brings them satisfaction.

REFERENCES


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**Appendix 1. Questionnaire - World Health Organization Quality of Life (WHOQOL-BREF)**

**Instructions**

The following questions ask how you feel about your quality of life, health, or other areas of your life. Please answer all questions. If you are unsure about which response to give to a question, please choose the answer that appears most appropriate. Very often the first response you think of is the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks. For instance, considering the last two weeks, on question would be:

<table>
<thead>
<tr>
<th>Do you receive support you need from others?</th>
<th>no</th>
<th>very little</th>
<th>average</th>
<th>much</th>
<th>full</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Circle the number that best fits the answer.

Please read each question, think about it and circle the number that best fits the answer.

**Circle number 1 if you received “no” support.**

1. How would you rate your quality of life?  
   - very poor
   - poor
   - neither poor nor good
   - good
   - very good

2. How satisfied are you with your health?  
   - very dissatisfied
   - dissatisfied
   - neither satisfied nor dissatisfied
   - satisfied
   - very satisfied

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weeks. Hence, circle number 4 if you receive “much” support as below.
The following questions ask about how much you have experienced certain things in the last two weeks.

<table>
<thead>
<tr>
<th>Question</th>
<th>not at all</th>
<th>a little</th>
<th>a moderate amount</th>
<th>very much</th>
<th>an extreme amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>3  To what extent do you feel that physical pain prevents you from doing what you need to do?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4  How much do you need any medical treatment to function in your daily life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5  How much do you enjoy life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6  To what extent do you feel your life to be meaningful?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7  How well are you able to concentrate?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8  How safe do you feel in your daily life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9  How healthy is your physical environment (weather, noise, pollution, leisures)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

The following questions ask about how completely you experienced or were able to do certain things in the last two weeks.

<table>
<thead>
<tr>
<th>Question</th>
<th>not at all</th>
<th>a little</th>
<th>moderately</th>
<th>mostly</th>
<th>completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 Do you have enough energy for everyday life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11 Are you able to accept your bodily appearance?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12 Have you enough money to meet your needs?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13 How available to you is the information that you need in your day-to-day life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14 To what extent do you have the opportunity for leisure activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

The following questions ask about how well or satisfied you felt about several aspects of your life in the last two weeks.

<table>
<thead>
<tr>
<th>Question</th>
<th>very dissatisfied</th>
<th>dissatisfied</th>
<th>neither satisfied nor dissatisfied</th>
<th>satisfied</th>
<th>very satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>15 How well are you able to get around?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16 How satisfied are you with your sleep?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17 How satisfied are you with your ability to perform your daily living activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18 How satisfied are you with your capacity for work?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19 How satisfied are you with yourself?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20 How satisfied are you with your personal relationships (friends, relatives, acquaintances, peers)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>21 How satisfied are you with your sex life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>22 How satisfied are you with the support you get from your friends?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>23 How satisfied are you with the conditions of your living place?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>24 How satisfied are you with your access to health services?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>25 How satisfied are you with your transport?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

The following question refers to how often you have felt or experienced certain things in the last two weeks.

<table>
<thead>
<tr>
<th>Question</th>
<th>never</th>
<th>seldom</th>
<th>quite often</th>
<th>very often</th>
<th>always</th>
</tr>
</thead>
<tbody>
<tr>
<td>26 How often do you have negative feelings such as blue mood, despair, anxiety, depression?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Did anyone help you fill in this questionnaire? .......
Appendix 2. Questionnaire – Quality of life of parents with Down syndrome children

1. Age: _______ Sex ( ) M ( ) F

2. Marital status: ( ) single ( ) married ( ) widow (er) ( ) separated
   ( ) living together ( ) divorced ( ) Other ___________________________

3. Children: ( ) yes ( ) no How many? ___________________________
   Children age: ___________________

4. Religion: _______________ Practice the religion: ( ) yes ( ) no

5. Place of birth: _____________________________________________

6. Nationality: ________________________________________________

7. City of residence: __________________________________________

8. State: ____________________________________________________

9. Type of housing?
   ( ) house or apartment, with family ( ) small hotel
   ( ) student’s house ( ) house or apartment, alone
   ( ) other: ___________________________________________________

10. Household: ( ) own ( ) rented ( ) mortgage
    ( ) other: ___________________________

11. Family income: ( ) < 1 minimum salary ( ) 1 to 5 minimum salaries
    ( ) 6 to 10 minimum salaries ( ) 11 or more minimum salaries

   (the minimum salary was R$ 350.00, provided by Law No. 11,321, of July 7, 2006)

12. Family means of transportation: ( ) car ( ) motorbike ( ) bus
    ( ) other Which? ___________________________

13. Has any paid job? ( ) yes ( ) no
    If yes, which? ___________________________________________

14. How long has your child been enrolled at the APAE? ___________

15. In your opinion, does caring of your child with Down syndrome influence your quality of life? ( ) yes ( ) no

16. If the previous answer was “YES”, how does it influence? ____________

How long did take to fill in this questionnaire? ______________________
Do you have any comments about the questionnaire?

THANKS FOR YOUR COLLABORATION