

The Relationship Between Parenting Stress in Parents and Oral Health-Related Quality of Life (OHRQoL) Children with Down Syndrome

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Abstract

To determine and evaluate the relationship between parenting stress in parents with oral health-related quality of life (OHRQoL) in children with Down Syndrome.

The research method is analytic with a survey using the Parenting Stress Index Short Form (PSI-SF) and Early Childhood Oral Health Impact Scale (ECOHIS) questionnaires. The sampling technique was carried out by purposive sampling and obtained 33 samples of parents with Down Syndrome children that met the inclusion criteria. Data were tested statistically using the non-parametric Spearman correlation test.

There was no significant relationship between parenting stress in parents and OHRQoL of Down Syndrome children, with a value of $r_s = -0.14$ and $p\text{-value} = 0.2256 (> 0.05)$.

There is a relationship between parenting stress in parents and OHRQoL of children with Down Syndrome, but it is not statistically significant.

Clinical article (J Int Dent Med Res 2021; 14(4): 1478-1484)

Keywords: Down Syndrome, parenting stress, OHRQoL.

Received date: 29 May 2021

Accept date: 17 August 2021

Introduction

The most common intellectual disorder is Down Syndrome, a genetic disorder accompanied by limitations in aspects related to communication and behavior, caused by an extra copy of chromosome 21 which is represented as trisomy, or part of the third copy of chromosome 21 which is called a translocation.¹⁻³ Mental age, speech, language, short-term verbal memory, delayed gross motor skills development, cognitive limitations, neurological disorders, sensorimotor integration disorders, psychosocial functioning, and health disorders are all areas of impairment in Down Syndrome.^{1,2} Each year, the probability of giving birth to a child with Down Syndrome is 0.1%.⁴ Based on basic health research in Indonesia in 2018, cases of Down Syndrome were 0.21%.⁵

The birth of a Down Syndrome child can alter the environment by creating additional difficulties

with parenting that are not found in typical development children.³ Families of children with special needs suffer from significantly increased levels of stress.⁶ The relationship between stress and parenting demands has been studied extensively in the past two decades, with evidence pointing to negative consequences on child development, family dynamics, and parenting satisfaction.⁷ Parenting stress is defined as "an unpleasant psychological reaction to parental demands", which is associated with high levels of parental distress, child distress, and dysfunctional interactions between parents and children.^{4,8}

Stress was found to be higher in mothers of children with Down Syndrome than in mothers of children who were typically developing, and current research links increased stress to differences in parenting styles.¹ There is evidence that parents with Down Syndrome children experience more stress and may be at greater risk of developing depressive disorders.⁹ This additional stress may be specific for the first few months after diagnosis, but parents also experience stress as the child gets older and faces difficult transitions such as learning to speak or finding a suitable school.⁹

Therefore, it is important to properly assess the elements of parenting stress that are an

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obstacle to the healthy development of children.¹⁰ Parenting Stress Index (PSI) is an assessment tool first developed by Abidin to reflect the conceptualization of parenting stress.^{8,10} The PSI provides a measure of parental stress levels related to parenting demands and identifies dysfunctional parenting styles.⁷ Parenting Stress Index Short Form (PSI-SF) is a shortened version of PSI.⁷

High levels of stress in the elderly have been associated with lower quality of life in children and adolescents.⁷ Medical and psychological complications, as well as barriers to proper health and oral health care, can worsen health and oral health-related quality of life (HRQoL and OHRQoL).¹¹ Children's oral health can be understood by knowing OHRQoL.¹² OHRQoL is defined as the impact of oral health or disease on the daily functioning, well-being, and quality of life of an individual.¹²

One of the OHRQoL assessments is using the Early Childhood Oral Health Impact Scale (ECOHIS).¹¹ The ECOHIS consists of two scales, the child and family impact scale, which is designed for parents/caregivers to answer a questionnaire because children do not have the cognitive skills necessary to assess their quality of life.^{11,13}

The oral health of children/adolescents with Down Syndrome has a negative impact on various aspects of their lives and their families.¹⁴ Oral health status Down syndrome is prone to orofacial disorders such as periodontal disease, malocclusion, and soft tissue disorders including a protruded tongue.¹⁵ Research by Latifi-Xhemajli Blerta et al.¹⁶ stated that children with Down Syndrome have poor dental health with a mean DMFT of 5.8. The impact of orofacial conditions on Down Syndrome is related to oral symptoms (pain, discomfort, difficulty chewing), systemic impact on nutrition and digestion and can have an effect on the quality of life (QoL) including social interactions, and emotional status.¹⁵ Research by AlJameel, AH et al.¹⁵ stated that mothers of children with Down Syndrome experience a range of quality of life impacts from oral conditions, which affect their child and the wider family.

There is no research on the relationship between parenting stress in parents and OHRQoL in children with Down Syndrome. This study aims to determine the description of parenting stress in parents with Down Syndrome

children, to know the OHRQoL of children with Down Syndrome, and to know and evaluate the relationship between parenting stress and OHRQoL of children with Down Syndrome.

Materials and methods

Participants

The sample size was calculated according to the minimum single sample size for the Spearman correlation in the hypothesis test using the correlation coefficient (r), and the minimum sample used was 29 parents of Down Syndrome children. The sampling technique was carried out by purposive sampling, with inclusion criteria, which are parents who have Down syndrome children who are registered at the POTADS Foundation, are willing to be research subjects, and fill out the informed consent. The research sample at the POTADS Foundation was however only 33 parents who met the inclusion criteria.

Methods

This research is an analytical study with a survey method, that is data collection through a questionnaire form. The data obtained will be analyzed using the non-parametric Spearman correlation test to find the relationship between parenting stress in parents and OHRQoL of children with Down Syndrome.

Materials

The tools used in this study were: the informed consent for filling out the questionnaire, the personal information form of the parents, the PSI-SF and ECOHIS questionnaires.

Parenting stress measure

Parenting stress was measured using Abidin's PSI-SF questionnaire. Abidin's PSI-SF was previously translated from English into Indonesian and tested for validation and reliability. The validation test is carried out twice, this is done because in the first validity test there are 4 invalid question points, the second validity test results in all positive correlation coefficients which indicate all PSI-SF question points are valid. The reliability test of the PSI-SF questionnaire obtained a reliability of 0.99 which indicates that the reliability is high. Abidin's PSI-SF scale consists of 36 questions with three subscale components, such as Parental Distress (PD), Parent-Child Dysfunctional Interaction (P-CDI), and Difficult Child (DC). The parenting stress scale uses a Likert scale model of attitude.

In conducting the research, the subject is asked to agree or disagree with the contents of the statement, strongly disagree (1) to strongly agree (5). Total stress is an indication of a person's overall stress level in carrying out their role as parents.¹⁷ There are two scores obtained from the PSI-SF, namely: raw score and percentile score.¹⁷ The raw score is calculated directly from the parents' answers to the questions.¹⁷ the percentile score is easier to interpret because it describes the relative position of the parents in all the parents assessed during the development and testing of the PSI-SF instrument.¹⁷ The score is:¹⁷

1. Typical stress scores are between 15 and 80 (for PD, P-CDI, and DC)
2. The high-stress score is between 81 and 89 (for P-CDI between 81-84, PD and DC between 81-89)
3. Clinically significant stress scores requiring additional follow-up are between 90 and 100 (for P-CDI above 85, PC and DC between 90-100)

OHRQoL measure

Measurement of OHRQoL in Down Syndrome children are measured using the ECOHIS questionnaire, which is absorbed into Indonesian and has been tested for validity (validity coefficient 0.372 and 0.901) and reliability (reliability coefficient 0.870) by Elfarisi et al.¹⁸ ECOHIS consists of two impact scales, that is the impact of children (9 questions) and family (4 questions). The results of filling out the ECOHIS questionnaire were calculated using the Guttman scale. The ECOHIS score was calculated as the sum of the response codes for child and family impact separately. All "Don't know" responses were excluded from the analysis.¹⁸ Response categories for scoring were coded: 1 = ever and 0 = never. A higher score indicates a greater impact on oral health and a poorer OHRQoL.¹¹ The OHRQoL score criteria can be classified, being less impactful (0 - 33.3)%, quite impactful (33.4 -66.6)%, and very impactful (66.7-100%).¹⁸

Procedure

Researchers have obtained ethical approval from the Health Research Ethics Committee and research permit approval from the POTADS Foundation. Researchers sent information sheets, informed consent forms, parenting stress questionnaires, and OHRQoL to

parents with Down Syndrome children at the POTADS Foundation via google form and in the form of hard copies stored at the POTADS Foundation. The study was conducted from January to February 2021.

Results

Table 1 shows the parents of Down Syndrome children who meet the inclusion criteria, 100% women. Most of them were 41-50 years old (48.5%). Respondents having Down Syndrome children 27.27% girls and 72.73% boys, with the most age <18 years (93.94%). The highest level of education for parents who have Down syndrome children is bachelor graduates at 51.52% and the most occupations are as housewives (63.64%).

| Karakteristik | f | % |
|----------------------------------|-----------|---------------|
| Gender of Parents | | |
| Men (Fathers) | 0 | 0 |
| Women (Mothers) | 33 | 100.00 |
| Age of Parents (years) | | |
| 31-40 | 13 | 39.4 |
| 41-50 | 16 | 48.5 |
| >50 | 4 | 12.1 |
| Gender of Children's | | |
| Boys | 24 | 72.73 |
| Girls | 9 | 27.27 |
| Age of Children's (years) | | |
| 2-18 | 31 | 93.94 |
| >18 | 2 | 6.06 |
| Parents Education | | |
| High School | 10 | 30.30 |
| Diploma | 16 | 18.18 |
| Bachelor | 17 | 51.52 |
| Parents' Employment | | |
| Employed* | 12 | 36.36 |
| Not employed (housewife) | 21 | 63.64 |
| Total | 33 | 100.00 |

Table 1. Distribution of Respondent Characteristics.
 Note: f=frequency;*= entrepreneurs, employees, government employees, teachers, translators, architects, consultants.

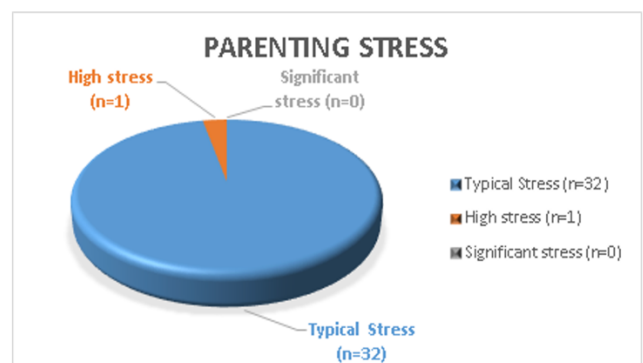


Figure 1. Distribution of Parenting Stress in Parents.

| Parenting Stress Category | Parenting Stress Factors | | | | | |
|-------------------------------|--------------------------|---------------|-----------|---------------|-----------|---------------|
| | PD | | P-CDI | | DC | |
| | f | % | f | % | f | % |
| Typical Stress | 32 | 96.97 | 25 | 75.76 | 30 | 90.91 |
| High Stress | 1 | 3.03 | 2 | 6.06 | 1 | 3.03 |
| Clinically Significant Stress | 0 | 0 | 6 | 18.18 | 2 | 6.06 |
| Total | 33 | 100.00 | 33 | 100.00 | 33 | 100.00 |

Table 2. Distribution of Factors in Parenting Stress.

Note: f=frequency; PD = Parental Distress; P-CDI= Parent-Child Dysfunctional Interaction; DC= Difficult Child.

Figure 1 shows a picture of parenting stress in parents with Down Syndrome children. Parents who experienced typical stress were 96.97%, high stress 3.03%, and clinically significant stress requiring additional follow-up by 0.00%. Table 2 shows the three factors in parenting stress that were assessed using the PSI-SF. In the PD factor, parents who experienced typical stress were 96.97%, and high stress 3.03%. The P-CDI factor consists of typical stress of 75.76%, high stress of 6.06%, and clinically significant stress of 18.18%, while stress generated from DC consists of typical stress of 90.91%, high stress 3.03%, and clinically significant stress 6.06%.

| OHRQoL Category | f | % |
|-----------------|-----------|---------------|
| Less Impactful | 19 | 57.58 |
| Quite Impactful | 8 | 24.24 |
| Very Impactful | 6 | 18.18 |
| Total | 33 | 100,00 |

Table 3 OHRQoL Distribution.

Note: f=frequency.

| Question Number | Alternative Answer | | | Score | % |
|--|--------------------|-------|-------------|------------|--------------|
| | Ever | Never | Don't Know* | | |
| Child Impact Scale | | | | | |
| Symptoms of a child | 1 | 28 | 5 | 28 | 84.85 |
| Child function | 2 | 13 | 19 | 13 | 40.63 |
| | 3 | 15 | 16 | 2 | 15 |
| | 4 | 11 | 21 | 1 | 11 |
| | 5 | 13 | 19 | 1 | 13 |
| Psychological circumstances | 6 | 10 | 22 | 1 | 10 |
| Self-image & social interactions | 7 | 8 | 25 | 8 | 24.24 |
| | 8 | 7 | 26 | 7 | 21.21 |
| | 9 | 5 | 26 | 2 | 5 |
| Score and Percentage Of Child Impact | | | | 110 | 37.97 |
| Family Impact Scale | | | | | |
| Parents condition | 10 | 8 | 23 | 8 | 25.81 |
| | 11 | 15 | 18 | 15 | 45.45 |
| Family function | 12 | 11 | 22 | 11 | 33.33 |
| | 13 | 6 | 25 | 2 | 19.35 |
| Score and Percentage Of Family Impact | | | | 40 | 30.99 |

Table 4. Responses of Parents with Down Syndrome Children to the ECOHIS Survey.

Note: * were not included in the data analysis and total scores.

Table 3 shows the description of OHRQoL in Down Syndrome children using measurements with ECOHIS, which is less impactful by 57.58%, quite impactful 24.24%, and very impactful 18.18%. Table 4 shows an overview of the responses of parents with Down Syndrome children from the ECOHIS questionnaire questions. Questions 1-9 show the impact on Down Syndrome children on OHRQoL, with a percentage of 37.97%, which is categorized as having quite impactful and the biggest answer is in question number 1, which is 84.85%. Questions number 10-13 show the impact on the family on the OHRQoL of Down Syndrome children, amounting to 30.99%, falling into the category of less impact and the highest answer is in question number 11, which is 45.45%.

| Variable | rs | t count | P-value | Quality | Relationship | Description |
|-----------------------------|-------|---------|---------|-----------------|--------------|-------------|
| Parenting Stress and OHRQoL | -0.14 | 0.76 | 0.2256 | Non-significant | 1.84 | Not related |

Table 5. Relationship between Parenting Stress in Parents and OHRQoL in Children with Down Syndrome.

Note: rs = correlation coefficient; statistically significant for p-value<0.05.

Table 5 shows the results of the non-parametric Spearman correlation test, which is there is a relationship between parenting stress in parents and OHRQoL of children with Down Syndrome, but it is not statistically significant, with a relationship of 1.84% and p-value > 0.05 which means insignificant.

Discussion

The data on the characteristics of respondents listed in Table 1 shows the data on the characteristics of the parents of Down Syndrome children who are all female (mothers), at most 41-50 years old, the majority of children with Down Syndrome are male, with the greatest age <18 years. In this data, it can be seen that all respondents are women (mothers) and the majority of jobs are housewives, this shows that the mother is the main caregiver. Maternal age is at most 41-50 years, indicating the risk of having a child with Down Syndrome increases with increasing maternal age.¹⁹ Research by Smith AL et al.¹⁹ stated that the parents of Down Syndrome

children are significantly older than other developmental disabilities.

In the results of the study (Figure 1), it was concluded that the parents of Down Syndrome children experienced parenting stress with the most categories, that is typical stress and none experienced clinically significant stress that required additional follow-up. This indicates that parents with Down Syndrome children experience a low level of parenting stress. The description of the results of this study regarding the frequency of parenting stress is in line with the research of Hodapp RM et al.²⁰ who stated that mothers who have Down syndrome children experience lower stress levels in the child-related stress domain compared to other types of learning disorders, besides Hodapp RM et al. said the mother's education level did not show a correlation with parenting stress. Based on research by Hodapp RM et al. this can be used as a reference that although the most educational level of parents with Down Syndrome children, that is bachelor graduates in the results of this study (Table 1), may not be related to parenting stress, it is necessary to do further research.

The reason for parenting stress on parents who have Down Syndrome children is low because Down Syndrome children have a social and fun nature, so the frequency of behavioral problems is low.³ Research by Eisenhower AS et al.²¹ shows that parents of Down Syndrome children consider their child to have lower behavioral problems than other children with special needs. Children with Down Syndrome smile more often at others so they are perceived as more positive and evoke better interpersonal reactions than others.²⁰ The research conducted did not directly measure these variables, but if the parents in this study considered their children to have a more positive personality overall, the parents will likely ignore the difficulties in communicating.

Caring for a child with Down Syndrome may not be as difficult as it seems, but there are some studies that parents experience stress and may be at greater risk of developing depressive disorders.⁹ There are several reasons why mothers with Down Syndrome children experience stress, such as Down Syndrome children are at risk of experiencing many health-related problems so that parents are required to provide greater care, increased financial burdens,

more problems related to advocacy, decreased feelings mother's competence¹, have mental functions below average and have behavioral and communication problems.⁹

The results of this study showed that in all factors, parents experienced the most typical stress (table 2). These results indicate parenting stress in parents with Down Syndrome children is low. These results are in line with the research of Smith AL et al.¹⁹ which states that parents of Down Syndrome children report lower stress levels on the PD and DC scales, and adaptive behavior contributes significantly to stress related to the P-CDI scale, so that when children have higher levels of adaptive behavior, so parents report their children are more likely to live up to their expectations. Overall the results of the research by Smith AI et al.¹⁹ suggest that parenting stress on parents of Down Syndrome children is lower than for children with developmental disabilities.

The results in table 3 show that the frequency of OHRQoL in children with Down Syndrome has the least impact. Research by Carrada CF et al.²² states that the impact of the teeth and mouth conditions of children with Down Syndrome on the OHRQoL family impact scale is not different from families without Down Syndrome disorder. These results suggest that the impact of oral conditions is considered less relevant by family members of a Down Syndrome child than all the daily care that this population requires²², because Down Syndrome children are at high risk of experiencing medical problems, such as heart disease, thyroid, and blood disorders.²³ The results had less impact on this study because parents at the POTADS Foundation had often received education about oral health.

The categories are quite impactful and very impactful as can be seen in Table 3. This shows that the oral health of children with Down Syndrome has a negative impact on their quality of life (QOL). Children with Down Syndrome have specific orofacial characteristics that can increase the risk of developing oral health problems.¹⁵ Orofacial conditions in children with Down Syndrome are associated with a negative impact on oral health-related quality of life (OHRQoL).²² Research by Aljameel AH et al.¹⁵ stated that oral health has an impact on the lives of children with Down Syndrome and their families, which indicates that these impacts affect

various aspects of their lives.

Table 4 shows the prevalence of negative impacts on the OHRQoL of Down Syndrome children and their families, respectively 37.97% is in the quite impactful category and 30.99% is in the less impact category. This shows that the impact on children is greater than the impact on the family. On the child impact scale, the greatest prevalence was related to pain in the teeth, mouth, and jaw (question no 1 in ECOHIS), while the larger prevalence on the family impact scale was related to guilt because of problems with the teeth and mouth or after the child received dental treatment (question no 11 in ECOHIS). This result is in accordance with the research of Aljameel AH et al.¹⁵ which shows that dental health problems in Down Syndrome children contribute to the pain felt by the child, causing an impact on the family, namely feelings of guilt and worry experienced by the mother. One of the negative impacts is due to the difficulty speaking in Down Syndrome children.¹⁵ The prevalence of oral health problems that most often occurs in Down Syndrome children is periodontal disease.¹⁴ This periodontal condition has a negative effect on the quality of life of the child with Down Syndrome, and this effect increases with disease severity.¹⁴

Based on data analysis and hypothesis testing about the relationship between parenting stress in parents with OHRQoL children Down Syndrome listed in Table 5, it shows an insignificant negative relationship. This is due to the low parenting stress experienced by parents of Down Syndrome in this study, as seen from the results of the frequency of parenting stress which shows that most of the stress categories are typical, none of which fall into the clinically significant stress category that requires additional follow-up.

The number of stress categories typical of parents with Down Syndrome may be caused by the positive personality traits of Down Syndrome children, they look more cheerful, happy, fun, and easy to get along with.²⁴ Parents of Down Syndrome children raise their child with "normality".³ Research by Hodapp RM et al.²⁰ stated that mothers with Down Syndrome children rated their children as having more positive personality traits and less maladaptive behavior than other intellectual disabilities and reported experiencing less stress.

The emotional well-being of parents is

very important to improve the good quality of life and maintain the health of children with Down Syndrome, including maintaining oral health.²² Down syndrome children need help from parents/caregivers to maintain the health of their teeth and mouth daily.²⁵ Parental motivation plays an important role in the continuity of the dental and oral care program for Down Syndrome children because parents are the main decision-makers regarding the child's oral health.²² The results showed that the negative impact on the OHRQoL of children with Down Syndrome was greater the impact on the child (quite impactful) than the impact on the family (less impact). These results indicate that the oral health of children with Down Syndrome affects the physiological (pain), functional and psychological aspects of the child's life because poor oral and dental health has decreased the quality of life.¹⁴ This indicates that even though the results of the parents of Down Syndrome children experiencing low parenting stress (typical stress category), the oral and dental health of Down Syndrome children has a negative impact on their quality of life.

This study has several limitations, such as that there is no analysis and hypothesis testing on the causal relationship between individual and external factors and parenting stress. In this study, there was no analysis and hypothesis testing of the impact of demographic variables and clinical examination of the teeth and mouth on OHRQoL in children with Down Syndrome. This study relies on reports from parents to assess OHRQoL. There are limited references regarding the relationship of parenting stress in parents with OHRQoL in Down Syndrome children because research has never been done before.

Conclusions

There is a relationship between parenting stress in parents with oral health-related quality of life (OHRQoL) in Down Syndrome children, but statistically, there is no significant relationship. Based on the results of the research, the suggestion that can be given is that it is necessary to research the causal relationship between individual and external factors and parenting stress on parents who have Down syndrome children, it is necessary to research the impact of demographic variables and clinical

examination of teeth and mouth on OHRQoL children with Down Syndrome. It is necessary to do further research because this study is a preliminary study on the relationship between parenting stress in parents and OHRQoL children with Down Syndrome.

Acknowledgments

We would like to thank all the participants who took part in the research as well as the Academic Leader Grand Universitas Padjadjaran for funding this project.

Declaration of Interest

The authors report no conflict of interest.

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