Original Article

Stress-mediated quality of life outcomes in parents of disabled children: A case–control study

Bhaswati Chakraborty, Arathi Rao, Ramya Shenoy[1], Latha Davda[2], BS Suprabha

Departments of Paedodontics and Preventive Dentistry and [1]Public Health Dentistry, Manipal College of Dental Sciences, Mangalore Manipal Academy of Higher Education, Manipal, Karnataka, India, [2]University of Portsmouth Dental Academy, Portsmouth, UK

ABSTRACT

Background: The purpose of the present study was to resolve whether caregiving for a child with disability influences the physical and mental health of the caregivers and whether stress is related to the quality of life of the caregivers. **Methods:** The Parental Stress Scale questionnaire for the assessment of parental stress and the Short Form-12 version 2 questionnaire for the assessment of physical and mental health quality of life were distributed among 69 parents of developmentally disabled children and 137 parents of healthy children (control group). Various sociodemographic factors were also included. **Results:** A significant difference was seen between the two groups in terms of employment, presence of disabled sibling, smoking, and physical activity. Parents of developmentally disabled children had significantly higher stress levels and worse mental health-related quality of life. Overall physical health quality of life was similar between cases and controls. Stress had a negative correlation with both mental and physical health quality of life of the parents. **Conclusion:** Stress related to raising a child with disability negatively influences the parental quality of life. Stress management aiming at its prevention and reduction might be significant aspects of intervention for the improvement of the quality of life of the caregivers.

KEYWORDS: Disabled, parents, stress

Introduction

The UN Enable has estimated that around 10% of the world's population lives with disabilities and over 150 million children worldwide have a disability.[1,2] In India, there are about 4,733,765 children in the age group of 0–19 years with disability making it to about 0.3% of the whole population. In Karnataka, there are about 493,915 children who are disabled.[3]

Caregiving for a child who is disabled is unswervingly related to the stress levels encountered by the parents which may influence the parental quality of life outcomes. Employment of measures for stress prevention or reduction can serve as vital aspects of intervention for the recovery of the quality of life of caregivers of children with disability and possibly influence the overall health and welfare of both the child and the parent.[4]

To our understanding, no study has been conducted in India which has examined the role of stress in parents of disabled children in relation to their quality of life.

The aim of the present study was to assess the amount of stress and to evaluate its effect on the quality of life

Address for correspondence:
Dr. Arathi Rao,
Department of Paedodontics and Preventive Dentistry,
Manipal College of Dental Sciences, Light House, Hill Road,
Mangalore - 575 001, Karnataka, India.
E-mail: arathi.rao@manipal.edu

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in parents of disabled children and healthy children. The study was conducted with the objectives to assess the amount of stress in parents of disabled children and healthy children through responses in the Parental Stress Scale, to assess the quality of life in parents of disabled children and healthy children through responses in Short Form-12 (SF-12) version 2, and to evaluate and compare the relation between stress and quality of life of parents of disabled children and healthy children.

The hypothesis behind the study was to resolve whether the stress associated with caregiving for a child with disability influences the quality of life of the caregivers. This aspect can aid in the advancement of effectual, enduring measures for enhancement of the quality of life of children with disability and their caregivers.

Methods

STROBE 2007 (v4) Statement and Checklist of items was used to design and report the study.[5] The present study used a case–control study design and enrolled parents of developmentally disabled children in the case group and parents of healthy children in the control group. The ethical clearance was obtained from the Institutional Ethics Committee.

Participants

The parent or the guardian who was mainly occupied in assisting and rendering care to the child was employed in the present study. Cases consisted of caregivers of children (aged 4–17 years) with disability. Cases were entitled to take part if the caregiver's child (aged 4–17) was perceived as a child with disability certified by a pediatrician. The school which was selected for the study has two wings: one for special children and the other for healthy children. Cases were parents of special children recruited from the wing for special children. Controls were parents of children (aged 4–17) who are healthy, from the same school. Participants were recruited after seeking informed consent, through verbal and written information given to them before the study.

Sample size

The sample size for the present study was calculated using G*Power 3.1.2 software (Heinrich-Heine-Universität Düsseldorf, Germany) (Free version), keeping effect size 0.5, with case: control ratio as 1:2 at 95% confidence interval (CI) and power of the study at 90%. The final sample size comprised of 69 cases and 137 controls. Cases and controls were matched by age.

Data collection

A total of 450 questionnaires were distributed by hand. One hundred and fifty questionnaires were distributed among the cases. Out of which, 100 questionnaires were returned back. Finally, fully filled 69 questionnaires with duly signed consent forms were included in the study. Three hundred questionnaires were distributed among the controls. Out of which, 229 questionnaires were returned back. Fully filled 137 questionnaires with duly signed consent forms were included in the study. The process of distribution and collection of questionnaire was completed in a period of 2 months from November to December 2017.

Sociodemographic backgrounds

Sociodemographic details included age (both parent and child), gender (both parent and child), educational attainment, employment status, relation of the child with the caregiver, total number of members in the family, family income, and siblings with disability or severe medical illness. Health behavior details included smoking status, alcohol consumption, exercise diet, and sleep quality.

Parental stress

The Parental Stress Scale questionnaire was used to evaluate the stress in parents. It is a self-reporting scale comprising 18 questions corresponding to blissful or optimistic affairs of parenthood (emotional advantages, self-fortification, and individual advancement) and pessimistic factors (hassles linked with resources, costs, and limitations of prospects). In terms of the relationship shared by the parent with their child or children, parents were required to mark the answer of each question on a five-point Likert scale: strongly disagree (1), disagree (2), undecided (3), agree (4), and strongly agree.[6]

Quality of life

The SF-12 version 2, an extensively used measure for figuring out health condition, was utilized to figure out the general health-associated quality of life of parents. It comprises 12 subscales that can be compacted into two summary scales: the Physical Health Component Score (PCS) and the Mental Health Component Score (MCS). By means of the scores derived from the 12 questions, the physical and mental health composite scores (PCS and MCS) are calculated. The values extend from 0 to 100, where the lowest score signifies poorer health quality and the highest score signifies optimum health conditions.[7]

Statistical analysis

The statistical package SPSS (17.0) version (IBM SPSS® Statistics, IBM Corp: London: UK (Trial Version)) was used for analysis. For all the tests, statistical significance was accounted at $P < 0.05$ level (two-tailed). To observe the association between case group and control group on caregiver's sociodemographic backgrounds and health behavior details, cross-tabulations and Chi-square analysis were carried out. *t*-tests were conducted to test for the equality of means for the quality of life and stress levels between parents in the case and control groups. Fisher's exact test was

considered when expected frequency values were <5. Odds ratio and 95% CI were also calculated to measure the association of stress levels and quality of life in caregivers of disabled children. The correlation between parental stress and quality of life was assessed using Spearman's correlation coefficient test.

Results

Caregiver and child demographics

Majority of the cases had male children and controls had female children. The difference in gender of the children was statistically significant. A maximum number of cases and controls were educated higher than 10th standard, and the difference was not significant. However, majority of the controls were full time employed, but majority of the cases were not employed, and the difference was significant. The difference in the monthly income was found to be insignificant among cases and controls. The presence of disabled sibling was higher in the case group than the control group, and the difference was statistically significant. There was an absence of smokers in the control group, and there was a significant difference in smoking among cases and controls. The difference in alcohol intake was statistically insignificant among the two groups. Majority of both the cases and controls carried out moderate exercise, but the difference in the physical activity was statistically significant and was more in the case group. Majority of the cases and controls consumed more fruits and vegetables in the diet and less of oily or high-calorie foods, and the difference was statistically insignificant. Sleep quality was scored as good by majority of the cases and controls. The difference in sleep quality was statistically insignificant among the two groups [Table 1].

Parental stress and quality of life in parents of children with and without disability

The mean parental stress scores between cases and controls were found to be significant. Higher mean parental stress scores were noted for the case group (44.97 ± 8.02) than the control group (37.87 ± 7.66). Student's *t*-test was done to compare the means, and it was significant. In comparison with the control group, cases had a lower quality of life in all domains. MCS was significantly worse in the case group when compared with controls in all the subdomains. A significant difference in PCS was noted between the case and control groups in the subdomains of general health and bodily pain [Figure 1]. Among quality of life in parents, MCS in all the subdomains resulted in higher odds and was significantly associated with parents of children with disability [Table 2]. The correlation between parental stress and quality of life was done using Spearman's correlation coefficient test. A negative correlation was present which suggests that with the increase in the stress levels, quality of life deteriorated [Table 3].

Discussion

According to the International Classification of Impairment, Disability, and Handicap, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.[8] It can be categorized broadly into two categories: developmental disability and medical disability.[9] The selection of cases and controls was standardized by including cases as parents of developmentally disabled children and controls as parents of healthy children. Matching was done among the case and control groups for gender and age. According to the Pearson's Chi-square test, there was no statistically significant difference between case and control groups considering the age and gender, which validated the matching. Sampling bias was minimized by enrolling parents in the control group whose children studied in the same school as that of cases but in the different wings. The external validity of the study is augmented by participation of a school-based population rather than enrolling individuals from the outpatient dental department.

The results of this study showed that various demographic factors, stress, and quality of life were significantly associated with parents of children with and without disability. In our study, although majority of the controls were full time employed and majority of the cases were not employed, the monthly income of the family among the two groups was statistically insignificant. Researchers from different specialties are examining what factors influence the capability of a family to strike a balance between caregiving and work. A systematic review examined the employment and financial effects on families having children with disability.[10] It was found that severity of the child's health and specific health conditions are related to increased expenditure and alterations in the parent's employment status such as reduction in the number of working hours or ceasing work all together. It was also concluded in the review that receiving care for disabled children in a medical home causes a reduction in both. In our study, the presence of disabled sibling was significantly higher and was higher in the case group. According to a review,[11] having more than one child with a disability influences the mental and physical health of the parents greatly, concerning their decisions about work, making it strenuous to carry out the task of caregiving appropriately and efficiently.

Smoking was seen to be significantly more in parents of children with disability which is in accordance to a study by Witt *et al*.[4] Previous studies have stated that in order to regulate emotion and alleviate negative emotions, people resort to smoking.[12] Stress also plays an important factor in this regard.[13] A study reported that stress even decreases the ability of an individual to resist smoking.[14] However, it is seen that nicotine

Table 1: Comparison of sociodemographic characteristics of parents of children with and without disability

Sociodemographic details	Case (69) (%)	Control (137) (%)	Test value χ^{2*}, df**, *P****, Fisher's exact test****
Primary caretaker			
Mother	53 (76.8)	93 (67.9)	2.43* 2** 0.296***
Father	16 (23.2)	42 (30.7)	
Others	0 (0.0)	2 (1.5)	
Gender			
Male	48 (70.6)	63 (46.0)	11.08* 1** 0.001***
Female	20 (29.4)	74 (54.0)	
Education			
Up to 10th standard	19 (27.5)	52 (38.0)	2.206* 1** 0.137***
Higher than 10th standard	50 (72.5)	85 (62.0)	
Employment status			
Full time	17 (24.6)	70 (51.1)	25.8* 2* 0.000***
Part time	10 (14.5)	33 (24.1)	
Not employed	42 (60.9)	34 (24.8)	
Family members (adults)			
1 adult	7 (10.1)	8 (5.8)	15.323* 8** 0.053***
2 adults	26 (37.7)	77 (56.2)	
3 adults	13 (18.8)	23 (16.8)	
4 adults	13 (18.8)	16 (11.7)	
5 adults	5 (7.2)	8 (5.8)	
6 adults	3 (4.3)	1 (0.7)	
8 adults	0 (0.0)	3 (2.2)	
9 adults	0 (0.0)	1 (0.7)	
10 adults	2 (2.9)	0 (0.0)	
Family members (children)			
1	17 (24.6)	29 (21.2)	3.68* 5** 0.597***
2	37 (53.6)	74 (54.0)	
3	3 (11.6)	23 (16.8)	
4	4 (8.7)	10 (7.3)	
5	1 (1.4)	0 (0.0)	
6	0 (0.0)	1 (0.7)	
Family members (total)			
2	1 (1.4)	5 (3.6)	10.409* 10** 0.405***
3	10 (14.5)	18 (13.1)	
4	20 (29.0)	52 (38.0)	
5	15 (21.7)	28 (20.4)	
6	11 (15.9)	16 (11.7)	
7	6 (8.7)	5 (3.6)	
8	3 (4.3)	7 (5.1)	
9	0 (0.0)	2 (1.5)	
10	1 (1.4)	3 (2.2)	
14	2 (2.9)	0 (0.0)	
15	0 (0.0)	1 (0.7)	
Income/month			
<15,000	36 (52.2)	68 (49.6)	2.533* 3** 0.469***
15,000-40,000	25 (36.2)	45 (32.8)	
40,000-80,000	2 (2.9)	12 (8.8)	
>80,000	6 (8.7)	12 (8.8)	
Sibling disability			
Yes	4 (5.8)	1 (0.7)	4.975* 1** 0.026*** 0.044****
No	65 (94.2)	136 (99.3)	

Contd...

Table 1: Contd...

Sociodemographic details	Case (69) (%)	Control (137) (%)	Test value χ^{2*}, df**, P***, Fisher's exact test****
Smoking			
Nonsmokers	63 (91.3)	137 (100.0)	6.327* 1** 0.012*** 0.010****
Smokers	6 (8.7)	0 (0)	
Alcohol intake			
Nondrinkers	67 (97.1)	120 (87.6)	5.134* 2** 0.077***
<15 drinks per week	2 (2.9)	14 (10.2)	
15 or more drinks per week	0 (0.0)	3 (2.2)	
Exercise			
Inactive	11 (15.9)	44 (32.1)	11.831* 2** 0.003***
Moderate	52 (75.4)	69 (50.4)	
Scheduled physical activity of at least 5 times per week for 30 min	6 (8.7)	24 (17.5)	
Diet			
Includes fruits and vegetables in diet	56 (81.2)	114 (83.2)	0.134* 1** 0.714*** 0.701****
Includes more of oily or high calorie foods	13 (18.8)	23 (16.8)	
Sleep quality			
Good	35 (50.7)	89 (65.0)	4.020* 2** 0.134***
Fair	32 (46.4)	46 (33.6)	
Poor	2 (2.9)	2 (1.5)	

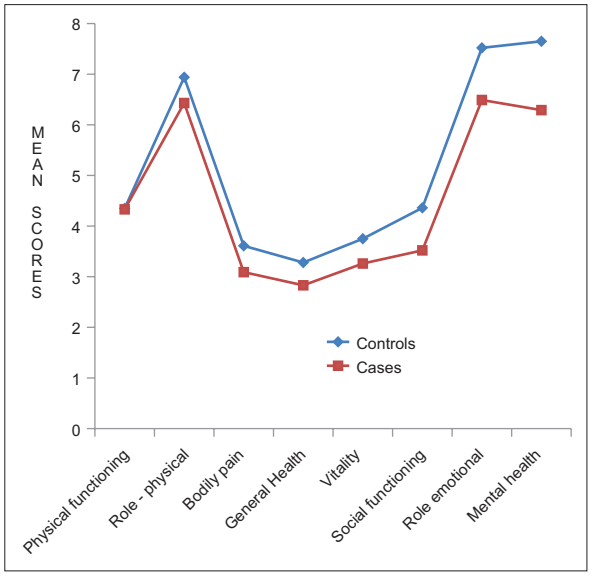

Figure 1: Health-related quality of life among cases and controls

Table 2: Association of parental stress and quality of life in parents of disabled children

	Odds ratio	P	Confidence interval
Total parental stress	0.214	0.00	0.115-0.40
Physical domain total	1.468	0.230	0.802-2.688
Mental domain total	2.878	0.001	1.549-5.345
Physical subdomain function	0.822	0.551	0.458-1.475
Physical subdomain role	1.273	0.533	0.684-2.367
Mental subdomain role	2.414	0.005	1.301-4.482
Mental subdomain health	4.166	0.000	2.188-7.933
General health	2.476	0.010	1.234-4.968
Bodily pain	2.336	0.005	1.283-4.253
Vitality	1.584	0.266	0.722-3.476
Social functioning	3.113	0.000	1.684-5.757

Table 3: Correlation between parental stress and quality of life

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Total stress parents		Mental domain total		Physical domain total	
Case	Control	Case	Control	Case	Control
-	-	−0.227	−0.316	−0.130	−0.350

dependency resulting from smoking seems to worsen stress, far from acting as an aid for mood control. The noticeable relaxant effect of smoking only reflects the reversal of the anxiety and bad temper that develop during nicotine depletion. This message that smoking does not decrease stress levels but actually exacerbates it needs to be far more widely recognized.[15]

In our study, the difference in consumption of alcohol was statistically insignificant between the case and control groups, which was also seen in a similar study by Witt *et al*.[4] While few studies reveal that under stressful conditions, alcohol ingestion increases, others have failed to prove so. The consumption of alcohol, in general, does not appear to cause a reduction in anxiety. Usually, during a drinking splurge, anxiety increases with time. A number of factors (drinking ambience, personality and frame of mind of individuals, prior experience with alcohol, and type of beverage) can appreciably modify the effects of alcohol in individuals.

These can explain the inconsistency in results present in the literature.[16]

Physical activity was found to be more in the case group when compared with the control group, the difference being statistically significant. Literature documents that regular exercise helps in averting or improving psychological and metabolic comorbidities caused by chronic stress.[17]

Majority of the cases (81.2%) and controls (83.2%) included fruits and vegetables in their diet and less of oily or high-calorie foods, the difference being statistically insignificant. Few studies have reported the association between stress and consumption of food, particularly the foods which are pleasurable and palatable that may be consumed to reduce stress.[18,19] In stress, different responses in food intake have been noted. It has been found that mild stress can lead to overconsumption of food, while severe stress can lead to less than normal intake of food.[20]

Sleep quality, a modifiable risk factor for stress, was reported to be good by majority of the cases and to be poor by minority of the cases and controls, the difference being statistically insignificant. A study by Cernovsky[21] revealed that sleep quality and stress do not have a significant correlation. However, another study by Hick and Garcia[22] revealed that with the increase in stress levels, the time duration of sleep decreases. Conversely, according to the Diagnostic and Statistical Manual of Mental Disorders, mostly sleep disorder develops with social, psychological, and medical stress. A study reported a strong correlation between insomnia and such stresses in 78% of the patients.[23] The management of sleep disorders includes regular consumption of balanced meals, carrying out moderate physical activity of 30 min for 3–4 times a week, and various mind and body relaxation methods.[24] In our study, majority of the cases and controls carried out moderate physical activity and included more of fruits and vegetables in their diet and less of oily foods. This might explain the cause for the sleep quality being good as reported by majority of both the groups.

Results of our study reveal that parents of children with developmental disability have greater stress and poorer quality of life than parents of healthy children, which are in accordance with the findings of previous studies concerning children with medical disabilities[4,25,26] and developmental disabilities.[27-30] Our study findings show that there was a negative correlation between parental stress and quality of life which proves that with the increase in stress levels, the quality of life of parents deteriorated. Parents of the case group had worse mental health when compared with parents of the control group, and the difference was statistically significant confirming the results of previously mentioned studies. Several probable explanations can be put forward in accordance with this. A major concern for the parents of disabled children is whether there would be "normal" development of their child with the increasing age.[30] In this era of modernization, few cultures still view disability as a chastisement for an individual's or a family's misconduct in a previous birth or in the current life.[31-33] This leads to the feelings of disgrace and indignity in the parents, which further paves the way for having pessimistic views of the disabled child's future.[32] However, parents may also be subjected to lesser benefits emotionally, that is, less fun, contentment, feeling of self-fortification, and personal development from their disabled children.[6] Managing the challenges of gratifying the needs and looking after the psychological well-being of their disabled children may aggravate the parental stress directly.[33] Negative insight and understanding of disability thus leads to higher stress levels and poor mental health quality of life in parents.

Parents of children in both the groups exhibited similar overall physical health, and the difference was statistically insignificant. However, in the subdomains of perception of general health and bodily pain, the difference was statistically significant. Problems related to physical health become apparent after a long period of time.[33] The physical health quality of life reported in some studies have been conflicting, where some studies revealed a significant difference between primary caregivers of disabled children and healthy children on perception of general health and bodily pain, while other studies did not come up with such differences.[34,35] This can be explained with the following reasons. Firstly, as the children were relatively young, parents could manage the activities of day to day life for their disabled children, thus placing not as much of physical burden on the primary caregivers. Second, the children's severity of disability might have played a role in this. It might not have been severe enough to take a toll on the physical health of the parents. The present study did not take into account the severity of the developmental disabilities of the children. Thirdly, the mean age of the parents of disabled children was around 40 years, so their child's disability might not have influenced directly their physical health quality of life.[36] However, in the present study, parents having a child with disability revealed higher stress, which had a negative correlation with both mental and physical health quality of life of the parents and thus had a negative impact on it. Such an effect on physical health might be due to parents being unable to make out enough time after their child's daily care since they have to devote time on their child's behavioral management, any treatments if they require at home or at hospital, leaving very less spare time to devote for their individual interests and relaxation.[37]

Conclusion

This study looked into the role of stress and renders imperative perception of the possible methods by which

raising a child with disability negatively influences the parental quality of life. Stress experienced by parents of disabled children may affect their quality of life and interfere in their ability to provide good health care including oral care. Most of the time importance is given only to the difficult areas associated with children with special needs such as soft diet high in carbohydrates and lack of muscle movement and coordination making it difficult to effectively brush the tooth predisposing these children to a higher risk for dental caries and gingival disease, etc., but the parental stress is totally ignored. Hence, parents may be at great threat for poor quality of health if their stress levels, and consequent mental and physical health, are not checked upon and taken care of. Furthermore, stress management aiming at its prevention and reduction might be significant aspects of intervention for the improvement of the quality of life of the caregivers. It may also have a significant influence on the health and well-being of both the parent and the child. It is, therefore, necessary not only to educate parents regarding their children but also to understand, assess, and counsel parental stress-related issues.

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Conflicts of interest
There are no conflicts of interest.

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