



## Health-Related Quality of Life of Primary Caregivers of Special Needs Children in Ibadan Metropolis, Nigeria

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### ABSTRACT

Primary caregivers of special needs children often manifest deficient emotional self-acceptance of themselves, financial challenges and other related health quality of life experiences especially in Ibadan Metropolis, Oyo State, Nigeria. In most cases, such deficient and or poor health quality of life usually lead to unwarranted challenges of suicidal thought and or actual suicide, frequent ill health and sometimes death. This informed the direction of the study to examine the influence of parental stress and social support on health related quality of life of primary caregivers of special needs children. The ex-post facto research format was applied along the utilization of structured questionnaire in gathering data from 150 primary health care providers with age ranging between 29 and 54 years (age = 38.5 years). Multiple regression statistical tool was employed to analyse data collected and it was tested at 0.05 level of significance. The findings among others showed that parental stress and social support had significant joint influence on health related quality of life among primary caregivers ( $F(2,147) = 37.885$ ;  $R^2 = 0.340$ ;  $P < .01$ ) while the joint influence accounted for 34.0%. Also, it revealed that parental stress and social support had significant independent influence on health related quality of life ( $\beta = 0.303$ ;  $p < .01$ .  $\beta = 0.449$ ;  $p < .01$ ). Further analysis revealed that primary health caregivers with high parental stress reported significantly negative health related quality of life than those with low parental stress ( $t(148) = 4.205$ ;  $p < 0.01$ ). Finally, primary health caregivers with high social support reported significantly positive health related quality of life than those with low social support ( $t(148) = -6.694$ ;  $p < 0.01$ ). It thus concluded that parental stress and social support influenced health quality of life among primary health caregiver of special needs children. On the bases of the findings, it recommended that clinical psychologist and other health related professionals should take cognisance of these factors in the development of therapeutic intervention directed at improving health quality of life of primary caregivers of special needs children.

Key words: Parental Stress, Social Support, Health Quality of Life, Primary Caregiver, Special Needs Children.

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### 1. INTRODUCTION

Primary caregiver of special needs children are often saddled with the responsibility of inadequate and dissatisfied care delivery to their wards. Thus, manifest emotional deficient behavior, isolation, financial challenges and other health related factors on inadequate quality of life of caregivers. Recent studies revealed that parents of special needs children perceive their own health as unsatisfactory, such as feeling of depression, stress, muscle pain, and diminished quality of life (Freitas, Rocha, & Haase, 2014; Guyard, Fauconnier, Mermet & Cans, 2011). Quality of life is defined as an overall general well-being that comprises objective descriptors and subjective evaluations of physical, social and emotional well-being together with the extent of personal development and purposeful activity, all weighted by a personal set of values. Individuals' needs reform the meaning of quality of life. Quality of life is about enrichment of everyday life. Moreover, there is focus on the individuals' choices and needs but life quality is also influenced by environmental factors. Basically the framework has three fundamental features: the subjective and objective measurement, life domains, and the influence of personal values (Shearer, 2010).



In caregiver quality of life studies, when the family includes a child with disability, intend to explore the parents' perspectives on how domains of their everyday life are influenced by the presence of a child with disabilities (Brown, Crisp, Wang, & Iarocci, 2006). It is a fact that many children and people with disabilities spend most of their time at home. Sometimes their disability level is so major that their parents are responsible for the fulfillment of their basic needs (Sulch & Kalra, 2003). Social support refers to the material and psychological resources that a person deems to be available to him or her via his or her interpersonal relationships. In turn, satisfaction with social support concerns the perception that such resources and the bonds with the members of the support network are adequate to the existing demands (Rodriguez & Cohen, 1998). Pfeifer et al. (2014) argue that perceived social support seems to exert more influence on the adaptation to stressful experiences than the social support that is actually received or the number of members of the support network.

## 2. STATEMENT OF PROBLEM

Establishing factors influencing quality of life of parents of children with special needs is a key component in the quality of life experienced by the parents and eventually by the child. However, there is little literature concerning parental stress and social support as to how they influence the quality of life of caregivers of children with special needs. The research concerning the parental stress experienced by parents who have children with special needs consistently shows that the parents experience a higher level of stress than parents of children without disabilities and parents of children with other disabilities (Johnson et al., 2011; Mancil et al., 2009; Phetrasuwan & Miles, 2009; Schieve et al., 2007).

## 3. OBJECTIVE

The main objective of this study is to examine the influence of parental stress and social support on quality of life of caregivers of special needs children.

## 4. METHODOLOGY

### 4.1 The Research Design

This study employed survey with the ex-post facto design. On the one hand, the independent variables are Demographic Variables, parental stress and Social Support, while the dependent variable is quality of life.

## 5. DATA PRESENTATION

Completed questionnaire were tagged serial numbers for adequate coding and to prevent missing questionnaire from respondents. Data were entered into statistical package for social sciences (SPSS version 20). Analysis was carried out using descriptive statistics of frequency and percentages was used to analyse the demographic characteristics of the questionnaire, while independent sample t-test, and regression analysis were used to test the stated hypotheses.

**Hypothesis one** which stated that Caregivers who experience less parental stress will report higher quality of life was tested with independent sample t-test analysis.

**Table 1: Summary of t- test comparing low and high parental stress on quality of life among caregivers of special needs children**

Parental stress	N	$\bar{X}$	SD	Df	t-value	P
Low	70	94.60	13.26	148	4.205	.000
High	80	83.41	18.48			

Table 1 shows that parental stress has significant influence on Quality of Life among caregivers [ $t(148) = 4.205$ ;  $p < 0.001$ ]. The result indicated that caregivers with low parental stress reported higher ( $\bar{X} = 94.60$ ) quality of life than those with high parental stress who scored ( $\bar{X} = 83.41$ ) with a mean difference of 11.19. The hypothesis was therefore confirmed.



**Hypothesis two** which stated that Caregivers who reported higher social support will also report higher quality of life was tested with independent sample t-test analysis.

**Table 2: Summary of t- test comparing low and high social support on quality of life among caregivers of special needs children**

Social Support	N	$\bar{X}$	SD	Df	t-value	P
Low	63	79.73	15.82	148	-6.694	.000
High	87	96.37	13.85			

Table 2 shows that social support has significant influence on Quality of Life among caregivers [ $t(148) = -6.694; p < 0.001$ ]. The result indicated that caregivers with high social support reported higher ( $\bar{X} = 96.37$ ) quality of life than those with low social support who scored ( $\bar{X} = 79.73$ ) with a mean difference of 16.64. The hypothesis was therefore confirmed.

**Hypothesis three** which stated that there will be significant joint influence of parental stress and social support on quality of life among caregivers was tested using regression analysis. This is presented in table 3 below.

**Table 3: Relative and joint contributions of parental stress and social support on quality of life among caregivers**

Predictor	Beta ( $\beta$ )	t-value	P	R	R <sup>2</sup>	F	P
Constant		2.552	.012				
Parental stress	.303	4.463	.000	0.583	0.340	37.885	.000
Social support	.449	6.599	.000				

Table 3 shows that parental stress and social support jointly influenced quality of life among caregivers ( $F(2,147) = 37.885; R^2 = 0.340; p < .001$ ). All the independent variables jointly accounted for 34.0% of the variance of quality of life, while the remaining 66.0% could be due to the influence of extraneous variables. Furthermore, parental status ( $\beta = 0.303; p < .001$ ) and social support ( $\beta = 0.449; p < .001$ ) were significant independent predictors of quality of life among caregivers. Therefore, the hypothesis was confirmed.

**Hypothesis four** which stated that there will be significant gender difference on quality of life of caregivers was tested with independent sample t-test analysis.

**Table 4: Summary of t- test comparing male and female on quality of life of caregivers**

Gender	N	$\bar{X}$	SD	Df	t-value	P
Male	63	91.16	15.14	148	1.133	.259
Female	87	88.09	17.90			

Table 4 shows that there is no gender difference on quality of life among caregivers [ $t(148) = 1.133; p > 0.05$ ]. The result indicated that both male ( $\bar{X} = 91.16$ ) and female ( $\bar{X} = 88.09$ ) caregivers had similar score on quality of life with a mean difference of 3.07. The hypothesis was therefore not confirmed.



## 6. DISCUSSION OF FINDINGS

Findings are presented in line with study objectives and hypothesis.

Hypothesis one which stated that caregivers who experience less parental stress will report higher quality of life was confirmed. The result indicated that caregivers with low parental stress reported higher quality of life than those with high parental stress. The impact parental stress levels of raising a child with a disability on quality of life is in tandem with numerous studies (Dellve et al., 2006; Vermaes, Janssens, Mullaart, Vinck, & Gerris, 2008; Fidler, Hodapp, & Dykens, 2010) have documented that both mothers and fathers reported more stress related to raising their child with a disability leading to poor quality of life than parents of typically developing children. These increased stress levels have been directly related to childrearing responsibilities and poor quality of life (Fidler et al., 2010), concern for their child's future (Pisula, 2007), and feelings of isolation from other parents raising children without a disability. In another related study with mothers of children with cerebral palsy, Glenn and colleagues (2009) found considerably higher levels of maternal stress when compared to mothers of typically developing children, with the highest levels of stress determined by factors such as role restriction, feelings of isolation, insufficient support from their spouse, and demandingness of their child leading to poor quality of life. Also, in another study (Tomanik et al., 2004) of mothers of children diagnosed as having pervasive developmental disorder, the behavioral difficulties associated with autism spectrum behaviors were found to contribute significantly to higher levels of parental stress. This clearly shows that parental stress has significant impact on quality of life among caregivers of children with special needs.

Hypothesis two which stated that caregivers who reported higher social support will also report higher quality of life was confirmed. The result indicated that caregivers with high social support reported higher quality of life than those with low social support. This finding is in tandem with Schilling and Schinke (2004); Helgeson (2008); Tadema and Vlaskamp (2009); Meadan, Halle and Ebata (2010) who reported that the perceived usefulness, reliability and flexibility of social supports can impact on caregivers well-being and Quality of Life. The reason attributed to this is that those who report higher levels of perceived social support from friends, family, support organisations, and their communities as a whole show lower level of stress hence higher levels of Quality of Life compared to those who report low levels of perceived social support as reported by Helgeson (2003); Schilling Tehee et al. (2009). In another related research of Pisula (2007), who reiterated that parents who reported less support, both natural and funded, when parenting children with special needs also view the child as having greater needs than a normal child and hence low quality of life.

Hypothesis three which stated that there will be significant joint influence of parental stress and social support on quality of life among caregivers was confirmed. The result indicated that parental stress and social support jointly influenced quality of life among caregivers accounting for 34.0% of the variance of quality of life. This finding is supported by Cummins (2001) and Sales (2003) both who reported the social 'ideal' of having children with severe disabilities at home as having a place in current society where families are smaller, and often there is less social support for caregivers. Caregivers other concerns with support services related to financial burdens, isolation from peer and social groups, lack of time and attention to focus on other siblings, lack of information provision regarding funded and unfunded services, and the inability to source appropriate respite facilities (Carpinter et al., 2000; Jorgensen *et al.*, 2009). These areas of concern need to be addressed to ensure positive outcomes for individuals with a disability and their caregivers. Pisula (2007) also stated that parents who received less support are prone to low quality of life than those who received more social support.

Hypothesis four which stated that there will be significant gender difference on quality of life of caregivers was not confirmed. The result indicated no significant difference on caregivers' quality of life. This finding is consonance with the research of Grunfeld et al. (2003) found that caregivers of both genders show high levels of anxiety and depression but low levels of quality of life. However, the study of Grov, Dahl, Moum and Fossa (2005) found that men caregivers experience more distress in their new role than their female counterpart hence low quality of life. These two results have clearly shown mixed findings on gender difference on quality of life.



## 7. CONCLUDING REMARKS

Based on these findings, this study therefore concludes as follows:

1. Caregivers who experience less parental stress reported higher quality of life.
2. Caregivers who reported higher social support also reported higher quality of life.
3. There was significant joint influence of parental stress and social support on quality of life among caregivers.
4. There was no gender difference in quality of life among caregivers.

## 8. CONTRIBUTION TO KNOWLEDGE

In light of the literature review and study evidence, in order to understand the influence of parental stress and social support on quality of life among caregivers, the following recommendations are suggested:

- ❖ Appropriate measures to help caregivers of special needs children deal with the various challenges effectively and develop new strengths and assets are recommended. In addition, it was found that most participants had low levels of perceived social support, even when they parented with inadequate levels of stress, therefore there is need for the development of strategies for the prevention and reduction of parental stress because they show which aspects of the investigated variables seem to have a more effective impact on the others.
- ❖ Also, there is need for reformed laws and policies regarding families of children with disabilities including education with no age limits for the disabled as well as establishment of centers providing evening activities this will go a long way in improving caregivers' quality of life.
- ❖ Finally, there is need for educating and sensitizing the community to embrace people with disabilities, by the state and by private initiatives, through one united association for people with disabilities thereby improving caregivers' quality of life.



## REFERENCES

1. Abdullah, Rania. (2014). The effectiveness of a guiding program to improve the quality of life among families of hearing disabled children. *Journal of the College of Education-Banha University*, Egypt, 99 (1), 425 to 446.
2. Abidin, R. R. (1992). The determinants of parenting behavior. *Journal of Clinical Child Psychology*, 21(4), 407-412.
3. Baker, B. L., McIntyre, L. L., Blacher, K., Crnic, C., Edelbrock, C., & Low, C. (2003). Preschool children with and without developmental delay: Behavioural problems and parenting stress over time. *Journal of Intellectual Disability Research*, 47(4-5), 217-230.
4. Carpinter, A., Irwin, C., & Rogers, G. (2000). *Just surviving: talking with parents of children with very high disability support needs about how they get by*. Wellington, New Zealand: Ministry of Health.
5. Cummins, R.A. (2001). The subjective well-being of people caring for a family member with a severe disability at home: a review. *Journal of Intellectual & Developmental Disability*, 26 (1), 83-100
6. Deimling, G. T., & Bass, D. M. (2006). Symptoms of mental impairment among elderly adults and their effect on family caregivers. *Journal of Gerontology*, 41, 778-784.
7. Dellve, L., Samuelsson, L., Tallborn, A., Fasth, A., & Hallberg, L. (2006). Stress and well-being among parents of children with rare diseases: A prospective intervention study. *Journal of Advanced Nursing*, 53, 392-402.
8. Emerson, E., & Hatton, C. (2007). Poverty, socio-economic position, social capital and the health of children and adolescents with intellectual disabilities in Britain: A replication. *Journal of Intellectual Disability and Research*, 51(11), 866-874.
9. Eppers, L., Debbie, G., & Barbara, E. H. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners*, 20, 423-428.
10. Fidler, D. J., Hodapp, R. M., & Dykens, E. M. (2010). Stress in families of young children with Down syndrome, Williams syndrome, and Smith-Magenis syndrome. *Early Education and Development*, 11, 395-406.
11. Freitas, P. M., Rocha, C. M., & Haase, V. G. (2014). Análise dos preditores do estado psicológico das mães de crianças com paralisia cerebral [Analysis of predictors of psychological status of mothers of children with cerebral palsy]. *Estudos e Pesquisas em Psicologia*, 14(2), 453-473.
12. Given, C. W., Given, B. A., Stommel, M., & Azzouz, F. (1999). The impact of new demands for assistance on caregiver depression: Tests using an inception cohort. *The Gerontologist*, 39, 176-85.
13. Glenn, S., Cunningham, C., Poole, H., Reeves, D., & Weindling, M. (2009). Maternal parenting stress and its correlates in families with a young child with cerebral palsy. *Child: Care, Health & Development*, 35 (1), 71-78.
14. Guajardo, N. R., Snyder, G., & Petersen, R. (2009). Relationships among parenting practices, parental stress, child behaviour, and children's social-cognitive development. *Infant & Child Development*, 18, 37-60.
15. Guyard, A., Fauconnier, J., Mermel, M.-A., & Cans, C. (2011). Impact sur les parents de la paralysie cérébrale chez l'enfant: Revue de la littérature [Impact on parents of cerebral palsy in children: A literature review]. *Archives de Pédiatrie*, 18(2), 204-214.
16. Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research*, 49(6), 405-418.
17. Hauser-Cram, P., Warfield, M. E., Shonkoff, J. P., & Kraus, M. W. (2001). Children with disabilities: A longitudinal study of child development and parent well-being. *Society for Research in Child Development Monographs*, 66, 1-131.
18. Helgeson, V.S. (2003). Social support and quality of life. *Quality of Life Research*, 12 (1), 25-31.
19. Johnson, N., Frenn, M., Feetham, S., & Simpson, P. (2011). Autism spectrum disorder: Parenting stress, family functioning, and health-related quality of life. *Families, Systems, & Health*, 29, 232-252.
20. Jorgensen, D., Parsons, M., Jacobs, S. (2009). *The experiences of informal caregivers in New Zealand*. New Zealand: Carers New Zealand and The University of Auckland New Zealand.



21. Lewis, P., Abbeduto, L., Murphy, M., Richmond, E., Giles, N., Bruno, L., Schroeder, S., Anderson, J., & Orsmond, G. (2006). Psychological wellbeing of mothers of youth with fragile X syndrome: syndrome specificity and within-syndrome variability. *Journal of Intellectual Disability Research, 50* (12), 894-904.
22. Magdi, Hanan. (2009). Social support and its relationship to the quality of life among patients with diabetes, unpublished Master Thesis, Egypt: Zagazig University.
23. Mancil, G. R., Boyd, B. A., & Bedesem, P. (2009). Parental stress and autism: Are there useful coping strategies? *Education and Training in Developmental Disabilities, 44*, 523-537.
24. Meadan, H., Halle, J. W., & Ebata, A. T. (2010). Families with children who have autism spectrum disorders: Stress and support. *Exceptional Children, 77*, 7-36.
25. Pfeifer, L. I., Silva, D. B. R., Lopes, P. B., Matsukura, T. S., Santos, J. L. F., & Pinto, M. P. P. (2014). Social support provided to caregivers of children with cerebral palsy. *Child: Care, Health and Development, 40*(3), 363-369.
26. Phetrasuwan, S., & Miles, M. S. (2009). Parenting stress in mothers of children with autism spectrum disorders. *Journal for Specialists in Pediatric Nursing, 14*, 157-165.
27. Pisula, E. (2007). A comparative study of stress profiles in mothers of children with autism and those of children with Down's syndrome. *Journal of Applied Research in Intellectual Disabilities, 20*, 274-278.
28. Polita, N. B., & Tacla, M. T. G. M. (2014). Rede e apoio social às famílias de crianças com paralisia cerebral [Network and social support to families of children with cerebral palsy]. *Escola Anna Nery, 18*(1), 75-81.
29. Pruchno, R. A., & Resch, N. L. (2009). Aberrant behaviors and Alzheimer's disease: Mental health effects on spouse caregiver. *Journals of Gerontology: Social Sciences, 44*, S177-S183.
30. Putnick, D. L., Bornstein, M. H., Hendricks, C., Painter, K. M., Suwalsky, J. T. D., & Collins, W. A. (2010). Stability, continuity, and similarity of parenting stress in European American mothers and fathers across their child's transition to adolescence. *Parenting: Science & Practice, 10*, 60-77.
31. Raphael, J. L., Zhang, Y., Liu, H., & Giardino, A. P. (2009). Parenting stress in U.S. families: Implications for paediatric health care utilization. *Child: Care, Health, and Development, 36*, 216-224.
32. Rodriguez, M. S., & Cohen, S. (1998). Social support. In H. Friedman (Ed.), *Encyclopedia of mental health* (Vol. 3, pp. 535-544). New York, NY: Academic Press.
33. Saisto, T., Salmela-Aro, K., Nurmi, E., & Halmesm, E. (2008). Longitudinal study on the predictors of parental stress in mothers and fathers of toddlers. *Journal of Psychosomatic Obstetrics & Gynecology, 29*, 219-228.
34. Sales, E. (2003). Family burden and quality of life. *Quality of Life Research, 12* (1), 33-41.
35. Schieve, L. A., Blumberg, S. J., Rice, C., Visser, S. N., & Boyle, C. (2007). The relationship between autism and parenting stress. *Pediatrics, 119*, 114-121.
36. Schilling, R.F., & Schinke, S.P. (1984). Personal coping and social support for parents of handicapped children. *Children and Youth Services Review, 6*, 195-206.
37. Schulz, R, O'Brien, AT, Bookwala, J, and Fleissner, K. (2006). Stress among family caregivers. *Cancer Nursing, 4*, 209-215
38. Schulz, R., & Beach, S. R. (2009). Caregiving as a risk factor for mortality: The caregiver health-effects study. *Journal of the American Medical Association, 282*, 2215-2219.
39. Sepa, A., Frodi, A., & Ludvigsson, J. (2004). Psychosocial correlates of parenting stress, lack of support and lack of confidence/security. *Scandinavian Journal of Psychology, 45*, 169-179.
40. Shearer, J. (2010). *Aspects of quality of life for children with a disability in inclusive schools. In R. Kober (Ed.), Enhancing the quality of life of people with intellectual disabilities: From theory to practice (Vol. 41, pp. 205-220). Springer.*
41. Sulch, D., & Kalra, L. (2003). Quality of life in caregivers. In A. J. Carr, I. J. Higginson, & P. G. Robinson (Eds.), *Quality of life* (pp. 31-39). London: BMJ Books.
42. Tadema, A.C., & Vlaskamp, C. (2009). The time and effort in taking care for children with profound intellectual and multiple disabilities: a study on care load and support. *British Journal of Learning Disabilities, 38*, 41-48.
43. Tehee, E., Honan, R., & Hevey, D. (2009). Factors contributing to stress in parents of individuals with autistic spectrum disorders. *Journal of Applied Research in Intellectual Disabilities, 22*, 34-42.



44. Tomanik, S., Harris, G. E., & Hawkins, J. (2004). The relationship between behaviours exhibited by children with autism and maternal stress. *Journal of Intellectual and Developmental Disability, 29*(1), 16-26.
45. Tomanik, S., Harris, G. E., & Hawkins, J. (2004). The relationship between behaviours exhibited by children with autism and maternal stress. *Journal of Intellectual and Developmental Disability, 29*(1), 16-26.
46. Vermaes, I. P. R., Janssens, J. M. A. M., Mullaart, R. A., Vinck, A., & Gerris, J. R. M. (2008). Parents' personality and parenting stress in families of children with spina bifida. *Child: Care, Health and Development, 34*, 665-674.
47. Whittingham, K., Wee, D., Sanders, M. R., & Boyd, R. (2013). Predictors of psychological adjustment, experienced parenting burden and chronic sorrow symptoms in parents of children with cerebral palsy. *Child: Care, Health and Development, 39*(3), 366-373.