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# Children Disability Milieus and Perceived Social Support as Predictors of Quality of Life of Family Caregivers in Akwa Ibom State

**Dorothy J. Okoro**
**Usen E. Inyang**

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**Affiliation**
Department of Psychology,
University of Uyo, Uyo.
dorothyokoro82@gamil.com,
usenessieninyang@gmail.com

## Abstract

*The family caregiver has remained a neglected lot, often ignored by the mental health professionals, making them vulnerable to poor quality of life. The study examined children's disability milieus and perceived social support as predictors of quality of life of family caregivers. The study adopted a cross-sectional survey design. The sample size was two hundred and five (205) caregivers of children with disability selected children's care centres in South-South, Nigeria. Participants' ages ranged from 24 to 55 years with a mean age of 37.4 years. These caregivers were selected using the purposive sampling technique. Berlin Social Support Scale and Quality of Life Scale were the instruments used for data collection. Multiple regression statistical method was used in testing the hypotheses formulated for the study. Results revealed that perceived social support had a significant negative prediction on the quality of life of caregivers ($\beta = -.415$; $t = -6.5$; $P<.05$). Results further indicated that age and duration of care had significant independent prediction on quality of life. Gender, nature of disability and severity of disability did not independently predict quality of life. However, there was a significant joint prediction of children's disability milieus and perceived social support on quality of life ($F= (6,203) =9.67$; $P<.05$). It was recommended that massive media and door-to-door campaigns should be carried out to educate people on the need to support caregivers of children with disabilities.*

**Keywords:** Children, Disability, Social Support, Quality of Life, Family Caregiver.

## Introduction

Raising a child with an intellectual disability presents unique challenges and has a significant impact on family functioning and well-being (Singer, 2006). Family members of children with disabilities often experience high levels of stress and depression, lower levels of family adaptability and cohesion, and greater negative social and psychological impact when compared to those of typically developing children (Benson & Karloli, 2009). The Nigerian health care system is based on the implicit assumption that, family members are available to provide care in the homes to people living with disability and other chronic illnesses. Previous report indicates that caregivers are increasingly being required to perform complex tasks similar to those carried out by paid health or social service providers (Asuquo *et al.* 2013). According to the Center for Disease Control and Prevention (2015), one in six children in the United States, or 15% of children aged 3 to l7 years old, are diagnosed with one or more developmental disabilities, such as autistic spectrum disorder (ASD), cerebral palsy (CP), intellectual disability (ID), Down syndrome, Rett syndrome, epilepsy, and other developmental delay conditions (CDC, 2015). These developmental disabilities are conditions that may involve long-term physical and mental impairments with symptoms that require special and intense care.

A model of quality of life called the set point theory advanced by Brickman and Campbell (1971) shows the tendency of humans to quickly return to a relatively stable level of life despite major positive or negative event or life changes. This theory postulates that quality of life tends to fluctuate around a stable level that generally remains the same over time. Accordingly, Brickman and Campbell (1971) asserted that after individuals experience positive events, their quality of life might rise transiently but then will revert to this stable level or set point. Likewise, when they experience negative events, such as having a child with disability, their quality of life might decline momentarily but will then regress to the previous level. Although it is not certain how people's happiness is initially established, some evidence suggest that the set point is determined at least in part by genetic factors (Diener, 2002). This means that the happiness of caregivers is at a stable level and no matter the experience they have, they are likely able to go back to that base line. For example, a caregiver's happiness may rise above the set point as a result of improvement in child's health or may decline due to the poor performance of the disabled child but after a while, it returns to it normal level.

There are reports on the predictive roles of children's disability milieus in the quality of life of family caregivers of children with disability. For example, Henson (2019) revealed that age affected the quality of life of family caregivers. Oelofsen and Richardson (2006) found a significant relationship between age and the quality of life of caregivers of children with disabilities. Davidson (2018) reported a positive relationship between duration of care and quality of life of family caregivers.

Studies have also revealed that perceived social support affects the quality of life of family caregivers. Brisset (2010) reported that there is a significant relationship between quality of life, social support and psychological distress. Another study by O'Reilly (2010) utilized the multidimensional scale of perceived social support to examine social support from family, friends, and significant others, and their relationships to different variables such as loneliness, stress, psychological well-being, and socio-cultural adaptation. He found that individuals with high level of social support and low levels of loneliness and stress experienced high levels of socio-cultural adjustment, low difficulties and psychological distress. Hulse-Kalacky (2012) reported that social support did not predict quality of life among family caregivers of children with disability.

The review shows there is disagreement related to which forms of social support families utilize most and which forms are most helpful. Additionally, the majority of the research investigating social support and caregiver quality of life in samples of families raising children with intellectual disabilities has focused primarily on samples of children in late childhood, adolescence, and early adulthood. Very few studies have investigated these constructs in families raising preschool-aged children with recent diagnoses. It has also been observed that despite the various challenges associated with caregiving of people living with disability and other related illnesses and the large number of people involved, empirical research on the issue is very scanty especially in Nigeria. Therefore, the objective of the study was to explore the predictive roles of children's disability milieus and perceived social support on the quality of life of family caregivers. It was hypothesized that social support will significantly predict the quality of life of family caregivers of children with disability. It was also hypothesized that children's disability milieus will independently and jointly predict the quality of life of family caregivers of children with disability.

## Method

### Design and Statistics

The study adopted a cross-sectional survey design. The justification for adopting this design was because the design allowed the researcher to make one-time only observation which involve as many naturally occurring variables as were necessary for the study. Simple percentage (%) method was used to analyze demographic data of respondents. Subsequently, a multiple regression statistical method was used in testing the hypotheses formulated for the study.

### Participants

The sample size was two hundred and five (205) caregivers of children with disability selected from the University of Uyo Teaching Hospital (UUTH), Special Education Centre, Uyo, Daughters of Charity Centre, Uyo, Daughters of Grace Care Centre, Ikot Ekpene Local Government Area and St Joseph Rehabilitation Centre, Essien Udim Local Government Area all in Akwa Ibom State. Participants' ages ranged from 24 to 55 years with a mean age of 37.4 years. These caregivers were selected using the purposive sampling technique.

### Instruments

Data for this study were derived mainly from the Berlin Social Support Scale by Schulz and Schwarzer (2003) and the Quality of Life Scale by Burckhardt *et al.* (2003).

Berlin Perceived Social Support Scales (BSSS) is a 17-item scale designed to measure the degree of support received by adolescents from families, friends, and other people. The scale is rated on a five-point Likert format of 1-5 (1= Strongly agree, 2 = Agree, 3 = Undecided, 4=Disagree, 5 = Strongly Disagree). The norm of the instrument is 48.25. This implies that scores of 48.25 and above indicate low social support while scores below 48.25 indicate high social support. The social support scale had an internal consistency of .87. A Cronbach alpha of .80 was obtained for the BSSS after a pilot study analysis using SPSS version 22.

Quality of Life scale describes how satisfied the participants are at a particular time. The Quality of Life Scale has 16 items. It is a 7-point Likert score ranging from "Terrible" (1), "Unhappy" (2), "Mostly Dissatisfied" (3), "Mixed" (4). "Mostly Satisfied" (5), "Pleased" (6) to "Delighted" (7). The higher the quality of the score, the higher the quality of life. A Cronbach alpha of .80 was obtained for the Quality of Life Scale after a pilot study analysis using SPSS version 22.

## Procedure

The researcher sought and obtained the consent of the participants to participate in the study. This was done by collecting ethical approval from the Akwa Ibom State Ministry of Health including information about the study (such as consent forms and questionnaire) to request research collaboration. Upon agreement, those participating in the studies were informed personally about the purpose of the research. Thereafter, participants responded to the questionnaire.

## Results

**Table 4.1: Demographic Information**

| Variables | N | Percentage |
|---|---|---|
| **Gender** | | |
| Male | 126 | 61.5 |
| Female | 79 | 38.5 |
| **Age** | | |
| Young(<35 years) | 132 | 64.40 |
| Old (> 35 years) | 73 | 35.60 |
| **Duration of Care per Day** | | |
| < 4 hours | 94 | 45.9 |
| 5 – 8 hours | 105 | 51.2 |
| 9 hours and above | 6 | 2.9 |
| **Severity of Disability** | | |
| Mild | 93 | 45.4 |
| Moderate | 93 | 45.4 |
| Severe | 13 | 6.3 |
| Profound | 6 | 2.9 |
| **Nature of Disability** | | |
| Congenital | 136 | 66.3 |
| Acquired | 69 | 33.7 |
| **TOTAL** | **205** | **100** |

As shown in Table 4.1, male caregivers were 79 (38.5%) while females were 126 (61.5%). 94 (45.9%) caregivers reported to be caring for children with disabilities for less than 4 hours, 105 (51.2%) caregivers reported being caring for children with disabilities for 5 to 8 hours per day while 6 (2.9%) caregivers reported being caring for children with disabilities for 9 hours and above per day. Furthermore, 93 (45.4%) caregivers care for children with mild disabilities, 93 (45.4%) caregivers care for children with moderate disabilities, 13 (6.3%) caregivers care for children with severe disabilities while 6 (2.9%) caregivers care for children with profound disabilities. 136 caregivers representing 66.3% care for children with congenital disabilities while 69 (33.7%) care for children with acquired disabilities.

**Table 4.2: Summary table of multiple regression showing relative contributions of children disability milieus and perceived social support in quality of life of family caregivers**

| Children disability milieus | B | t-value | Sig | R | $R^2$ | F | P | Df |
|---|---|---|---|---|---|---|---|---|
| Gender | -.012 | -.168 | >.05 | 5.34 | 1.91 | 9.67 | <.05 | 203 |
| Age | -.32 | 5.39 | <.05 | | | | | |
| Dur.of care | -.46 | -12.36 | <.05 | | | | | |
| Nature of disability | -.060 | -.68 | >.05 | | | | | |
| Severity | .130 | 1.50 | >05 | | | | | |
| Perceived social support | -.415 | -6.5 | <.05 | | | | | |

The result presented in Table 4.2 above shows that children's disability milieus and perceived social support yielded a coefficient of multiple correlations (R) of 5.34 and multiple correlation square ($R^2$) of 1.91. This shows that 1.91% of the variance in quality of life is accounted for by the combined effects of the disabled children variables. Table 4.2 above also indicates that gender showed no significant prediction on quality of life independently (β = -.012; t = -.168; P>.05). Age has a significant independent prediction on quality of life (β = -.32; t = 5.39, P<.05). Duration of care also have a significant independent prediction on quality of life (β = -.46; t = -12.36; P<.05). Nature of disability did not show a significant independent prediction on quality of life (β = -.060; t = -.68; P>.05). Severity of disability did not also independently predict quality of life (β = .130; t = 1.50; P>.05). In addition, social support had a significant negative prediction on quality of life of caregivers (β = -.415; t = -6.5; P<.05). Furthermore, Table 4.2 indicates that there was a significant joint prediction of children's disability milieus on quality of life (F= (6,203) =9.67; P<.05). This implies that gender, age, duration of care, nature of disability, severity of disability and perceived social support jointly predicted quality of life of family caregivers. Although there was a significant joint prediction of the children's disability milieus on quality of life, only age and duration of care independently predicted quality of life. Thus, the first hypothesis was confirmed while the second hypothesis was declined.

## Discussion of Findings

The finding showed that perceived social support predicted predict quality of life of family caregivers of children with disability. It also revealed that children's disability milieus did not all independently predict quality of life of family caregivers of children with disability as only age and duration of care had significant independent predictions on quality of life of family caregivers. The finding is consistent with the findings of Brisset (2010) who reported that caregivers with high social support had a better quality of life than those with low social support. The finding also confirms the finding of O'Relly, (2010) who found that social support is a significant predictor of quality of life of caregivers of children with disabilities. The result means that caregivers who have social support experience a higher level of quality of life than those who have no social support.

This finding of age is not consistent with the findings of Henson (2019) who reported that age affected the quality of life of family caregivers of children with disability. The finding is also consistent with the findings of Oelofsen and Richardson (2006) who found a significant relationship between age and quality of life of caregivers of children with disabilities. A possible reason for this significant result is that caregivers irrespective of age are in the same situation and likely to receive the same level of training required caring for their disabled children, hence a reason why both old and young caregivers did not differ in their quality of life. The finding is also in line with the findings of Davidson (2018) who reported a positive relationship between duration of care and quality of life of family caregivers of children with disability. Severity of disability did not have a significant predictor of quality of life of caregivers of children with disabilities. This may be true because of the emotional attachment caregivers, especially parents have with their children such that no matter the level of disability, they still love and care for their children at the same level. The finding is also consistent with the findings of Joseph and Fineman (2011) who reported that there is no significant relationship between the nature of disability and the quality of life of caregivers. A possible explanation for this insignificant result is that since caregivers are more concerned with the general well-being of children with disability than focusing on the kind of disability, they may not differ in their quality of life irrespective of the type of disability a child that is caring for is suffering.

## Research Limitations

Despite adherence to the necessary procedures required in this study, some limitations were however encountered. They include; The study focused only on family caregivers of children with disabilities and was not designed to include family caregivers of people with other health issues. Participants also experienced fatigue due to pressing care demands and the fraction of time spent in completing the questionnaire. Protocols associated with COVID rules and guidelines made it difficult to access certain family caregivers of some children's care homes.

## Recommendations

It was recommended that massive media and door-to-door campaigns should be carried out to educate people on the need to support caregivers of children with disabilities. This will improve the level of social support caregivers receive and result in improved quality of life of these caregivers. Policy makers and other stakeholders should make effort and employ more hands to care for children with disabilities so that each person will spend less time a day caring for these children which will, in turn, improve the quality of life of caregivers. More educational centres should be established in the state so that children with disability will have access to education despite their condition.

## Conclusion

Based on the findings of this study, it was concluded that perceived social support, age and duration of care are significant independent predictors of quality of life of family caregivers of children with disability. It was also concluded that gender, age, duration of care, nature of disability, severity of disability and perceived social support jointly predicted quality of life of family caregivers of children with disability.

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