# Stress Implication of Rearing Children with Cerebral- Palsy and Down-Syndrome: Perceptions of Caregivers in Ilorin, Nigeria

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#### Abstract

This study investigated stress implication of rearing children with cerebral-palsy (CP) and Down-syndrome (DS) as perceived by caregivers in Ilorin, Nigeria. The study highlighted the levels, causes as well as coping strategies adopted by caregivers. A qualitative research approach was adopted using semi –structured interview. The population sample consists of twenty-five participants (caregivers). Thematic analysis was used to analyze data collected from respondents. It was revealed by majority of respondents (88%) that rearing of children living with CP and DS is extremely stressful. Total dependency, low mental assimilation and inadequate communication were revealed by majority of the respondents (95%) as major causes of stress. Poor coping strategies were adopted by caregivers (64%) in dealing with stress. Based on the findings of this study, it was recommended that Caregivers be assisted by professional bodies to more scientific ways of coping with stress resulting from rearing of children living with CP and DS in Ilorin, Nigeria.

**Keywords**: Cerebral-palsy, Down-syndrome, Stress, Rearing, Caregiver

## Introduction

Generally, the act of parenting and caregiving is a serious business that requires a lot of effort mentally, socially, and economically. Rearing children with special needs such as Cerebral-palsy (CP) and Down-syndrome (DS) implies that parents and caregivers have to do more than it is necessarily required to nurture and properly integrate them into the society, helping them adapt and to be able to contribute meaningfully to the society. The prevailing cases of CP and DS within Ilorin viz-a-viz the inadequate rearing of these categories of children could care and parenting prompting these children to roam the streets aimlessly is capable of denying such children their right to proper parenting and meaningful living (Lasisi & Ibrahim, 2024). Parents of children with CP and DS in Ilorin have resorted to hiding their children and denying them access to proper medical care due to fear of stigmatization and other forms of cultural and primordial beliefs (Abdullahi et al., 2022). The records obtained from the University of Ilorin Teaching Hospital (UITH) being the only tertiary health institution in Kwara State with the capacity to handling cases of CP and DS showed that only fifty (50) CP and DS are on the hospital records receiving treatment between 2012 and 2023 (UITH, 2024). Although CP and DS are uncommon diagnosis, these figures may not be the reflection of the actual cases when compared to the number of such kids roaming the street as can be observed especially in the rural communities within Ilorin.

Rearing children with disability such as CP and DS can be very cumbersome due to their peculiar health conditions which results in several deficiencies biologically, mentally and physically (Faught et al., 2022). Caregivers undergo varying degrees of stress in nurturing their kids and wards but rearing children with CP and DS require extra physical and intellectual alertness in other to provide adequate care for these categories of children (Harniess et al., 2022). In developed world, effective communication and social support by professionals may likely be responsible for increased acceptability of children diagnosed with CP and DS resulting in positive adjustment in the families of children diagnosed with such disabilities.

In Nigeria, the level of stress emanating from rearing CP and DS children is dependent on the amount of social support that is available to the parents (Oguntade et al., 2022). Most parents of children living with CP and DS are vulnerable to stress with depressive tendencies emanating from discrimination leading to negative perceptions about self (Low self-esteem), the situation and fate (Ede et al., 2022, & Oguntade et al., 2022). Children with CP and DS are most likely to have one or more acute or chronic

health challenges which can trigger the stress and emotional health condition of parents and caregivers as a result of negative psychological thoughts (Ede et al., 2022, & Santos et al., 2023).

In Kwara State, stigmatization, anxiety, and irrational customary and religious beliefs are the primary stressors of parenting children with CP and DS (Adegboyega, 2019). The socioeconomic status of parents with CP and DS children is another factor that can hinder positive treatments and professional interventions (Abdullahi et al., 2022). When parents and caregivers are themselves emotionally and mentally unstable, physically distorted, and medically unfit, the level of care that is expected to be rendered could be affected thereby further endangering the health condition of the child with an intellectual disability such as CP and DS (Hoff & Laursen, 2019). The coping ability of the caregivers is of immense importance to the management of DS and CP Children. When one considers chronic health conditions such as heart defects, gastrointestinal disorders, respiratory diseases, and ophthalmologic problems often associated with these ailments, it is expedient for parents and caregivers to remain strong, healthy and focused in the nurturing of the child to keep the child alive.

Like in other parts of Kwara state and Nigeria at large, the perception of people towards children living with CP and DS in Ilorin is of grave concern especially to mental health experts, psychologists and professional counsellors. Often, such children are either associated with evil spirits, bad luck, or products of the mothers' promiscuous lifestyles among other forms of ill-perceived notions towards such children, these acts have resulted in increased psychological trauma on the part of parents and children with disabilities (CWDs) (Omiegbe & Ezehi, 2023).

In this study, the theoretical reviews serves as guiding lens through which the exploration and understanding of the stress implications of rearing children with CP and DS is based. Premised upon *Stress and Coping Theory* by Lazarus & Folkman (1984) and *Family System Theory* by Bowen (1966), this research aims to delve in to the nuance of parenting children with disabilities such as CP and DS including the perceived causes and coping mechanisms adopted by the caregivers. Stress and Coping Theory focuses on individual perception of stress, stressful events and the manageability of stress by such individuals (Proulx & Aldwin, 2016). It explores the cognitive and behavioural processes involved in the management of stress and helpful in understanding the views of caregivers on the level of stress associated with rearing of children with CP and caregivers. The Family System Theory (Bowen, 1966) on the other hand, underscores the importance of understanding family dynamics and the interconnectedness among family members whereby what affects a particular member of family have a direct or indirect effect on other family members. Rearing children with CP and DS affect the

lifestyles, the psychological wellbeing of other family members and deplete the available resources of members of families; this was established in the Family System Theorists (Bowen, 1996) and empirically substantiated in the studies of Holff & Laursen (2019), and Oguntade et al. (2022) and Adejoh et al. (2023).

According to the World Health organization (WHO, 2023) stress can be described as a condition of worries that results from a tensed or difficult situation. It is a natural reaction to challenges which varies among human-beings. Stress is an essential concept in the field of natural sciences and psychology that is used to describe a reaction to elements of stress system encompassing stressful stimulus effects and responses (Lu et al., 2021). Stress is a normal body reaction to changes which can be harmful when excessive resulting in harmful health conditions such as severe body pain, loss of concentration, high blood pressure, aggressive behaviour, insomnia among others (Lasisi & Ibrahim, 2023). Stress can be acute when accumulated leading to wear and tear on the body. Some common psychological effects of stress are irritability, depression, panic attacks, and sadness among others.

Cerebral Palsy (CP) is a medical condition characterized by impaired muscular coordination which is usually associated with other forms of disabilities as a result of damage to the brain during formation before birth or during birth which may be mild, moderate or severe (Vitrikas et al., 2020). CP is a congenital disorder associated with muscular movements and postures resulting from brain damage which mostly occur before birth. According to Fahey et al. (2017), CP is a major brain development disorder that is currently estimated to be diagnosed in one out every one thousand births. Like the DS, the main cause of this diagnosis is not explicitly known with genetical mutation at formation stage of the brain the most realistic suspected cause.

According to Chapman (2017), DS is a genetic condition caused by an individual having extra chromosome 21 in some or all of the body cells and it is characterized by growth, developmental, and learning delays that vary in patients in accordance with the level of severity or otherwise. Some of the most prevalent features of Down Syndrome include inadequate height (shortness than normal), flat face, short nose, slanted eyes, Almond-shaped ears, and deep lines stretching across the palms of the hands. Other common characteristics include weakness of the muscles, heart defects and diseases, and infections (Bull, 2020).

Shroff (2022) defined DS as a defect from birth that encompasses enormous medical and social challenges which is usually caused by trisomy of the whole or proportionate aspect of chromosome 21 (having extra copy of chromosome 21). DS is the commonest among genetic disease all over the world

and responsible for most intellectual malfunctions in individuals, constituting about one percent (1%) of every one thousand, and five hundred birth (1 % / 1500) in the world (Poety, et al., 2018). There are various factors that culminate into DS, these include the following;

- 1. Pregnancy in old age: when a woman becomes pregnant at the age of 35 and above, there is a high probability of the fetus having DS. A pregnant woman at the age of twenty- five (25) has a probability of one ratio one thousand, two hundred and fifty (1: 1,250) and this ratio increased to one ratio of one hundred (1:100) at the age of forty (40).
- 2. Mutation and developmental defects: DS can emanate as a result of some or all cells in the body having full or partial copies of chromosome 21, presence of the genetic translocation for DS in parents. This gene is transferable by both men and women to the next generation of children.
- 3. Having had a child with DS: parents who have reproduced a child with DS have a high probability rate of birthing another child with similar conditions (Coppede, 2016).

Caregiving is an essential aspect of parenting that deals with how a child is nurtured from infancy to adulthood, this can be done through the provisions of all necessary supports psychologically, socially, morally and materially. Every child needs caregiving for him to grow and attain adequate human development, the level of care that's required may vary among children and depends on the kind of child be it a normal or a child with special needs. According to Crist et al. (2019), caregiving is a situation where by an older individual provides help to a younger person or a patient either professionally and or unprofessionally in order to assist the individual attain maximum possible growth, development and wellness. Children with disabilities such as CP and DS rely tremendously on the amount of care and nurture vested on them to properly adapt or adjust in the society. Caregiving is a very cumbersome and burdensome task that requires the caregivers' mental, social and economic resources. In the views of Hejazi et al (2022), caregiving can be broadly divided into two which are; Formal and Informal forms of caregiving. The Formal caregiving is concerned with the kind of caregiving provided by paid agents from service providing organizations who provides care to individual patients in a formal setting such as clinics, nursery homes, and other assisted living facilities. The informal caregiving is concerned with the kind of care given by a nonpaid agent or persons within the community such as parents, guardian and volunteers among others.

Societal perception of people living with CP and DS underscores the importance of this study especially from the Nigerian context and Ilorin specifically. According to Vadivelan et al (2020), stigmatization, discrimination, rejections and poisoning are some forms of inhuman treatment meted

on children living with chronic disabilities such as CP and DS, these wanton behaviour often result in chronic anxiety disorder, depression, social isolation and suicide cases among Children living with Disabilities (CWDs). The inability of the CWDs to fully engage in meaningful living resulting from discriminatory treatment from the society could hinder these kids the opportunity to meaningful life which may lead to frustration among the parents and the CWDs.

According to Olaitan (2021), CWDs have often times become the chief victims of the social imbalances in Nigeria in form of aggression transfer from the caregivers and other close associates. These children are subjected to physical stigmatization in form of bullying and battering, forceful drug administration, sexual molestation and harassment and poisoning from family members and other caregivers (Iguh & Ugwu, 2023). The nonphysical stigmatization often suffered by CWDs includes intimidation, denial of medication and other medical benefits, deprivation and pity (Olaitan, 2021). Also, poor social economic status of parent rearing children with disabilities results in frustration, financial stress, conflicts and other psychological strains which negatively affect the entire family structure (Adejoh, et al., 2024). Family of children living with CP and DS sometimes resort to selling of personal belongings to cater for the high financial demands in rearing such children especial in the rural areas. Caring for children diagnosed with DS and CP has a negative financial implication on the social status and the quality of life in the family structures where such children are reared (Elangkovan & Shorey 2020). The uniqueness of DS and CP among other forms of disabilities has underscored the need for urgent amelioration of the plights of parents with DS and CP children especially in Ilorin

CP and DS are prevailing health conditions that require a lot of time, energy, and resources in order to nurture children with such conditions. As health conditions that seem to have no cure, CP and DS come with some level of anxiety and lots of stigmatization from society which culminates in stress and other forms of emotional distortions on caregivers. Parenting is a key factor in assisting children with disabilities CP and DS manage their health challenges. Several studies have been carried out on CP and DS, however, there has been limited studies in the area of stress of parenting children with CP and DS especially in the context of this study to the researcher's best knowledge, hence the researcher's interest in bridging the knowledge gap. For instance, Adejoh, et al. (2024), Oguntade, et al. (2022), Ede, et al. (2022) and Omeigbe (2019) among others, conducted their studies in other parts of the country with little focus on stress and coping mechanism of caregivers of children with CP and DS. Adegboyega (2019) and Abdullahi (2022) who conducted their studies on Children with disabilities (CWDs) in Kwara State concentrated their efforts on the aspect of discrimination against CWDs

without delving significantly into the aspect of caregivers' stress. This study seeks to address an essential gap in the existing literatures through the examination of the stress experiences of caregivers of children with CP and DS in Ilorin, Nigeria. Although literatures were studied and adequately reviewed, the literature did not entirely cover my study variables and context but the knowledge was very useful in the aspect of literature review and in establishing the background to this study.

The Objectives of the study are to;

- 1. Investigate the level of stress involved in rearing children living with CP and DS as perceived by caregivers in Ilorin, Nigeria.
- To examine the perceived causes of stress involved in rearing CP and DS children in Ilorin, Nigeria.
- 3. Explore the coping strategies adopted by caregivers in managing stress resulting from rearing CP and DS children in Ilorin, Nigeria.

# **Research Questions**

Three research questions were raised and answered in this study, thus;

- 1. What is the level of stress involved in rearing CP and DS children in Ilorin, Nigeria?
- 2. What are the perceived causes of stress of rearing CP and DS children in Ilorin, Nigeria?
- 3. What are the coping strategies adopted by caregivers of CP and DS children in Ilorin, Nigeria?

# Methodology

This study was a Qualitative Research Design type, Semi-structured interview using open-ended questions was used for data collection from the respondents (caregivers). Semi-structure type of interview allows for in-depth exploration of the experiences of the caregivers. However, audio recordings were used with the consent of the respondents (caregivers) to capture their views on stress implications of rearing CP and DS children in Ilorin, Nigeria. The population of this study comprises all caregivers of children living with CP and DS in Ilorin, Nigeria while twenty five caregivers participated as respondents (population sample) in this study using convenience sampling technique. Researcher finds convenience sampling technique suitable for this study due to unwillingness of caregivers comprising of the health practitioners, parents, nannies in special schools and professional counsellors to create time and venues outside their official hours, offices and homes. Also, Purposive sampling technique was used to select caregivers of children living with DS and CP from UITH, Schools for children with special needs and parents who voluntarily showed readiness and willingness to participate in the study within Ilorin, Nigeria. Purposive sampling was adopted to limit the

participants to caregivers of children living with CP and DS as drawn from relevant institutions and experienced based caregivers only to ensure validity of responses. The responses were shared with the participants to validate and authenticate the collected data (responses). Thematic analysis was used to analyze collected data while Coding System was used to categorized the data collected from the respondents in to three themes which include; the level of stress experienced by caregivers of children living with CP and DS, the perceived causes of stress associated with rearing children with CP and DS and the coping strategies adopted in dealing with stress resulting from rearing CP and DS children in Ilorin, Nigeria.

# **Presentation and Discussion of Results**

Results obtained from respondents were thematically analyzed, presented in themes and discussed below;

Theme One: Perceived Level of Stress.

Twenty two (22) out of twenty five (25) respondents (88%) described stress of rearing CP and DS children as extremely high, two others (2) respondents (8%) described the stress of rearing CP and DS children as moderately stressful. However, one respondent (4%) did not find it stressful at all but considered it as a normal part of caregiving. Since the majority (88%) of the respondents agreed that parenting children living with CP and DS is extremely stressful, it is reported from the findings of this study that rearing children with CP and DS is extremely stressful thus research question one is answered. This findings is supported by previous studies of Holff & Laursen (2019), and Oguntade et al. (2022) and Adejoh et al. (2023)

Theme Two: Perceived causes of stress.

Twenty three (23) of the twenty (25) representing 95 % of respondents agreed that the major causes of stress associated with rearing children with CP and DS include high level of dependency, low mental assimilations and the inability of the children to communicate their feelings. However, two (2) of the twenty five (25) respondents representing 8% viewed inadequate parental support as a major stressor. Since majority of respondents 95% agreed that perceived causes of stress associated with rearing children with CP and DS results from high level of Dependency, low Mental Assimilation and inability of the CP and DS children to communicate their feelings, thus research question two is answered. This finding is in agreement with Raza et al. (2022) but in contrast with Ovais, et al. (2024) who posited that inadequate financial support is the major stressor associated with parenting children with CP and DS

although the concept of caregiving as used in this study is broader than the concept of parenting, therefore researcher aligns with the submissions of Raza et al (2022).

# Theme Three: Coping Strategies.

16 of the 25 respondents (64%) reported their coping strategies to include religious beliefs, patience and love. Four other caregivers (16%) state the use of drugs such as painkillers and sleeping pills as their coping strategy. Furthermore, another four caregivers (16%) stated that joining support groups and the use of instructional materials in communication was their strategies of reducing the stress of rearing children living with CP and DS. Since majority of the respondents adopted a non-scientific approach as coping strategies, it is reported based on the findings of this study that majority (64 %) of caregivers of children living with CP and DS demonstrated poor coping strategies in dealing with stress resulting from rearing of children living with CP and DS in Ilorin, Nigeria. thus research question three is answered. This finding is supported by previous study of Abdullahi et al. (2022).

## Conclusion

Based on the findings of this study, it is concluded that rearing of children living with CP and DS in Ilorin, Nigeria is extremely stressful. Also, the perceived causes of stress associated with rearing of children living with CP and DS in Ilorin, Nigeria include high level of dependency, low mental assimilation and the inability of the children to properly communicate their feelings. Furthermore, it was concluded that caregivers of the children living with CP and DS in Ilorin, Nigeria adopted poor and non-scientific coping strategies in dealing with their stress.

#### Recommendations

Based on the results obtained the data analysis, the study recommends that;

- 1. Caregivers of children with CP and DS should be assisted by family members, professional colleagues and associates at home and at work place to reduce the stress associated with rearing children living with CP and DS in Ilorin, Nigeria.
- 2. Caregivers should be assisted by government, cooperate organizations and relevant stakeholders by engaging professionals such as licensed counsellors, psychologists and mental health practitioners to educate caregivers of children living with CP and Ds on adequate, and scientific parenting skills suitable for the rearing of children living with CP and DS in Ilorin, Nigeria.

3. Caregivers of children living with CP and DS should be educated by professional counselors and other relevant professionals on the need to adopt scientific stress management strategies in coping with stress resulting from rearing of children living with CP and DS in Ilorin, Nigeria.

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