

**STRESS AND COPING MECHANISM OF PARENTS/CAREGIVERS OF DOWN SYNDROME AND CEREBRAL PALSY CHILDREN IN ILORIN METROPOLIS, KWARA STATE**

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***Abstract***

*This study investigates the stress levels and coping mechanisms among parents of children diagnosed with cerebral palsy (CP) and Down syndrome (DS) in Kwara State, Nigeria. The research aims to understand the unique challenges faced by these parents and identify effective coping strategies employed to manage stress in their care-giving role. Descriptive research design was adopted for this study. Data were collected from a sample of parents using two set of instrument; the Parental stress scale (PSS) and The Brief-Coping Orientation to Problem Experienced Inventory (Brief-COPE) . One research hypothesis was tested at a 0.05 level of significant and two research questions were answered in the study. PPMC was used to analyze the relationship while percentage was used to analyze the research questions. Findings reveal that parents of children with CP and DS experience high levels of stress due to various factors including financial strain, social stigma, lack of support services, and emotional burden. However, parents demonstrate a poor coping mechanism to navigate the stress associated with raising children with special needs. Coping strategies identified include seeking social support from family and friends, accessing specialized healthcare services, engaging in religious/spiritual practices, and practicing self-care activities. It was recommended that Parents of CP and DS children in Kwara adopts more effective stress management and coping strategies in managing high level of stress emanating from nurturing of CP and DS children in Kwara State among others.*

## Introduction

Parenting children with disability such as Down syndrome (DS) and Cerebral Palsy can be very cumbersome due to their peculiar health conditions which result in several deficiencies biologically, mentally, and physically (Faught et al., 2022). All parents undergo varying degrees of stress in nurturing their kids and wards but parenting of children with DS and CP requires extra physical and intellectual alertness and adequate care must be provided and made easily accessible to parents of DS children (Ballantyn et al., 2019). In developed world, effective communication by professionals and social support have increase the level of acceptance and positive adjustment in the families of children diagnosed with DS (Huiracocha et al., 2017).

Despite advocacy, continuous education, and sensitization, some societies have continued to exhibit discriminatory tendencies towards DS and CP children and their parents in different parts of Nigeria (Umegbolu, 2021). The effect of inequality in the manner of treatment of DS and CP children compare to their 'normal' counterparts has often resulted in emotional, social, and physical stress (Ogunsakin, 2021). Parenting a child with disabilities such as DS and CP can affect family functioning due to high stress intensiveness, adjustment difficulties and poor coping strategies which sometimes lead to depression and suicidal ideation (Burke et al., 2019) Caring for children with DS requires the collective efforts of the family members and parents who are not only concerned about the disabled child but also on the impact of such child on the siblings by taking more of the parents' attention and depriving their social life styles (Mbazima, 2016: Philips et al., 2017 & Randolph, 2023).

In Nigeria, the level of stress emanating from parenting DS children is dependent on the amount of social support that is available to the parents (Onyedibe et al., 2018). Most parents of children with DS and CP 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 DS and CP 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).

There is a correlation between stress and parenting children with disability and the vulnerability of such parents to depressive tendencies and other severe psychological and medical conditions. Parents mostly react negatively to the effect that their baby has DS and or CP with disbelief and denial of the commonest reactions (Abdullahi et al., 2022). Some families may decide to hide the test result or the diagnosed child due to the perceived stigmatization that is attached to people living with disabilities especially DS and CP, and this is evident in the huge disparity in the records available in the hospital compare to the actual numbers of such persons especially in the rural areas. Data from the University of Ilorin Teaching Hospital (UIITH) which is the only tertiary medical center with the capacity to handle DS and CP cases showed that shows that only fifty children comprising thirty one cases of CP (15 male and 16 female) and nineteen DS (nine (9) male and ten (10) female) has been diagnosed across the state including referral cases between 2012 and 2023. Of this numbers, only few are brought by their parents on their clinic days for treatments and other medical care, others may have abandoned their

medication owing to socio-economic factors, poor orientation and awareness, cultural and societal disposition about children with such conditions.

In Kwara State, stigmatization, anxiety, and irrational customary and religious beliefs are the primary stressors of parenting children with DS and CP (Bukoye, & Rotimi 2013, Adegboyega, 2019). The socioeconomic status of parents with DS and CP children can hinder positive treatments and professional interventions (Reiss, 2013, Abdullahi et al., 2022). When parents and caregivers are themselves emotionally unstable, physically distorted, mentally unstable, 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 DS and CP (Hoff & Laursen, 2019). The coping ability of the caregivers is of immense importance to the management of DS and CP Children especially when one considers chronic health conditions such as heart defects, gastrointestinal disorders, respiratory diseases, and ophthalmologic problems that is usually associated with these conditions, it is expedient for parents and caregivers to remain strong, healthy and focused in the nurturing of the child to keep the child alive.

In Ilorin, like other parts of Nigeria the perception of people towards children and parents of children living with disabilities is of grave concern, 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 of parents and children with disabilities (Olorukooba et al 2013: Omiegbe, 2016, Omiegbe & Ezechi 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 (Cleveland clinic, 2021). 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.

Coping is a conscious strategy used to reduce negative emotions. The coping mechanism can be cognitive, behavioral, social, and or individual (Wikipedia, 2023). Parents of children with DS and CP suffer enormous stress and anxiety, these parents especially the mothers often resort to religion and spirituality as a mechanism for adjustment and problem solving (Karaca & Senar, 2021). Talking to other parents with similar experiences is also a way of reducing stress due to the opportunity of exchanging ideas and sharing information. Tips on mechanisms for caring for DS and CP children can be learned and exchanged through interactions among the parents. Generally, Coping can be grouped into four categories which include the following

1. Problem-Solving: This coping system is concerned with individuals addressing the causative factors leading to stressful events or situations. This can be achieved through planning, competitive reduction, and resting.
2. Meaning-focused: in this situation, an individual is involved in the use of cognitive abilities to attain or get meaning to a situation and also find the best management strategy in managing the stressful event. To achieve this, people can employ reflective and critical thinking until a meaning is found to solve the stressful event.
3. Emotion-Focused: this is mainly concerned with the reduction of stress through the elimination of irrational emotions that are attached to stressful events. This can be done through religiosity, humor, and refraining from positive acceptance.
4. Seeking support: This happens in a situation where an individual resorts to seeking help from society as a way of coping with the stressful event of his life (Algorani & Gupta, 2023).

According to Algorani & Gupta (2023), coping mechanism can be defined as a series of thoughts and behaviour that are deployed to ensure effective management of life stressors which may emanate from internal and or external situations or events of life. All human beings pass through one form of stress or the other which result from various life experiences that are handled differently by different people. Coping can be Reactive or Proactive, in Reactive Coping Mechanism, individuals react to the stressful event after the event leading to stress has occurred. On the other hand, a Proactive coping mechanism has to do with a situation where individual ensures that stressful events are guided against and are prevented from occurring. While the reactive method is centered on controlling the stressful situation, the proactive method of coping is mainly concerned with prevention and perhaps the best coping mechanism (O'Connor et al., 2021).

There are various types of mechanism to cope with stressful events and life situations especially such that emanate from unwanted life experiences, they include Adaptive and Maladaptive coping methods (Cramer, 2015).

#### Adaptive Coping Methods:

1. Physical exercise such as sport and games can serve as a natural therapy for stress reduction and a good strategy for coping with stressful life events.
2. Relaxation: This includes visiting beautiful places, listening to good music, holidaying, meditation, and self-exposure to the natural environment.
3. Humor: this is done by taking stressful events from a lighter perspective such as taking things easy as a strategy for coping with life stressors.
4. Talk about stressful events: Talking about life stressors to friends and family member is a good way of coping with stressful situations, talking about your challenges or sharing your problem, especially with a trusted ally can ease tension and reduce the negative effects of the stressors.

5. Critical thinking (Problem-solving method): This coping mechanism is concerned with identifying the stressor and reflecting on plausible ways of overcoming or averting the problem (stressor) in the future

Maladaptive coping methods:

According to Moritz et al (2016), the maladaptive coping method is the direct opposite of the adaptive method of coping. This study has identified the following as maladaptive coping mechanisms. They are;

1. Self-soothing: Although soothing self isn't a bad thing but when it becomes a habit then it's maladaptive behavior that must be avoided. Examples of self-soothing include internet abuse, addiction, and bloated emotional expression beyond normal proportion.
2. Escape: This is concerned with a situation of self-isolation and withdrawal from friends and relatives. The individual engages in personal activities such as watching movies, spending too much time on the internet, reading, and so on.
3. Numbing: Numbing has to do with people having to be aware of a particular behaviour they seek to overcome such by engaging in activities to override such event. Such activities may include alcohol consumption, excessive use of the internet, drug abuse and other illicit substances, and feeding on junk.
4. Self-harm: sometimes people indulge in self-harm as a way of coping with stressful events. Maladaptive behaviour such as suicidal ideation, drug abuse, rape, and other nefarious acts are used as coping strategy.
5. Compulsion and risk-taking: Stress can sometimes make individuals engage in heinous acts such as unnecessary risk-taking like gambling, unsafe sex, and reckless driving theft as ways of reacting to stress and stressful events.

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). It 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. Information obtained from the national institute of health's workshop on basics and transactional research in CP retrieved from <https://videocast.nih.gov/summary.asp?Live=18384bhcp=1> showed that there is evidence of genetical factors accounting for 30% causes of CP among children.

The effect of a particular genetic mutation varies in accordance to the severity among individuals (Fahey et al., 2017). The symptoms may also vary from mild to severe among children diagnosed with CP. The most common symptoms include floppy legs and arms, Stiff Muscles also known as Spasticity. Other symptoms are irregular posture, uncontrolled movement in form of unsteady walk steps. The most common effect of CP include difficulty in swallowing, eye muscles which hinders them from focusing properly, reduced range of motion due to muscle

stiffness. Some CP patients may have intellectual disabilities, epilepsy, blindness and deafness among other diagnosis. There is no known medical cure but early identification and regular treatment can help improve muscular functions and general living condition (Herskind et al., 2015).

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. 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. Shroff (2022) define 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. DS is the commonest among genetic disease all over the world and responsible for most intellectual malfunctions constituting about one percent (1%) of every one thousand, Five hundred birth (1 % / 1500) in the world.

There are various factors that culminate into DS. The commonest among them are as follows;

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 of one thousand, two hundred and fifty (1,250) and this ratio increased to one ratio of one hundred (1:100) at the age of forty (40).
2. 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.

Lawler (2021) identifies three types of DS to include the following;

1. Translocation Down syndrome (TDS): This type of DS represents about four (4) percent of the total diagnosed cases all over the world. This condition results from a circumstance whereby a baby is birthed with the normal 46 chromosomes but with the presence of additional genetic material from chromosome 21 that differed from another chromosome within the cell.
2. Mosaicism: this is sometimes referred to as Mosaic DS it represents about two percent (2%) of the total cases of diagnosed children living with DS. Children birthed with this condition have some cells with normal numbers of chromosome which is forty- six (46) and which is forty- seven (47) including an extra copy of chromosome 21 which translate to less severity of the symptoms of DS.
3. Trisomy 21: this is the most common among the three and constitutes about 95% of the cases which result from the presence of 47 chromosomes in each of the body cells instead of the normal 46 chromosomes. This error which happens in cell division is called

Nondisjunction. This error leaves an egg cell with an extra copy of chromosome 21 before or during conception.

CP and DS are prevailing health conditions that require a lot of time, energy, and resources to be able to nurture children with such conditions. As a health condition that seems to have no cure, it comes with some level of anxiety on the part of the caregivers and lots of stigmatization from society which culminates in stress and other forms of emotional distortions. It is important to assist these individuals with this type of disability to live a meaningful and possibly contribute to the Nigerian society. Parenting is a key factor in assisting children with disabilities (CWDs) to manage their health challenges while in the same vein, adequate parenting of these children will depend largely on the parents' ability to manage stressful conditions and devising good coping mechanism of stress. Several studies have been carried out on CP and DS, however, there has been limited studies in the area of stress and coping mechanism of parenting children with CP and DS especially in Ilorin metropolis of Kwara State to the researcher's best knowledge, hence the researcher's interest in bridging the knowledge gap. For instance, Obasi et al (2018), Ezeonu et al. (2021), Elkaza (2021) and Ede et al. (2022), Onyedibe (2018) and Omeigbe (2019) among others conducted their studies in other parts of the country with little focus on stress and coping mechanism of parenting children with CP and DS, Ogunsakin (2021) and Abdullahi (2022) who conducted their studies on CWDs in Kwara state concentrated their on the aspect of discrimination against CWDs. Although their studies did not entirely or cover my study variables, their knowledge was very useful in the aspect of literature review and in establishing the background to this study.

The purpose of this study is to;

1. Explore the relationship between stress and coping mechanism of parents of CP and DS Children in Ilorin Metropolis of Kwara State.
2. Examine the extent of Stress in parenting Children with CP and DS Children in Ilorin Metropolis of Kwara State.
3. Determine the best Coping Mechanism of Parents with CP and DS Children in Ilorin Metropolis of Kwara state.

One null research Hypothesis will be used to test the relationship between the two main variables at a 0.05 level of significance, thus;

H<sub>0</sub>: There is no significant relationship between stress and coping mechanism of parent of CP and DS children in Ilorin Metropolis of Kwara State.

The following research questions are to be answered in this study;

1. What is the extent of stress experienced by parents of children with CP and DS in Ilorin Metropolis of Kwara State?
2. What is the most effective coping mechanism adopted by parents of children with CP and DS in Ilorin Metropolis of Kwara State?

## Methodology

This study adopts a descriptive research design of correlational type. Descriptive research design is among the best design used in investigating contemporary challenges. It has the capacity to elicit relevant data from a large population size through the administration of relevant research instruments on the respondents (Aggarwal, & Ranganathan 2019). The population of the study consists of fifty five (55) selected parents of children with CP and DS within Ilorin metropolis which were purposively selected. These parents were sampled from UITH, Tomo'ore and Coddled mind special schools and parents that were visited within Ilorin metropolis. The Brief-Coping Orientation to Problem Experienced Inventory (Brief-COPE) by Carver, (1997) and the Parental Stress Scale (PSS) by Berry & Jones, (1995) was used to elicit relevant information from respondents for the purpose of this study. Both instruments are standardized and passed reliability and validity test and have been used locally and internationally. The brief-COPE Instrument is a twenty-eight (28) items instrument with all items germane to the extraction of relevant information needed for the measurement of coping mechanisms among parents, it's a liker scale item with the scoring order ranging from "Not at all" (1) to "Doing it a lot" (4). The Parental Stress Scale is Eighteen (18) items instrument with the ability of eliciting relevant information needed for the measurement of parental stress. Like the brief-COPE, The PSS scoring ranges from "Strongly Disagree" (1) to Strongly Agree (5). The study adopts Percentage and Pearson Products Moment Correlation (PPMC) to answer research questions and test the null hypothesis at a 0.05 level of confidence respectively.

## Results and Discussion

### Research Question One

What is the level of stress of parents/caregivers of the children with Down syndrome in Kwara State?

Table 1

Frequency of the Levels of Stress among Parents/Caregivers of Children with Down syndrome

Levels	Range of Scores	Frequency	Percentage
Low	28 - 56	19	34.5
Moderate	57 – 84	15	27.3
High	85 – 112	21	38.2

Table 1 shows the results obtained from answering research question one. From the table, it is shown that the parents and caregivers with low level of stress were 19 and they represented 34.5%. Those that have moderate stress were 15 and they represent 27.3 and those with high

stress were 21 which represented 38.2%. Since the majority of the participants were (those with high stress) 21 and 38.2%, the level of the stress among the parents/caregivers of the participants was high.

#### Research Question Two

What is the level of coping mechanism of parents/caregivers of the children with Down syndrome in Kwara State?

Table 2

Frequency of the Levels of Coping Mechanism among Parents/Caregivers of Children with Down syndrome

Levels	Range of Scores	Frequency	Percentage
Low	18 - 44	50	90.9
Moderate	45 – 68	3	5.5
High	69 – 90	2	3.6

Table 2 shows the results obtained from answering research question two. From the table, it is shown that the parents and caregivers with low level of coping mechanism were 50 and they represented 90.9%. Those that have moderate coping mechanism were 3 and they represent 5.5% and those with high coping mechanism were 2 which represented 3.6%. Since the majority of the participants are (those with low coping mechanism) 50 and 90.9%, the level of the coping mechanism among the parents/caregivers of the participants was low.

#### Research Hypothesis One

There is no significant relationship between stress and coping mechanism of parents/caregivers of the children with CP and DS in Kwara State.

Table 2

P.P.M.C. Table Showing the Relationship between Stress and Coping Mechanism of the Parents/Caregivers of Children with Down syndrome in Kwara State.

Variable	No	Mean	St. Dev	df	r. observed	Sig.	P
Stress	55	43.53	6.12				
				53	-0.84	0.00	**
Coping Mechanism	55	69.16	5.81	1			

\*\* (Significant at 0.05 critical region)

Table 2 shows the results obtained from testing hypothesis one. From the table, it is shown that r. observed was -0.84, degree of freedom was 53 and Significance was 0.00. Since significant level was less than 0.05, the null hypothesis was rejected. Thus, there was a significant relationship between stress and coping mechanism of parents/caregivers of the children with CP and DS in Kwara State.

### Conclusion

From the results obtained from the analysis above, it is concluded that there was a high level of stress recorded among the parents of CP and DS children in Kwara States. Also, the results show a low level of coping mechanism among parents of children diagnosed with CP and DS in Kwara State. Furthermore, it was concluded that there is a significant relationship between stress and coping mechanism of parents of CP and DS children in Kwara State.

### Recommendations

Based on the results of this study, it is recommended that;

Parents of CP and DS children in kwara adopts more effective stress management strategies

Parents of CP and DS employ a more effective mechanism in coping with the high level of stress emanating from the nurturing of CP and DS children in Kwara State among others.

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