

Neurological disorders: perceived causes, effects and coping strategies among caregivers in Lagos, Nigeria

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Abstract

Despite high prevalence of neurological disorders among African children, efforts to highlight caregivers' lived experiences remain under-explored. This study investigates the perceived causes, impacts, and coping strategies among caregivers of children with paediatric neurological conditions (cerebral palsy, hydrocephalus, jaundice, down syndrome, autism and epilepsy) in Lagos, Nigeria. The study utilizes a phenomenological research method to capture the experiences of caregivers and acquire insights into their shifting attitudes. A semi-structured in-depth interview guide was used to conduct face-to-face interviews with 21 caregivers in two facilities that provide care and treatment for children with neurological diseases. Three themes emerged from the thematic analysis. The study found that caregivers attributed neurological impairment to medical difficulties during pregnancy, labour, and delivery as well as the general attitude of medical personnel. The effects of caregiving on caregivers included frustration, conflicts, financial stress, mental and emotional strain, impacts on work schedule and family time. To deal with these issues, caregivers were able to cope with assistance from significant others and personal sacrifices by selling personal belongings to meet the financial demand of caring for children with neurological disorder. The study recommends the development of interventions and policies that can alleviate the burden on caregivers and improve the overall well-being of children with neurological disorders and their families.

Key words

caregivers, effects of caregiving, coping mechanisms, neurological disorders, Nigeria

Key points

1. Adds to existing knowledge on neurological disorders and highlights the need for further research.
2. The findings contribute to an understanding of the impact of caregiving on caregivers' lives, emphasizing the need for support systems.
3. The study provides insights into caregivers' adaptive mechanisms and highlights areas where additional support and resources can be provided.
4. Adds to the cultural understanding of caregiving in the Nigerian context and provides a basis for developing culturally sensitive interventions.

Introduction

Neurological impairments in children can arise from various factors such as genetic diseases, neurotoxins, hypoxia, infections, injuries, adverse peri-natal events, undernutrition, neonatal jaundice, and incomplete vaccination (Abuga et al., 2021; Kumar et al., 2022). Additionally, cultural beliefs in some societies attribute certain neurological conditions to supernatural causes or as punishment for parental crimes or abominations (Eseigbe et al., 2015; Bakare, 2020). These disorders in children often manifest as impairments in physical, memory, motor, language, and cognitive functioning, leading to chronic problems (Kumar et al., 2022). There is evidence to suggest that neurological disorders among children are growing in Africa as demonstrated in a study by Wilmshurst, et al (2016) that examined the prevalence of neurodevelopmental disorders in a rural Kenyan population and found a high prevalence of neurological disorders among children.

In a 2017 survey by the African Child Neurology Association (ACNA; 2020), it was found that there has been a significant rise in neurologic conditions among children compared to previous decades. This underscores the pressing need for enhanced healthcare services, specialized training, and public awareness efforts. The World Health Organization (WHO, 2018) stated that neurological disorders, including epilepsy and developmental issues, are major causes of disability in Africa. The report stressed early detection, proper treatment, and support systems to better the lives of affected children. These studies again highlight the increasing prevalence of neurological disorders in African children, necessitating improved healthcare, awareness campaigns, and targeted interventions. However, the perceived causes, effects and coping experiences of caregivers for children with these disorders remain insufficiently explored. This study, hence, explored the perceived causes of the condition, the effects and coping strategies among caregivers caring for children with neurological disorders in Lagos, Nigeria.

Caring for children with neurological disorders affects not only the child but also the caregivers (Abdullahi & Isah, 2020; Vadivelan et al., 2020; Ammann-Schnell et al., 2021), resulting in caregiver burden. This refers to stress and psychological symptoms experienced by family members caring for those with disabilities (American Psychological Association, 2020). Parents of such children face higher stress, anxiety, depressive symptoms, and stigmatization compared to those with typically developing children ((Masulani-Mwale et al, 2016; Ashworth et al., 2019; Rani & Thomas, 2019; Davis et al., 2021; Larkin et al., 2021). Studies show that neurological impairments demand significant care from parents (Feinstein et al., 2020). Caregivers face challenges like treatment uncertainty, acting as informal healthcare providers, limited social support, treatment abandonment, and emotional exhaustion (Kozłowska et al., 2021; Taib et al., 2021; Adejoh et al., 2021; De Clercq et al., 2022). Moreover, managing children with neurological impairments causes financial stress due to limited resources and multiple responsibilities (Obembe et al., 2019; Liu et al., 2020).

Consequently, caregivers often employ problem-focused, active emotion, and avoidant emotion coping strategies, which involve cognitive and behavioral efforts to manage the demands that exceed their available resources (Taib et al., 2021; Ezeonu et al., 2021). While previous studies have explored these coping mechanisms, there is a paucity of data focusing on Nigeria and the Sub-Saharan Africa region, with existing literature primarily relying on quantitative methods (Abdel Malek et al., 2020).

Methods

To properly describe the lived experiences of caregivers of children with neurological disorders (Olorunlana et al., 2018; Neubauer et al., 2019), the study utilized the phenomenological design. Phenomenological design is a qualitative research approach that builds on the assumption that the universal essence of phenomenon ultimately depends on how its audience experiences it (Adula & Kant, 2022). It seeks to explain the nature of things through the way people experience them. This approach highlights the specifics of caregiving and identifies children's neurological disorders as perceived by caregivers in caregiving situation, by so doing extracting the purest data from the research. In answering the study's research questions, we were guided by some of the underlining assumptions and major questions of the approach which are: 1. Subjective experience: i.e., what are the subject's experiences related to the phenomenon? 2. Intentionality and construction of meaning rather than generalizability or objective truths: i.e., what factors have influenced the experience of the phenomenon?

The research was conducted in two facilities (Benola Cerebral Palsy Initiative and Lagos University Teaching Hospital, Idi Araba) located in Lagos, Nigeria, which specializes in the treatment and care of children with neurological disorders. The participants consisted of caregivers who were visiting these facilities for the treatment and care of their children. They included eighteen females and three male caregivers, with eight patients having Cerebral Palsy, three having Hydrocephalus, three having Jaundice, two having Down syndrome, two having Autism, one having Epilepsy, one having Seizure, and one having Spinal Deformation. Verbal consent was obtained from the participants, and a total of twenty-one caregivers agreed to participate in face-to-face interviews. The interviews were conducted using a semi-structured in-depth interview guide to ensure consistency and allow for open-ended responses. The interviews aimed to gather rich and detailed information about the caregivers' experiences. The data collected from the interviews were analyzed using NVivo 12, a qualitative data analysis software. Thematic analysis was employed to identify recurring patterns and themes within the data. Three overarching themes were identified, and each theme was further divided into sub-themes to provide a comprehensive understanding of the caregivers' experiences.

To ensure ethical considerations, the study obtained approval from the institution's ethical board before conducting the research, with ethical approval number ADM/DCST/HREC/APP/3134. Informed consent was obtained from each participant, and their participation in the study was entirely voluntary. Confidentiality and anonymity of the participants' information were maintained throughout the research process.

Results

Sociodemographic profile of research subjects

Table 1: Sociodemographic profile of the participants

S/N	Age and sex of participants	Number of children with neurological problems	Neurological problems experienced by the child
1	47 (Female)	1	Jaundice
2	55 (Female)	1	Cerebral palsy
3	47 (Female)	1	Cerebral palsy
4	69 (Female)	1	Jaundice
5	33 (Female)	1	Seizure
6	35 (Male)	1	Jaundice
7	33 (Female)	1	Cerebral palsy
8	48 (Female)	1	Cerebral palsy
9	36(Female)	1	Autism
10	40(Female)	1	Cerebral palsy
11	38(Male)	1	Cerebral palsy
12	35(Female)	1	Cerebral palsy
13	41 (Female)	1	Autism
14	39 (Female)	1	Down syndrome
15	45 (Male)	1	Down syndrome
16	32 (Female)	1	Epilepsy
17	37 (Female)	1	Hydrocephalus
18	43 (Female)	1	Cerebral palsy
19	38 (Female)	1	Hydrocephalus
20	40 (Female)	1	Hydrocephalus
21	36 (Female)	1	Spinal deformation

Causes of neurological disorder

Some caregivers could not identify the causes of their child's neurological disorder; for some, it was because of medical complications during pregnancy, at delivery and after birth. Some caregivers identified accidents during pregnancy, delayed delivery, and nonchalant attitude of medical personnel during or after delivery as the causes of their child's neurological disorder.

Some caregivers were unaware of what led their children to develop neurological disorders. In other words, the causes are unclear to them, as seen in some of their statements: *I am not so sure of the cause since it occurred after birth* (Parent 20 Female Age 40); *I do not know (pause) I do not know* (Parent 5 Female Age 33).

Medical complications during pregnancy, at delivery and after birth

Some other caregivers attributed the causes of neurological disorders to medical complications during pregnancy, delivery and after birth. Such complications included a baby with undiagnosed jaundice at birth, genetic disorder, meningitis and other infections during pregnancy, including tetanus, convulsion and mucus and blood discharges.

A caregiver attributed the child's neurological disorder to how the child had jaundice without her noticing it, and even the nurse on duty could not detect it. When eventually detected, it caused damage to the child.

So, when he was about to be discharged but around 1A.M, this boy developed severe jaundice. No Doctor or any Nurse around. The condition was escalating. The brain was totally damaged even some of my people said I should kill the boy... (Parent 4 Female Age 69).

To another caregiver, she stated that late pregnancy or pregnancy in older age and low birth weight were identified as the cause of the child's health condition.

My husband and I were a little old when we had her; the doctors said her low birth weight caused it. When we noticed her social difficulties when she was young, I think she was almost three years old and thought it was shyness, but after a while, we noticed it affected communication and speech too. She was poor with eye contact, always anxious, and sensitive to sounds, repeating movements, words and actions. After careful monitoring, we took her to the hospital; they did a lab and imaging tests. We were referred to a clinical psychologist and neurologist and saw a speech therapist; she was diagnosed with autism and undergoing therapy there (Parent 13 Female Age 41).

Some caregivers attributed the child's health condition to a genetic disorder that causes developmental delay and intellectual disability.

...with what we got from the doctors, it can happen when a person has extra genetic cells that are more than 21 chromosomes. This causes developmental delay and intellectual disability; you know those things (Parent 15 Male Age 45).

Caregivers also recalled that they were told that meningitis, infections during pregnancy and tetanus were the causes of neurological disorders in their child. 'According to doctors, I was told that meningitis, infection during pregnancies, usually cause it' (Parent 18 Female Age 43)

I gave birth to him on December 4, 1999, at a hospital at Ajegunle-Apapa. After the delivery, I was told he had tetanus. So, they treated him, but after a year, he had a convulsion and was discharging mucus and blood. We were directed to LUTH, and they told us to do an EGG test when we got there. We did the EGG test at a hospital in Yaba. The rest of the test shows that he has cerebral palsy. Since then, we have been taking him to a psychiatric hospital, Yaba. He is on medication such as Tegretol, epilim and co-Diovan (Parent 3 Female Age 47).

Delayed delivery

Caregivers recalled their experiences during delivery, and some attributed the child's health condition to delayed delivery.

I cannot say precisely the cause of the illness. The only thing I can say is that the baby's delivery was delayed, and by the time I delivered the baby, I was told he was tired and could not cry very well. So, they treated him, and three days later, he started crying, but after another three days, he could not cry again. We took him to the hospital again, he was treated, and we were told he was okay. After a period when a child was supposed to be able to sit down on his own, he could not sit down (Parent 7 Female Age 33).

The nonchalant attitude of medical personnel during or after delivery

Caregivers identified the nonchalant attitude of medical personnel, including inadequate care of the baby immediately after delivery and paying close monitoring before delivery.

Exactly, so I also understood that that could have also affected the baby, so when she came out, of course, Nigeria mentally, they left the baby, they were on me, they were more on me the mother, they did not pay much attention on her, they were trying to resuscitate me back, but umm as a mother, I was always disturbing that this baby was not sucking, she was not sucking, bring my baby, I want to see my baby but of course, the woman would say calm down, calm (Parent 1 Female Age 47).

Effects of caring for children with neurological disorder on caregivers

Caregivers identified the effects of a child's neurological disorder to include frustration, conflict and argument, financial stress and impacting their businesses and mental and emotional health, impacting work schedule, family time and business.

Frustration, conflicts, arguments and bitterness

Caregivers often get into arguments and conflicts about how best to care for the child and, most importantly, the ongoing expenses of the father.

My husband gets frustrated sometimes and brings up conversations of an uncle or aunt that wants to take our child to a traditional doctor or a prophet somewhere. This causes severe arguments between us sometimes (Parent 17 Female Age 37).

... The constant pestering for money gets to my husband and weighs him down, and in turn, he shouts at me as if the child is not ours. We are working on living in peace and looking for a better and lasting solution (Parent 20 Female Age 40).

Financial stress and impacting business

Caregivers clearly stated how and what money is spent on most of the time, including physiotherapy and other treatment. The financial strain has negatively impacted those with businesses and other forms of responsibilities within the household.

Caring for a child with a neurological disorder cannot be compared to caring for an average child with a brief illness. I must keep spending on different needs to make him feel part of this world. The physiotherapy bills, all those other things he needs, bills are

not something I would say I think about, and I am happy, and this is because it affects some other aspects of the household like paying the electricity bills and more, but my wife has been beneficial with some bills. I have been spending a lot regarding my son's condition, which has weighed on my business sometimes, but I do not have an option. I must keep paying for treatment because he is my son, and I cannot change that. I will always love him regardless of his condition (Parent 11 Male Age 38).

Well, it has affected my family financially and made everyone so unhappy. It is sad. As I said, the illness had stripped us of the little income we make due to frequent hospital visits (Parent 18 Female Age 43).

The mental and emotional stress on caregivers

Caregivers demonstrated the impact of caregiving on their mental health as some would cry at times, get angry, feel traumatised, unable to sleep well and feel stigmatised and depressed.

It is not a bed of roses, but it has been okay. Sometimes we struggle, and sometimes I find myself crying or just getting angry for no reason, but we thank God (Parent 5 Female Age 33).

Then the emotional and physical stress combined with bathing and feeding him. He can sit on his own, but he cannot crawl or walk, so we have to carry him sometimes if we cannot use his wheelchair, which is very hard on us (Parent 10 Female Age 40).

It is traumatic to see my child in constant pain; it has not been emotionally balanced for me. Not being able to take my child home, the thought that anything can happen at any time is a constant struggle waking up and sleeping in the hospital (Parent 18 Female Age 43).

Stigma is psychological; it stresses me mentally, knowing my child goes through so much already and is still stigmatised. Expenses, it is expensive to get drugs and pay bills (Parent 19 Female Age 38).

Caregivers' employment schedule and freedom of time

Caregivers complained about the burden of care on their work schedule, as spouses run shifts to care for the child at a particular time during working hours. Some of the issues identified were absenteeism, getting to work late, and even having to resign to care for the child.

It has not been easy, I tell you, it has not been easy most significantly for me, for both of us, for our working pattern, if I have to get a job, someone has to be at home, if he has to work, I have to be at home, so that one too is an issue (Parent 1 Female Age 47).

You know, in Nigeria, you have to hustle, have your shop, and do advertisements, but with this kind of child, you cannot carry her around. Even in a commercial bus, when you sit with somebody with a child like this, fellow passengers start moving away from you. So, it affects me. It makes me not to have freedom of my own because I really want to take care of her knowing that nobody can take care of her for me (Parent 2 Female Age, 55).

I have not been at work since Wednesday (*today is Friday*), although my husband had to go on Thursday. I have not gone to work because they know my child is not well, so they understand (Parent 12 Female Age, 35).

Well, it is just me (yes). Well, my life has been on hold since April. I was promoted at work on May 1; she fell sick on April 26. I was still going to work thinking her illness would not be severe, but by the second week of May, she was not getting any better; she was still in ICU. Then, it dawned on me that it was not a minor issue, so I had to resign on May 20. She was in the ICU for 116 days (Parent 16 Female Age, 32).

Less time for the rest of the family members

In addition to the deleterious effect of care burden on the work and businesses of caregivers, it also impacts other family members as much time is devoted to the child with the neurological disorder.

We do not have time for ourselves as one of us would have to see to our child's welfare. Caring for our child has enormously impacted our family because most of our time is spent caring for our son (Parent 14 Female Age 39).

We hardly have time to spend together as a family with other kids. She requires attention most times, and even when we return from a long day's work, she is still the first point of call before anything else (Parent 21 Female Age 36).

Most of the challenges faced in managing my child's condition are lack of personal time. (Parent 9 Female Age 36)

Caring for our child also takes a toll on our other children as we do not spend enough time with them. Also, a lack of social life for ourselves is a challenge (Parent 15 Male Age 45).

Copying with financial demands

Caregivers were able to cope with the financial demands for the treatment and maintenance of the child through personal efforts, forgoing feeding in the house, help from another sibling, selling off personal properties and depending on God's continued provisions.

It has been so expensive to cater for his medical bills; sometimes, I get help from my siblings. As you can see, when you first came, you met my sister here instead of me because I had to work (Parent 19 Female Age 38).

All these things cost money. To cater for the private physiotherapy in my house twice a week, I had to sell everything, including my wedding ring, just to take care of the child (Parent 8 Female Age 48).

The main challenge is funding. See now. At the time, I did not have food to eat to take care of this child. My child in America has been helping me even though I was in the civil service for 35 years (Parent 4 Female Age 69).

Stronger bond between spouses

Caregivers' experience shows that the child's health condition brought a stronger bond between the spouses.

Ah, no, not at all; we are closer than ever because this is our first child. We are both new to this experience, and we know there is nothing we can do to change it. We know that our child will be unique from other children; he will take time to walk, talk and do other things and to us, that one is okay. We do not mind. We are in this together (Parent 12 Female Age 35).

Hmm, well, in this case, there was a problem in the beginning. It was all new to both of us, and I thought passing the blame towards one another could ease the pain we both felt, but that was all in the past. We both understand the situation was not our fault, and we love him so much (Parent 10 Female Age 40).

Discussion

This study aimed to explore the experiences of caregivers regarding the perceived causes of neurological disorders, the effects on caregivers and coping mechanisms employed in Lagos, Nigeria. The study identified various types of neurological disorders experienced by children, such as jaundice, cerebral palsy, seizure, autism, Down syndrome, epilepsy, hydrocephalus, and spinal deformation. A similar study conducted in Shagamu, Ogun State, Nigeria, identified over 4,476 outpatient children with different degrees of neurological conditions, exhibiting cognitive decline, language delays, and poor motor and social skills (Akodu et al., 2022; Sakihara et al., 2023).

Caregivers in this study perceived the causes of neurological disorders to be related to medical complications during pregnancy, delivery, and the postnatal period. These perceptions align with scholarly views that highlight the impact of fetal susceptibility to environmental elements, toxin exposure, labour and delivery difficulties, genetic diseases, and infections on the manifestation of neurological disorders later in life (Mathiesen et al., 2021; Rani & Dhok, 2023). Other causes mentioned by caregivers included accidents during pregnancy, delayed delivery, and the indifferent attitude of medical personnel during or after delivery, which have not been extensively explored in the literature. However, some caregivers were unable to identify the specific cause of their child's neurological disorder, assuming it could be attributed to genetic diseases or infections, contrary to cultural beliefs that associate such disorders with supernatural or punitive causes (Eseigbe et al., 2015; Bakare, 2020).

The findings of this study revealed that caring for children with neurological disorders has negative impacts on parents and families. Managing children with severe impairments and behavioral difficulties significantly affects caregivers. Consistent with these findings, other scholars have identified significant risks of mental health problems, financial burdens, restricted family life and leisure, stress, lack of external support, and limited community recognition (Vadivelan et al., 2020; Ransmayr, 2021; Moosa-Tayob & Risenga, 2022). Caregivers expressed frustration, marital conflicts, and intermittent arguments about the best approach to providing care and mitigating the adverse effects of caring for a child with a neurological disorder. One caregiver expressed their emotional impact by saying, *"sometimes we struggle, and sometimes I find myself crying or just getting angry for no reason."* If appropriate coping mechanisms are not implemented, these emotional burdens can continue to affect caregivers.

Regarding time management between caregiving and employment, some caregivers attempted to balance both responsibilities by taking frequent absences from work. A participant affirmed: *“I have not been at work since Wednesday (today if Friday), ... they know my child is not well, so they understand”*. Another had to resign even though she just got promoted *“I was promoted at work 1st May; she fell sick on April 26... by the second week of May, ... I had to resign on May 20. She was in the ICU for 116 days.”* In some cases, caregivers were forced to resign from their jobs, even after receiving promotions, due to the demands of caring for their child's neurological disorder. This finding aligns with other studies that have shown that families of children with special healthcare needs often forego employment, and caring for children with disabilities negatively affects mothers' labour market participation, working hours, and income (Foster et al., 2021; Wondemu et al., 2022).

The study identified coping strategies employed by caregivers after identifying major challenges, with financial challenges being a significant factor. Participants expressed the impact of financial burdens on other aspects of their household, but they managed to cope through personal efforts, support from family members, selling personal belongings, and developing stronger resilience. According to a participant, *“bills are not something I would say I think about, and I am happy, and this is because it affects some other aspects of the household ...”* These findings are consistent with previous research by Taib et al. (2021), which highlighted coping strategies such as finding the right support person, managing a high workload, and balancing home and work difficulties. Similarly, Iacob et al. (2020) emphasized the role of resilience among caregivers. However, Abrams et al. (2019) suggested that family and friends may struggle to comprehend the demands of caregiver.

Conclusion

In conclusion, this study illuminates the causes, consequences, and coping strategies among caregivers of children with neurological disorders in Lagos, Nigeria. The research highlights factors contributing to these disorders, encompassing medical complications during pregnancy, genetic disorders, and infections. Caregivers endure substantial challenges including financial strain, familial conflicts, and emotional challenges. Caregiving responsibilities have an impact on employment and time freedom. Caregivers can benefit from a variety of coping strategies such as problem-focused, active emotion, and avoidant emotion coping. This research enriches existing literature by delving into the underexplored experiences of Sub-Saharan Africa's caregivers, using a phenomenological approach. These insights can shape improved support and interventions for caregivers. Comprehensive aid, encompassing finances, healthcare, and psychological backing, is essential. Awareness and stigma reduction are crucial. The study extends knowledge on pediatric neurological disorders, caregiving, and coping strategies in Lagos and Sub-Saharan Africa. Its implications span healthcare, policy, and support systems. Further research avenues emerge: a longitudinal study for enduring effects, a comparative study with typically developing children, and interventions to gauge effectiveness. These avenues address gaps in understanding causes, impacts, coping, and support, contributing to enhanced caregiver well-being and targeted interventions.

Authors' contributions

	<i>Author</i>	<i>Authors' Contribution</i>
1	<i>Samuel Ojima Adejoh</i>	<i>15%</i>
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References

- Abdullahi, A. and Isah, A. (2020). Caregiver's perspectives on facilitators and barriers of active participation in cerebral palsy rehabilitation in Northwest Nigeria: a qualitative study. *BMC Health Serv Res.* 20, 615. <https://doi.org/10.1186/s12913-020-05487-w>.
- Abrams, H. R., Leeds, H. S., Russell, H. V., and Hellsten, M. B. (2019). Factors influencing family burden in pediatric hematology/oncology encounters. *Journal of Patient-Centered Research and Reviews*, 6(4), 243.
- Abuga, J. A. Kariuki, S. M., Abubakar, A., Nyundo, C., Kinyanjui, S. M., Van Hensbroek, M.B., Newton, C.R. (2021). Neurological impairment and disability in children in rural Kenya. *Developmental Medicine & Child Neurology*, 64: 347–356.
- Adejoh, S.O., Boele, F., Akeju, D., et al. (2021). The role, impact, and support of informal caregivers in the delivery of palliative care for patients with advanced cancer: A multi-country qualitative study. *Palliative Medicine*. 35(3):552-562. doi:10.1177/0269216320974925
- Adula, M., & Kant, S. (2022). Interpretative Phenomenological Perceptual Study of Women Entrepreneurs Facing Challenges in Entrepreneurial Activity in the Horn of Africa. *Journal of Entrepreneurship, Management, and Innovation*, 4(2), 321 - 335. <https://doi.org/10.52633/jemi.v4i2.154>
- Akodu, O.S., Ogunlesi, T.A., Adekanmbi, A.F., Gbadebo, F.A. (2022). Neurological diseases at the pediatric neurology clinic in a semi-urban Nigerian tertiary hospital. *Sudan J Paediatr.* 22(1):83-89. doi: 10.24911/SJP.106-1588669565. PMID: 35958080; PMCID: PMC9361490.
- American Psychological Association. (2022). Caregivers burden. <https://dictionary.apa.org/caregiver-burden>.
- Ammann-Schnell, L., Groeschel, S., Kehrer, C. Frolich, S. and Krageloh-Mann, I. (2021). The impact of severe rare chronic neurological disease in childhood on the quality of life of families—a Study on MLD and PCH2. *Orphanet Journal of Rare Diseases*, 16(211): 1-16.
- Ashworth, M., Palikara, O., Van Herwegen, J. (2019). Comparing parental stress of children with neurodevelopmental disorders: The case of williams syndrome, down syndrome and autism spectrum disorders. *J Appl Res Intellect Disabil.* 2019;32(5):1047-1057. DOI: 10.1111/jar.12594. Epub. PMID: 30950174.
- Bakare, M. (2020). Community perception about children with hydrocephalus in Lagos State, Nigeria. *The Nigerian Journal of Sociology and Anthropology* 18(1): 148-164. DOI: 10.36108/NJSA/0202/81(0101).
- De Clercq, L.E., Prinzie, P., Warreyn, P., Soenens, B., Dieleman, L.M., De Pauw, S.S.W. (2022). Expressed emotion in families of children with and without autism spectrum disorder, cerebral palsy and down syndrome: relations with parenting stress and parenting behaviors. *J Autism Dev Disord.* 52(4):1789-1806. DOI: 10.1007/s10803-021-05075-9.
- Eseigbe, E.E., Enogela, J., Adama, S.J., Nuhu, F.T., Sheikh, T.L., Eseigbe, P. (2015). Perspectives of mothers on childhood epilepsy in Kaduna, Northern Nigeria. *Sub-Saharan Afr J Med.* 2:39-46. DOI: 10.4103/2384-5147.150470.
- Ezeonu, C.T., Obu, D.C., Daniyan, O.W., Asiegbu, U.V., Oyim-Elechi, O., Edafioghor, L.O., Okoro, K.J. (2021). Coping strategies of caregivers of persons with a disability attending a special education Center in Abakaliki, Southeast Nigeria: a cross-sectional study. *Pan Afr Med J.* 18;39: 249. DOI: 10.11604/pamj.2021.39.249.26884. PMID: 34659622; PMCID: PMC8498670.

- Feinstein, J. A., Feudtner, C., Blackmer, A. B., Valuck, R. J., Fairclough, D. L., Holstein, J., Gregoire, L., Samay, S., & Kempe, A. (2020). Parent-reported symptoms and medications used among children with severe neurological impairment. *JAMA network open*, 3(12), e2029082. <https://doi.org/10.1001/jamanetworkopen.2020.29082>
- Foster, C.C., Chorniy, A., Kwon, S., Kan, K., Heard-Garris, N., Davis, M. M. (2021). Children with special health care needs and forgone family employment. *Pediatrics*. 148(3): e2020035378. doi: 10.1542/peds.2020-035378. PMID: 34433691; PMCID: PMC9219960.
- Iacob, C.I., Avram, E., Cojocaru, D., & Podina, I.R. (2020). Resilience in familial caregivers of children with developmental disabilities: A meta-analysis. *Journal of Autism and Developmental Disorders*, 50(11), 4053-4068.
- Kozłowska, K., Sawchuk, T., Waugh, J.L., Helgeland, H., Baker, J., Scher, S., Fobian, A.D. (2021). Changing the culture of care for children and adolescents with functional neurological disorder, *Epilepsy & Behavior Reports*, 16,2021,100486, ISSN 2589-9864,<https://doi.org/10.1016/j.ebr.2021.100486>.
- Kumar, G., Sharma, V., Kumar, A. (2022). Clinical profile of pediatric neurology disorders: a study from a semi-urban medical college in northwestern India. *Cureus* 14(10): e30359. doi:10.7759/cureus.30359.
- Larkin, F., Hayiou-Thomas, M.E., Arshad, Z., Leonard, M., Williams, F.J., Katseniou, N., Malouta, R.N., Marshall, C.R.P., Diamantopoulou, M., Tang, E., Mani, S., Meins, E. (2021). Mind-Mindedness and stress in parents of children with developmental disorders. *J Autism Dev Disord*. 51(2):600-612. DOI: 10.1007/s10803-020-04570-9.
- Liu, Z., Heffernan, C., & Tan, J. (2020). Caregiver burden: a concept analysis. *International journal of nursing sciences*, 7(4), 438–445. <https://doi.org/10.1016/j.ijnss.2020.07.012>.
- Malek, S.A., Rosenbaum, P., Gorter, J.W. (2020). Perspectives on cerebral palsy in Africa: Exploring the literature through the lens of the International Classification of Functioning, Disability and Health. *Child Care Health Dev*. 46: 175– 186. <https://doi.org/10.1111/cch.12733>
- Masulani-Mwale, C, Mathanga, D, Silungwe, D, Kauye, F & Gladstone., M, 2016. Parenting children with intellectual disabilities in Malawi: the impact that reaches beyond coping? <https://doi.org/10.1111/cch.12368>
- Mathiesen, L., Buerki-Thurnherr, T., Pastushek, J., Aengenheister, L., Knudsen, L.E. (2021). Fetal exposure to environmental chemicals; insights from placental perfusion studies. *Placenta*. 2021; 106:58–66.
- Moosa-Tayob, S., Risenga, P.R. (2022). Challenges of caregivers providing care to children with disabilities at non-governmental organisations in Tshwane townships, South Africa. *Afr J Disabil*. 28;11:930. doi: 10.4102/ajod.v11i0.930. PMID: 35936924; PMCID: PMC9350488.
- Neubauer, B.E., Witkop, C.T., Varpio, L. (2019). How phenomenology can help us learn from the experiences of others. *Perspect Med Educ*. 8(2):90-97. doi: 10.1007/s40037-019-0509-2. PMID: 30953335; PMCID: PMC6468135.
- Obembe, O.B., Adeyemo, S., Ogun, O.C., Ijarogbe, G.T. (2019). The relationship between coping styles and depression among caregivers of children with cerebral palsy in Nigeria, West Africa. *Arch. Clin. Psychiatry*, 46(6):145-150. <https://doi.org/10.1590/0101-60830000000215>.
- Olagbegi, O. M., Orekoya, K., Adekunle, M., Oyewole, O. O., Adepoju, M., & Soetan, O. (2021). Burden and quality of life of informal caregivers of children with cerebral palsy. *Rev. RENE.*, 22(1), 1–9. <https://doi.org/10.15253/2175-6783.20212261752>

- Olagunju, A.T., Bioku, A.A., Ohaeri, J.U., Oluwaniyi, S.O, Li, A., Olagunju, T.O. et al. (2021). A comparative study of perceived burden in parent caregivers of adolescents with epilepsy in a resource-restricted setting: investigating the explanatory factors of perceived burden. *Epilepsy & Behavior*;120, 107992. <https://doi.org/10.1016/j.yebeh.2021.107992>
- Olorunlana, A., Igharo, M.A., and Mark, D.O. (2018). Basics of research designs. In Nwaodu, NO, Ijeoma, EOC, Nzewi, O and Wande, BP (eds.), *Research Methodology in Behavioural Science and Law: A Symbiosis*. South Africa: University of Fort Hare Press, pp. 16–37.
- Rani, A., and Thomas, P.T. (2019). Stress and perceived stigma among parents of children with epilepsy. *Neurological Sciences* 40(7):1363-1370. doi: 10.1007/s10072-019-03822-6. Epub. PMID: 30903416; PMCID: PMC6579768.
- Rani, P., and Dhok, A. (2023). Effects of pollution on pregnancy and infants. *Cureus*. 18;15(1):e33906. doi: 10.7759/cureus.33906. PMID: 36819435; PMCID: PMC9937639.
- Ransmayr, G. (2021). Challenges of caregiving to neurological patients. *Wien Med Wochenschr* 171, 282–288. <https://doi.org/10.1007/s10354-021-00844-8>.
- Sakihara, K., Kita, Y., Suzuki, K., Inagaki, M. (2023). Modulation effects of the intact motor skills on the relationship between social skills and motion perceptions in children with autism spectrum disorder: A pilot study, *Brain and Development*. 45(1):39-48,ISSN 0387-7604, <https://doi.org/10.1016/j.braindev.2022.09.001>.
- Taib, F., Beng, K.T., Chan, L.C. (2021). The challenges, coping mechanisms, and the needs of the in-hospital parents caring for children with life-limiting neurological disorders: A qualitative study. *Indian L Palliat Care*; 27:483-9
- Vadivelan, K., Sekar, P., Sruthi, S.S., Gopichandran, V. (2020). Burden of caregivers of children with cerebral palsy: An intersectional analysis of gender, poverty, stigma, and public policy. *BMC Public Health* 20, 645. <https://doi.org/10.1186/s12889-020-08808-0>
- Wondemu, M.Y., Joranger, P., Hermansen, Å. et al. (2022). Impact of child disability on parental employment and labour income: A quasi-experimental study of parents of children with disabilities in Norway. *BMC Public Health* 22, 1813. <https://doi.org/10.1186/s12889-022-14195-5>.