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Prevalence and Parental Psychological Burden of Cerebral Palsy in the Paediatric Population Consulting at the Buea and Limbe Regional Hospitals

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ABSTRACT

***Background**: Cerebral palsy (CP) is the most common physical disability of childhood, and the resulting disability varies from mild to total dependence. It is a lifelong condition that affects the individual, family and immediate community and requires time, energy and extensive resources which is a burden not only to the care givers but to the society.*

***Methods**: A hospital based cross-sectional study was conducted. The study took place at the Buea and Limbe Regional hospitals where medical records of children who are followed up were reviewed. The number of children who presented with cerebral palsy during the study period was obtained. Parents/caregiver of children with CP who have lived >3 months with their children were invited to come with their children to the hospital. Clinical and basic characteristics of the caregivers and patients were collected. The Zarit-Caregiver-Burden-Scale (Zarit-CBS), General Health Questionnaire (GHQ-28), Patient Depression Questionnaire (PHQ-9), and the GAD (GAD-7) Score were used to measure outcome variables. Data were then analysed using SPSS software version 29.*

***Results:** A total of 120 children presented with CP during the study duration with an overall prevalence of CP at BRH and LRH of 0.6% (0.59% and 0.62% respectively), and a male predominance of 60%. Out of them, 49 accepted to participate in the study. Birth asphyxia (46.9%), neonatal infection (44.9%) and maternal chronic disease (30.6%), were the main predisposing factors. Bilateral Spastic CP (67.4%) was the predominant clinical presentation and speech delay, (83.3%) the main associated comorbidity. Most of the parents (42.9%) experienced severe burden with respect to care. About half (51.0%) of them had a psychological disorder with the General Health Questionnaire (GHQ-28) and up to 10.2% had moderately severe depression with a Patient Depression Questionnaire (PHQ-9). Moderate generalised anxiety disorder (GAD) with GAD – 7 score between 10 and 14 was found in 28.6%.*

***Conclusion:** The prevalence of CP was relatively low at BRH and LRH and caregivers are greatly affected psychologically by the condition of their children and by the act of caring for their children, revealed by the results on depression and anxiety.*

Keywords
Cerebral palsy, Prevalence, Parental burden, Psychological impact, Zarit Burden Score.

Background
The term "cerebral paralysis" (CP) was used for the first time more than 170 years ago, by the English orthopaedic surgeon William Little, who correlated a difficult labour and neonatal hypoxia with limb spasticity and consequential musculoskeletal deformities [1]. According to a recent definition, CP describes a group of permanent disorders of the development, of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. These motor disorders are often accompanied by disturbances of sensation, perception, cognition, communication, epileptic seizures, and by secondary musculoskeletal problems [2].

Globally, the prevalence of CP is reported as occurring in approximately 2-2.5 of 1000 live births [3] but, it has been found to be higher in Africa, with an estimated prevalence of 2–10 cases per 1 000 births [4]. In Cameroon, the prevalence varies between 4.8% - 20.4% [5-7] even though these studies were done in tertiary centres and the estimated national prevalence could not be obtained due to paucity of data.

The aetiologies of CP are multiple and can affect any part of the brain, thus contributing to the broad range of clinical findings. Approximately 92% of cases of CP are traced to the perinatal period and risk factors include preterm birth, perinatal infection, intrauterine growth restriction, acidosis or asphyxia, and multiple gestation, any of which can lead to brain injury. Fewer than 10% of cases are attributable to intrapartum hypoxia [8]. CP occurs at an older age in about 8% of patients, often from head injury or infection before the age of 2 years. Despite identification of risk factors, 80% of cases have no clear cause and are considered idiopathic [8]. In Cameroon, a study done in Yaounde revealed perinatal asphyxia as the main aetiology (70.1%) [5].

Despite the availability of trained personnel, the increase rate in the practice of caesarean section and the increase use of electronic foetal monitoring, the rate of CP remains quite constant in the western and keeps rising in Africa [9]. This is because the trained personnel are mostly found in Urban centres and due to socioeconomic diversity (e.g., poverty, large family size, cultural beliefs) permitting a smaller portion of the population to have access to basic obstetric and postnatal care [9]. This non reduction in the rate of CP may also be attributed to the increasing survival of the very preterm and very low birth weight infant secondary to improvements in neonatal and obstetric care [10].

Motor function disorders, which are the core symptoms, are frequently associated with paresis of the limbs, involuntary movements, as well as impaired balance and motor coordination [1,11]. The level of support a child with CP might require satisfying his biological and psychosocial needs depends on the severity of the disability and the limitation faced daily. The caregiver must therefore cope with the motor and sensory disabilities and implement a wide range of necessary interventions and rehabilitations.

This long-term responsibility for the disabled child frequently leads to negative emotions, such as anxiety and depression (sadness, anger and distress) experienced by the caregiver, and adversely affects the functioning of the parents and the entire family. The most common effects of long-lasting caregiving burden include anxiety and depressive disorders of varied intensity [11,12]. However, the intensity of anxiety and depressive symptoms in the parents is not related exclusively to factors associated with the child's disability, but is also linked to personal, social, economic and environmental variables resulting from the parents' needs and health status as well as factors occurring in the family; this fact reflects the multidimensional effects of these determinants in health-related quality of life (HRQOL) in individuals taking care of children with CP [11]. To address these issues, rehabilitation centres must be made available and must follow the Community-based Guidelines Matrix model of the WHO 2010 which is a multi-disciplinary approach. Unfortunately, these centres are not widely available in developing countries, and when available, most do not adhere to the recommended practices in the care of children with cerebral palsy and most parents cannot afford the cost of these centers. So, this will cause must caregivers to bear the burden of care of these children which has a huge impact on their quality of life. This study then aimed to determine the prevalence of CP in BRH and LRH and to assess how care of a child with CP could affect one's life and psychological health.

Materials and Methods
A hospital based cross sectional study was conducted in the paediatric units of the BRH and RHL from January 2024 to April 2024. It involved children aged between 3 months and 18 years who presented with cerebral palsy, from the 1st January 2017 to 31st December 2023 (7 years) obtained after the hospital records were reviewed and the parents of these children contacted by phone calls.

The RHL is the principal referral level hospital in the region and the BRH is the second referral level hospital in this region with each having at least one specialist in pediatrics, obstetrics and gynecology, internal medicine, and surgery. Apart from these specialists, there is a huge turnover of patients in these health facilities.

The study population was made up of children aged between 3months and 18 years diagnosed with CP and who were being followed up at LRH and BRH together with their parents. We included all parent/ child pair who presented with CP, within the age range, who were being followed in these hospitals and for whom the parent had taken atleast 3 months of direct caregiving. All parents of children with CP who do not live with their children and those who did not give their consent were excluded. The estimated sample size was 72 calculated using the Cochran formula. Administrative authorization was obtained from the

Regional Delegation of Public Health for the Southwest Region and the Directors of the health facilities involved in the study; of BRH and RHL. After obtaining authorization, the hospital registers were reviewed from 2017 to 2023 to obtain the list of children who presented with cerebral palsy and to obtain the phone number of the parents. Parents of children living with CP were contacted and invited to come with their children to BRH and LRH for a free routine consultation where they were examined by a paediatrician. A questionnaire designed for the study was used to collect socio-demographic, clinical, para clinical data for each parent/child pair after clearly explaining the objectives of the study and obtaining consent. The questionnaire consisted of two sections. The first section was on the disease characteristics of CP and had the child's socio-demographic information such as age, sex, place of birth, place of residence; the history of the pregnancy, birth history, mode of delivery, gestational age at birth, birth weight, other medical problems, occurrence of harmful events during or after birth, assessment of mobility and fine motor control derived from Surveillance of Cerebral Palsy in Europe (SCPE) guidelines which was adapted to the local context in order to assess the clinical subtypes. The existence of comorbidity was also determined.

The second section focused on the impact of caregiving on the parents and had two parts: the first part covered the socio-demographic information of the parents and included the age, sex, level of education, marital status, occupation, income, number in the family and type of family.

The second part focused on the psychological burden. It evaluated the psychological outcome (mental health) of parents of CP children. Data were obtained via face-to-face interviews using scores. *Zarit-Caregiver-Burden-Scale (Zarit-CBS)* which is a caregiver self-report measure where they are asked to indicate the extent of burden experienced while providing care to their relative. It contains 12 items. Each item on the interview is a statement which the caregiver is asked to endorse using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always). *The General Health Questionnaire-28 (GHQ-28),* which is a screening device for identifying minor psychiatric disorders in the general population and within community or non-psychiatric clinical settings such as primary care or general medical out-patients. Four subscales somatic symptoms, anxiety and sleeplessness, social dysfunction, and severe depression make up the shorter, 28-item GHQ that was developed by Goldberg & Hillier. It assesses the respondent's current state and asks if that differs from his or her usual state. *Patient Health Questionnaire-9 (PHQ-9),* which is a multipurpose instrument for screening, diagnosing, monitoring and measuring the severity of depression. *Generalized Anxiety Disorder-7 (GAD-7)* test which is a diagnostic self-report scales for screening, diagnosis and severity assessment of anxiety disorder.

Parents completed the questionnaires individually, in the presence of the researcher. Before examination, they were given brief oral instructions on completing the questionnaire, and, in accordance with the need, they were given additional help (reading questions aloud, interpretation of questions or explanation of words that respondents did not understand).

Independent variables included: age, sex, gestational age at birth, birth weight, maternal chronic disease, alcohol consumption during pregnancy, peri-partum determinants, resuscitation at birth, congenital malformation, neonatal disease, post-natal disease, surgery, motive of consultation, associated morbidity and type of disability. The dependent variable were prevalence of cerebral palsy, parental psychological burden and mortality. Data collection ensured patient confidentiality. The data collected each day was coded and entered electronic data collection forms created with Google Form which reduced the workload at the end and ensured no missing data. The folder containing the data was safely protected with a password and placed in a confidential location known only to the researcher. The entered data was always double checked to avoid errors. Backup of data was performed daily to avoid loss of information. These data were processed and analysed using Microsoft Excel 2019 and Statistical Package for Social Sciences (SPSS) version 29. Frequencies and proportions were used for categorical variables whereas continuous variables were presented in terms of means and standard deviations. Results were illustrated using tables, histograms and pie charts.

Results

A total of 19902 patients were seen during the study period, of which 9515 patients were from LRH and 10387 were from BRH. Among them, 120 were diagnosed with CP giving a prevalence of 0.60% and among them forty-nine parent/child pair accepted to participate in the study.

Out of the 120 patients diagnosed with CP, 72 were males while 48 were females accounting for 60% and 40% respectively. 61 cases were from BRH with 37 males and 24 females, giving us a prevalence of 0.59% (i.e. a prevalence of 0.36% and 0.23% for males and females respectively). On the other hand, at LRH there was a total of 59 cases out of which 35 were males and 24 were females, hence, a prevalence of 0.62% (0.37% and 0.25% for males and females respectively) and an overall prevalence of 0.36% and 0.24% for males and females respectively as seen on Table 1.

Table 1: Prevalence of cerebral palsy per town and sex.

Characteristics		Frequency	Prevalence (%)
Patients consulted			
BRH		10387	52
LRH		9515	48
Total		19902	
Patients with CP			
BRH	Males	37	0.36
	Females	24	0.23
	Total	61	0.59
LRH	Males	35	0.37
	Female	24	0.25
	Total	59	0.62
Total		**120**	**0.60**

A total number of 49 parent/child pair with cerebral palsy

participated in the study, with their ages ranging from 5months – 132months (11years) with (mean ± SD: 53.04 ±32.160). Most (59.2%) of our participants were ≤5 years, majority (53.1%) were followed up at the Limbe Regional Hospital while most of them were born at the hospital (40.8%). The Socio-demographic characteristics of the children are illustrated on Table 2.

Table 2: Socio-demographic characteristics of children diagnosed with cerebral palsy.

Characteristics	Frequency (*n=49*)	Percentage (%)
Age groups (year)		
≤5	29	59.2
>5	20	40.8
Place of delivery		
Hospital	20	40.8
Private clinic	11	22.4
Health centre	16	32.7
Unknown (not specified)	2	4.1
Attending hospital		
LRH	26	53.1
BRH	**23**	**46.9**

Some number of risk factors of CP were found among mothers and children with CP who consulted at BRH and LRH. Maternal chronic disease (30.6%), advanced maternal age (16.3%) and alcohol consumption during pregnancy (20.4%) were the greatest maternal risk factors. We also had multiple pregnancies (6.1%) and genetic syndrome (2.0%). Antenatal causes included acute foetal distress (12.2%), premature rupture of membranes (12.2%) and microcephaly (10.2%). For the perinatal risk factors 46.9% of the children had birth asphyxia and were resuscitated at birth, 44.9% had neonatal infection, 22.4% jaundice, 22.4% deliveries through emergency caesarean section, preterm birth (20.4%), prolong labour (18.4%), post term birth (12.2%) and meconium aspiration (6.1%) were all significant perinatal risk factors. Post-natal disorders such as meningitis, head surgeries and severe malaria were the main postnatal risk factors and accounted for 8.2%, 4.1% and 4.1% respectively. The antenatal, perinatal and post-natal predisposing factors to cerebral palsy are summarised on Table 3. Majority of the children were born at term (67.3%), in a hospital (40.8%), through vaginal delivery (75.5%), with a 5- min APGAR score between 4 and 5 (30.6%). 67.3% had normal birth weights between 2500g - 4000g while 18.4% had less than 2500g and 14.3%, more than 4000g. Congenital malformation was present in 14.3% of children. Inability to sit (42.9%) was usually the very first complain followed by inability to walk (26.5%), then instability to keep neck upright (20.9%), convulsion (4.1%), or irritability (4.1%) and body stiffness (2.0).

Comorbidities included speech delay, (83.3%) orthopaedic deformities (62.5%), epilepsy (47.9%), behavioural disorders (18.7%), swallowing disorder (16.7%), under nutrition (16.7%), drooling (14.6%), respiratory congestion (14.6%), and visual impairments (6.2%) as illustrated in Figure 1. Bilateral spastic CP was predominantly diagnosed (67.4%) followed by ataxic CP (13.0%). Dyskinetic dystonic CP (8.7%) and Choreo-athetotic CP (4.3%) were next, then unilateral spastic CP (4.3%). The non-classifiable form was found in 2.2% of children. Some patients had also improved on their psychomotor development due to physiotherapy. Clinical forms of cerebral palsy are illustrated on Table 4. Out of these children, 10 of them had died during the study duration giving a case fatality rate of 8.3%.

Table 3: Predisposing factors to cerebral palsy amongst the paediatric population of BRH and LRH.

Characteristics	Frequency	Percentage (%)
Maternal risk factors		
Maternal chronic disease	15	30.6
Alcohol consumption	10	20.4
Advanced maternal age	8	16.3
Multiple pregnancies	3	6.1
Genetic syndrome	1	2.0
Ante-natal causes		
Acute foetal distress	6	12.2
Premature rupture of membranes	6	12.2
Microcephaly	5	10.2
Perinatal causes		
Asphyxia	23	46.9
Neonatal infection	22	44.9
Jaundice	11	22.4
Caesarean section	11	22.4
Preterm birth	10	20.4
Prolong labour	9	18.4
Post term birth	6	12.2
Meconium aspiration	3	6.1
Instrumental delivery	1	2.0
Post-natal causes		
Meningitis	4	8.2
Head surgery	2	4.1
Severe malaria	**2**	**4.1**

Table 4: Clinical forms of cerebral palsy at BRH and LRH.

CP Type	Subtype	Frequency (*n=46*)	Percentage (%)
Spastic CP	Bilateral	31	67.4
	Unilateral	2	4.3
Ataxic CP		6	13.0
Dyskinetic CP	Dystonic CP	4	8.7
	Choreo-athetotic CP	2	4.3
Non- classifyable		1	2.2

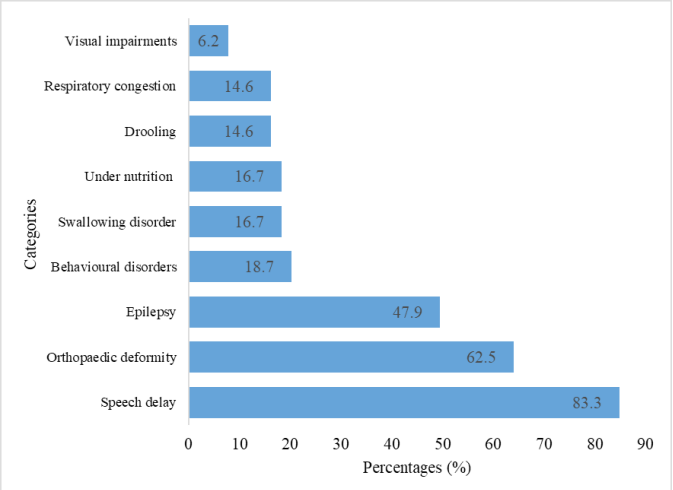

Figure 1: Comorbidities associated with cerebral palsy.

Majority (89.8%) of the parents/caregivers of these children were females, about half of them (59.2%) had ages ranging from 30-39 years with 67.3% being self – employed. One third (24.5%) were single, and 42.9% had attained the university level. 49.0% earned between 50.000 – 100.000 XAF per month while 30.6% earned less than 50.000 XAF per month. 44.9% had a family size of 4-5 people and 67.3% lived with the extended family (Table 5). A high burden of care was found in 42.9% of parents with CP children and 30.6% had mild to moderate burden. Half (51.0%) of the parents had psychological disorder with a GHQ-28 of >23 out of which about a third (30.6%) had mild depression with a PHQ-9 between 5 to 9 and 30.6% also had mild anxiety with a GAD-7 score of 5 to 9. Up to 28.6% suffered from moderate generalised anxiety disorder, while 10.2% had moderately severe depression (Table 6).

Table 5: Caregiver's socio-demographic characteristics.

Variables	Categories	Frequency (*n=49*)	Percentages (%)
Age group (years)	15-20	1	2.0
	21 – 29	10	20.4
	30 – 39	29	59.2
	>40	9	18.4
Sex	Males	5	10.2
	Females	44	89.8
Occupation	None	4	8.2
	Public sector	5	10.2
	Private sector	7	14.3
	Self employed	33	67.3
Marital status	Single	12	24.5
	Married	35	71.4
	Cohabitating	2	4.1
Level of education	Primary	10	20.4
	Secondary	18	36.7
	Tertiary	21	42.9
Income (XAF)	> 50k	15	30.6
	50k – 100 k	24	49.0
	100k – 200k	3	6.1
	>200k	7	14.3
Family size	3	3	6.1
	4 – 5	22	44.9
	6 – 7	16	32.7
	>7	8	16.3
Type of family	Nuclear	16	32.7
	Extended	33	67.3

Table 6: Parental psychological burden of cerebral palsy.

Variables	Categories	Frequency	Percentages (%)
Zarit-CBS	No to mild burden (0-10)	13	26.5
	Mild to moderate burden (10-20)	15	30.6
	High burden (>20)	21	42.9
GHQ-28	No psychological disorder (<23)	24	49.0
	Psychological disorder (>23)	25	51.0
PHQ-9	Minimal or none (0 – 4)	20	40.8
	Mild (5 – 9)	15	30.6
	Moderate (10 – 14)	9	18.4
	Moderately severe (15 – 19)	5	10.2
GAD-7 score	Minimal or none (<5)	18	36.7
	Mild (5 – 9)	15	30.6
	Moderate (10 – 14)	14	28.6
	Severe (>15)	2	4.1

Discussion

This study was made to determine the prevalence and parental psychological burden of cerebral palsy amongst children consulting at the BRH and LRH.

The overall prevalence of CP in these hospitals was 0.6% i.e., 0.59% and 0.62% for BRH and LRH respectively. This is lower than previous studies reported by Mangamba et al. (4.86%)[6] and far lower than that reported by Mbonda et al. (20.39%) [7] and Nguefack et al. (18.35%) [5] in other areas of Cameroon. This low prevalence can be explained by the fact that, these studies were carried out in first category hospitals which receives patients from all over the country and have specialised paediatric neurology services. Also, in the later studies the prevalence of CP was determined amongst the total number of children attending the child neurology clinic of the paediatric department of their study hospital, while we determined the prevalence using the total number of children attending all the paediatric units of both hospitals. This was to better appreciate the burden of cerebral palsy amongst all the other paediatric diseases. Contrary to the studies in Cameroon, the prevalence was close with Subasi et al., in Turkey [13] who had an incidence of 7.74/1000 children. This similarity can be explained by the fact that our studies were both carried out over a period of 7 years and in secondary hospitals. Most of the patients with CP were males (60%) which is in line with previous studies conducted in other areas of Cameroon [5-7] and in other African countries [14]. This gender-specific CP risk is mainly attributable to genetic, neurobiological, and hormonal differences between males and females. Evidence from experimental studies conducted with animals and adult patients diagnosed with stroke, outlined that sexual hormones, especially oestrogens, could protect against cerebral hypoxic/ischemic lesions [15]. Majority of our participants were less than 5 years (59.2%) with mean age of 53.04 (±32.160) months (4.42 years). This is similar to Moifo et al.,[16] where 77.4% of children were aged between 1 month and 5 years old. This corresponds to the age of clinical manifestation of neurodevelopmental delay and the parents are worried and tend to consult more. Also, older children with CP tend to be hidden from the society by their family due to shame of handicap. Amongst the parents, female made up 89.8% and within the age range of 30-39 years (59.2%). This is similar to a study done by Gugała et al., in Poland where 63.2% of participant where female [11]. This high female predominance can be explained by the fact that mothers spent more time with their children than fathers. In Cameroon, 54.9% of caregivers were less than 30 years in a study done by Ngeufack et al. in 2013 [5]. This difference can be explained by the fact that the children in our study were older than in his study.

This study aimed to increase social awareness by drawing attention to the preventable risk factors in the etiology of CP. Perinatal disorders like birth asphyxia, neonatal infections, and chronic maternal illness were predominant risk factors suggesting improved antenatal and perinatal care could improve outcomes. This is similar to that of other LMICs: Mangamba et al.,[6] had birth asphyxia in 55.1% of cases, jaundice in 32.8%, neonatal infection in 25.8% and maternal chronic disease was found in 3.0% of cases.

Moifo et al.,[16] had asphyxia and antenatal infections identified as leading risk factors accounting for 68.4% while Nguefack et al.,[5] found birth asphyxia in 70.1% of cases. Duke et al., in Nigeria had asphyxia as one of the major causes [14]. In Botswana on the other hand, neonatal infection was the predominant cause followed by birth asphyxia and maternal infection with HIV [17]. According to Bax et al.,[18] clinical factors correlated with CP were prematurity (45.2%), infections during pregnancy (39.5%) and multiple pregnancy (12%). Unlike in high income countries where the predominant risk factor is preterm birth [19], it was not the case in our study, where we recorded just 20.4% due to preterm birth. This is because, preterm birth account for the most common risk factor (43.5%) of neonatal mortality according by Njinkui et al.,[20] and the mortality rate of preterm admission was 31.8% according to a study done at LRH [21]. Meningitis accounted for the common cause of post-natal CP which was also described by Mangamba et al. [6] and Nguefack et al. [22], unlike in Nigeria and Benin where cerebral malaria was the main post-natal aetiology [14,23]. This difference can be accounted by the fact that in Cameroon, the treatment of malaria is free for children under five years and as CP may occur as a sequelae of cerebral malaria in younger children, this free treatments increased the number of hospitalisation of children with severe malaria as evidenced by a study done in the Buea health district by Nkwenti et al., in 2019 [24].

Bilateral spastic CP which is characterized by spasticity (velocity dependent increase in tone), hypereflexia, clonus, and Babinski reflex was the predominant clinical presentation (67.4%) followed by ataxic CP (13.0%). This spastic predominance is in accordance with literature and with other studies in Cameroon [6,7,16,22], in Benin [23], Uganda [25], Nigeria [14] and Asia [26]. In Benin, 67.5% had bilateral spastic CP and Duke et al., in Nigeria found bilateral spastic CP in 60.2% of cases followed by unilateral spastic CP in 39.8% then ataxic CP in 9.8% of cases. The high incidence of spastic CP could be explained by the predominance of birth asphyxia which, depending on its severity, creates lesions localized either in one cerebral hemisphere or spread across both hemispheres. Speech delay was the most frequent associated co-morbidity (83.3%) followed by orthopaedic deformities (62.5%). This is in line with some studies in Cameroon. Nguefack et al.[5], found speech delay in 63.4% of cases, epilepsy in in 57.5% and swallowing disorder in 55.2% of cases. Mangamba et al.,[6] had speech delay in 74.2%, epilepsy in 34.4%, and drooling in 33.3% but in contrast to a study in Turkey were epilepsy was the most common secondary accompanying problem [27].

This study also aimed to evaluate the psychological impact on parents in charge of children with CP. Caring for a child with cerebral palsy is associated with severe burden in 42.9% of parents. Most of the parents had psychological disorder (51.0%) ranging from mild to severe depression and anxiety. This is in correlation to a study carried out in Iraq where 49.3% of mothers caring for children with cerebral palsy experienced a high level of psychological burden [28]. Several sources of stress and anxiety such as financial burden, adverse health condition due to pain in the body as a result of caring, lack of social support and the burden of caring for a disabled child were identified in other African countries like Zambia [29], South Africa [4], and in India [30]. Emotional pain and depression were experienced by the majority of mothers in Zimbabwe as a result of having given birth to a child with CP and not clearly understanding the prognosis [31].

More than half of our participants (59.2%) suffered from mild to moderately severe depression and 63.3% had mild to severe anxiety. This is similar to Gugała et al., in a study assessing anxiety and depression in primary parental caregivers of children with cerebral palsy compared to a control group, anxiety and depression in parents of children with cerebral palsy was twice higher compared to parents of healthy children [11]. Assessment of the related causes showed that the prevalence of anxiety and depression was based on loneliness, gender, self-reported health status, economic status of the family, living conditions as well as social support perceived and received. Also, it was observed that the risk of depression was higher in females taking care of patients.

It has been stated that, long term caregiving leads to strain in caregivers and there is a need to design interventions to alleviate the burden. This was the conclusion that Dambi and Jelsma [32] came about after their study on the impact of hospital-based and community based models of cerebral palsy rehabilitation. Also, as the health and well-being of primary caregivers often have an influence on the well-being of the individuals with disabilities [33], caregivers in charge of children with CP therefore need assistance and respite care to alleviate the burden of care as this increased burden may lead to more psychological challenges [34].

Study Strength

Free routine visits were offered to these children and all participants were met face to face which permitted a better evaluation. This is one of the few studies carried out in Cameroon on the parental psychological burden of cerebral palsy.

Study Limitation

The main limitation of this study is that of memory bias. Some mothers might have forgotten some of the pertinent events in the perinatal period or might have given inaccurate information on some events and about 50% of recognised children with cerebral palsy could not be included in the study.

Conclusion

A relatively low prevalence of cerebral was found among children consulting at the Buea and Limbe Regional Hospitals. The predominant predisposing factors were birth asphyxia, neonatal infection and maternal chronic disease. Spastic CP was the main clinical form, with impaired speech and orthopaedic deformities being the most associated disorders.

This study also revealed that the parents/caregivers of children with CP had a high burden of care and were psychologically affected by their caring experiences. Several psychological disorders emerged from generalised anxiety to depression and there is need to design interventions to alleviate these silent mental diseases.

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APPENDIX : QUESTIONNAIRE.

Date…….
Patient code……

Child sociodémographique information

Age: ……
Sex: □ Male □ Female
Place of birth: ……..
Place of residence: ……..
Gestational age at birth: □< 28 weeks □ 28-32 weeks □ 32- <37weeks □ 37- <42weeks □> 42 weeks
Birth weight: □< 1000g □ 1000-1500 g □ 1500- <2500g □ 2500- <4000g □> 4000g

Ante/ peripartum determinants

Number of ANC	**□ 0 □ < 4 □>4**
Gestational diabetes	□ Yes □ No
Malaria	□ Yes □ No
Hypertension in pregnancy (Eclmpsia/Pre-eclampsia)	□ Yes □ No
HIV	□ Yes □ No
Hepatitis	□ Yes □ No
Illicit drugs	□ Yes □ No
TORCH Infection (Toxoplasmosis, Rubella, Cytomegalo virus, Herpes)	□ Yes □ No
Smooking/Alcohol	□ Yes □ No
Urinary tract infection	□ Yes □ No

Maternal age at conception : ……..
Any other maternal condition :……

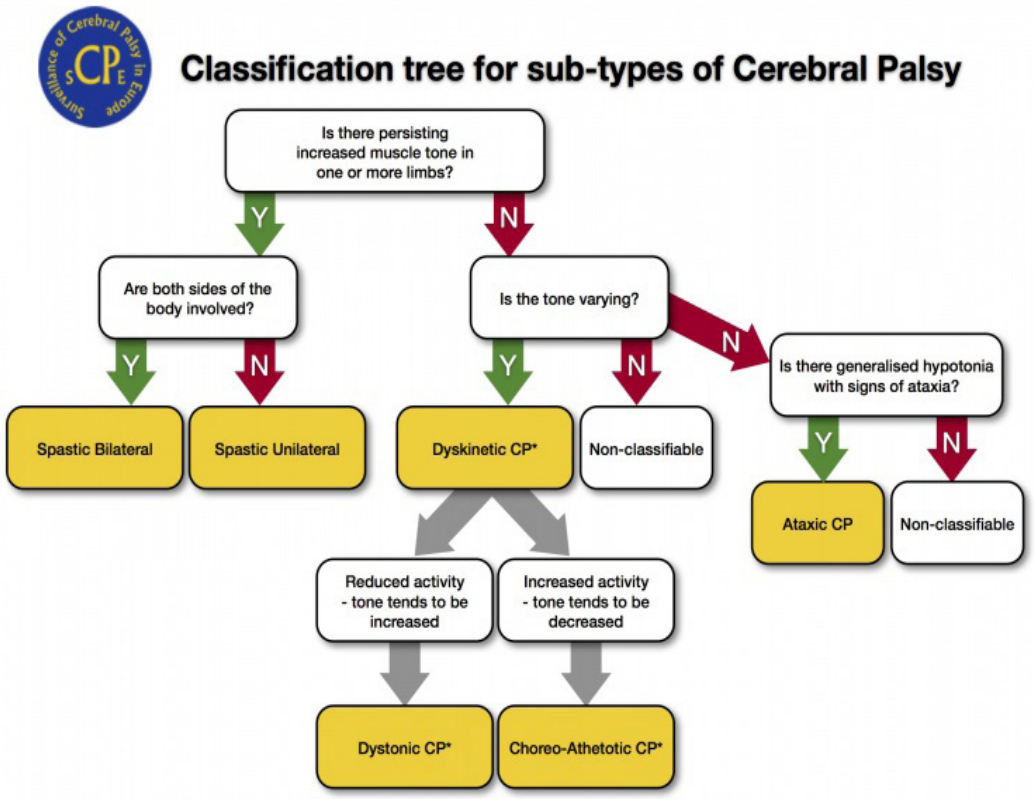
Intrapartum determinants

Duration of labor	□ Normal □ Prolonged
Color of amniotic fluid	□ Meconium stained □ Blood □ Clear
Mode of delivery	□ Vaginal □ Instrumental □ CS (□ Elective □ Emergency) Indication …….
Prolonged rupture of membranes	□ Yes □ No
Obstructed labor	□ Yes □ No
Cord prolapse	□ Yes □ No
Fetal distress	□ Yes □ No

Neonatal determinants

Resuscitation at birth	**□ Yes □ No**
Apgar score at the 5th minute	□ 0-3 □ 4-5 □ 6 □7-10
Congenital malformation	□ Yes □ No
Jaundice	□ Yes □ No
Trauma	□ Yes □ No
Surgery	□ Yes □ No

Neonatal infection: □ Yes □ No
If yes, what? …….
Where was it managed: ……..
For how long: ……
Any other illness: ……



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□ Speech delay
□ Behavioral disorder
□ Drooling
□ Epilepsy
□ Visual impairement
□ Orthopedic deformity
□ Respiratory disorder
□ Swallowing disorder
□ Under nutrition

Socio demographic data of caregiver.

Age(years) during birth of child	**□ 15-20 □ 21-29 □30-39 □> 40**
Sex	□ Male □ Female
Occupation	□ None □ Public Sector □ Self-Employed □ Private Sector
Religion	□ Christian □ Muslim □ Others
Marital Status	□ Single □ Married □ Cohabitating □ Divorced
Level of education	□ Primary school □ Secondary school □ University □ None

Income/ month	□ <50FCFA □ 50k – 100k FCFA □ 100k – 200k FCFA □ >200k FCFA
Family size	□ 3 □ 4 – 5 □ 6 - 7 □ >7
Type of family	□ Nuclear □ Extended

General Health Questionnaire (GHQ-28)

Full name of the patient:	Date accomplished:
Full name of the assessor:	

Please read this carefully. We should like to know if you have had any medical complaints and how your health has been in general, over the past few weeks. Please answer ALL the questions on the following pages simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past. It is important that you try to answer ALL the questions. Thank you very much for your co-operation.

Have you recently…

Question		Choices			
A1	Been feeling perfectly well and in good health?	○ Better than usual	○ Same as usual	○ Worse than usual	○ Much worse than usual
A2	Been feeling in need of a good tonic?	○ Not at all	○ No more than usual	○ Rather more than usual	○ Much more than usual
A3	Been feeling run down and out of sorts?	○ Not at all	○ No more than usual	○ Rather more than usual	○ Much more than usual
A4	Felt that you are ill?	○ Not at all	○ No more than usual	○ Rather more than usual	○ Much more than usual
A5	Been getting any pains in your head?	○ Not at all	○ No more than usual	○ Rather more than usual	○ Much more than usual
A6	Been getting a feeling of tightness or pressure in your head?	○ Not at all	○ No more than usual	○ Rather more than usual	○ Much more than usual
A7	Been having hot or cold spells?	○Not at all	○ No more than usual	○ Rather more than usual	○ Much more than usual
B1	Lost much sleep over worry?	○Not at all	○ No more than usual	○ Rather more than usual	○ Much more than usual
B2	Had difficulty in staying asleep more once you are off?	○Not at all	○ No more than usual	○ Rather more than usual	○ Much more than usual
B3	Felt constantly under strain?	○Not at all	○ No more than usual	○ Rather more than usual	○ Much more than usual
B4	Been getting edgy and bad-tempered?	○Not at all	○ No more than usual	○ Rather more than usual	○ Much more than usual
B5	Been getting scared or panicky for no good reason?	○Not at all	○ No more than usual	○ Rather more than usual	○ Much more than usual
Question		Choices			
B6	Found everything getting on top of you?	○Not at all	○ No more than usual	○ Rather more than usual	○ Much more than usual
B7	Been feeling nervous and strung-up all the time?	○Not at all	○ No more than usual	○ Rather more than usual	○ Much more than usual
C1	Been managing to keep yourself busy and occupied?	○More so than usual	○ Rather less than usual	○ Rather less than usual	○ Much less than usual
C2	Been taking longer over the things you do?	○Quicker than usual	○ Longer than usual	○ Longer than usual	○ Much longer than usual
C3	Felt on the whole you were doing things well?	○Better than usual	○ Less well than usual	○ Less well than usual	○ Much less well
C4	Been satisfied with the way you've carried out your task?	○More satisfied	○ Less satisfied than usual	○ Less satisfied than usual	○ Much less satisfied
C5	Felt that you are playing a useful part in things?	○More so than usual	○ Less useful than usual	○ Less useful than usual	○ Much less useful

C6	Felt capable of making decisions about things?	○More so than usual	○ Less so than usual	○ Less so than usual	○ Much less capable
C7	Been able to enjoy your normal day-to-day activities?	○More so than usual	○ Less so than usual	○ Less so than usual	○ Much less than usual
D1	Been thinking of yourself as a worthless person?	○Not at all	○ No more than usual	○ Rather more than usual	○ Much more than usual
D2	Felt that life is entirely hopeless?	○Not at all	○ No more than usual	○ Rather more than usual	○ Much more than usual
D3	Felt that life isn't worth living?	○Not at all	○ No more than usual	○ Less useful than usual	○ Much more than usual
D4	Thought of the possibility that you might make away with yourself?	○Definitely not	○ I don't think so	○Has crossed my mind	○ Definitely have
D5	Found at times you couldn't do anything because your nerves were too bad?	○Not at all	○ No more than usual	○ Rather more than usual	○ Much more than usual
D6	Found yourself wishing you were dead and away from it all?	○Not at all	○ No more than usual	○Rather more than usual	○ Much more than usual
D7	Found that the idea of taking your own life kept coming into your mind?	○Definitely not	○ I don't think so	○ Has crossed my mind	○ Definitely has

A ____ **B** ____ **C** ____ **D** ____ **Total**

Zarit Caregiver Burden Assessment (Short, 12-items)

Name: _____ Date:_____

The following is a list of statements that reflect how people sometimes feel when taking care of another person. After reading each statement, indicate how often you experience the feelings listed by circling the number that best corresponds to the frequency of these feelings.

	Never	Rarely	Sometimes	Frequently	Nearly Always
1) Do you feel you don't have enough time for yourself?	0	1	2	3	4
2) Do you feel stressed between caring and meeting other responsibilities?	0	1	2	3	4
3) Do you feel angry when you are around your relative?	0	1	2	3	4
4) Do you feel your relative affects your relationship with others in a negative way?	0	1	2	3	4
5) Do you feel strained when are around your relative?	0	1	2	3	4
6) Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
7) Do you feel you don't have as much privacy as you would like, because of your relative?	0	1	2	3	4
8) Do you feel your social life has suffered because you are caring for your relative?	0	1	2	3	4
9) Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
10) Do you feel uncertain about what to do about relative?	0	1	2	3	4
11) Do you feel you should be doing more for your relative?	0	1	2	3	4
12) Do you feel you could do a better job in caring for your relative?	0	1	2	3	4

Scoring Instructions: Add Items 1-12 **Total 1-12 (maximum score = 48) _____**

Michel Bédard, PhD,1,2 D. William Molloy, MB,3 Larry Squire, MA,1 Sacha Dubois, BA,3 Judith A. Lever, MSc(A),4 and Martin O'Donnell, MRCP(I)3 The Gerontological Society of America Vol. 41, No. 5, 652–657 **The Gerontologist The Zarit Burden**

Interview: A New Short Version and Screening Version.

Zarit Burden Interview

Assessing Caregiver Burden

Gerontologic health scientific literature identifies a number of scales to measure caregiver burden. The Zarit Scale of Caregiver Burden or the Zarit Burden Interview is the most widely used instrument. Originally designed and tested in 1980 containing 29 items, it was reduced to 22 questions. Subsequent adaptation of the scale made it particularly attractive. The research reported in The Gerontologist (2001, Vol 41, No. 5, 652-657) that a short 12-item version and 4-item screening version were found to correlate well with the full 22-item version. The short and simple 4-item screen, proven to be valid and reliable for its designated use, is self-administered by the caregiver. The screen has proven to be a helpful resource tool for caregivers and their families.

A courtesy of L'Orech Yomim/Center for Healthy Living, Inc. 2011

Zarit Burden Interview: Short (12-items)

Total score range: 0 to 48
0-10: no to mild burden
10-20: mild to moderate burden
> 20: high burden

Original: Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. The Gerontologist 1980; 20:649

Name: _____ Date: _____

Patient Health Questionnaire (PHQ–9)

1. Over the last two weeks how often have you been bothered by any of the following problems?

	Not at all (0)	Several days (1)	More than half the days (2)	Nearly every day (3)
a. Little interest or pleasure in doing things.	☐	☐	☐	☐
b. Feeling down, depressed, or hopeless.	☐	☐	☐	☐
c. Trouble falling/staying asleep, sleeping too much	☐	☐	☐	☐
d. Feeling tired or having little energy	☐	☐	☐	☐
e. Poor appetite or overeating.	☐	☐	☐	☐
f. Feeling bad about yourself, or that you are a failure, or have let yourself or your family down.	☐	☐	☐	☐
g. Trouble concentrating on things, such as reading the newspaper or watching TV.	☐	☐	☐	☐
h. Moving or speaking so slowly that other people could have noticed. Or the opposite; being so fidgety or restless that you have been moving around more than usual.	☐	☐	☐	☐
i. Thoughts that you would be better off dead or of hurting yourself in some way.	☐	☐	☐	☐

Total Score: _____

1. If you checked off <u>any</u> problem on this questionnaire so far, how <u>difficult</u> have these problems made it for you to do your work, take care of things at home, or get along with other people

☐ Not difficult at all ☐ Somewhat difficult ☐ Very difficult ☐ Extremely difficult.

PHQ-9 Management Summary

Score	Depression severity	Comments
0-4	Minimal or none	Monitor; may not require treatment
5-9	Mild	Use clinical judgment (symptom duration, functional impairment) to determine necessity of treatment
10-14	Moderate	
15-19	Moderately severe	Warrants active treatment with psychotherapy, medications, or combination
20-27	Severe	

GAD-7

Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious, or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid, as if something awful might happen	0	1	2	3

Total Score	_____ =	Add Columns	_____ + _____ + _____

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
☐	☐	☐	☐

When screening for anxiety disorders, a score of 8 or greater represents a reasonable cut-point for identifying probable cases of generalized anxiety disorder; further diagnostic assessment is warranted to determine the presence and type of anxiety disorder. Using a cut-off of 8 the GAD-7 has a sensitivity of 92% and specificity of 76% for diagnosis generalized anxiety disorder.

The following cut-offs correlate with level of anxiety severity:

- Score 0-4: Minimal Anxiety
- Score 5-9: Mild Anxiety
- Score 10-14: Moderate Anxiety
- Score >15: Severe Anxiety

Based on a recent meta-analysis, some experts have recommended considering using a cut-off of 8 in order to optimize sensitivity without compromising specificity.

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