Prevalence, clinical presentation and factors associated with chronic respiratory disease among children with cerebral palsy at Kenyatta National Hospital. -A hospital based cross-sectional study.

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DECLARATION

This dissertation proposal is my original work and has not been presented for the award of a degree in any other university.

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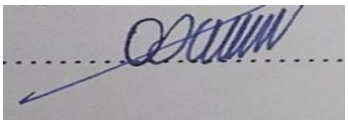
Signature:  **Date:** 20th January, 2023

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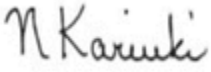
Signature:  **Date:** 20th January, 2023

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ABBREVIATIONS

CP: Cerebral Palsy

GMFCS: Gross Motor Function Classification System

SRDB: Sleep Related Breathing Disorder

OSAS: Obstructive Sleep Apnea

GOR: Gastroesophageal Reflux

CT: Computerized Tomography

HRCT: High-resolution Computed Tomography

SPO2: Arterial Oxygen Saturation by Pulse Oximetry

ENT: Ear, Nose and Throat

KNH: Kenyatta National Hospital

UoN: University of Nairobi

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ABSTRACT

Background: Respiratory complications are the major causes of morbidity and repeated hospitalizations in children with cerebral palsy (CP). These children have risk factors related to their neurological impairment and muscle weakness, predisposing them to respiratory complications. Identifying the magnitude and clinical presentation of chronic respiratory disease among these children will be valuable to inform guidelines on optimization of their management.

Study objectives: To determine the prevalence, clinical presentation and factors associated with chronic respiratory disease among children with CP receiving care at Kenyatta National Hospital (KNH).

Method: A hospital based cross-sectional study caried out at the KNH, on children with CP, enrolled from inpatient, gastroenterology, neurology and occupational therapy clinics. Caregivers were interviewed and children examined to obtain relevant sociodemographic and clinical information, and data was captured on a paper case record form. A consecutive sampling technique was used to reach sample size of 103. Key outcomes of interest were chronic respiratory signs and symptoms, and sociodemographic and clinical risk factors. Prevalence of chronic respiratory disease was computed for chronic lung disease and chronic upper airway disease. Logistic regression was conducted to evaluate factors associated with chronic respiratory disease.

Results: 103 participants were enrolled, male participants were 54.4%, median age was 3years, 22% had severe CP, 53.4 had chronic seizures %, 12.5% had severe swallowing incoordination, 55.3% coughed during meals and 10.0% had severe malnutrition. Chronic respiratory symptoms were as follows - chronic cough in 28.2%, chest congestion in 27.2%, wheeze in 16.5%. 42.7% had snoring and 7.8% had sleep apnoea. Abnormal respiratory signs included resting SPO2 below 95% in 29%, finger

clubbing in 17.5%, chest wall indrawing in 17.5%, chest rattles in 6.8%, nasal flaring in 36.9%, stridor in 6.8% and grunting in 6.8%. The prevalence of chronic lung disease was 21%, of chronic upper airway disease was 42.7%. Combined prevalence of any type of chronic respiratory disease was 55% (95% CI *45%, 65%)*. Univariate analysis revealed CRD was associated with male sex (OR 2.23, p=0.04) and swallowing incoordination (OR 4.0, p=0.01), and adjusted analysis revealed that swallowing incoordination remained independently associated with chronic respiratory disease (OR 3.8, p=0.02).

Conclusions and Recommendations: The prevalence of chronic respiratory disease among children with cerebral palsy was high. Commonest clinical presentation was cough, congested chest and snoring, and swallowing incoordination was an independent risk factors in this study population. We recommend routine screening of children with cerebral palsy for chronic respiratory disease and their linkage into specialized care for the same.

1.0 CHAPTER1: BACKGROUND

Cerebral palsy is a motor disability affecting sensory and cognitive ability.(1) Its prevalence is higher in low-income nations as compared to the high-income nations.(2)In Kenya there are no statistical data on the prevalence of cerebral palsy. A systematic review by Kristen et al, that looked at paediatric cerebral palsy in Africa found an approximate prevalence of 2-10 per 1000 children in Africa(3).

Cerebral palsy has various complications with respiratory complications being the most devastating and cause of highest mortality among children with cerebral palsy.(4) Respiratory complications are the major causes of morbidity and repeated hospitalizations in children with cerebral palsy.(5) These children have various risk factors that are related to the neurological impairment and muscle weakness that predispose them to respiratory problems which have serious impact on morbidity and mortality(6). These risk factors include but not limited to, poor swallowing in coordination ,kyphoscoliosis, seizures, malnutrition gastro- esophageal reflux(7)

The repeated respiratory complications also have a significant impact in their quality of life and pose significant financial and psychological impact on their care givers and a huge financial burden to the hospitals.(5) There is existing literature on the risk factors studied in different setting but paucity in determining the prevalence and severity of the respiratory disease in our setting.

This study will seek to identify the prevalence of chronic respiratory disease among children with cerebral palsy attending the Kenyatta national hospital, which is a tertiary referral hospital. The study will also seek to identify the respiratory clinical presentation among these children and also assess the risk factors predisposing them to respiratory complications.

2.0 CHAPTER 2: LITERATURE REVIEW

2.1. Prevalence and Types of Cerebral Palsy

Cerebral palsy is a non-progressive neurodevelopmental disorder, resulting from insult of the developing brain affecting motor functions, movement, muscle tone and motor skills(8). Cerebral palsy is a lifelong disease with heterogenous presentation in levels and disability. Cerebral palsy in classified based on the area of the bran that is affected, as explained in figure 1. (9)

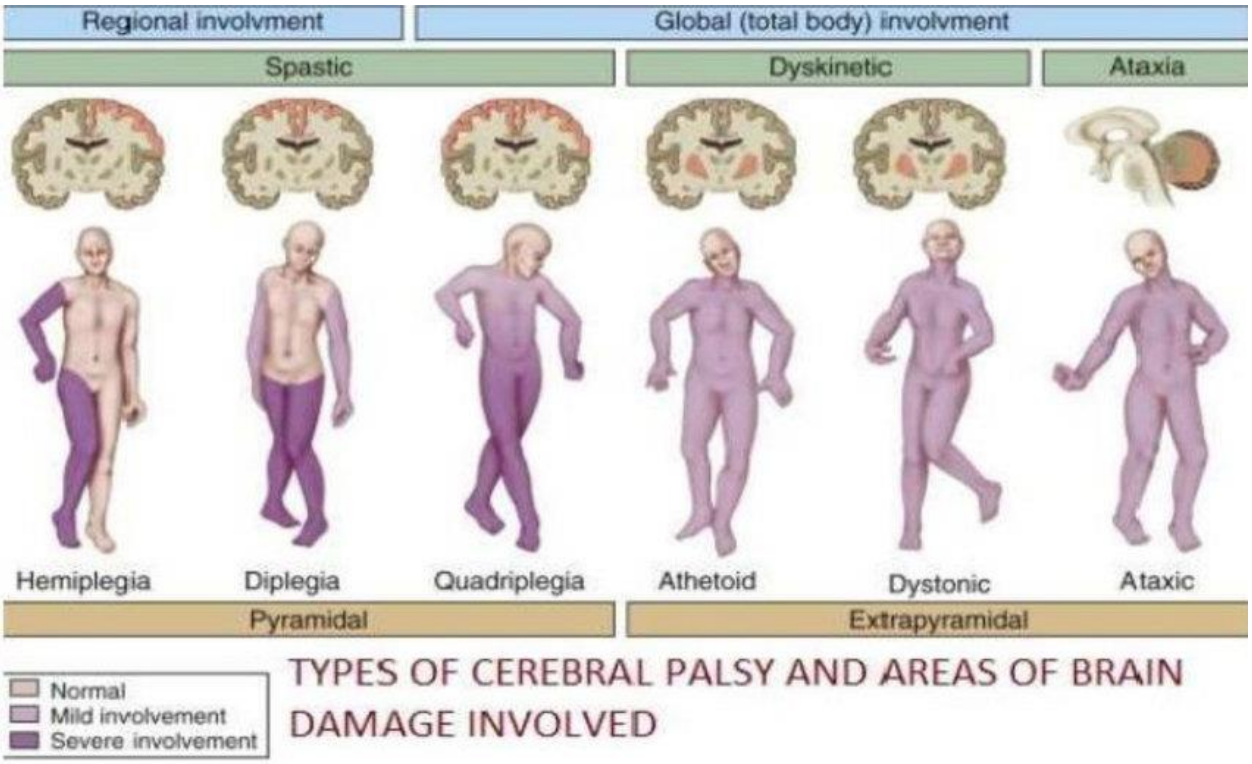


Figure 1:Types of Cerebral Palsy and Areas of Brain Damage Involved(9)

In a population based study in Uganda the prevalence of cerebral palsy wa about 2.9(2.4-3.6) cases per 1000 children(10) as compared to 1.8-2.3 cases per 1000 children in high income countries. A systematic review that looks at the prevalence of cerebral palsy in African countries showed a study in Egypt by Ell Talawy et al with a prevalence of 2 cases per 1000, and a study by Couper in South Africa where the prevalence was 10 cases per 1000.(3)

2.2 Respiratory Complications in children with Cerebral Palsy

Respiratory complications are the major causes of morbidity and repeated hospitalizations in these patients(5).A study in Sweden showed that 53% of the study population of 1856 with cerebral palsy died of respiratory failure (11)

In the registry of cerebral palsy in Australia, respiratory problems were very common, with wheeze or daily cough in 58%, 10% with obstructive sleep apnea, cough with drinking in 40% and around 20% had abnormalities on clinical pulmonary exam (12). Children with cerebral palsy have an increased risk of sudden death during sleep and most of these patients have a group of respiratory problems such as chronic bronchitis, recurrent aspiration pneumonia and (nocturnal) respiratory insufficiency.

Children with cerebral palsy have repeated hospital admissions which are related to respiratory illnesses. Over a 5-year period, prospective data-linkage research involving young persons with Cerebral Palsy discovered characteristics that were strongly related with recurrent respiratory admissions. GMFCS Level V, at least two courses of antibiotics in the previous year, at least one respiratory hospitalization in the previous year, oropharyngeal dysphagia, constant respiratory symptoms (daily cough, or weekly sounding chesty, wheezy or phlegmy), mealtime symptoms when well (wheezing, coughing, gurgly voice, sneezing, choking),current seizures and nightly snoring were among them.(13) Children with cerebral palsy have several risk factors that predispose them to respiratory problems which have a major impact on morbidity and mortality. Notably, poor nutrition, recurrent aspiration, impaired airway clearance, spinal and thoracic deformity, impaired lung function, and recurrent respiratory infections negatively affect respiratory status(14).

Table 1: Studies on respiratory morbidity among children with cerebral palsy

Author, Year, Country	Title	Study Population	Key Findings
Blackmore et al, 2016. Australia.	Prevalence of symptoms associated with respiratory illness in children and young people with cerebral palsy	N = 551 Age: 1 - 26years	Prevalence of Cough 45.5 Wheeze 16.4% Chesty/phlegmy 21.4%
Baikie et al, 1999. Australia	Inhalation pneumonitis in children with severe cerebral palsy	N = 63 Age: 14 months - 16years	Cough/wheeze 58% Apnoea10% Snoring 44% Crackles 19%, Wheeze 17%
Nobukazu et al. 2019. Japan	Effect of aspiration on the lungs in children: a comparison using chest computed tomography findings.	N = 85 Age: 11 years 2 months ±7 years 2 months)	Pneumonia 63.5% Bronchiectasis 31.8% Atelectasis 20%
Engin et al. 2016. Turkey	Sleep disordered breathing in children with Cerebral Palsy	N = 168 Age: 2 - 18years	Snoring 9.6% in CP and 6.4% without CP SRDB 18.1% in CP and 7.4% without CP

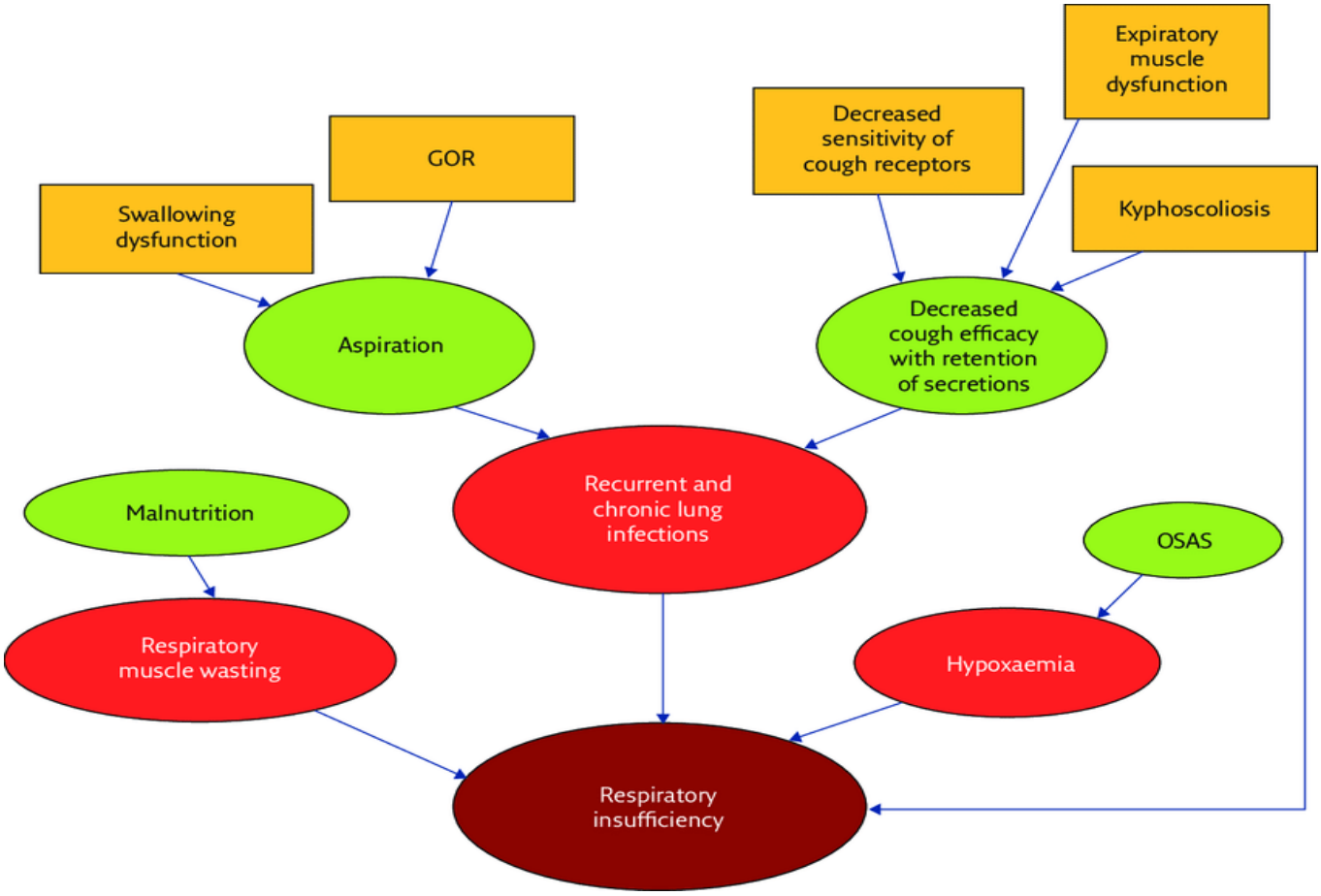
2.3. Pathophysiology of Respiratory disease and predisposing factors

Depending on the severity of the disease, the ineffective cough and clearance of secretion cerebral palsy children may present with recurrent respiratory infections, pneumonia, and

atelectasis which cause airway obstruction and lung damage, which will further result in impairment of respiratory functions and nutritional status of these children.(14) These children may also present with abnormal gas exchange and sleep-related breathing disorders.(15) Due to changes in muscle tone, these children may develop scoliosis.

The reduced compliance of the chest wall and asymmetrical lung expansion exacerbate the lung impairment. The spinal cord deformity can result in reduction of cough and lung secretion clearance(16).

Other factors that predispose to respiratory disease include hypocalcemia, as a result of inadequate calcium intake due to poor feeding and malnutrition(17), vitamin D deficiency as a result of non-ambulation with restricted sun exposure, resulting in low bone density and rickets in these children.(18) The weakened ribs result in pulling of the diaphragmatic muscles and flaring of the diaphragm. In severe cases there is vertebral softening causing kyphosis, all this result in poor inspiration and expiration resulting in poor respiratory function predisposing to respiratory disease.(19)



GOR: Gastro esophageal reflux, OSAS: obstructive sleep apnea syndrome

Figure 2:Pathophysiology of respiratory disease in children with cerebral palsy. (7)

The underlying predisposing factors in children with cerebral palsy are multiple and most risk factors can present simultaneously as shown in figure 2 above(7) .

2.3.1 Gastro esophageal reflux

Gastro esophageal reflux is persistent and common among cerebral palsy with an incidence of 32%-75% .(14) It is due to increased intra-abdominal pressure due to increased spasticity of abdominal muscles and also due to esophageal and sphincter muscle in coordination(20).

Video fluoroscopy can be used to assess swallowing in coordination. A study showed that 68.2% of children aged 7months to 19years, during their swallowing study showed significant silent aspiration(21)

2.3.2 Oropharyngeal motor dysfunction

Children with cerebral palsy have oropharyngeal motor dysfunction which attribute to direct aspiration. van den Engel-Hoek et all found that these children during one or all phases of swallowing had dysphagia(22)

Dysphagia was shown to be prevalent in children with cerebral palsy in 43 percent of the 1,357 children studied in Northern Ireland, independent of the classification(23).In a study by Hellen Nataly et al, 14 children out of the 24 child severe dysphagia, had recurrent pneumonia(24).

2.3.3 Seizures

In about one third of children with cerebral palsy, seizures are present. In a study by Pratibha Singhi et al. of the 452 children studied, 35.4%, (160) had seizures with an incidence of 66% seen in spastic hemiplegic children(25).

Uncontrolled seizures increase the likelihood of salivary aspiration in children with CP, putting them at risk for respiratory illness; hence, optimal epilepsy control may minimize respiratory disease(26).

2.3.4 Upper Airway Obstruction

Upper airway obstruction is common among children with CP and is due to loss of pharyngeal muscle tone. This can result in sleep apnea, hypercarbia, hypoxemia with increased risk of pulmonary hypertension. In a cohort of hospitalized children with cerebral palsy in South Africa the prevalence was 8.8%(7).

Airway obstruction severity tends to increase with increasing age in CP patients, this is thought to be due to increased hypotonia of the pharyngeal muscle and tracheostomy is likely to be required. Georgios Kontorinis et al studied the progression of airway obstruction and time for intervention among 15 children at an average age of 9 years with CP and airway obstruction, and 9 out of the 11 who had undergone adenotonsillectomy (average age of 4.5-14yrs) underwent tracheostomy after 1.9 years. 80% of these children above 10years underwent tracheostomy while those children below 5years surgical intervention was uncommon(27).

2.3.5 Compromised Airway clearance

Cough is a 3phase mechanism: inspiratory, compressive and expiratory. This complex physiology may lack or be ineffective in children with cerebral palsy resulting in excessive pulmonary secretion, aspiration and atelectasis(28)

2.3.6 Mobility

The mobility of a child with cerebral palsy can determine the risk of respiratory illness. The mobility can be assessed using the GMFCS.(29) This is a five level classification. The risk for respiratory illness is much higher in children with level V(30) in comparison to those in level I to IV. Amanda Marie et al indicates that the respiratory problems in children with GMFCS V was not due to their gross motor function but rather due to the eating and drinking difficulty and suggests that oropharyngeal motor or sensory and their in ability to coordinate breathing and swallowing played a major factor in increasing their risk for respiratory illness.(30).

A study by Ersöz M et al showed that chest mobility in spastic CP patients was decreased as evaluated by Chest Expansion, when compared with normal controls of similar age and gender ($p< 0.001$) and the difference increased in older children(31). This decrease affects the respiratory function of these children

2.3.7 Kyphoscoliosis

Chest wall and spinal cord curvature deformities result in lung function restriction.in children with Cerebral Palsy the uneven gravity and muscle tone, in addition to this deformity result in decreased chest wall compliance with unequal chest expansion. The reduced chest expansion result in ventilation perfusion mismatch leading to increased work of breathing which will predispose to respiratory failure.

2.3.8 Malnutrition

children with cerebral palsy are predisposed to malnutrition due to motor dysfunction, resulting in swallowing incoordination and regurgitation. A study done in Kenyatta National Hospital by koriata , where 140 children with cerebral palsy were studied, 70.35 were malnourished, among them severe wasting was found in 35.0% and severe stunting was seen in 10.2%(17)

Malnutrition results in reduced muscle strength and impairs function of muscle of respiration resulting in weak cough reflex and impaired airway clearance predisposing to repeated respiratory infections. Malnutrition also lowers the immunity making these children susceptible to infections including respiratory infections.

2.4 Clinical presentation of Chronic Respiratory Disease

2.4.1 Symptoms of chronic respiratory disease among children with CP

Children with cerebral palsy often present to the healthcare facility with episodes of noisy breathing, persistent cough, recurrent chest infections, apneic attacks(20).

A study by Baikie et al of 63 children with non-ambulant spastic quadriplegic CP discovered that respiratory symptoms were frequent in children with cerebral palsy, where 58% presented with wheeze or cough, 84% had cough with feeding at least 1 day per week, 'asthma' episodes in the last 6 months in 34 percent, snoring in 44 percent, and documented apneas in 10%. Focal respiratory symptoms were present in 24% of the time, including crackles in 19% and wheezing in 17%, and cough following a milk feed in 44% of the time(32)

Impaired swallowing coordination, reflux and seizures all contribute to aspiration among these children. Clinical presentation like coughing, change in breathing patterns and voice, but may also be silent

Respiratory symptoms among children with cerebral palsy were more from GMFSC III and above. Study by Amanda Marie Blackmore et al showed that GMFSC V had difficulties in feeding and drinking and the symptoms were more related to this than their gross motor function, all the 81 patients in GMFSC V presented with respiratory symptoms while feeding, with 62 out 81 of them presenting with wheeze, cough or sneezing(30).

2.4.2 Imaging Findings for Chronic Respiratory Disease

A study by Nobukazu et al, was conducted in children with neurological impairment such as cerebral palsy, designed to use CT scans to investigate whether there is an association between aspiration and lung injury, showed that of the 85participants (63.5%)54 of them showed signs of pneumonia. The results of CT images were parenchymal bands ([7.1%] 6 participants), bronchiectasis ([31.8%] 27 participants), bronchial wall thickening ([54.1%] 46 participants), and bronchiectasis (2 1 [2.4%] participants), intraluminal airway fragments ([4.7%] 4 Participants), atelectasis ([20.0%]17 participants), tree bud pattern (8 [9.4%] participants), and other findings (4 [4.7%] participants) (33)

2.5 Study justification

Children with cerebral palsy often present to the pediatric units with recurrent chest infections which result in repeated episodes of hospitalization. Respiratory complications are the major causes of morbidity and repeated hospitalizations in these patients.(5). These children have various risk factors that are modifiable and early intervention can improve Quality of life, morbidity and mortality.

A published audit of child deaths from the CP Register in Victoria, Australia by Reddihough et al showed that infection was the cause of death of almost half the CP patients and pneumonia including aspiration made up 39.4%.(12) Identification of the severity and pattern of lung disease based on their clinical presentations and examination findings will help predict their outcomes and allow for early intervention thus reducing morbidity and mortality.

2.5 Research Question

What is the prevalence, clinical presentation and factors associated with chronic respiratory disease among children with cerebral palsy receiving care at Kenyatta National Hospital?

2.6 Study Objectives

2.6.1 Primary objectives

1**.** To determine the prevalence of chronic respiratory disease among children with cerebral palsy receiving care at Kenyatta National Hospital.

2. To describe the clinical presentation of chronic respiratory disease among children with cerebral palsy receiving care at Kenyatta National Hospital.

2.6.2 Secondary objective

1. To evaluate sociodemographic and selected clinical factors associated with chronic respiratory disease among children with cerebral palsy receiving care at Kenyatta National Hospital. Factors of interest include socio-demographic and clinical factors (e.g., severity of cerebral palsy, co-morbidities such as swallowing in co-ordination, gastroesophageal reflux, recurrent pneumonia)

3.0 CHAPTER THREE: METHODS

3.1 Study Design

The study was a hospital based cross-sectional study

3.2 Study setting and study site

This study was conducted at the Kenyatta National Hospital, the oldest public hospital in Kenya, located to the west of upper hill in Nairobi, the capital city of Kenya. It is a tertiary, referral and the teaching hospital of the University of Nairobi.

It has a bed capacity of over 2500, with general pediatric wards, paediatric outpatient clinics, specialized inpatient and outpatient units and a paediatric intensive unit. Pediatric services offered include neurology, gastroenterology, cardiac, renal, pulmonology, endocrinology, oto-rhino-laryngology (ENT), occupational and physiotherapy among other services.

On average the occupational therapy attends to an average of 10-15 children with cerebral palsy every day. Neurology clinic which is done on every Tuesday of the week has an average of 40-60 children per clinic day with an average of 15 children with cerebral palsy.

3.3 Study population

The study population was all the children with cerebral palsy seeking care at the Kenyatta National Hospital.

Inclusion criteria:

- Age group: 6months -12years
- Have a diagnosis of Cerebral Palsy
- Receiving care at the Kenyatta National Hospital
- Those willing to give consent

Exclusion criteria:

- Confirmed diagnosis of congenital heart disease as this may present with similar symptoms to chronic respiratory disease or any heart condition (this is a pragmatic study and Echo will not be done on all kids to rule out congenital heart disease)
- Absence of parent or guardian with authority to give consent.

3.5 Study Period

The study was conducted from July 2022 to November 2022

3.6 Sample size calculation

The sample size estimate was based on objectives 1 and 2, computed to enable determination of prevalence of chronic respiratory disease, and/or prevalence of characteristic clinical presentation (chronic cough). Sample size has been calculated using the Fischer's formula as follows:

$$n = \frac{Z^2 P(1-P)}{D^2}$$

Where the following assumptions apply:

n = Minimum required sample size

Z^2 = Normal deviation at the desired confidence interval. In this case it will be taken at 95%, Z value at 95% is 1.96

P = Estimated prevalence of CRD in children with cerebral palsy shall be 58% based on the a study by bakie et al where cough was at 58%(32)(similar to Australian cerebral palsy registry from a study by Proesmans M. which indicates the prevalence of cough in the registry was 58%.)(7)

D= Degree of precision; will be taken to be 0.10

$$n = \frac{1.96^2 * 0.58 * 0.42}{0.1^2}$$

$$n = 94$$

Assuming that ~10% of children have incomplete data on any key variable, we increase the sample size by 10% - and shall aim to enroll a minimum of 103 children.

3.7 Sampling Procedure

We used consecutive sampling and patients with a diagnosis of cerebral palsy who met the inclusion criteria were recruited for the study.

3.8 Definitions of Key Outcomes

I. Cerebral Palsy:

Cerebral palsy is defined as clinical diagnosis based on the presence of abnormality of movements including paucity of movement, asymmetrical movements, unusual shaky

movements or other abnormalities of movement, tone disorders, such as spasticity, dystonia or tone fluctuation, hypotonia or floppiness ,motor development abnormalities, consisting of, late head control, crawling and rolling, difficulties in feeding, delay in milestones achievement: unable to sit by 8 months (corrected for gestational age) and early hand preference before 1 year of age (corrected for gestational age) and unable to walk by 18 months (corrected for gestational age)(34).

II. Chronic Respiratory Disease

Chronic respiratory disease - is defined for the purposes of this study as two or more respiratory symptoms and/or signs persisting, or present on most days for two or more months. (adapted from the modified version of America Thoracic Division of Lung Disease for children) (35). The definition is pragmatic and will use only signs and symptoms as no radiological investigations will be done.

Based on the clinical presentation of the signs and symptoms, chronic respiratory disease for the purpose of this study will be further classified into chronic lung disease, and chronic upper airway disease as follows:

Chronic upper airway disease: presence of chronic upper airway obstruction (persistent stertor/snoring, or persistent stridor).

Chronic Lung Disease: presence of chronic symptoms suggestive of lung disease (chronic cough, congested chest, wheeze).

Severe Chronic Respiratory Disease:

Disease will be classified as severe using the following parameters:

Oxygen saturations <95% at rest, and/or presence of finger clubbing.

Obstructive sleep apnoea defined severe upper airway disease/obstruction.

Chronic Respiratory Symptoms include:

Cough sputum, wheeze, breathlessness / dyspnea,

Nasal congestion, snoring, sleep disordered breathing, obstructive sleep apnea.

Abnormal Respiratory Signs

- Tachypnoea (>90TH centile for age), abnormal SPO2 (<95% at rest, or with agitation, or => 3% decline with agitation/exercise), Cyanosis, finger or toe clubbing, abnormal chest examination.
- Loud 2nd heart sound in pulmonary area (P2), with or without signs of right sided cardiac failure (cor pulmonale). (2)
- Where recent imaging is available such as chest radiograph or high resolution computerized tomography scan of the chest, any abnormal finding will be documented, however imaging will not be conducted purely for the purposes of the study.

III. **Associated factors of interest include:** -

- Severity of cerebral palsy level I-V based on the Gross Motor Function Classification System Expanded and Revised of 2007 by CanChild Centre for Childhood Disability Research, McMaster University (29):
    - level I: no limitations when walking
    - level II: Has some limitations while walking in some settings
    - level III: Use of hand-held mobility device or uses wheelchair for walking greater distances
    - level IV: In most settings uses wheelchair
    - level V: Use of a wheel chair in al situations and additional support may be required for the torso or head
- Swallowing incoordination- defined by symptoms of difficulty in swallowing.
  The presence of feeding dysfunction will be assessed using a scale developed from previously published reports by Reilly et al on prevalence of feeding difficulties in children with cerebral palsy(36):
    - Normal: no dysfunction detected
    - Mild: mild feeding and swallowing dysfunction
    - Moderate: feeds on well moistened feeds and has difficulties with liquids
    - Severe: requires tube feedings

- Dysphagia will be assessed using the Dysphagia outcome severity scale (as reported by care giver).(37)

a. Levels 1 and 2: unable to take nutrition by mouth
b. Levels 3, 4, and 5: able to take nutrition by mouth, but requires thickened fluids and/or thickened or pureed foods
c. Levels 6 and 7: able to eat and drink a normal diet by mouth.

- Recurrent Hospitalization- this will be defined as 2 or more hospital admissions in the past one year due to respiratory illness as the primary cause of admission.
- Prolonged hospitalization – hospitalization for longer than 14 days due to respiratory illness within the preceding two years.
- Moderate to severe malnutrition, wasting (WHZ < -2, or low BMI) or
- underweight (WAZ <-2).

IV. Socio-demographic factors include: -Age, sex, home air pollution (cooking fuel), home ventilation and overcrowding, parental education level, economic status.

3.9 Study tool

A structured case record form was used to collect socio-demographic information, relevant clinical information obtained through parent report (history), and abstracted from the patient file, and relevant physical examination findings.

3.10 Study Procedures

This study was conducted after getting approval from the KNH-UoN ethics committee and approval to collect data from the KNH research Centre.

Screening and Enrollment: The principal investigator recruited 1 research assistant (Qualification: An ongoing medical under graduate student who has rotated in the pediatric rotation and on school holidays), who was then trained on the protocol by the principal investigator. The study subjects were enrolled from the neurology, POPC, gastroenterology, and the occupational therapy clinics and the children's wards. The principal investigator screened the clinic register to identify potential study subjects with a clinical diagnosis of cerebral palsy, we conducted a short screening interview to further verify eligibility. We included all the patients from all the clinics and the children's ward with a diagnosis of cerebral palsy for this study.

The guardians of the children who met the inclusion criteria were taken through the consent form and the purpose of the study was explained to them to seek participation of the minors and once a parent agreed to consent, he/she was given a consent form to sign.

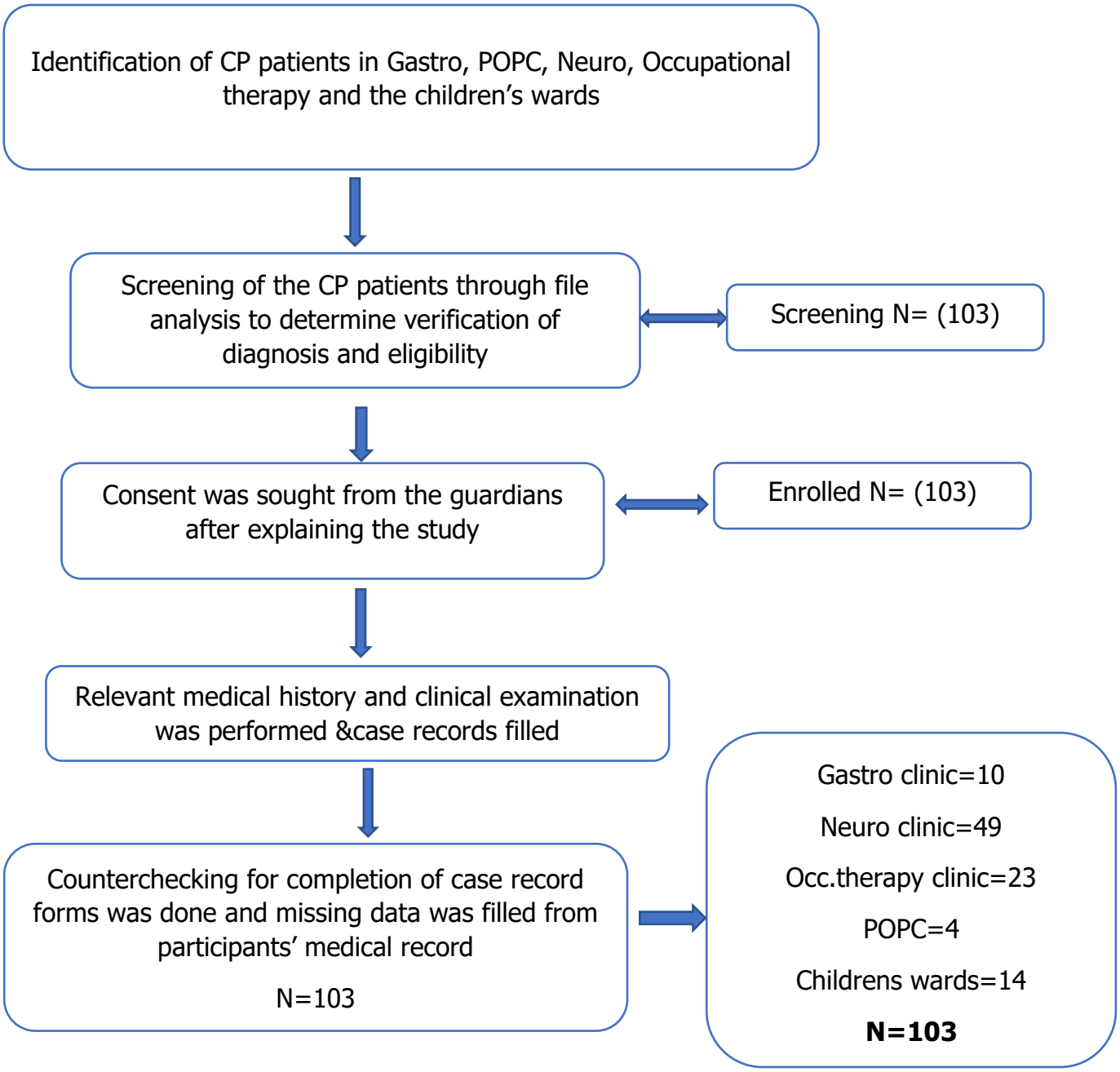


Figure 3: flow diagram for screening and enrollment:

Gastro-Gastroenterology, Neuro-Neurology, Occ.therapy-Occupational therapy, POPC-Paediatric outpatient clinic

Clinical Procedures: The principal investigator and research assistant, then went ahead to take the relevant history including current and recent symptoms, and past medical history from the primary care givers. Physical examination relevant to respiratory disease, cerebral palsy and measurement of vital signs including pulse oximetry was carried out when the child is calm. Weight was taken using the special fitted chair on the weighing scale that was available at the neurology clinic for those participants above two years who could not support themselves. Length/height for children that were able to fully extend their legs were measured using the stadiometer. Relevant past medical information was abstracted from the patient medical file. All data was recorded in the structured case form.

Pulse oximetry: Arterial oxygen saturation was measured using a hand pulse oximeter with appropriate probes for age, the principal investigator and the research assistant performed hand hygiene and the probe was cleaned with a sanitizer before and after each patient examination. The procedure was explained to the care giver and consent was sought. The probe was placed at the appropriate site (for infants, the great toe, for older children the index finger or any other hand digit), ensuring that the light source was directly opposite the photo detector and there was no gap between the probe and the skin. Verification of the accuracy of the reading was done by correlating the palpated heart rate if it matched the heart rate reading on the pulse oximeter. The measurement was taken when the child is calm. If the child got agitated or cried during the measurement it was noted as a separate reading when agitated or crying. The readings were then recorded on the case record form.

3.10 Data Management and Analysis

The filled questionnaires were collected and stored in a lockable drawer by the principal investigator. All the questionnaires were checked for completeness after data collection. Data was entered and stored in excel spreadsheets using excel forms. The data was then be imported in to R version 4.0.2 for analysis. Descriptive analysis was carried out to summarize the demographic characteristics of the participants and clinical features. Exploratory analysis was also done and the results were presented on tables and charts. Bivariate analysis was used to check the association of categorical independent variables e.g., type of cerebral palsy and categorical dependent variables e.g., presence or absence of lung disease. Binary logistic regression was used to analyze the impact of the independent variables e.g., age, age of

onset, economic status of parents, sex and severity of cerebral palsy on the presence or absence of lung disease.

Quality assurance

A further follow-up was done on the patients' records to fill in any missing data.

3.11 Ethical Considerations

Approval to conduct the study was sought from KNH/UON Research and Ethics committee (Ref: KNH-ERC/A/221.see appendix 5), as well as endorsement from the KNH Pediatrics and Child health head of department (Ref KNH/PAEDS-HOD/48 Vol II. see appendix 6). Participation was by choice and removal of oneself from the study was allowed at any point. A consent form was duly and willingly signed by the participants guardian and the guardian was explained to the fact that no repercussions would be faced by the participant or guardian from withdrawing from the study at any point in time. The anonymity of the participants was ensured by coding the observations. There was no use of names or participant identifiers. The cost of the study was not transferred to the participant. The study did not by any means interfere with the participants' treatment or cause harm to them. Respect and dignity of the participant was prioritized. Study results will be availed to the KNH Ethics and Research Committee and the UON Department of Pediatrics and Child Health. Data collection in the wards was carried out only after the acceptance of a formal request to collect data by the KNH Research and Programs department.

CHAPTER 4: RESULTS

4.1Socio-demographic characteristics of the study participants.

This study was conducted at Kenyatta National Hospital. The study participants were children with cerebral palsy aged 6 months to 12 years. A total of 103 participants took part in this study. Study participants were drawn from 5 areas namely: gastroenterology clinic 9.7% (n = 10), neurology clinic 47.6% (n = 49), occupational therapy 22.3% (n = 23). The rest were drawn from POPC. The proportion of male participants was 54.4% (56 out of 103) and females were 45.6% (47 out of 103). The median age of the participants was 3.0 years with an interquartile range of 1.35 to 5.45 years. Majority of the participants were below between 0-5 years 71.8% (74) while the rest were above 5 years.

Table 1: Socio-demographic characteristics of the study participants (N=103)

Variable	**Subcategory**	**Frequency or Median**	**Percent or IQR**
Study area	Gastroenterology clinic	10	9.7
	Neurology clinic	49	47.6
	Occupational therapy	23	22.3
	Paediatric wards	17	16.5
	POPC	4	3.9
Children characteristics			
Gender	Female	47	45.6
	Male	56	54.4
Age group in years	0-5 years	74	71.8
	6-14 years	29	28.2
Age in years	Median	3.0	1.4, 5.5
Parent and household characteristics			
Age group	<25 years	9	8.7
	25-30 years	19	18.5
	Above 30 years	75	72.8

Primary caregiver	Father	5	4.9
	Mother	79	76.7
	Relatives	10	9.7
	Others	9	8.7
Education	Primary or lower	19	18.6
	Secondary or higher	87	81.6
Family income in Kenya shillings	<,5000	18	17.5
	5,000-10,000	27	26.2
	>10,000	55	30.1
	Not comfortable disclosing	3	2.9

The majority of the children 76.7% (n = 79) were under the care of the mother followed by those under the care of relatives at 9.7% (n = 10). The median age of the guardians was 33.0 years (IQR 30.0, 38.5). the majority of the parents were below 25 years 91.3% (n =94) while the rest were above 25 years. In terms of family income, 30.1% (n = 31) earned more than KSHs 10,000. Those who earned between KSHs 5,000 to 10,000 were 26.2% (n = 27).

4.2. Clinical characteristics of children with cerebral palsy

We assessed the weight and nutritional status of the children using weight for age Z scores and weight for height Z scores. The proportion of children with normal weights and plus those who were mildly underweight was 53.7% (51 out of 95). Majority of the children either had normal nutritional status or mild malnutrition 75.8% (n = 72). Those with moderate to severe malnutrition were 24.2% (n = 23). We also assessed stunting using height for age Z scores. Majority of the children had stunted growth 65.0% (n = 67).

In terms of GMFCS severity, majority of the children were at GMFSC level 3-4 at 58% (n = 60). 22.3% (n = 23) had GMFSC level 5 while level one was 14.6% (n = 15). The children were also assessed for swallowing incoordination whereby only 12.5% (n = 13) had severe swallowing incoordination, those who had no problem with swallowing were 35.0% (n = 36), these were equal to those with moderate swallowing incoordination. Those who coughed during meals and those with chronic seizures were 55.3% (n = 57) and 53.4% (n = 55) table 2.

Table 2: Clinical characteristics of the study participants (N=103)

Variable	Subcategory	Frequency or Median	Percent or IQR
General clinical Characteristics			
Weight for age z-score	Above -2	51	53.7
	-2 to -3	44	46.3
Underweight (WAZ)	Normal to mild (WAZ > -2)	51	53.7
	Mod-severe (WAZ < -2)	44	46.3
Wasted (WHZ or BMI)	Normal to mild (WHZ > -2)	72	75.8
	Mod-severe (WHZ < -2)	23	24.2
Stunted (HAZ)	Above -2	36	35.0
	-2 to -3	67	65.0
Gross motor function Severity score (GMFSC)	Level 1(none)	15	14.6
	Level 2(mild impairment)	5	0.5
	Level3-4(moderate impairment)	60	58
	Level 5(severe impairment)	23	22.3
Swallowing incoordination/aspiration	None	36	35.0
	Mild	18	17.5
	Moderate	36	35.0
	Severe	13	12.5
Coughs during meals	yes	57	55.3
Seizures	Yes	55	53.4
Chest deformities/wear chest braces	Yes	9	8.7
Dysphagia outcome severity scale	Levels 1 & 2(minimal)	9	9.1
	Levels 3,4 & 5(moderate)	62	63.3
	Levels 6 & 7(severe)	27	27.6

4.3. Clinical Presentation of Chronic Respiratory Disease

To answer objective 1 for the prevalence of chronic respiratory disease, we first analysed the respiratory symptoms and signs of each participant, then further attempted to divide the respiratory findings into chronic lung disease and chronic upper respiratory airway disease with each of their prevalence and then finally the overall prevalence of chronic respiratory disease.

A minority of the participating children, 28.2% (n = 29) had a chronic cough. Those with chest congestion were 27.2% (n = 28). The proportion of children with a respiratory wheeze was 16.5% (n = 17). Those who get breathless on most days (4 or more days in a week) for as much as 2 or more months in a year were 17.5% (n = 18). On physical examination, 17.5% (n = 18) of the respondents had finger clubbing, 4.9% (n = 5) had a dusky colour. Another 17.5% (n = 18) had chest wall indrawing of which 9.7% (n = 10) had subcostal indrawing, 3.9% (n = 4) had intercostal indrawing and 1.9% (n= 2) had suprasternal indrawing. Children who presented with nasal flaring were 36.9% (n = 38) of the respondents, and 46.6% (n = 48) had noisy breathing. Majority of the patients 70.9% (n = 73) had oxygen saturations of above 95% followed by 17.5% (n = 18) who had saturations of between 93 and 95% and only 13.6% of the patients had been hospitalized more than once for respiratory illness. Of those with chest deformities, 8.7% (n = 9) had a barrel chest and pigeon chest each. Those with a depressed sternum were 4.9% (n = 5). On auscultation, majority of the children had normal breath sounds 61.5% (n = 75), 22.9% (n = 28) had crepitations and 15.6% (n = 19) had a wheeze. table 2. While 96.1% (n = 99) had a resonant chest, 3.9% (n = 4) had dull lungs on percussion (table 3)

Table 3: Clinical characteristics of chronic lung disease

Variable N=103	**Subcategory**	**Frequency or Median**	**Percent or IQR**
Cough	Present	29	28.2
Congested chest	Present	28	27.2
Respiratory wheeze	Present	17	16.5

Breathlessness	Present	18	17.5
Finger clubbing	Present	18	17.5
Central colour	Pink	98	95.1
	Dusky	5	4.9
Tachypnoea	RR<90th centile	66	64.1
	RR>90th centile	37	35.9
	Median centile	5	5.4
Oxygen saturations	>95%	73	70.9
	93 - 95	18	17.5
	90 – 92	4	3.9
	<90	8	7.7
	Median	97.0	95.0, 99.0
Chest wall indrawing	Yes	18	17.5
Type of chest wall indrawing	None	85	82.5
	Subcostal	12	9.7
	Intercostal	4	3.9
	Suprasternal	2	1.9
Noisy breathing	Absent	58	56.3
	Wheeze	17	16.5
	Chest rattles	7	6.8
Chest shape	Normal	80	77.7
	Barrel chest	9	8.7
	Depressed sternum	5	4.9
	Pigeon chest	9	8.7
Auscultation findings	Normal sounds	75	61.5
	Crepitations	28	22.9
	Wheeze	19	15.6
Percussion	Dull	4	3.9
	Resonant	99	96.1

Based on the clinical presentation of the signs and symptoms presented above in table 5, We further grouped the characteristics into types, based on the prominent presenting features. Although we would have liked to get the accurate type based on radiological features, due to the fact that this was one of the limitations we had in our study, we used the signs and symptoms to attempt to get the various types of respiratory diseases as follows; chronic lung disease into obstructive airway disease characterized by persistent wheeze at 19(16%) and chronic excessive sputum at 28(27%) with congested chest and crepitation. The second group as severe chronic respiratory disease: based on oxygen saturations and presence of clubbing depicted by the presence of chronic hypoxia 30 (29%) with a resting SPO2 of less than 95%, of whom 12 had SPO2 of 92% and below and clubbing 18 (18%) respectively.

4.3.1 Chest auscultation and percussion findings

Right lung

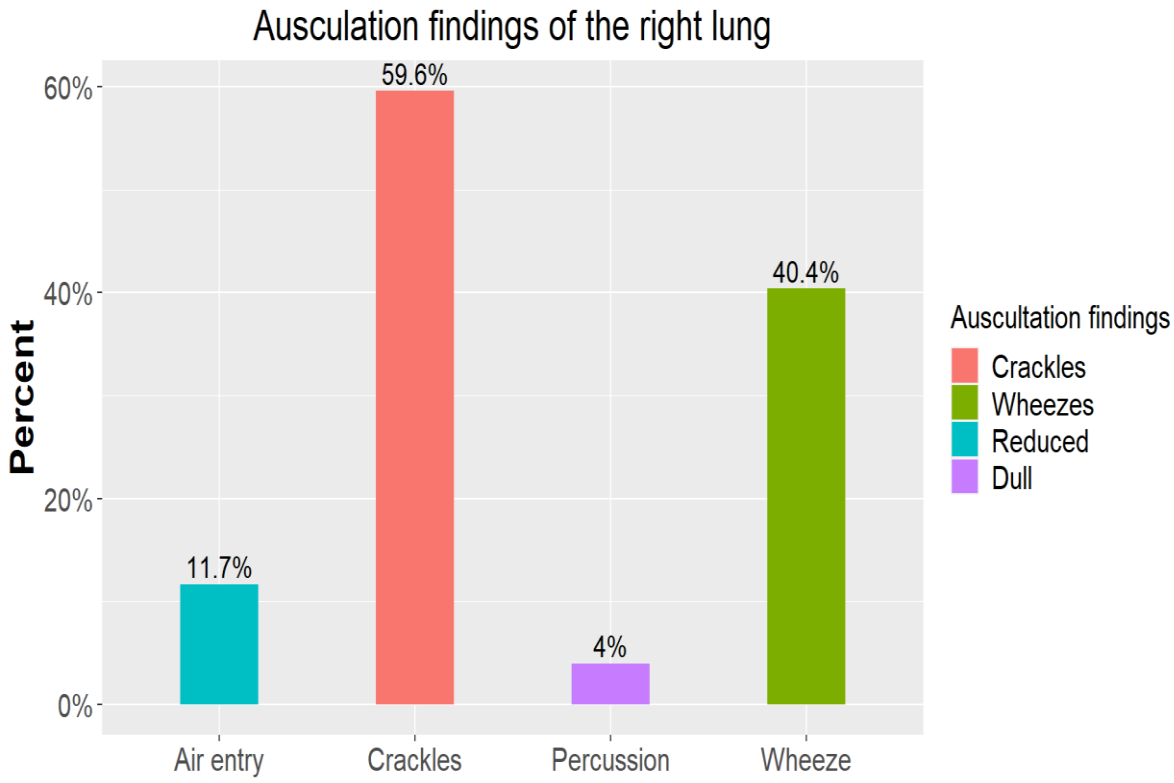


Figure 5: Auscultatory findings of the right lung

On chest auscultation and percussion findings, 11.7% of the children had reduced air entry. Those with abnormal breath sounds were crackles 59.6% and wheezes 40.4%. On percussion, only 4% had a dull sound while 18.4% had a respiratory wheeze (figure 6).

Left lung

Just like the right lung, reduced air entry in the left lung was 11.7%. Those with abnormal breath sounds were: Wheezes 39.5% and crackles 60.5%. figure 7.

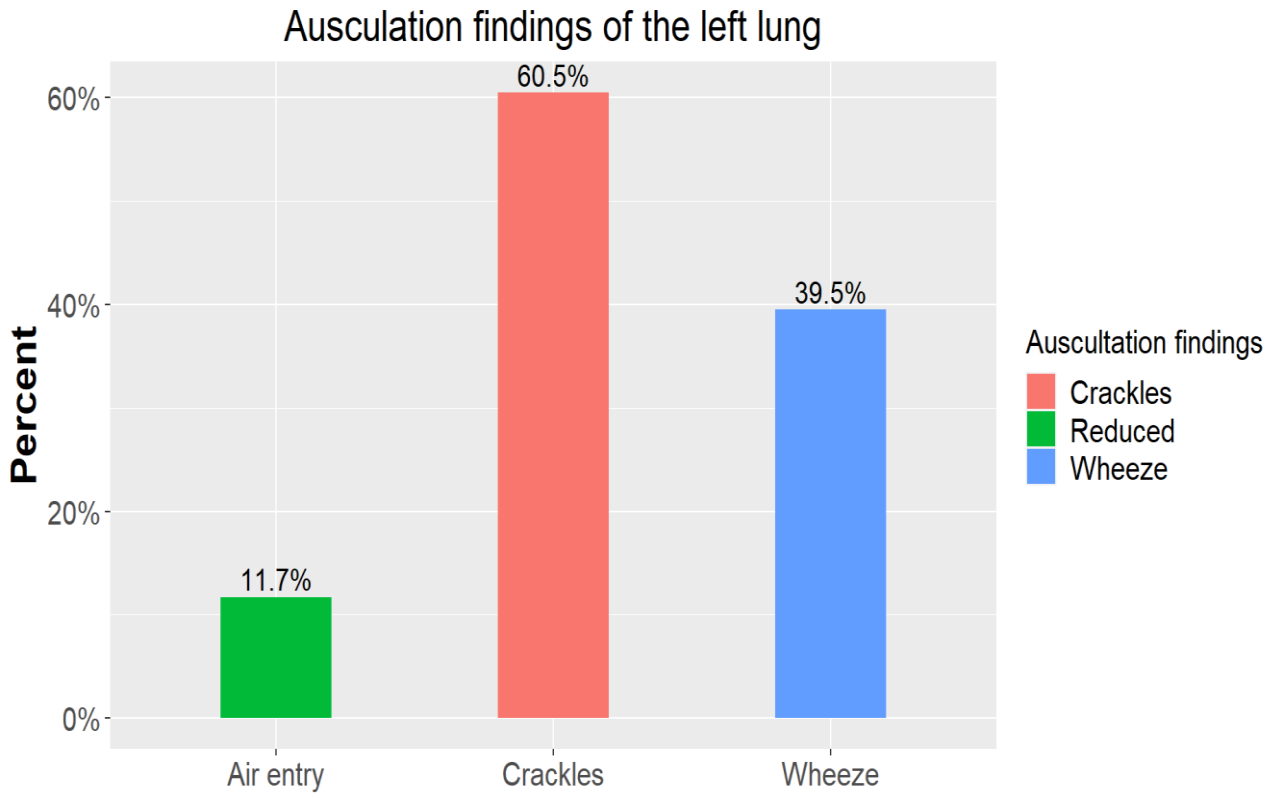


Figure 6: Auscultatory findings of the left lung

4.4. Prevalence of chronic lung (lower respiratory tract) disease

We calculated the prevalence of chronic lung disease based on presence of two or more of four clinical signs and symptoms suggestive of lower respiratory tract disease – specifically cough, congested chest, wheeze and crepitations. Among the 103 study participants 13 (13%) reported two symptoms, 7 (7%) reported three symptoms, and 2 (2%) reported four symptoms. Summing up those with two or more chest symptoms, 22 participants met the criteria of 2 or more signs and symptoms giving a prevalence of chronic lung (LRT) disease of 21% (95% CI 41%, 61%) (Table 4).

Table 4: Prevalence of chronic chest symptoms and of chronic lung disease (N=103)

No. clinical symptoms/signs suggestive of lower respiratory tract disease	**Frequency or Median**	**Percent % or IQR**
None	42	41%
1	39	38%
2	13	13%
3	7	7%
4	2	2%
Median no. of criteria	2.0	0,3
Classification as chronic lung disease		
Less than 2 criteria	81	79%
2 or more lung symptoms/signs	22	**21%**

4.5. Chronic upper airway disease

We then analysed reported signs and symptoms suggestive of chronic upper airway (upper respiratory tract) disease and the findings were: Fourty-four (42.7%) of 103 children reported

snoring, and severe obstruction as defined by presence of obstructive sleep apnoea was present in 8 (7.8%) of the children (Table 3). Seven (6.8%) children reported stridor.

Table 3: Prevalence of chronic upper respiratory tract symptoms and disease.

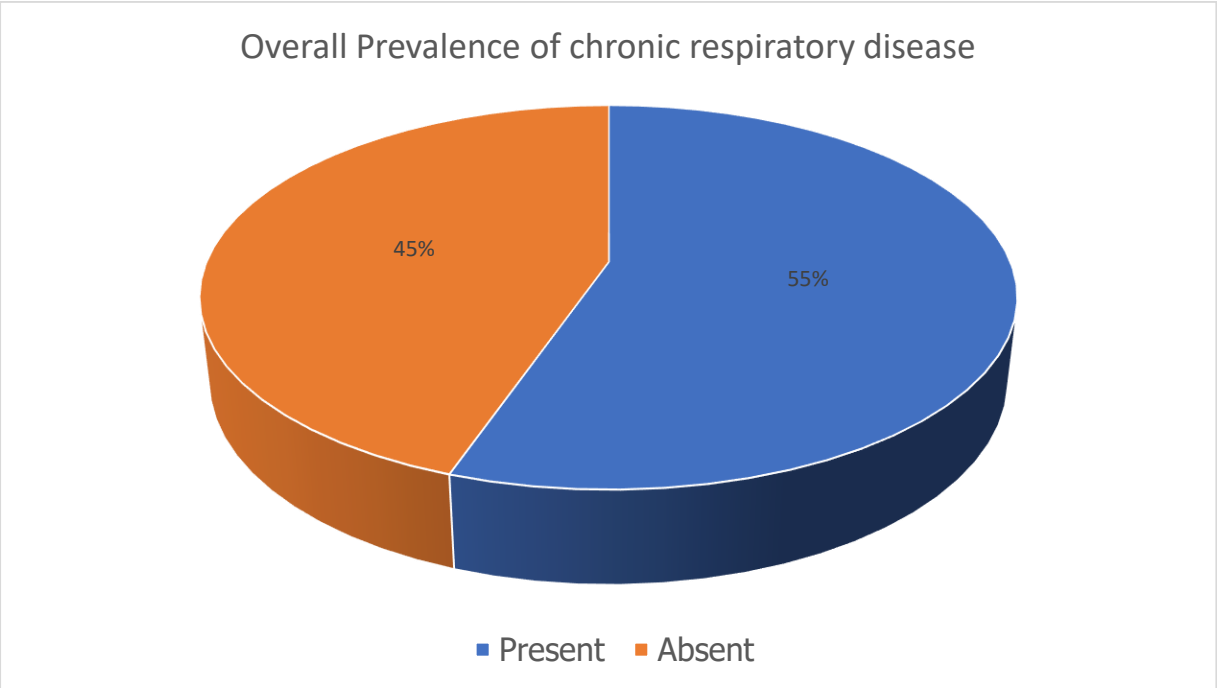
Variable N=103	**Subcategory**	**Frequency or Median**	**Percent or IQR**
Snoring	Present	44	42.7
Sleep apnoea	Present	8	7.8
Noisy breathing	Absent	58	56.3
	Stridor	7	6.8

4.6. Overall Prevalence of chronic respiratory disease (either upper or lower respiratory tract disease)

To determine overall prevalence of chronic respiratory disease we then analyzed data for each child total symptoms or signs for disease of either the lower or upper respiratory tract. This provided total no. of chronic respiratory symptoms in each child. Those with two or more chronic respiratory symptoms were classified as having chronic respiratory disease. We found that 45% (n = 46) had <2 chronic respiratory symptoms or signs, and 55% (n=57) had two or more chronic respiratory symptoms or signs. This gave a prevalence of chronic respiratory disease among the study participants of 55% (95% CI 45%, 65%). (Table 4 and figure 7).

Table 4: Overall Prevalence of chronic respiratory disease among children with cerebral Palsy (N = 103)

Characteristic	Frequency/Median	Percent %/IQR
Number of respiratory clinical abnormalities		
None	38	36.9
1	8	7.8
2	28	27.2
3	8	7.8
4	16	15.5
5	2	1.9
More than 5	3	2.9
Median no. of criteria	2.0	0,3
Classification as chronic respiratory disease		
Less than 2 criteria	46	45
2 or more symptoms/signs	57	**55%**



4.7. Factors associated with chronic respiratory disease among children with cerebral palsy receiving care at Kenyatta National Hospital

4.7.1. Bivariate analysis

To assess factors associated with chronic lung disease in children with cerebral palsy, we computed odds ratios and p-values at 5% significance level. P-values were computed using Pearson's chi-square test. Two factors were found to have an association with presence of chronic lung disease. These factors were sex OR 2.23 (95% CI 1.01, 4.93), p-value 0.04 and swallowing incoordination OR 4.0 (95% CI 1.69, 9.47). Using odds ratio, male children were 2.23 times more likely to have chronic lung disease compared to female children.

Those children whose swallowing is uncoordinated were 4.0 times more likely to have chronic lung disease compared to those whose swallowing is coordinated (table 7).

Table 7: Factors associated with Chronic respiratory disease in Children with Cerebral Palsy (unadjusted analysis)

Variable	**subcategory**	**CRD present Freq (%) (N= 57)**	**CRD absent Freq (%) (N= 46)**	**Crude odds Ratio (95% CI)**	**P value**
Sociodemographic Factors					
Sex	Male	36 (64.3%)	20 (35.7%)	2.23 (1.01, 4.93)	**0.04**
	Female	21 (44.7%)	26 (55.3%)	**reference**	
Monthly household income	Low (<10,000sh)	17 (37%)	28 (63%)	0.59 (0.26, 1.31)	0.19
	High (10000+)	28 (50.9%)	27 (49.1%)	**reference**	
Clinical Factors					
Underweight	Yes (WAZ < -2)	39 (58.2%)	28 (41.8%)	1.39 (0.62,3.14)	0.42
	No	18 (50%)	18 (50%)	**Reference**	

Wasted	Yes (WHZ OR BMI < -2)	15 (65.2%)	8 (34.8%)	1.68 (0.63, 4.45)	0.30
	No	38 (52.7%)	34 (47.2%)	**Reference**	
Hospitalised past year	Yes	25 (64.1%)	14 (35.9%)	1.79 (0.79, 4.04)	0.16
	No	32 (50%)	32 (50%)	**Reference**	
Cerebral Palsy Clinical Characteristics					
Severity of neurologic impairment (GMFCS score)	Level 4-5	49 (59%)	34 (41%)	2.16(0.80,5.85)	0.12
	Level 1-3	8 (40%)	12 (60%)	**Reference**	
Co-morbidities					
Swallowing incoordination	Present	44 (60%)	22 (40%)	4.0 (1.69, 9.47)	**0.01**
	Absent	12 (30%)	24 (70%)	**Reference**	
Seizures	Present	33 (60%)	22 (40%)	1.5 (0.69, 3.28)	0.31
	Absent	24 (50%)	24 (50%)	**Reference**	

4.7.2. Multivariable analysis

Variables that had p-values less than 0.05 at 95% significance level were selected for multivariable analysis. The selected variables were gender and swallowing in coordination with p-values of 0.04 and 0.01 from the bivariate analysis.

We then fitted a binary logistic regression model for the purpose of adjusting for each variable with chronic respiratory disease as the outcome. Binary logistic regression model is used when the outcome is binary e.g., present/absent.

After adjusting for swallowing incoordination, sex was not statistically significant at 5% significance level; p-value 0.07. Though not significant, the OR 2.19 (95% CI 0.95, 5.13) indicates that male children were 2.19 times more likely to have chronic lung disease compared to female children.

After adjusting for sex, children with swallowing incoordination were 3.8 times more likely to have chronic respiratory disease compared to those without swallowing incoordination OR 3.8 (95% CI 1.62, 9.44), p-value 0.02. Swallowing incoordination was significantly associated with having chronic respiratory disease at 5% significance level (table 6).

Table 8: Factors associated with chronic respiratory disease in the Children with Cerebral Palsy (adjusted analysis)

Variable	**Adjusted Odds Ratio (95% CI)**	**P value**
Sex (male compared to female)	2.19 (0.95, 5.13)	0.07
Swallowing incoordination (present vs absent)	3.8 (1.62, 9.44)	0.02

CHAPTER 5: DISCUSSION

Respiratory complications are the major causes of morbidity , repeated hospitalization and mortality among children with cerebral palsy(5). Identification of the presenting clinical presentation of the respiratory sign and symptoms allows for early management and mortality. This study sought to evaluate the clinical characteristics of respiratory disease and factors associated with developing chronic respiratory disease.

The majority of the participants 47.6% (n=49 out of 103) were enrolled from the neurology clinic. Almost 53.4% (n=55) had seizures, in comparison to a study by Pratibha et al, of the 452 children studied,34.4% (160 out of 452) had seizures. (24).

In terms clinical characteristics of the participants, the majority of the children, (77.0%) had normal nutritional status, 13.0% had moderate malnutrition and 10.0% had severe malnutrition. A study done in Kenyatta National Hospital by Koriata found 70.35% (n=140) of her study population were malnourished(17), a larger population(n=140) than this study (n=103) which could be explained by the small study population in this study. In assessing the severity of cerebral palsy,22.3%(n=23) had GMFSC V. Severity of cerebral palsy is associated with a higher risk of respiratory illness as seen in a study by Blackmore et al where children with level 5 had a much higher chance of respiratory illness in comparison with level I to IV (5). This was also seen in our study where 60% of those in level V presented with chronic respiratory disease.

In computing for the prevalence for chronic respiratory disease in this study, we first assessed the frequency of signs/symptoms of chronic respiratory disease that each participant had and assessed for those who met the criteria (total participants (n=103), n = 57, (55%) ,95% CI 45%, 65%), computing a prevalence of 55.3%. A minority of the participating children, 28.2% (n = 29) had a chronic cough, compared to a study by Baikie et al in Australia where they looked at inhalation pneumonitis in children with cerebral palsy (n=63) where prevalence of cough/wheeze was 58%(32). Another study by Blackmore et al(30) where they looked at the prevalence associated with respiratory illness among children with cerebral palsy, they found, cough was at 45.5% and wheeze was at 16.5% similar to this current study, where

wheeze was 16.5% (n = 17), chesty/phlegmy was 21.4% compared to this study where those with chest congestion were 27.2% (n = 28).In our study snoring was the predominant symptom at 42.7%(n=44) which was similar to the findings by Baikie et al (n=63) at 44%(32).

Children with cerebral palsy present with symptoms during feeds as seen in this study. where 55.3%(n=57) coughed during meals ,in comparison with the study by Baike et al although the feeds in her study were liquid as compared to our study where the cough was during any food consistency, she found that cough following a milk feed in 44% of the time(34).

In a study by Engine et al where he compared sleep disordered breathing in children with cerebral palsy with those without cerebral palsy, he found 9.6% presented with snoring and 18.1% had sleep related breathing disorder(SDRB) among those with cerebral palsy(38) as compared to this study where snoring was much higher at 44% and sleep apnoea was at 7.8% respectively though in this study we included even those on anticonvulsants as compared to his study where those on anti-convulsant where excluded at that can alter sleep patterns.

In this present study, 22.9%(n=28) had crackles on auscultations, compared to a study by Baikie et al where crackles were at 19%. In our study there was no statistical significance between presence of seizures and chronic respiratory illness (OR 1.5,0.69-3.28, P value of 0.31 at 95%Cl), though there was 1.5 times of having chronic respiratory disease if you had seizures as compared to not having seizures. Among the participants in our study, dysphagia level 3,4, and 5 was at 63% similar to study by Hellen Nataly et al (24) where 14 children out of the 24 children studied had severe dysphagia although unlike our study where we used symptoms as explained by care giver she used videofloroscopy to assess for dysphagia.

In this current study, children with swallowing incoordination were 3.8 times more likely to have chronic respiratory disease compared to those without swallowing incoordination OR 3.8 (95% CI 1.62, 9.44), p-value 0.02. Swallowing incoordination was significantly associated with having chronic lung disease at 5% significance level. This is similar to a study by van den Engel-Hoek at al who found that these children during one or all phases of swallowing had dysphagia. Although in our study, as compared to his we did not use videofloroscopy but

relied on symptoms as described by the care giver which was among our limitations for this study.

5.1 Study strengths and limitations.

This was the first study to look at clinical respiratory characteristics among children with cerebral palsy in KNH. The study was conducted at KNH Which is a tertiary hospital and thus the results are not generalizable to represent the population of children with cerebral palsy. Variables were obtained from parent report such as previous symptoms, hospitalizations, seizure episodes and this may result in recall bias. The study design is a cross-sectional study and data was collected at one-point intime, and for associated factors cause and effect may not be firmly established. Diagnosis of co-morbidities was pragmatic and include clinical symptomatic diagnosis, Dysphagia, swallowing incoordination and videofloroscopy was not done or to exclude congenital heart disease. Echo was not done for confirmation and diagnosis was excluded from medical records of participants. No Radiological tests such as High-resolution Ct scans were carried out during the study and this limited our ability to characterize structural abnormalities in the lung. And the participants at the time of the study did not have any prior tests with them.

5.2 Conclusion

The prevalence of chronic respiratory disease is high in children with CP, with one fifth having chronic lung disease, and two-fifths having chronic upper airway disease, and half overall having any form of CRD. The commonest clinical presentation is chronic cough and congested chest, and chronic snoring for lower and upper airway disease respectively. Swallowing incoordination is a significant risk factor for CRD in this study population.

5.3. Recommendations

We recommend assessment of respiratory problems and co-morbidities for children with cerebral palsy at each clinic visit by use of a screening tool that will assess for respiratory signs and symptoms and this will allow for early referral to pulmonology clinic for further evaluation and management. Based on the association between chronic respiratory disease and swallowing in coordination found in this study, we recommend evaluation of swallowing in coordination as part of routine management among children with cerebral palsy to evaluate for the presence and severity for early intervention and management. We also recommend for

further studies to be carried out to look at respiratory radiological characteristics of the lungs for children with cerebral palsy at Kenyatta National Hospital.

REFFERENCES

1. Bax M, Frcp DM, Rosenbaum P, Dan B, Universitaire H, Fabiola R, et al. Review Proposed definition and classification of cerebral palsy. Exec Comm Defin Cereb Palsy. 2005;(April 2005):571–6.

2. Oskoui M, Coutinho F, Dykeman J, Jetté N, Pringsheim T. An update on the prevalence of cerebral palsy: A systematic review and meta-analysis. Dev Med Child Neurol. 2013;55(6):509–19.

3. Donald KA, Samia P, Kakooza-Mwesige A, Bearden D. Pediatric cerebral palsy in Africa: A systematic review. Semin Pediatr Neurol [Internet]. 2014;21(1):30–5. Available from: http://dx.doi.org/10.1016/j.spen.2014.01.001

4. Blair E, Langdon K, McIntyre S, Lawrence D, Watson L. Survival and mortality in cerebral palsy: Observations to the sixth decade from a data linkage study of a total population register and National Death Index. BMC Neurol. 2019;19(1):1–11.

5. Murphy NA, Hoff C, Jorgensen T, Norlin C, Young PC. Costs and complications of hospitalizations for children with cerebral palsy. Pediatr Rehabil. 2006;9(1):47–52.

6. Blackmore AM, Bear N, Biostats M, Blair E, Gibson N, Jalla C, et al. Factors Associated with Respiratory Illness in Children and Young Adults with Cerebral Palsy. J Pediatr [Internet]. 2015;1–8. Available from: http://dx.doi.org/10.1016/j.jpeds.2015.09.064

7. Proesmans M. Respiratory illness in children with disability: a serious problem? Breathe. 2016;12(4):e97–103.

8. Gulati S, Sondhi V. Cerebral Palsy: An Overview. Indian J Pediatr. 2018;85(11):1006–16.

9. Padmakar P P, kumar KS, S Parveen P. Management and Treatment for Cerebral Palsy in Children. Indian J Pharm Pract. 2018;11(2):104–9.

10. Kakooza-Mwesige A, Andrews C, Peterson S, Mangen FW, Eliasson AC, Forssberg H. Prevalence of cerebral palsy in Uganda: a population-based study. Lancet Glob Heal [Internet]. 2017;5(12):e1275–82. Available from: http://dx.doi.org/10.1016/S2214-109X(17)30374-1

11. Himmelmann K, Sundh V. Survival with cerebral palsy over five decades in western Sweden. Dev Med Child Neurol. 2015;57(8):762–7.

12. Reddihough DS, Baikie G, Walstab JE. Cerebral palsy in Victoria, Australia: Mortality and causes of death. J Paediatr Child Health. 2001;37(2):183–6.

13. Blackmore AM, Bear N, Langdon K, Moshovis L, Gibson N, Wilson A. Letter Respiratory hospital admissions and emergency department visits in young people with cerebral palsy : 5-year follow-up Respiratory disease accounts for a high this population is poorly understood , but disease would enable families and clini- admis. 2019;0(0):11–2.

14. Boel L, Pernet K, Toussaint M, Ides K, Leemans G, Haan J, et al. Respiratory morbidity in children with cerebral palsy: an overview. Dev Med Child Neurol. 2019;61(6):646–53.

15. Fitzgerald DA, Follett J, Van Asperen PP. Assessing and managing lung disease and sleep disordered breathing in children with cerebral palsy. Paediatr Respir Rev. 2009;10(1):18–24.

16. Garuti G, Verucchi E, Fanelli I, Giovannini M, Winck JC, Lusuardi M. Management of bronchial secretions with Free Aspire in children with cerebral palsy : impact on clinical outcomes and healthcare resources. Ital J Pediatr [Internet]. 2016;4–9. Available from: http://dx.doi.org/10.1186/s13052-016-0216-0

17. koriata nancy simat. Nutritional Status of Children With Cerebral Palsy Attending Kenyatta National Hospital. 2012; Available from: https://pdfs.semanticscholar.org/fdaa/2905b9a0be95bb39c06b503026d127970127.pdf

18. Akpınar P. Vitamin D status of children with cerebral palsy (Should vitamin D levels be checked in children with cerebral palsy?). North Clin Istanbul. 2018;5(4):341–7.

19. Holick MF. Resurrection of vitamin D and rickets. J Clin Invest. 2006;116(8):2062–72.

20. Seddon PC, Khan Y. Respiratory problems in children with neurological impairment. Arch Dis Child. 2003;88(1):75–8.

21. Mirrett PL, Riski JE, Glascott J, Johnson V. Videofluoroscopic assessment of dysphagia in children with severe spastic cerebral palsy. Dysphagia. 1994;9(3):174–9.

22. Van Den Engel-Hoek L, Erasmus CE, Van Hulst KCM, Arvedson JC, De Groot IJM, De

Swart BJM. Children with central and peripheral neurologic disorders have distinguishable patterns of dysphagia on videofluoroscopic swallow study. J Child Neurol. 2014;29(5):646–53.

23. Erasmus CE, Van Hulst K, Rotteveel JJ, Willemsen MAAP, Jongerius PH. Clinical practice: Swallowing problems in cerebral palsy. Eur J Pediatr. 2012;171(3):409–14.

24. Lagos-Guimarães HNC, Teive HAG, Celli A, Santos RS, Abdulmassih EMDS, Hirata GC, et al. Aspiration pneumonia in children with cerebral palsy after videofluoroscopic swallowing study. Int Arch Otorhinolaryngol. 2016;20(2):132–7.

25. Jekovec-Vrhovsek M. Epilepsy in children with cerebral palsy. East J Med. 2012;17(4):166–70.

26. Marpole R, Blackmore AM, Gibson N, Cooper MS, Langdon K, Wilson AC. Evaluation and Management of Respiratory Illness in Children With Cerebral Palsy. 2020;8(June).

27. Kontorinis G, Thevasagayam MS, Bateman ND. Airway obstruction in children with cerebral palsy: Need for tracheostomy? Int J Pediatr Otorhinolaryngol [Internet]. 2013;77(10):1647–50. Available from: http://dx.doi.org/10.1016/j.ijporl.2013.07.017

28. Siriwat R, Deerojanawong J, Sritippayawan S, Hantragool S, Cheanprapai P. Mechanical insufflation-exsufflation versus conventional chest physiotherapy in children with cerebral palsy. Respir Care. 2018;63(2):187–93.

29. Palisano R, Rosenbaum P, Bartlett D, Livingston M, Walter S, Russell D, et al. GPalisano, R., Rosenbaum, P., Bartlett, D., Livingston, M., Walter, S., Russell, D., … Galuppi, B. (2007). Gross Motor Function Classification System Expanded and Revised. Reference: Dev Med Child Neurol, 39, 214–223. https://doi.org/10.1111/j.1469-8749.2. Ref Dev Med Child Neurol. 2007;39:214–23.

30. Blackmore AM, Bear N, Blair E, Gibson N, Jalla C, Langdon K, et al. Prevalence of symptoms associated with respiratory illness in children and young people with cerebral palsy. Dev Med Child Neurol. 2016;58(7):780–1.

31. Ersöz M, Selçuk B, Gündüz R, Kurtaran A, Akyüz M. Decreased chest mobility in children with spastic cerebral palsy. Turk J Pediatr. 2006;48(4):344–50.

32. BAIKIE G. inhalation pneumonitis in children with severe cerebral palsy. 1999; Available from: https://hdl.handle.net/11343/38142

33. Tanaka N, Nohara K, Ueda A, Katayama T, Ushio M, Fujii N. Effect of aspiration on the lungs in children : a comparison using chest computed tomography findings. 2019;1–7.

34. NICE. Cerebral palsy in under 25s: assessment and management | Guidance and guidelines | NICE. 2017.

35. Ferris BG. Epidemiology standardization project. Am Rev Respir Dis. 1978;118(6 II).

36. Reilly S, Skuse D, Poblete X. Prevalence of feeding problems and oral motor dysfunction in children with cerebral palsy: A community survey. J Pediatr. 1996;129(6):877–82.

37. O'Neil KH, Purdy M, Falk J, Gallo L. The dysphagia outcome and severity scale. Dysphagia. 1999;14(3):139–45.

38. Koyuncu E, Türkkani MH, Sarikaya FG, Özgirgin N. Sleep disordered breathing in children with cerebral palsy. Sleep Med [Internet]. 2017;30:146–50. Available from: http://dx.doi.org/10.1016/j.sleep.2016.01.020

39. Fleming S, Thompson M, Stevens R, Heneghan C, Plüddemann A, Maconochie I, et al. Normal ranges of heart rate and respiratory rate in children from birth to 18 years of age : a systematic review of observational studies. Lancet [Internet]. 377(9770):1011–8. Available from: http://dx.doi.org/10.1016/S0140-6736(10)62226-X

APPENDIX 1: PARTICIPANT INFORMATION AND CONSENT FORM

PARENTAL CONSENT

Study Title

Prevalence, Clinical Presentation and Factors associated with Chronic Respiratory Disease among Children with Cerebral Palsy at Kenyatta National Hospital

Principal Investigator \ and institutional affiliation: Salma Omar: Resident department of paediatrics and child health

Co-Investigators and institutional affiliation: Prof. Elizabeth Obimbo, University of Nairobi, Dr Ahmed laving, University of Nairobi, Dr. Nyambura Kariuki, University of Nairobi

Introduction: I would like to tell you about a study being conducted by the above listed researchers. The purpose of this consent form is to give you the information you will need to help you decide whether or not your child should participate in the study. Feel free to ask any questions about the purpose of the research, what happens if your child participates in the study, the possible risks and benefits, the rights of your child as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions to your satisfaction, you may decide if you want your child to be in the study or not. This process is called 'informed consent'. Once you understand and agree for your child to be in the study, I will request you to sign your name on this form. You should understand the general principles which apply to all participants in medical research: i) Your child decision to participate is entirely voluntary ii) You child may withdraw from the study at any time without necessarily giving a reason for his/her withdrawal iii) Refusal to participate in the research will not affect the services your child is entitled to in this health facility or other facilities.

May I continue? YES / NO

Background

Respiratory complications are the major causes of morbidity and repeated hospitalizations in children with cerebral palsy. These children have various risk factors that are related to the neurological impairment and muscle weakness that predispose them to respiratory problems which have significant impact on morbidity and mortality

Purpose

To identify the magnitude of chronic respiratory disease among your children with cerebral palsy.

Study procedures

The research personnel will explain to you the study and once you have understood I will allow you to sign the informed consent. The study personnel will take a brief history of your child to be able to fill in the questionnaire. The study personnel will take your child's weight, height and Mid Upper Arm circumference (MUAC). Thereafter they will examine your child by carrying out their respiratory rate, heart rate and placing a probe on their finger or toe so as to take the oxygen saturations. Then they will auscultate their chest. The study personnel will sanitize their stethoscope and pulse oximetry probe before and after each examination of your child. They will perform hand hygiene and covid protocol will be maintained at all times.

Voluntary participation

Your decision for your child to participate in this study is voluntary. Once you understand and agree for your child to be in the study, the research personnel will request you to sign your name on this form.

Confidentiality

The data collected will be used solely for the purpose of this study. We will keep everything you tell us as confidential as possible. We will use a code number to identify your child in a password-protected computer database and will keep all of our paper records in a locked file cabinet.

Benefits

There will be no financial benefit given to your child for participating in this study. Your child's participation will not affect or delay their planned treatment. We will refer your child to the appropriate clinic for care and support if necessary. Also, the information you provide will help us better understand magnitude of chronic respiratory disease among children with cerebral palsy.

Risk of Participation

We will not alter your planned treatment. The examinations carried out on your child will not cause any harm to your child.

Right of withdrawal

You may withdraw your child from the study at any time without necessarily giving any reason for the withdrawal. The refusal or withdrawal of your child from this study will not affect the services your child is entitled to, in this health facility or other facilities.

CONSENT FORM (STATEMENT OF CONSENT)

The person being considered for this study is unable to consent for him/herself because he or she is a minor (a person less than 18 years of age). You are being asked to give your permission to include your child in this study.

Parent/guardian statement

I have read this consent form or had the information read to me. I have had the chance to discuss this research study with the study personnel. I have had my questions answered by him or her in a language that I understand. The risks and benefits have been explained to me. I understand that my participation and that of my child in this study is voluntary and that I may choose to withdraw it any time. I understand that all efforts will be made to keep information regarding me and my child's personal identity confidential.

Parent/legal Guardian signature /Thumb stamp: _____ Date __

Parent/legal Guardian printed name: _____

Researcher's statement

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given his/her consent.

Printed Name: _____ Date: _____

Signature:

In case you have any questions concerning the study, feel free to contact the following persons during official working hours:

PRINCIPAL INVESTIGATOR:

Dr. Ahmed Salma Omar
Post Graduate student in the Department of Paediatrics and Child Health
University of Nairobi
Tel: 0705036221
Email: salmaomar@students.uonbi.ac.ke

SUPERVISORS:

Prof. E. Prof E Maleche Obimbo. (MBChB, MMed, MPH, FPulm)
Professor of Paediatric and Respiratory Medicine,
University of Nairobi.
Tel No: +254 020 2726300/+254 0202725102
Email: dept-paediatrics@uonbi.ac.ke

DR. Ahmed Laving
MBChB, MMed (Gastroenterologist)
Paediatric Gastroenterologist
University of Nairobi
Tel No: +254 020 2726300/+254 0202725102
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Dr Nyambura Kariuki
MBChB, MMed (Haemato-oncology)
Pediatric Haemato-oncologist
University of Nairobi
Tel No: +254 020 2726300/+254 0202725102
Email: dept-paediatrics@uonbi.ac.ke

Regulatory Body

KNH-UON ERC

Telephone (254-020) 2726300 Ext 44102

Email: uonknh_erc@uonbi.ac.ke

Website: www.erc.uonbi.ac.ke

APPENDIX 2: ARIFU YA MADA NA FOMU YA IDHINI

IDHINI YA MZAZI

Kichwa cha Utafiti

Kuenea, Hali iliyoko sasa na yanayohusiana na Ugonjwa Sugu wa Kupumua miongoni mwa Watoto wenye Mtindio wa Ubongo katika Hospitali ya Kitaifa ya Kenyatta.

Mpelelezi mkuu na uhusiano wa kitaasisi: Salma Omar; Idara ya madaktari wa Watoto na Afya ya Mtoto,

Chou kikuu cha Nairobi.

Wachunguzi-wenza na uhusiano wa kitaasisi: Prof Elizabeth Obimbo, chuo kikuu cha Nairobi, Dkt. Ahmed Laving, chuo kikuu cha Nairobi, Dkt. Nyambura Kariuki, chuo kikuu cha Nairobi.

Utangulizi

Ningependa kukuambia juu ya utafiti unaofanywa na watafiti waliotajwa hapo juu. Madhumuni ya fomu hii ya idhini ni kukupa habari ambayo utahitaji kukusaidia kuamua ikiwa mtoto wako anapaswa kushiriki katika utafiti. Jisikie huru kuuliza maswali yoyote juu ya madhumuni ya utafiti, nini kinatokea iwapo mtoto wako atashiriki kwenye utafiti, hatari na faida zinazowezekana, haki za mtoto wako kama kujitolea, na kitu kingine chochote juu ya utafiti au fomu hii ambayo sio wazi. Wakati tumejibu maswali yako yote kwa kuridhika kwako, unaweza kuamua ikiwa unataka mtoto wako ashiriki kwenye utafiti huu au la. Utaratibu huu unaitwa 'idhini ya kutaarifisha'. Mara tu ukielewa na kukubaliana na mtoto wako kushiriki kwenye utafiti hu, nitakuomba utie saini na unakili jina lako kwenye fomu hii. Unapaswa kuelewa kanuni za jumla ambazo zinatumika kwa washiriki wote katika utafiti wa matibabu i) uamuzi wako wa mtoto kushiriki ni wa hiari ii) wewe na mtoto wako anaweza kujiondoa kwenye utafiti wakati wowote bila kutoa sababu ya kujiondoa kwake III) kukataa kwa Shiriki katika utafiti hautaathiri huduma ambazo mtoto wako anastahili katika kituo hiki cha afya au vifaa vingine.

Mandharinyuma ya Utafiti

Matatizo ya kupumua ndiyo kisababishi kikuu cha magonjwa na kulazwa kwa watoto walio na ugonjwa wa kupooza ubongo. Watoto hawa wana vipengele mbalimbali vya hatari ambavyo vi nahusiana na uharibifu wa neva na udhaifu wa misuli ambao huwaathiri kwa matatizo ya kupu mua ambayo huathiri pakubwa magonjwa na vifo.

Nia

Ili kutambua ukubwa wa ugonjwa sugu wa kupumua kati ya watoto wenye ugonjwa wa kupoo za ubongo na kuweza kuunda hojaji ya hatari ya kupumua kwa madaktari kutoa huduma ya us hahidi kwa watoto wenye ugonjwa wa kupooza ubongo katika hatari ya ugonjwa mbaya wa ku pumua

Taratibu za utafiti

Mchunguzi mkuu atachukua historia fupi ili kuweza kujaza dodoso. Baada ya hapo, uchunguzi wa mtoto huyo utafanywa kwa kutumia kiwango cha kupumua cha mtoto na kumfanyia uchun guzi wa kidole au kidole cha mshiriki ili kuchukua viwango vya oksijeni vya mtoto. Halafu mcha nganyiko wa kifua utafanywa. Stethoscope na pulse oximetry uchunguzi itakuwa sanitized kabl a na baada ya kila uchunguzi. Usafi wa mikono na itifaki ya covid vitadumishwa wakati wote.

Kushiriki kwa hiari

Wale walinzi wa kisheria au wazazi watakao kubali kutia saini kwa ridhaa ndio watakao shiriki katika utafiti. hakuna adhabu yeyote itakayo pewa walinszi wa watoto au watoto wenyewe kwa kukataa kushiriki kwenye utafiti hu.

Usiri

Takwimu zilizokusanywa zitatumika tu kwa madhumuni ya utafiti huu. Tutaweka kila kitu unachotuambia kama siri iwezekanavyo. Tutatumia nambari ya siri kumtambua mtoto wako katika hifadhidata ya kompyuta iliyolindwa na nywila na tutaweka rekodi zetu zote za karatasi kwenye baraza la mawaziri la faili lililofungwa.

Faida

Hakutakuwa na faida yoyote ya kifedha iliyopewa mtoto wako kwa kushiriki katika utafiti huu. Ushiriki wa mtoto wako hautaathiri au kuchelewesha matibabu yao yaliyopangwa. Tutapeleka mtoto wako kwa kliniki inayofaa kwa utunzaji na msaada ikiwa ni lazima. Pia, habari unayotoa itatusaidia kuelewa vyema ukubwa wa ugonjwa sugu wa kupumua kati ya watoto walio na ugonjwa wa kupooza kwa ubongo

Hatari ya Kushiriki

Sisi si kubadilisha tiba yako iliyopangwa. Vipimo vya uzito wa mwili na uchunguzi wa mtoto hautaongeza hatari inayohusishwa na matibabu.

Haki ya kujiondoa

Unaweza kumwondoa mtoto wako kwenye masomo wakati wowote bila kutoa sababu yoyote ya kujiondoa. Kukataa au kujiondoa kwa mtoto wako kutoka kwa utafiti huu hakuathiri huduma ambazo mtoto wako anastahili, katika kituo hiki cha afya au vifaa vingine

Fomu ya idhini (taarifa ya idhini)

Mtu anayezingatiwa kwa utafiti huu hawezi kumkubali kwa sababu yeye ni mchanga (mtu chini ya miaka 18). Unaulizwa kutoa ruhusa yako ya kujumuisha mtoto wako katika utafiti huu.

Taarifa ya mzazi/mlezi

Nimesoma fomu hii ya idhini au habari ilinisomewa. Nimepata nafasi ya kujadili utafiti huu na wafanyikazi wa masomo. Nimekuwa na maswali yangu kujibiwa naye kwa lugha ambayo ninaelewa. Hatari na faida zimeelezewa kwangu. Ninaelewa kuwa ushiriki wangu na ule wa mtoto wangu katika utafiti huu ni wa hiari na kwamba naweza kuchagua kuiondoa wakati wowote.

Ninaelewa kuwa juhudi zote zitafanywa kuweka habari kuhusu mimi na kitambulisho cha kibinafsi cha mtoto wangu.

Sahihi/kidole gumba……. tarehe …….

Jina kahili…….

Nambe ya Simu…….

Iwapo takuwepo na swali lolote kuhusu utafiti huu, kuwa huru kuwasilianana na watu wafuatao kwa yakati za rasmi za kikazi:

MPELEZI MKUU:

Dkt. Ahmed Salma Omar

Post Graduate student in the Department of Paediatrics and Child Health

University of Nairobi

Simu: **0705036221**

Barua pepe: salmaomar@students.uonbi.ac.ke

MSIMAMIZI MKUU:

Prof. E. Prof E Maleche Obimbo. (MBChB, MMed, MPH (Epi), FPulm)

Professor of Paediatric and Respiratory Medicine,

University of Nairobi.

Simu: +254 020 2726300/+254 0202725102

Barua Pepe: dept-paediatrics@uonbi.ac.ke

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MBChB, MMed (Gastroenterologist)

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Dkt. Nyambura Kariuki

MBChB, MMed (Haemato-oncology)

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Regulatory Body

KNH-UON ERC

Simu: (254-020) 2726300 Ext 44102

Barua pepe: uonknh_erc@uonbi.ac.ke

Tovuti: www.erc.uonbi.ac.ke

Appendix3: Estimated Study Budget

Category	**Remarks**		**units**	**Unit cost in Ksh**	**Total in Ksh**
Development of Proposal	Drafts printing		1000 pages	5	5000
	Proposal Copies		10 copies	500	5000
Data collection	Research assistant		1	500 sh per questionnaire	20000
	stationary				500
	Case form printing		300 pages	5	1500
	Consent form printing		150pages	5	750
	Medical Equipment	Pulse-oximeter	2pieces	4000	8000
		stethoscope	2pieces	6000	12000
		MUAC tape	2pieces	200	400
		tape measure	2pieces	300	600
Thesis Write up	Computer services				20000
Data Analysis	Printing Drafts		1000pages	5	5000
	Statistician				25000
Thesis write up	Printing Thesis		10 copies	500	5000
Contingency funds					40000
TOTAL					**148,750**

APPENDIX 4: STUDY TIMELINES

Activity	Estimated time
Proposal Development and Presentation	January 2022
Submission of Proposal for Ethical Approval	March 2022
Ethical Correction and seeking permission	June 2022
Data Collection	July -November 2022
Data Analysis	November 2022
Thesis writing	November 2022

APPENDIX 5: ERC APPROVAL LETTER

UNIVERSITY OF NAIROBI
FACULTY OF HEALTH SCIENCES
P O BOX 19676 Code 00202
Telegrams: varsity
Tel:(254-020) 2726300 Ext 44355

KNH-UON ERC
Email: uonknh_erc@uonbi.ac.ke
Website: http://www.erc.uonbi.ac.ke
Facebook: https://www.facebook.com/uonknh.erc
Twitter: @UONKNH_ERC https://twitter.com/UONKNH_ERC

KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 726300-9
Fax: 725272
Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/221

9th June, 2022

KENYATTA NATIONAL HOSPITAL APPROVED 09 JUN 2022 KNH/UoN ERC P.O. Box 20723 - 00202, NAIROBI

Dr. Salma Omar Ahmed
Reg. No. H58/34053/2019
Dept. of Paediatrics & Child Health
Faculty of Health Sciences
University of Nairobi

Dear Dr. Ahmed,

RESEARCH PROPOSAL: PREVALENCE, CLINICAL PRESENTATION AND FACTORS ASSOCIATED WITH CHRONIC RESPIRATORY DISEASE AMONG CHILDREN WITH CEREBRAL PALSY AT KENYATTA NATIONAL HOSPITAL (P159/03/2022)

This is to inform you that KNH-UoN ERC has reviewed and approved your above research proposal. Your application approval number is **P159/03/2022.** The approval period is 9th June 2022 – 8th June 2023.

This approval is subject to compliance with the following requirements;

i. Only approved documents including (informed consents, study instruments, MTA) will be used.
ii. All changes including (amendments, deviations, and violations) are submitted for review and approval by KNH-UoN ERC.
iii. Death and life threatening problems and serious adverse events or unexpected adverse events whether related or unrelated to the study must be reported to KNH-UoN ERC 72 hours of notification.
iv. Any changes, anticipated or otherwise that may increase the risks or affected safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH-UoN ERC within 72 hours.
v. Clearance for export of biological specimens must be obtained from relevant institutions.
vi. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. Attach a comprehensive progress report to support the renewal.
vii. Submission of an executive summary report within 90 days upon completion of the study to KNH-UoN ERC.

Prior to commencing your study, you will be expected to obtain a research license from National Commission for Science, Technology and Innovation (NACOSTI) https://research-portal.nacosti.go.ke and also obtain other clearances needed.

Yours sincerely,

DR. BEATRICE K.M. AMUGUNE
SECRETARY, KNH-UoN ERC

c.c. The Dean, Faculty of Health Sciences, UoN
The Senior Director, CS, KNH
The Chairperson, KNH- UoN ERC
The Assistant Director, Health Information Dept., KNH
The Chair, Dept. of Paediatrics & Child Health, UoN
Supervisors: Prof. Elizabeth M. Obimbo, Dept. of Paediatrics & Child Health, UoN
Dr. Ahmed Laving, Dept. of Paediatrics & Child Health, UoN
Dr. Nyambura Kariuki, Dept. of Paediatrics & Child Health, UoN

APPENDIX 6: AUTHORITY TO COLLECT DATA LETTER

KENYATTA NATIONAL HOSPITAL
P.O. BOX 20723, 00202 Nairobi

Tel.: 2726300/2726450/2726550
Fax: 2725272
Email: knhadmin@knh.or.ke

Ref: KNH/PAEDS-HOD/48 Vol.II

Date: 29th June 2022

Dr. Salma Omar Ahmed
Reg.No.H58/34053/2019
Department of Paediatrics & Child Health
Faculty of Health Sciences
University of Nairobi

Dear Dr. Ahmed

RE: AUTHORITY TO COLLECT DATA IN PAEDIATRICS DEPARTMENT

Following approval of your Research proposal by, the KNH/UON-Ethics & Research Committee and subsequent filing of the Study Registration Certificate, this is to inform you that authority has been granted to collect data in ***Paediatrics Department***, on your study titled ***"Prevalence, clinical presentation and factors associated with chronic respiratory disease among children with cerebral palsy at Kenyatta National Hospital"***.

Kindly liaise with the Senior Assistant Chief Nurse, General wards for facilitation.

You will also be required to submit a report of your study findings to the office of the HOD, Paediatrics - KNH after completion of your study.

29/6/2022

Dr. Cyriaque Mbarubukeye
Ag. Head of Department, Paediatrics

Cc. SACN, Paediatric General Wards
SACN, Paediatric Specialized Wards/Units
✓ACN Incharge, Paediatric Outpatient Clinic - POPC 23

APPENDIX 7: RESPIRATORY RATES AND HEART RATES AND CENTILES BY AGE GROUP (32)

PERCENTILES(39)

Web Table 4: Proposed respiratory rate cut-offs (breaths/minute) based on centile charts

Age Range	1st centile	10th centile	25th centile	Median	75th centile	90th centile	99th centile
0 – 3m	25	34	40	43	52	57	66
3 – 6m	24	33	38	41	49	55	64
6 – 9m	23	31	36	39	47	52	61
9 – 12m	22	30	35	37	45	50	58
12 – 18m	21	28	32	35	42	46	53
18 – 24m	19	25	29	31	36	40	46
2 – 3y	18	22	25	28	31	34	38
3 – 4y	17	21	23	25	27	29	33
4 – 6y	17	20	21	23	25	27	29
6 – 8y	16	18	20	21	23	24	27
8 – 12y	14	16	18	19	21	22	25
12 – 15y	12	15	16	18	19	21	23
15 – 18y	11	13	15	16	18	19	22

Age ranges given in years (y) and months (m).

Web Table 5: Proposed heart rate cut-offs (beats/minute) based on centile charts

Age Range	1st centile	10th centile	25th centile	Median	75th centile	90th centile	99th centile
Birth	90	107	116	127	138	148	164
0 – 3m	107	123	133	143	154	164	181
3 – 6m	104	120	129	140	150	159	175
6 – 9m	98	114	123	134	143	152	168
9 – 12m	93	109	118	128	137	145	161
12 – 18m	88	103	112	123	132	140	156
18 – 24m	82	98	106	116	126	135	149
2 – 3y	76	92	100	110	119	128	142
3 – 4y	70	86	94	104	113	123	136
4 – 6y	65	81	89	98	108	117	131
6 – 8y	59	74	82	91	101	111	123
8 – 12y	52	67	75	84	93	103	115
12 – 15y	47	62	69	78	87	96	108
15 – 18y	43	58	65	73	83	92	104

Age ranges given in years (y) and months (m).
"Birth" refers to the immediate neonatal period.

APPENDIX8: CASE RECORD FORM

BIODATA:

1.Subject number: (Serial number) __ __ __ - __ __ __
2.Date of interview: _ _ / _ _ /20 _ _
3.Date of Birth(dd/mm/yy): _ _ / _ _ / _ _ _ _
4.Age: __ __ years __ __ months
5. Participant gender (circle as appropriate): M F
6.Details of caregiver:(Accompanying the child today)

a. Caregiver age: _____ years b. Caregiver gender (Circle): M F
c. Relationship to child: Mother Father Aunt Uncle
Sister Brother Grandmother Grandfather
Other If other specify _____

7.Maternal level of education: None [__] Primary [__] Secondary [__] Tertiary [___]
8. Who is the child's primary caregiver? (Who takes care of the child at home most of the time?)

a. mother b. Aunt c. Uncle
d. father e. Grandmother f. Grandfather
g. Nanny h. brother i. Sister
j. Other, Specify_____

9. Age of primary caregiver: __ __ years

10. Monthly income of parents/Care giver

a. Less than ksh5000
b. Ksh 5000-10000
c. Ksh 10-20000
d. More than ksh 20000

Location of interview

Out-patient unit. Y / N

a. Neurology clinic b. Gastroenterology clinic c. ENT clinic __

d. Pulmonology clinic e. POPC f. Occupational Therapy

g. Physiotherapy h. Other, specify: _____

In-patient unit_

General Paediatric ward __ ENT ward____

Paediatric Surgical ward __ Other, specify_____

RESPIRATORY SYMPTOMS

1. Does he/she cough on most days (4 or more days per week) for as much as 2 or more months of the year

   a. YES b.NO

2. Does he/ she have a congested chest or produce sputum on most days (4 or more days per week) for as much as 2 or more months of the year

   a. YES b. NO

3. Does he/ she have a wheeze on most days (4 or more days per week) for as much as 2 or more months of the year

   a. YES b.NO

1. Does he/ she have breathlessness on most days (4 or more days per week) for as much as 2 or more months of the year

   a. YES b. NO

2. Does he/ she snore
   a. YES b.NO

3. Does he/ she have sleep apnea or difficulty in breathing during sleep
   a. YES b. No

RISK FACTORS

4. Does he/ she have uncontrolled seizures
   a. YES b.NO

5. Does he/ she cough during meals?
   a. YES b.NO
6. Assessment of feeding difficulties in relation to food consistency (as reported by care giver)?
   a. Normal: no dysfunction detected
   b. Mild: mild feeding and swallowing dysfunction
   c. Moderate: feeds on well moistened feeds and has difficulties with liquids
   d. Severe: requires tube feedings
7. Does he/she have chest deformities or where chest braces?
   a. YES b.NO
8. The GMFCS classification of severity of motor impairment?

a. Level I: walks without limitations
b. Level II: walks with limitations in some settings
c. Level III: walks using a hand-held mobility device or uses wheelchair for greater distances

d. Level IV: uses a wheelchair in most settings
e. Level V: uses a wheelchair in all settings and may require additional support for the head or torso.

9. The Dysphagia outcome severity scale (as reported by care giver).

d. Levels 1 and 2: unable to take nutrition by mouth
e. Levels 3, 4, and 5: able to take nutrition by mouth, but requires thickened fluids and/or thickened or pureed foods
f. Levels 6 and 7: able to eat and drink a normal diet by mouth.

10. Number of hospital admissions for Respiratory illness in past 1 year_____
11. Duration of hospital admission in weeks prior to study

a. 1st admission……weeks
b. 2nd admission……. weeks
c. 3rd admission……...weeks

PHYSICAL EXAM

Anthropometrics (Current):

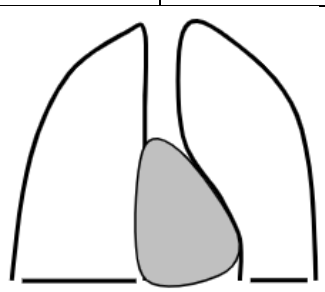
Weight: __ __ __. __kg (to one decimal). WAZ Score: _____ Height: __ __ __. __cm (to one decimal). HAZ Score: _____. WHZ score _____. MUAC _____cm

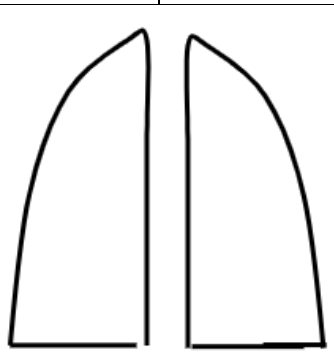
Vital signs at rest (Ensure child has been sitting for at least 10 min)

1.RR: _____bpm. ___ percentile
2.HR: _____bpm. ___ percentile
3.Temperature: _____°C.
4.SPO2: ___ ___%
Other signs:
1.Finger clubbing: Yes [___] No: [___]
2.Central colour (check tongue and gums): Pink [__] Dusky [___] Blue [___]
3.Flaring nostrils: Yes [__] No [___]
4.Chest indrawing: Yes [___] No [___].
If yes: Suprasternal/supraclavicular [___] Intercostal [___] Lower chest wall [___] Subcostal [___]

5.Noisy breathing: Yes [___] No [___].
If yes, specify: Wheeze [__] Stridor [__] Snoring [__] Chest rattles [__] Grunting [__]
6.Chest symmetrical: Yes: [___] No [___]. If abnormal, specify: Pigeon chest [___] Barrel shaped [___] Depressed sternum [___]

7.Chest auscultation and percussion findings:

Sign	Right lung		Front	Front	Left lung	
Breath sounds	Normal	Abnormal			Normal	Abnormal
Wheeze	Yes	No			Yes	No
Crackles	Yes	No			Yes	No
Air entry	Normal	Reduced			Normal	Reduced
Percussion	Resonant	Dull			Resonant	Dull

Sign	Right lung		Front	Front	Left lung	
Breath sounds	Normal	Abnormal			Normal	Abnormal
Wheeze	Yes	No			Yes	No
Crackles	Yes	No			Yes	No
Air entry	Normal	Reduced			Normal	Reduced
Percussion	Resonant	Dull			Resonant	Dull

.

Loud 2nd heart sound at pulmonary area	Yes	No

8.CHEST RADIOGRAPH REPORTING FORM (will be filled for those who have current radiological images at the time of study)

Names: ..... KNH No: __ __ __ __ __ __ __ __Date of CXR: __ __ / __ __ /__ __ __ __

Date of Birth: __ __ / __ __ /__ __ __ __ Age: __ __ yrs. __ __ mths.
Gender: M / F Study No: __ __ __ __ __ View: AP/PA

Quality of Radiograph: __Adequate __Sub-optimal but interpretable

__Poor (Uninterpretable) Specify *quality problem: __Expiratory __Over-exposed __Under-exposed. __Rotated. __Motion __Other, specify: ..... REPEAT CXR IF POOR QUALITY*

Abnormality Seen? Tick *No* or *Yes* *Normal* or *Abnormal*	**Details** ***Tick type of abnormality***	**Location of abnormality** ***Right: UL, ML, LL Left: UL, LingL, LL***	**% Of lungs with specific pathology** ***(To nearest 5%)***	**Radiologist observation (narrative)**
A. Airspace opacification _No. _Yes	Lobar, Segmental Patchy Other:	Right: Left:		
A. Opacification with volume loss _No. _Yes	Fibrosis/atelectasis Lobar, segmental, Linear (fibrotic streaks) Other:			
A. Interstitial patterns _No. _Yes	Reticular Reticulonodular Ground glass Nodules (small) Nodules (large)			

A. Lung volumes _Normal. _Abnormal	Volume loss Hyperinflation Asymmetry			
A. Tracheo-Bronchial abnormalities _Normal. _Abnormal	Peribronchial thickening Tramlines +/- Signet rings Large Airway narrowing Displaced trachea			
Abnormality Seen? Tick *No* or *Yes* *Normal* or *Abnormal*	**Details** ***Tick type of abnormality***	**Location of abnormality** ***Right: UL, ML, LL Left: UL, LingL, LL***	**% Of lungs with specific pathology** ***(To nearest 5%)***	**Radiologist observation (narrative)**
A. Perihilar areas & Major Bronchi _Normal. _Abnormal	Peri-hilar LN Increased bronchovascular markings			
A. Pleura _Normal. _Abnormal	Pleural effusion Pleural thickening		NA	
A. Cardiac _Normal. _Abnormal	Cardiomegaly Filling of pulmonary bay Other…….		NA	
A. Mediastinum _Normal. _Abnormal	Specify:		NA	
A. Other pathology, specify				

A. Overall extent of pathology	__ __ % of right lung abnormal	__ __ % of left lung abnormal	__ __ % of whole lung abnormal	
A. Radiologic Diagnosis _Normal chest _Abnormal chest (Fill next box)	Principal Pathology (predominant)	Non-principal Pathology	Additional observation	Conclusion: (see list below*)

Breathe Poa: Chest radiograph form. Version 1.1 March 2021. Prepared by E Maleche Obimbo (MBChB, MMed, MPH (Epi), FPulm)

*Differentials for Chronic Lung Disorders: Chronic/persistent consolidation (pneumonia); Lung fibrosis/atelectasis; Interstitial lung disease; Bronchiectasis; Obliterative bronchiolitis; Hilar lymphadenopathy; Lung masses; Lung cavitation; Pleural effusion; Pleural peel/thickening; Emphysema; Congenital lung abnormalities

APPENDIX 9: PLAGARISM REPORT

PREVALENCE, CLINICAL PRESENTATION AND FACTORS ASSOCIATED WITH CHRONIC RESPIRATORY DISEASE AMONG CHILDREN WITH CEREBRAL PALSY AT KENYATTA NATIONAL HOSPITAL

ORIGINALITY REPORT

15%	10%	10%	3%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	Fitzgerald, D.A.. "Assessing and managing lung disease and sleep disordered breathing in children with cerebral palsy", Paediatric Respiratory Reviews, 200903 Publication	2%
2	www.frontiersin.org Internet Source	1%
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