

MASTERS DEGREE-DISSERTATION

MASTERS OF SCIENCE MSc – CLINICAL
EPIDEMIOLOGY

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THE OUTCOMES OF CHILDREN WITH CEREBRAL PALSY AND UPPER AIRWAYS OBSTRUCTION AT RED CROSS WAR MEMORIAL CHILDREN'S HOSPITAL

Reneva Petersen

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Thesis presented in partial fulfilment of the requirements for the degree of Master of Clinical Epidemiology in the Faculty of Health at Stellenbosch University.

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December 2016

Declaration

I, the undersigned, hereby declare that the work contained in this assignment is my original work and that I have not previously submitted it, in its entirety or in part, at any university for a degree.

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The outcomes of children with cerebral palsy and upper airways obstruction at Red Cross War Memorial Children's Hospital

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Abstract

Aim

The aim of this study was to describe the prevalence and outcomes of a cohort of children with cerebral palsy and upper airways obstruction admitted over a five year period to a single institution in Cape Town, South Africa.

Methods

A retrospective cohort study was conducted of all children between the ages of 2 and 18 years admitted with cerebral palsy during the study period. Information about the classification and severity of cerebral palsy, investigation and management of upper airways obstruction and patient outcomes were collected.

Results

Three hundred and thirty children with cerebral palsy were admitted over the five year period. The prevalence of UAO in the cohort during the study period was 8.8% ($n=29$). The median age on admission of children with UAO was four years. (IQR: 2, 6)

Six (20.7%) children with upper airways obstruction died during the study period as compared to 30 (9%) children without upper airways obstruction. Feeding complications and severe physical disability were found to be associated with upper airways obstruction ($p=0.0000$) as well as study mortality ($p=0.0004$)

Significance

This report highlights the contribution of UAO to respiratory compromise in children with cerebral palsy.

Word count: 191

What this paper adds

The prevalence of upper airways obstruction in a cohort of hospitalised children from Africa with cerebral palsy is 8.8%.

Children from our cohort present at a younger age compared to other reports.

Feeding complications and severe physical disability are associated with UAO in this cohort of children with CP.

Background and significance

Cerebral palsy (CP) has been defined as a “group of disorders of the development of movement and posture, causing activity limitation that is attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour; by epilepsy, and by secondary musculoskeletal problems.”¹ While the prevalence of CP has been reported to be around 2-2.2/1000 live births in developed countries, it is estimated that this may be as high as 10/1000 in Africa.² Respiratory complications are reported to be significant contributors to morbidity and mortality in children with cerebral palsy and other developmental disabilities.³

Children with CP are at increased risk for obstructive sleep apnoea and upper airways obstruction (UAO).³⁻⁶ This is thought to be the result of mid-facial and gastro intestinal abnormalities as well as the underlying low neuromuscular tone of the upper airway which predisposes to upper airway compromise.^{3,7} Additional potential contributors to UAO during sleep in children with CP are tonsillar and adenoidal hypertrophy, subglottic stenosis, laryngomalacia, tracheomalacia, and obesity.⁴

Common symptoms of upper airways obstruction include snoring, noisy breathing, stridor and obstructive sleep apnoea. These are believed to be underreported by parents, particularly in children with other significant medical conditions such as CP.⁸ Children may also present with complications of chronic UAO including pulmonary hypertension and cardiac failure.

The acute management of severe UAO may necessitate admission to an intensive care unit while chronic UAO may result in long term respiratory insufficiency, secondary cardiac complications and mortality. Chronic UAO is an important contributor to poor quality of life in both neurotypical as well as children with developmental disabilities such as CP.⁶

The management of UAO in children with CP is complex due to the multifactorial nature of the aetiologies. Adenotonsillectomy is generally recommended as an appropriate first-line intervention.⁷ When severe airways obstruction persists following adenoidectomy and tonsillectomy, more invasive surgical procedures may be attempted, for example uvulopalatopharyngoplasty, maxillofacial procedures or tracheostomy, for definitive airway management.⁹⁻¹¹ Non-invasive management in the form of continuous nasal positive pressure or home oxygen have also been utilized to administer respiratory support where a decision has been made that surgical intervention is not appropriate.⁷

There is a paucity of data to guide current best practice in the management of children with CP and severe UAO. The available publications present reviews of practices in first world settings and report mainly on small groups, often mixed with other disabilities. These studies are not able to report on health or quality of life outcomes for children with CP. The author could find no reports about the prevalence, severity and management of UAO in children with CP from developing countries or resource limited settings.

The aim of the study was to report the prevalence of UAO in a cohort of children with CP admitted to a South African hospital over a five year period. Furthermore, we aimed to describe the characteristics of this group and to explore possible associations between the nature and severity of CP, their comorbidities and outcomes of the children during the study period.

Methods

A retrospective cohort study was conducted of all children with CP admitted to Red Cross War Memorial Children's Hospital (RWMCH), Cape Town, South Africa, during the study period of January 2009 to December 2013. Red Cross War Memorial Children's Hospital is one of two tertiary institutions in the Cape Town metropole and is a designated referral hospital for children with neuro-disabilities from the metro west area, which includes a paediatric population in excess of 500,000.¹² Outcome data was collected until December 2014 to allow for at least one year follow up for children who were admitted in 2013.

Participants

All children with a diagnosis of CP between the ages of 2 and 18 years who were admitted to any ward at RWMCH and who were documented to have a diagnosis of UAO between 1 January 2009 and 31 December 2013 were included in the study. Children with known craniofacial disorders including craniosynostosis or cleft palate were excluded. Children for inclusion were identified from the hospital admission data based on ICD 10 codes for cerebral palsy. Data collection was performed by the principal investigator who is a developmental paediatrician.

Demographic and clinical information were collected on all patients with CP during the study period. Data included the aetiology of CP, classification of CP, as well as the presentation, investigation and management of UAO and mortality during the study period. Nutritional assessment was performed by plotting admission weight for age using the Life Expectancy Project growth charts for children with cerebral palsy.¹³

Statistical analysis

Statistical analysis was performed using the STATA 13 programme¹⁴ using continuous and categorical variables.

Categorical variables were reported as percentages. Numerical variables, which were not normally distributed, were reported as median with interquartile range. Study mortality was reported as a relative percentage. Comparison between groups was performed using the Fischer's exact test. A p value < 0.05 was considered significant.

A multivariable logistic regression analysis for the outcome mortality was carried out. The factors studied were entered into the model as independent variables provided they were associated in the univariate analysis (with $p < 0.05$). Forward stepwise procedures were used to construct the model (significance level for entry or removal was 5%). Multivariable logistic regression analysis was also performed to determine possible predictors for UAO in the cohort.

Ethical considerations

Ethical approval was obtained from University of Cape Town, Human Research Ethics Committee prior to commencement of any study activities. HREC/REF: 916/2014

As the study was retrospective in nature and involved no risks to patients, permission was obtained from the Human Research Ethics Committee to waive individual signed consent. Patient data was anonymised to ensure confidentiality.

Results

A total of 330 children with cerebral palsy were admitted during the study period. There was a male predominance amongst the children admitted ($n=187$, 56.7%). In keeping with other reports from sub-Saharan Africa, the most common reported aetiology for cerebral palsy in the cohort were complications in the perinatal period ($n= 177$, 53.6%).^{15, 16} The majority of children had severe spastic cerebral palsy (Spastic CP = 86.7% and Gross Motor Functional Classification [GMFCS] scale IV and V= 69%) (Table I).

Children with upper airways obstruction

Twenty nine of the children with cerebral palsy were documented to have signs and symptoms of upper airways obstruction as admission diagnosis or major contributing factor to admission (prevalence of UAO=8.8 %). Children with UAO appeared to have more significant physical disability compared to the overall cohort (96% were classified as GMFCS IV and V as compared to 66% [$p=0.01$] of the overall cohort) and presented with a higher frequency of documented feeding complications compared to children without UAO ($p=0.002$) (Table I). Feeding complications reported in the cohort included gastro oesophageal reflux, silent aspiration as well as incoordinate swallowing.

The median age of children admitted with CP and UAO was four years (IQR: 2- 15years). The median duration of admission was eight days (IQR: 1-50 days). The median admission weight was 10 kg. (IQR:6.8-30kg). Twenty-one children (72%) with UAO were assessed to have normal nutritional status. Seven children (24%) were classified as underweight for age and only one child (3%) was classified as overweight.

Upper airways obstruction: investigation and management

The most common presenting symptoms on history included snoring in 14 children (48.3%) and noisy breathing in six children (20.6%). There were no parental or caregiver report of awake obstructive apnoea but nine children (31%) presented with a history of obstructive sleep apnoea (Table II). Fourteen children (48%) were known to the institution with chronic upper airways obstruction prior to hospital admission of which seven (50%) had been investigated previously in the form of nasal endoscopy and seven (50%) had been managed by adenoidectomy or tonsillectomy.

A limited number of investigations were done to determine the cause and severity of UAO in the cohort. Two children (6.9%) had radiographs of the posterior nasal space on admission, which confirmed adenoidal

hypertrophy in both cases. Three children (10.3%) had electrocardiograms reported as normal, and eight children (27.6%) were assessed by overnight sleep oximetry. Severe sleep apnoea was confirmed in three children (37.5%) on sleep oximetry. Fourteen children (48%) had nasal endoscopy done during admission. Findings on endoscopy included adenotonsillar hypertrophy in five children (35.7%), reflux related changes in two children (14%), vocal cord paralysis in two children (14%) and multifactorial changes in three children (21%). In two children (14%), endoscopy findings were reported as normal. Twenty-two children (75%) were reviewed by an otolaryngologist during the admission. None of the children in the study were assessed with formal polysomnography as this was not available at our institution during the study period.

The final cause of UAO was ascribed to multifactorial contributors in 19 children (65.5%). Adenoidal or tonsillar hypertrophy was considered to be a contributing factor to UAO in only five children (17%). Other causes of UAO reported in the cohort included one child (3.4%) with vocal cord paralysis, one (3.4%) with laryngo-tracheobronchitis and one (3.4%) with laryngomalacia. The multivariate logistic regression analysis model found feeding complications and severe physical disability to be associated with UAO (Table IV). In 11 children (37.9%), the UAO was managed by continuous insufflation of the pharynx (CIP) (Table III). The mean (SD) duration of CIP placement was four days (IQR=2- 8 days). In contrast only three children (10.3%) were managed by continuous nasal positive airway pressure and four children (13.8%) required mechanical ventilation. Six children (20.9%) were admitted to the intensive care unit with median admission duration of 3.5 days (IQR: 2-4 days). In 18 cases (66.6%), a decision was made in discussion with families to offer supportive medical treatment only. Placement of a surgical airway in the form of a tracheostomy tube was performed on four children (13.8%) during first admission for UAO. In total, nine (31%) children were managed with tracheostomy tube placement during the study period.

Thirty-six children with CP died during the study period, of which six were children with UAO. Mortality during the study period for children with UAO was 20.7%. Severe physical disability and feeding complications were found to be associated with mortality in the multivariate regression analysis model. Three children had tracheostomies in situ when they died. Mortality data from medical records could not confirm final cause of death in these children as the majority of children ($n=4$, 66.6%) died at home. The median age at death was seven years and five months. The range was from three years and five months to 14 years and six months. Twelve children (41%) with UAO were readmitted to hospital in the year following their first admission for continuing UAO complaints. Three of these children required readmission to the intensive care unit. (Children who were managed conservatively were more likely to be readmitted with upper airways complaints ($p=0.008$).

Discussion

Our study reports a high prevalence of UAO amongst a cohort of hospitalised children with CP in Cape Town, South Africa as well as a high mortality rate for this group. This is the first study to document the prevalence and outcomes of UAO in hospitalised children with CP in Africa. The inclusion of all children with CP admitted over the study period presents supportive information as to potential contributory factors to UAO in children with cerebral palsy in this resource limited setting.

Many of the children in our cohort had a history of chronic symptoms of UAO and yet limited investigations had been done to evaluate the cause or severity of the UAO prior to study admission. A study by Wilkinson et al.¹⁷ in Australia reported a similar lack of investigations in their cohort. Most of the children in this study were reported to have had gradual onset of symptoms but with limited investigations to assess aetiology or severity.

A study by Shintani et al. in 1997¹⁸ investigated UAO in an outpatient based cohort of Japanese children with CP by means of a survey and reported symptoms of chronic UAO in 20% of a cohort of 223 children. The study did not report outcomes of the children or investigations that had been performed but did report pharyngeal collapse as the most frequent cause of UAO.¹⁸ Our findings support concerns that the prevalence and severity of UAO in children with CP may be underestimated by parents and in routine clinical practice.^{8, 17}

In twenty four percent of our cohort the initial surgical management of UAO was adenotonsillectomy. However, nine children (31 %) required formal airway management in the form of tracheostomy tube placement. The tracheostomy home care program was pioneered at our institution in 1989 and has enabled children with surgical airways to be cared for safely at home in a resource limited setting where the cost of home oxygen or provision of positive pressure airways support devices is not feasible.¹⁹ In a recent study conducted over 6 years, Kontorinis et al.⁷ from the United Kingdom investigated the progression of UAO in 15 children with CP admitted to their unit. In this cohort children presented at a mean age of eight years and tracheostomy placement was performed in 53% of the cohort at mean age of 11.6 years. They concluded

that UAO in children with CP progressed with age, and postulated that deterioration in oropharyngeal tone was a major contributor to progression of UAO.

In contrast, children in our study presented at a much younger age (median age of four years) and had a lower rate of adenotonsillectomy (24% vs 63.6%) as well as tracheostomy placement (31% vs 53%). The lower rate of tracheostomy tube placement might be accounted for by the younger age of our cohort. It is possible that children in the South African context present at a younger age with severe UAO because of the increased severity of CP in our setting.

The high prevalence of respiratory infections as a cause of hospital admission in developing countries could also have a role as contributing factor to the burden of disease in this cohort.²⁰ In addition the large number of cases (62%) where a decision was made in favour of conservative management as opposed to tracheostomy placement may account for the lower proportion of tracheostomy placements in our study.

Risk factors for UAO in children with CP identified from our regression analysis include feeding complications and severe disability. (GMFCS IV and V) The unusual finding of reduced risk for UAO in children with epilepsy in this cohort could be explained by possible biased admission of children with poorly controlled seizures to our institution as the referral centre for both epilepsy and cerebral palsy.

These findings have potential implications for clinical management by suggesting subgroups of children who are at high risk of UAO. This could support clinical recommendations for routine review of UAO symptoms at follow up visits as well as screening for obstructive sleep apnoea in children in GMFCS IV and V, particularly those with comorbidities of epilepsy and feeding complications. Recommendations from the research presented by Kontorinis et al.⁷ included suggestions that UAO should also be considered in children as they enter adolescence and screening and management of upper airway symptoms should be included in care plans for adolescents and adults with CP.

Severe physical disability (GMFCS IV and V) and feeding complications were found to be associated with mortality in this cohort from Africa. This finding is in keeping with international data and emphasizes the high risk for mortality in our local setting.²¹ Cohorts from Africa have reported a higher frequency of children with severe physical disability compared to other settings which may place our children at increased risk for poor quality of life and early mortality.^{16, 22}

In resource limited settings, access to subspecialist services, surgical airway management or non-invasive airway support is limited. The appropriate management of children with CP, severe physical disability and UAO presents a challenge. Furthermore adult services for patients with CP are not well developed in South Africa and the growing number of adolescents with surgical airways remains without any designated adult service providers to take over their care. The effect on family quality of life and economic consequences of current management strategies remain to be seen.

Limitations

The study is limited by its retrospective design and small study number. The study was conducted in a tertiary hospital in a resource constrained setting in Africa. Our results may reflect outcomes in a more severe cohort with cerebral palsy and hence may not be generalizable to children with cerebral palsy in other settings. As the study reports children admitted to hospital, study findings may also not accurately reflect the burden of UAO for the population of children with CP in Cape Town. Children with severe UAO may have died before reaching hospital and milder cases in the community may remain undiagnosed.

Conclusion

This study highlights the contribution of UAO to respiratory compromise and mortality in children with cerebral palsy. Symptoms of UAO may be missed by parents or caregivers and disease severity may be underestimated by clinicians. Investigation and management of UAO requires resources in the form of access to subspecialist services and multidisciplinary team support. This is challenging in resource limited settings particularly in the absence of clear clinical guidelines. Tracheostomy tube placement is used as definitive airway management both internationally and locally. However, information about outcomes in accordance with International Classification of Functioning, Disability and Health core sets, especially with regards to quality of life of affected children and caregivers, is lacking internationally and locally. Further research into this important clinical problem is indicated.

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Table I: Descriptive statistics of children with CP				
	Children with CP* Without UAO <i>n</i> =301 (%)	Children with CP and UAO <i>n</i> =29 (%)	Odds Ratio with 95% CI	p value
Sex			0.9 (0.4-2)	0.82
Male	170 (56.6)	18 (58.6)		
Aetiology				
Antenatal	17(5.7)	2(6.9)		
Perinatal	162(53.8)	15(51.7)		
Postnatal	69(22.9)	6(20.7)		
Unknown	37(12.2)	6(20.7)		
Incomplete data	16(5.3)			
Distribution			0.3 (0.1-1.5)	0.159
Bilateral	272(90.4)	29 (100)		
Unilateral	29(9.6)			
Predominant tone abnormality				
Spastic	261(86.7)	25 (86.2)		
Dystonic	16(5.3)	3 (10.3)		
Mixed	18(6)	1 (3.5)		
Hypotonic	3(1)			
GMFCS classification			14 (1.8-105)	0.01
I-III	61(20.2)	1(0.5)		
IV-V	200(66.5)	28(96.5)		
Epilepsy	221(73.4)	14 (48.3)	3.3 (1.5-7.1)	0.003
Visual impairment	89(29.6)	12 (41.4)	0.6 (0.3-1.4)	0.25
Hearing impairment	16(5.3)	4 (13.8)	0.4 (0.1-1.2)	0.09
Musculoskeletal complications	144(47.8)	14 (48.3)	1.3 (0.6-2.7)	0.56
Feeding complications	125(41.5)	21 (72.4)	3.7 (1.6-8.6)	0.002
Gastrostomy tube	96(31.9)	18 (62.1)	0.6 (0.4-1.2)	0.138
Mortality	30 (9)	6 (20.7)	2.4 (0.9-6.2)	0.085

Of the 330 children identified during the study period from ICD 10 codes as admissions with CP, 301 children (91%) had *CP without UAO and 29 children (9%) had CP with UAO
 CP, cerebral palsy; UAO, upper airway obstruction; CI, confidence interval; GMFCS, Gross Motor Function Classification System; NCPAP, nasal continuous positive airway pressure; CIP, continuous insufflation of pharynx ; IPPV, intermittent positive pressure ventilation
 Unknown, no cause after full investigation; Incomplete data, incomplete medical records

Table II: UAO symptoms, investigation and management	
	Children with CP and UAO <i>n</i> =29 (%)
Symptoms of UAO	
Snore	14 (48.3)
Stridor	9 (31.0)
Noisy breathing	6 (20.6)
Sleep apnoea	9 (31.0)
Investigations for UAO	
Posterior nasal space x-ray	2 (6.8)
Sleep oximetry	8 (27.6)
Awake nasal endoscopy	14 (48.3)
Respiratory support provided during admission	
NCPAP	3 (10.3)
CIP	11 (37.9)
IPPV	4 (13.8)
Management	
Adenotonsillectomy	7 (24.1)
Tracheostomy	9 (31.0)
Supportive care	18 (62.1)
Outcomes	
Mortality	6 (20.7)
Readmission for UAO	12 (41.3)

CP, cerebral palsy; UAO, upper airway obstruction; NCPAP, nasal continuous positive airway pressure; CIP, continuous insufflation of pharynx ; IPPV, intermittent positive pressure ventilation

Table III: Respiratory support of children with UAO		
	<i>n</i> (%)	Duration in days, median (IQR)
Admission	29 (100)	7 (1-50)
Respiratory support		
NCPAP	3 (10.3)	1 (1-3)
CIP	11 (37.9)	4 (2-8)
IPPV	4 (13.8)	2.5 (1.5-3)
ICU admission	6 (20.7)	3.5 (2-4)

UAO, upper airway obstruction; IQR, interquartile range; NCPAP, nasal continuous positive airway pressure; CIP, continuous insufflation of pharynx; IPPV, intermittent positive pressure ventilation; ICU, intensive care unit

Table IV: Multivariate logistic analysis for mortality and UAO in children with CP				
	Crude <i>p</i> value	Crude OR	Adjusted OR	95% CI
Mortality				
Feeding problems	0.0003	3.8	2.9	1.36-6.4
Severe physical disability (GMFCS IV and V)	0.002	4.8	2.5	0.8-7.7
UAO				
Feeding problems	0.01	3.7	2.7	1.1-6.8
Severe physical disability (GMFCS IV and V)	0.002	14.1	10.1	1.3-79.6
Without Epilepsy	0.003	3.3	4.4	1.9-9.9

UAO, upper airway obstruction; CP, cerebral palsy; GMFCS, Gross Motor Function Classification System; *p* value, statistical significance; OR, odds ratio, CI, confidence interval

APPENDIX A

Author Guidelines for contributors to *Developmental Medicine & Child Neurology*

Updated May 2013

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- a) Editorial review
- b) After acceptance
- c) After publication

5. Style points

1. Good publication practice

The journal follows the guidelines of the International Committee of Medical Journal Editors (www.icmje.org) and Wiley Blackwell's Best Practice Guidelines on Publication Ethics (www.wiley.com/bw/publicationethics/). In particular, please note the following points.

a) Authorship

Our criteria for authorship are based on the International Committee of Medical Journal Editors guidelines. More information can be found here: www.icmje.org

Credit for authorship should be based on

1. Substantial contributions to research design, or the acquisition, analysis or interpretation of data;
2. Drafting the paper or revising it critically;
3. Approval of the submitted and final versions.

The corresponding author must state that all the authors have read the manuscript and agreed to its being submitted for publication. The covering letter should state that all individuals listed as authors meet the appropriate authorship criteria, that nobody who qualifies for authorship has been omitted from the list, that contributors and their funding sources have been properly acknowledged, and that authors and contributors have approved the acknowledgement of their contributions. The covering letter should include a short description of each author's contribution and should state whether he or she had complete access to the study data that support the publication.

Contributors who do not qualify as authors should be listed, and their contribution described, in an acknowledgement section at the end of the article. When authors are publishing on behalf of a group, the membership of the larger authorship group should be listed in an appendix, or may be shown in a separate display box. Up to ten authors may be included on the title page.

b) Reporting guidelines:

For Original Articles, Systematic Reviews and Meta-analyses, the Editors and Editorial Board require that authors follow the guidelines of the Equator network when reporting research methods and findings (www.equator-network.org/library/) and the AACPDM Guidelines where appropriate for Systematic Reviews of Treatment Interventions (see **Summary document**)

Submissions must be accompanied by the appropriate checklist, fully completed with page numbers where applicable. Please select the most suitable checklist from the following and download the appropriate checklist:

Systematic Reviews or Meta-analyses: PRISMA: (Click [here](#))

Systematic Reviews or Meta-analyses following AACPDM Guidelines: Please complete both the PRISMA checklist and the AACPDM checklist: (Click [here](#))

Randomised controlled trials: CONSORT guidelines: (Click [here](#))

Observational studies: STROBE guidelines: (Click [here](#))

Other types of study e.g. Diagnostic Accuracy: please visit the Equator website www.equator-network.org/library/

For Editorials, Commentaries, Book Reviews, other types of Review (i.e. not Systematic), Case Reports, Letters and Clinical Insights, no checklist is required.

c) Clinical trial registration

If publishing the results of a clinical trial, please include the clinical trial registration number. All trials should be registered in a publicly accessible database. Please upload a copy of the trial protocol as a supplementary file.

d) Duplicate publication

Authors should declare that the submitted work and its essential substance have not previously been published and are not being considered for publication elsewhere. Manuscripts must not be submitted simultaneously to another journal. All suspected cases of multiple submissions or redundant publication will be subject to investigation.

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Ethical approval Authors of research articles should demonstrate that the research has been approved by a named research ethics committee, that the committee's recommendations have been adhered to, and that written informed consent for participation and publication has been obtained.

Please include a statement in the text of your paper to indicate that ethical approval has been given and give the name of the body (research ethics committee, institutional review board etc.) that approved the study.

If the institution's research ethics committee did not consider that their approval was needed, this should be stated in the text.

Consent Please indicate in the text that patients or their carers have given informed consent to the research and to publication of the results.

If recognizable photographs or verbal descriptions of an individual are used in an article, written consent from the appropriate person(s) for publication must be submitted to, and kept by, the author. **All** case reports and clinical photographs require consent. Names, initials, or any other means of identification should not be shown on any photograph. Please use the Consent Form available from the DMCN submission site (**Click here**)

f) Funding

All sources of funding or support should be noted in the acknowledgements section of the manuscript (including grants from funding bodies, sponsorship or grants from commercial organisations, and donation of materials). During the online submission process, you will need to clarify the involvement of any funder in study design, data collection and analysis, and manuscript preparation. It is mandatory that a DMCN Disclosure Form is completed when your paper is submitted, and your paper will not be sent for review until we have received your form.

g) Disclosures

Disclosures of interest **must** be made during the online submission process for authors and during the review process for referees. Please note that the corresponding author submitting on behalf of co-authors must obtain full information from each author prior to submission and complete the DMCN Disclosure Form which can be found on the submission site (click **here**). All authors and referees must provide details of financial interests in any company or institution that might benefit from the publication of the article. Authors and referees should also declare any other potential competing interests that readers or editors might consider relevant to the research submitted for publication. In making disclosures, please consider these three areas (please refer to http://www.icmje.org/ethical_4conflicts.html for further information):

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3. Any personal, professional, political, institutional, religious, or other associations that a reasonable reader would want to know about in relation to the submitted work.

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3. Presentation and formatting of your paper

a) Maximum length requirements

Article type	Abstract	“What this paper adds”	Text words (excl refs)	References	Figures/ tables
Original article	Structured, 200 words	1 to 5 points	3000	25	4
Systematic review	Structured, 200 words	1 to 5 points			<input type="checkbox"/> As appropriate <input type="checkbox"/>
Other review	Unstructured, 150 words	1 to 2 points	3000	25	4
Case report	Unstructured, 150 words	1 to 2 points	1500	15	2
Letter to the Editor	None	None	750	5	1
Editorial, commentary, opinion	None	None	700	5	0
Clinical Insights	None	None	200-300	2	1

b) All papers

General: Use single-line spacing for all parts of the submission. Include tables and figure legends in your main article file, after the references. Submit figures (illustrations) as separate files, as described below. Name all files using the surname of the first author (e.g. Smith.doc, Smith fig1.tif, etc.).

Title page Include the title of the paper, authors' names, main appointments and primary affiliations (i.e. one affiliation only per author), and word count. Identify the corresponding author and give his or her postal address, fax number, and e-mail address.

Abstract On the second page of original articles and systematic reviews, provide a full structured abstract of no more than 200 words, with the following headings: Aim; Method, Results, Interpretation. Where relevant the Method section should follow Equator guidelines and should include means (sd) or medians and sex for study and control groups, definition of clinical characteristics, entry criteria for study, assessments used, duration and frequency of intervention, and timing of outcome assessments. Where relevant “Results” should follow Equator guidelines and should summarize significant results with statistical values, including negative findings if related to the study hypothesis. Non-significant trends should not be noted in the abstract.

Non-systematic reviews and case reports should have a non-structured abstract without headings of up to 150 words, covering the aims, method, results, and conclusions of the study.

On the abstract page, also provide a shortened form of the title (up to six words) for use as a running foot.

'What this paper adds' All original articles and systematic reviews should have a section 'What this paper adds' after the abstract. This should comprise up to five bullet points of 5-10 words each, summarizing the new knowledge contributed by the study. Other articles should have one or two similar bullet points.

c) Original articles

Articles should comprise an introductory section (but not headed 'Introduction'), followed by 'Method' (with optional subheadings, such as 'Participants' [rather than 'Subjects'] and 'Statistical analysis'), 'Results', and 'Discussion' sections. The Discussion section should include the limitations of the study. Subheadings should otherwise be kept to a minimum.

Papers longer than 3000 words, such as those reporting randomized controlled trials, may be published at the Editors' discretion.

Randomised controlled trials should include a short trial protocol as supplementary information.

d) Reviews

We publish two types of review. One is a fully detailed comprehensive review of a subject, such as a systematic review, with full referencing and a word-count appropriate to the topic and amount of material to be covered. The other is intended to be a more personal view providing the reader with up-to-date information about the subject in question in a relatively brief format, referring to significant international papers but not forming a comprehensive overview of the literature. Authors are advised to refer to the paper by **Grant et al: A Typography of Reviews published in Health Information and Libraries Journal, 2009, 26:2**, before submitting a review paper to DMCN.

e) Case reports

DMCN accepts case reports only if they significantly add to our understanding of a condition or present a novel finding. They should comprise an introductory section as above, followed by the 'Case Report', then a 'Discussion' section.

f) Letters to the Editor

Letters are published at the Editors' discretion. They may comment on a published paper, or raise issues that are new to DMCN. In the case of letters commenting on a published paper, normally the author of that paper will be invited to comment on the letter, with both letter and comments being published in the same issue.

g) Clinical Insights

Clinical images with a description of approximately 200-300 words and one or two references that fit within a printed page will be considered for publication in DMCN. The images can include photographs of patients, X-rays, EEGs, and other investigations, videos, or other material considered appropriate by the Editors. Images should adhere to the guidelines below (Figures). If a video is submitted please submit 2-4 illustrative stills that can be printed in the Journal. Please also see 'Approval and Consent' above.

h) References

The Vancouver style is used, as recommended by the International Committee of Medical Journal Editors. Cite using a superscript number in the text, with a numerical list of references at the end of the paper presented in order of citation. Cite only peer-reviewed, published material. The journal does not recognize abstracts or submitted (as opposed to accepted, or 'forthcoming') papers as proper citations; such material should not be listed with the references but cited only in text, followed by '(personal communication)'.

List all authors unless more than six, in which case list the first three followed by 'et al', using Index Medicus abbreviations for journal names (see www.nlm.nih.gov/tsd/serials/lji.html). Order and punctuate bibliographic information as follows, omitting issue month and number unless needed to distinguish issues. For additional citation formats, adapt appropriate examples from the NLM's *Citing Medicine* (www.ncbi.nlm.nih.gov/bookshelf/br.fcgi?book=citmed).

Abrams RA, Tsai AM, Watson B, Jamali A, Lieber RL. Skeletal muscle recovery after tenotomy and 7-day delayed muscle length restoration. *Muscle Nerve* 2003; 23: 707–14.

Auvin S, Joriot-Chekaf S, Cuvellier J-C, Vallée C. Familial alternating hemiplegia of childhood or channelopathy? [letter]. *Dev Med Child Neurol* 2004; 46: 500.

Mesibov GB, Kuncle L, Schopler E. Asperger syndrome or high functioning autism? Current issues in autism. New York: Plenum Press; 1998.

Finnegan LP, Kaltenbach K. Neonatal abstinence syndrome. In: Hoekelman RA, Nelson NM, editors. Primary pediatric care. 2nd ed. St. Louis: Mosby Yearbook, Inc.; 1992. 1367–78.

For references to online sources, supply the author names, full title, and full URL including the date on which the site was accessed.

i) Figures and tables

Note that the Editors may decide that large figures or tables should be published online-only

Tables, figure legends and short appendices Set out on separate pages at the end of (and as part of) the main document, after the references.

Tables and appendices to be published online only: Present as separate files in Microsoft Word or Rich Text format.

Figures (e.g. illustrations, charts and photographs): Present electronically as separate files (not in the main text of the article). Guidelines about acceptable file formats and illustration preparation are provided at authorservices.wiley.com/bauthor/illustration.asp

Please label radiographs, CT, or MRI scans with left [L] and right [R], and if appropriate with anterior [A] and posterior [P]. Areas of interest should be marked with an arrow. For EEGs please indicate the gain, timescale, and lead position.

Graphs should be as simple as possible, not three-dimensional, and not framed. Shading should be white, black, or strong hatching, not grey. No background lines should be used (except for bars and axes).

Colour If colour printing of figures is essential for their comprehension; please indicate this in the covering letter. There is normally a charge to the author for printing in colour. It is possible to publish a figure in black and white in the print version of the issue but in colour in the online version at no extra charge. Please refer to the Colour Work Agreement (CWA) form for more information.

Figures should be numbered in order in the text. A caption must be supplied for each figure. The caption should not repeat what is written in the text material and should follow the Journal style (please refer to recent issues for examples). All captions should be placed in a list at the end of the main document. Please remember to supply captions for figures that will be published electronically. The caption must describe all labels in a figure. For images, the caption should include the type of image, its plane, whether or not contrast material was used, the pulse sequence information for MR images and the features to be observed by the reader. However, full details of the MR sequences should be described in the methods section, not in the caption.

j) Statistical reporting

The Editors advise reading “Statistical recommendations for papers submitted to *Developmental Medicine & Child Neurology*” (Rigby AS, *Dev Med Child Neurol* 2010; 52: 293–298) for guidelines on appropriate use and reporting of statistical analyses.

k) Supporting information (supplementary material)

DMCN publishes online supporting information (including audio and video files, data sets, additional images, and large appendices) that cannot be included in the print version of an article. This material should be relevant to and supportive of the parent article. For guidelines see authorservices.wiley.com/bauthor/suppmat.asp. Authors are encouraged to submit video material to support their papers (e.g. to demonstrate techniques or methods, or to demonstrate a randomised controlled trial protocol). **l) Author Podcasts and Author Videos**

Authors are encouraged to submit a short (two minute) podcast or video highlighting the key features of their article, outlining what is novel in their paper, to encourage readers to access the content.

1. The recording must be continuous and of sufficient quality for us to publish online i.e. no shaking, blurring or interference.
2. The resolution should be 1280 x 720 (16 x 9 HD) or 640 x 480 (4:3 SD), if possible.
3. The recording should last no longer than two minutes.
4. The file must be less than 2GB in size.
5. The file must be saved in MPEG, MP3 or MP4 format.

Here are some tips to assist your recording:

1. Choose a neutral, flat, still background with good light and without background noise.
2. Make sure you are central in the view finder/screen on the camera and that you are sitting an appropriate distance away so that your upper body fills the screen.
3. Please dress formally, remain relatively still throughout the recording and smile.
4. Follow the script below.
5. Speak slowly, and breathe normally when you reach a natural pausing place.
6. If possible, use a tripod, or ensure that the camera/recording device is placed on a flat surface to avoid shaking.
7. Ask a colleague to start and stop the recording.

Your script should follow this format:

1. "Our/my paper in DMCN is [a study of XXXX or a review of XXXXX]"
2. "What's already known about this topic is [xxxxx]"
3. "What's new in our/my article is [xxxx]"

Please be aware that the content of the video should not display overt product advertising. In addition to the video file, please can you send an accompanying still portrait of yourself/ yourselves. The picture should be a head shot and can be taken using a digital camera or mobile phone. This should be saved as a JPEG or TIFF file. Please send the video file along with your portrait and an Online Video Broadcast Release Form, by email to DMCN Journal dmcn@editorialoffice.co.uk together with details of the paper to which it refers.

4. Selection and publication

a) Editorial review

Submissions are normally sent to at least two independent referees. Case reports and reviews are assessed by the Editors and one or more independent referees. During the submission process, authors have the opportunity to, and are encouraged to, suggest three suitable independent referees (with their contact details) but the choice of referee rests with the Editors. Most papers also undergo statistical review before acceptance.

Editors and editorial board members are not involved in editorial processes or decisions about their own work.

Reviewers are asked to disclose potential conflicts of interest when they are invited to review a paper and when they submit their review.

Papers thought to have immediate, clinically important consequences may be considered for fast-track publication. The decision to prioritize remains with the Editors.

b) After acceptance

The Editors reserve the right to determine whether accepted papers will be published in the online version of an issue ('E-Papers') or in both the print and the online version. E-Papers are listed in the table of contents of the issue in which they are published, and their abstracts and citation information appear in the print issue.

After acceptance, authors will be able to track the progress of their article through production to publication by registering for Author Services with Wiley Blackwell. Authors will be sent information about how to register for Author Services once their article has been accepted.

When an accepted paper has been copy-edited, has been approved by the authors, and is ready for publication, it will normally be posted online in the journal's 'EarlyView' section before allocation to an issue. EarlyView articles are in their final form and are fully published and citable.

Authors receive a free PDF of the paper soon after publication. Reprints may be ordered when returning proofs. Please send no payment: an invoice will be sent shortly after you receive the reprints.

c) After publication

If errors affecting the interpretation of data or information are discovered after publication, an erratum will be published in the next available issue of the journal and published online.

5. Style points

Jargon Avoid it strenuously. The journal aims to communicate across disciplines, and many of its readers do not have English as their first language, so plain language is always preferred. The Editors may clarify and shorten manuscripts accepted for publication as necessary.

Abbreviations These should be kept to a minimum and restricted to those that are generally recognised. They must be spelled out in full on first usage in text and again in figure captions and table footnotes. They should be avoided in titles, headings and subheadings.

Participant details Give mean (SD) age in years and months (not decimal years) and sex (*n*, not %). Ensure this information is included in the abstract. In the text, indicate where study and comparison groups are from and how participants were selected.

Measurements Use SI units, except for blood pressure (mmHg); convert imperial units to metric. Do not use percentages for sample sizes below 50; use the symbol '%' in tables. Show standard deviations as (SD), not \pm . Abbreviate probability with a lower case italicized *p*.

Numbers In general, use numerals, but spell out numbers at the beginning of sentences. Spell out numbers 'one' to 'nine' if they refer to nouns that are not units of measurement, e.g. 'The results from four children confirm the findings'. For ages and time periods, use years, months, weeks and days, not decimals (e.g. 5 years 3 months, not 5.25 years).

Equipment and drugs: Include (in parentheses) the name of the manufacturer, the city, and country of production.

APPENDIX B**Study protocol as accepted by HREC 11 December 2014**

The outcomes of children with cerebral palsy and upper airways obstruction at Red Cross War Memorial Children's Hospital

Background and significance

Cerebral palsy (CP) has been defined as a group of disorders of the development of movement and posture, causing activity limitation that is attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour; by epilepsy, and by secondary musculoskeletal problems. (1) It is the most common cause of physical disability in children across the world with prevalence in developed countries of 1-2/1000. (23) (24,25)

Limited information is available regarding the epidemiology of cerebral palsy in developing countries. A review of intellectual disability in a rural district in the Northern Province published in 2002 reported the presence of cerebral palsy in 8.4% of their cohort.(26) Given the burden of disease from infectious diseases compared to developed countries and the difference in quality of perinatal care available in developing countries, the prevalence of cerebral palsy in the public sector in South Africa can be expected to be higher than the previously quoted figures. (27-30)

Respiratory complications are significant contributors to morbidity and mortality in children with cerebral palsy and other developmental disabilities. Children with cerebral palsy are at increased risk of obstructive sleep apnoea and upper airways obstruction.(4)(5,6)(3) Mid-facial and gastro intestinal abnormalities as well as the underlying low neuromuscular tone of the upper airway predispose children with cerebral palsy to upper airway compromise.(3)(7) Contributors to upper airways obstruction during sleep in children with cerebral palsy are tonsillar and adenoidal hypertrophy, subglottic stenosis, laryngomalacia, tracheomalacia, and obesity.(4)

The symptoms of upper airways obstruction include snoring, noisy breathing, obstructive sleep apnoea and awake airway obstruction and are thought to be underreported by parents.(8) Children may also present with complications of chronic upper airways obstruction including pulmonary hypertension and cardiac failure.(7)

Upper airway obstruction may be exacerbated during upper and lower respiratory infections and may require admission to intensive care unit and result in long term respiratory insufficiency and mortality.(7)(17) Chronic upper airways obstruction is an important contributor to poor quality of life in both neurotypical as well as children with developmental disabilities like CP.(6)

The management of upper airways obstruction in children with cerebral palsy is complex due to the multifactorial nature of the aetiology and there are no clear guidelines for this important clinical problem. Adenotonsillectomy is generally recommended as an appropriate first intervention. (14) When severe airways obstruction persists after interventions like adenoidectomy and tonsillectomy, more invasive procedures have been attempted for example uvulopalatopharyngoplasty, maxillofacial procedures as well as tracheostomy for definitive airway management. (17, 18, 19)

Non-invasive interventions in the form of continuous nasal positive pressure or home oxygen have also been utilized to administer respiratory support where surgical intervention could not take place. (14, 19)

There is a paucity of data to guide current best practice in the management of children with cerebral palsy and severe upper airways obstruction. The available publications all present reviews of practices in first world settings and report mainly on small groups, often mixed with other disabilities. Many are retrospective in nature and do not report long term outcomes or indicators of quality of life of children post intervention.

This research aims to describe the investigation, management and outcomes of children who were admitted to a tertiary setting in Cape Town with cerebral palsy and upper airways obstruction. The results from this study may inform future practice at our institution as well as suggest possible recommendations for the management of airways obstruction in resource limited settings.

Research question:

What are the outcomes of children with cerebral palsy who were admitted to a tertiary hospital in Cape Town with upper airways obstruction?

Objectives:

1. To describe the investigation, management and outcomes of children admitted over a 5 year period with upper airways obstruction and cerebral palsy.
2. To compare the outcomes of children admitted with upper airways obstruction based on the nature and severity of the motor disorder of cerebral palsy.

Aims:

1. To describe the prevalence and severity of upper airways obstruction in children with cerebral palsy admitted over a 5 year period.
2. To document all investigations performed during hospital admission to evaluate the nature and severity of upper airways obstruction.
3. To document all interventions performed for management of upper airways obstruction in children with cerebral palsy.(surgical and non-surgical)
4. To describe the cohort of children admitted with upper airways obstruction through classification of nature and severity of motor disorder (GMFCS scale) and reporting any comorbid conditions associated with cerebral palsy.
5. To compare outcomes of children with upper airways obstruction based on underlying nature and severity of motor disorder.

Research design and methods:

This will be a descriptive study. A cross sectional retrospective folder review of all children admitted to Red Cross War Memorial Hospital with cerebral palsy during the study period will be performed.

Study population and sampling:

Selection criteria:

1. All children with a diagnosis of cerebral palsy between the ages of 2 – 18 years who were admitted to any ward at Red Cross War Memorial Children's Hospital and documented to have a diagnosis of upper airways obstruction between 1 January 2009 and 31 December 2013 will be included in the study.

Exclusion criteria:

1. Children known with craniofacial disorders including craniosynostosis/ cleft palate will be excluded.
2. Children who are known with neurodegenerative/ neurometabolic disorders which might contribute to progressive airways obstruction will also be excluded.

A retrospective folder review will be conducted of all children with a diagnosis of cerebral palsy who were admitted between 1 January 2009 and 31 December 2014. Demographic and clinical information will be collected including the aetiology of cerebral palsy, classification of cerebral palsy, as well as the presentation, investigation and management of upper airways obstruction and recorded on a predefined data collection form. Outcome information collected will include one year mortality, number of readmissions in subsequent year, as well as duration of hospital admission.

See Appendix 1

Ethical considerations

Ethical approval will be obtained from UCT HREC prior to commencement of any study activities.

Informed consent

Permission will be sought from UCT health ethics review committee as well as the Red Cross War Memorial Children's Hospital to confirm that signed consent forms may be waived for this study. As this study

involves no patient contact and no risk to patient, informed consent will not be obtained from the parent or legal guardian.

Data management

The principal investigator will check the completed data collection forms for errors and completeness. An information database will be set up in EPIDATA by the principal investigator which will be kept on a password protected computer. Information will be entered into this electronic database by a research assistant.

Patient confidentiality

Patient confidentiality will be strictly maintained. Study documentation will be securely stored in a locked cabinet in the principal investigator office.

Data analysis

Data will be exported from EPIDATA into STATA 13 after it has been cleaned and checked by the principal investigator. Statistical analysis will be performed using the STATA program using continuous and categorical variables. A p value of < 0.05 will be considered significant.

Categorical variables will be reported as percentages and relative percentages with confidence intervals and displayed in frequency tables or bar charts. Numerical variables which are normally distributed will be analysed and reported using the summary statistics: mean, standard deviation and range. Numerical variables which are not normally distributed will be analysed and the median with interquartile range will be reported.

The main outcomes (one year mortality, number of readmissions in subsequent year, as well as duration of hospital admission) will be reported as relative percentages with confidence intervals.

Comparison between groups will be performed by using the X^2 statistic for binary outcomes and the Kruskal Wallis test for numerical outcomes which are not normally distributed.

Data dissemination plan:

Publication will be sought in a peer review journal: Developmental Medicine and Child Neurology

Presentation at national (SAPA 2016) and international conferences (American Academy of Cerebral Palsy meeting 2015)

Presentation to Red Cross War Memorial Hospital as well as Tygerberg children's Hospital at annual research day meetings in 2015.

Budget & budget justification

TIME PERIOD	ITEM	COST
1 DECEMBER 2014-30 NOVEMBER 2015	PERSONNEL	R10000
	CONSUMABLES	R500
October 2015	RESEARCH TRAVEL	R10000
	SPECIALIZED ITEMS	R2500
TOTAL		R23000

BUDGET JUSTIFICATION:

Research assistant:

A research assistant will be used to enter data collection forms into the study database once a week for 5 hours for a period of 4 months. Assistance with data entry is essential as the principal investigator is a full time employee of a busy academic hospital and will not be able to complete both folder reviews as well as data entry within the project timeline.

Consumables: paper for printing of data collection forms and additional paperwork will be purchased at an estimated cost of R500.

Equipment:

Office computer, printer, furniture and copier will be utilized from the existing infrastructure at Red Cross War Memorial Hospital.

Research travel: an abstract will be submitted for presentation at the American academy of cerebral palsy and developmental medicine. The conference registration fee as well as visa costs are included in the budget. Additional funding will be sought for transport and accommodation costs.

Funding application will be made to the University of Cape Town for a departmental research grant as well as conference funding from University of Stellenbosch to cover the cost of budget items.

Limitations:

The study will be limited by its retrospective design which is susceptible to bias and confounders. It may not be possible to obtain all the relevant information from the folders, folders may be lost or missing which will result in missing data and affect the final results.

The results of the study may not be generalizable to the all children with cerebral palsy.

However as the research question involves a vulnerable population and a life threatening condition, the study design is considered the most appropriate way to address this issue.

References:

APPENDIX C

STUDY QUESTIONNAIRE

as approved by HREC December 2014

STUDY NUMBER

FOLDER NUMBER

DATE OF BIRTH SEX

CEREBRAL PALSY

AETIOLOGY OF CP: TICK

ANTENATAL PERINATAL POSTNATAL

CLASSIFICATION OF CP TICK

BILATERAL UNILATERAL

TONE ABNORMALITY: TICK

SPASTIC DYSTONIC MIXED ATAXIC HYPOTONIA

GMFCS: TICK APPROPRIATE LEVEL

I II III IV V

COIMPAIRMENTS:

EPILEPSY Y/N VISUAL IMPAIRMENT Y/N HEARING IMPAIRMENT Y/N

MUSCULOSKELETAL IMPAIRMENT Y/N GASTROINTESTINAL COMPLICATIONS Y/N

PRESENCE OF GASTROSTOMY Y/N

ADMISSION DIAGNOSIS UPPER AIRWAYS OBSTRUCTION: Y/N

AGE ON ADMISSION IN MONTHS: _____

SYMPTOMS OF UAO ON ADMISSION:

SNORE: Y/N STRIDOR: Y/N NOISY BREATHING OTHER: Y/N

SLEEP APNOEA: Y/N AWAKE APNOEA: Y/N

URTI: Y/N

LRTI: Y/N

WEIGHT NUTRITIONAL CLASSIFICATION

INVESTIGATIONS:

CXR: Y/N PNEUMONIA Y/N RVH: Y/N

ECG: Y/N ABN: Y/N RVH: Y/N

PNS XRAY: Y/N ADENOIDAL HYPERTROPHY ON PNS: Y/N

ABG: Y/N RESULT:

SLEEP SATURATIONS: Y/N RESULT: _____

FORMAL OVERNIGHT POLYSOMNOGRAPGY: Y/N

RESULT: _____

NASAL ENDOSCOPY: Y/N RESULT _____

ENT CONSULT: Y/N PULMONOLOGY CONSULT: Y/N CARDIOLOGY CONSULT: Y/N

CP DOCTOR CONSULT: Y/N MDT DISCUSSION: Y/N

FINAL ASSESSMENT OF AETIOLOGY OF UAO: _____

MANAGEMENT: PLEASE TICK

NCPAP: Y/N DURATION: CIPP TUBE: Y/N DURATION:

IPPV: Y/N DURATION ICU ADMISSION: Y/N DURATION OF ICU ADMISSION: _____ DAYS

MANAGEMENT: TONSILLECTOMY: Y/N ADENOIDECTOMY: Y/N

TONSILLECTOMY AND ADENOIDECTOMY: Y/N SUPPORTIVE MANAGEMENT ONLY:

TRACHEOSTOMY: Y/N OTHER :

DISCHARGE SATS___ DISCHARGE SLEEP SATS___

MEDICATION:

OUTCOMES:

DURATION OF HOSPITAL ADMISSION: _____ DAYS

NUMBER OF READMISSIONS TO HOSPITAL FOR UAO COMPLAINTS: READMISSIONS OTHER

NUMBER OF READMISSIONS TO ICU FOR UAO COMPLAINTS:

DEATH: Y/N

DEATH WITHIN ONE YEAR

DEATH AFTER ONE YEAR BUT IN STUDY PERIOD

CAUSE OF DEATH

NOSOCOMIAL INFECTIONS: _____

WEIGHT AT 1 YEAR

NUTRITIONAL STATUS

APPENDIX D

ETHICS

Permission was obtained from the University of Cape Town HREC to proceed without individual consent as the study was retrospective in nature and did not pose any risks to participants. In addition permission was obtained from the hospital management to proceed without individual consent. Confidentiality was strictly maintained.

APPENDIX E

Acknowledgements:

I would like to acknowledge the records department Red Cross War Memorial Children's Hospital for their help in obtaining more than 500 patient folders.

I would like to acknowledge the tireless work of Mrs Leonie Alston, senior administration clerk in the Cerebral Palsy clinic at Red Cross War Memorial Hospital in support of this research project as well as in our clinical service.

I would also like to acknowledge Sister Jane Booth for her support with this research project as well as her care of our children with tracheostomies.

APPENDIX F

TURNITIN REPORT

RESPONSE TO TURNITIN REPORT