

Pediatric Nursing Grand Rounds



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NURS 421: CLIN MGMT-Children of Family
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Arthrogryposis Multiplex Congenita

What is it?



Arthrogryposis Multiplex Congenita



Patient Medical History



Age/DOB

13
01/01/2009

Allergies

NKA

Gender

Male

Location

Unit 8C, CHKD

Chief Complaint

Pt had left hip surgery and bilateral clubfoot surgery. He now presents with right foot discomfort secondary to recurrence from syndrome and clubfoot involvement

Plan: To OR for right clubfoot release and talectomy (another surgery)

Family/Psychosocial Hx

Asthma: Brother
Diabetes mellitus: Father
Gallbladder problem: Mother
HTN: Father
IBS: Mother and Grandmother
Pt suffers from a developmental delay (non-verbal)
Father & Grandfather present

Cultural Considerations

- Patient: Multi-racial
- Mom: Caucasian
- Dad: African American
- Primary Language: English
- Religion: None Indicated



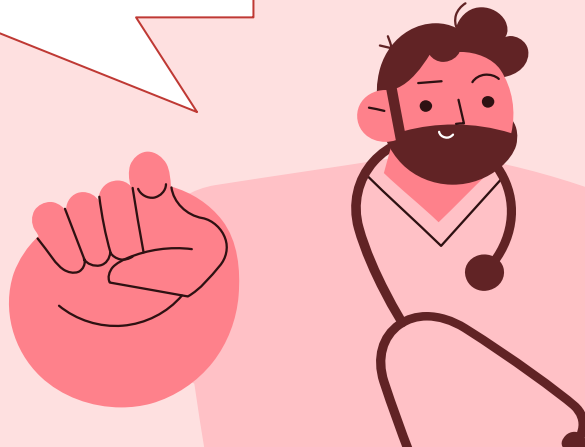
Health History

Past Medical Hx

- Hypersecretory
- Eczema
- Constipation
- Dysphagia
- Abnormal gait
- Speech problems (non-verbal)
- Eye problems (eyeglasses)
- Developmental delay s/t congenital issues
- Failure to thrive/malnutrition/low BMI

Birth Hx

- Arthrogyposis
- Plagiocephaly
- Facial deformity
- Difficult intubation - congenital epiglottic deviation (Ankyloglossia)
- Craniosynostosis
- Strabismus
- Achilles tendon lengthening, G-tube 2009
- Bifrontal cranioplasty for stenosis 2010
- Left hip open reduction 2012





Plagiocephaly



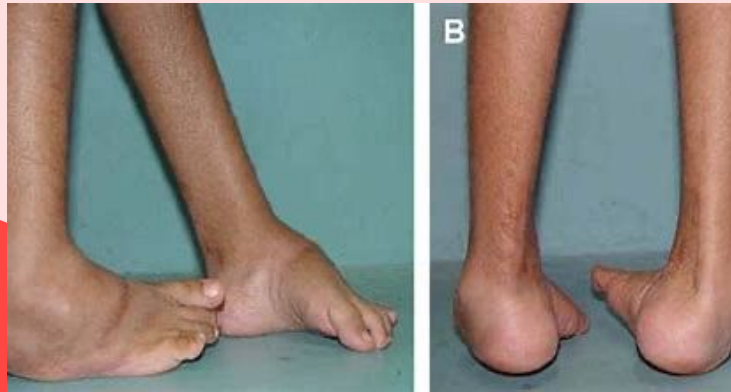
Brachycephaly



Dolichocephaly



Photo sources: www.cranialtech.com



Expected Developmental Stage

Identity VS. Role Confusion

- Increased risk for Role Confusion r/t medical Dx
 - Pt experiences anxiety r/t hospitalization which inhibits him from relaxing; thus contributing to his pain
 - Risk for depression
 - Risk of low self-esteem r/t being caregiver dependent

Developmental Theory allowed me to adjust patient care based on the developmental level of each patient. For example, this patient is expected to be entering the Identity VS. Role Confusion stage which means that he may have a need to develop a sense of self and personal identity. Success allows the patient to stay true to self while failure can lead to role confusion and weak sense of self. Knowing this I was able to encourage the Pt to be more independent and praise him for completing tasks on his own.

Review of **systems**



GA/Neuro/Pain

Pt appears to be in distress r/t right foot (crying/moaning)
A&O x3, nonverbal
Pt rates pain 8/10



Eyes/Ears

Sclera white
Externally normal



Respiratory

Clear Room Air
SpO2: 99%
Occasional cough (productive)
Respirations uneven with labored breaths



Cardiovascular

Rate normal
Cap refill <3
BP: 111/71
P: 97

Review of **systems**



Abdomen

Soft
Not distended
non-tender



Genitourinary

Yellow urine
No strong odor



Musculoskeletal

Left leg shorter than
right leg by 2-3 cm
Right foot is in severe
equinus, supination, and
forefoot abduction (foot
joints lacks flexibility)



Skin

Warm
No lesions
Dry lips r/t drooling
Appropriate for race
No abnormal bleeding or
bruising



Actual Nursing Diagnosis

Ineffective Airway Clearance

r/t hypersecretory

Impaired Transfer Ability

r/t pain in right foot

Fall Risk

Recurrent Clubfoot r/t
Arthrogryposis Dx
Altered gait

Delayed Growth

r/t problems with
epiglottis, G-tube
dependent since birth, &
malnutrition

Chronic Pain

r/t Arthrogryposis Dx &
recurrent clubfoot that
causes discomfort

Dry Mouth

r/t drooling and
excessive secretions

Potential Nursing Diagnosis



**Risk for Impaired
Social Interaction**

r/t Pt being non-verbal



**Risk for Chronic Low
Self-esteem**

r/t deformities of the skull,
face, and all 4 extremities

Expected **Goals/Outcomes**



Maintain Open Airway

Pt will use Incentive Spirometer 5-10 times every hour that he is awake.

Pt will be suctioned Q4h along with vitals

Decrease Pain

Patient and family goal is for Pt to decrease pain level from 8/10 to 4/10 after receiving PRN analgesics



Expected **Goals/Outcomes**



Mobility

Pt will transfer from bed to chair using a walker before every meal

Decrease Pain Cont.

Pt will participate in pain distraction activities with child life team at 1400.





Interventions

Airway

Use suction to decrease secretions and maintain a clear airway
Vitals Q4h (check O2)
Incentive Spirometer



Neuro/Pain

PRN Tylenol, Oxycodone,
Valium
Distraction Therapy

Education Informed Consent

MD and nurse provided family with as much information as possible before consent was given



Mobility

Roll Q2h (Pt can move in bed independently)
Physical Therapy comes to help ambulate

Teaching Needs

Ambulating



Physical Therapy stopped by to teach Pt and family how to ambulate using walker

Home Med Administration



Nurse provided father with education about giving OTC pain meds on a rotating system to prevent breakthrough pain

Surgery



MD came in to speak with family about the planned procedure to fix the patient's right foot and relieve discomfort

Incentive Spirometer



Nurse educated Pt and family about the how, when, and why of the Incentive Spirometer

Nursing Research Article

Understanding the Educational Needs for Parents of Children With Clubfoot



This research article relates to my 13 year old patient because one of his medical diagnosis is congenital clubfoot s/t arthrogryposis. This patient also has deformities of his upper extremities and skull. The article is about a study that nurses completed to measure the educational needs of parents with children who have clubfoot. According to the article, clubfoot is one of the most common congenital birth defects. Since it is a common defect it makes sense that there is an increased need for parent education. The study found that the most common parent education needs of children with clubfoot are (1) understanding the process of treatment and (2) problems concerning the bracing portion of treatment. This research study is applicable to my 13 year old patient and the setting because the dad expressed a lot of questions about how to better care for his son and the nurse and doctor had to provide education and resources for the patient's family.



Thanks!

Any questions?

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References

<https://www.youtube.com/watch?v=vNjeB8lA4nE>

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Paulsen-Miller, M., Dolan, L. A., Stineman, A., & Morcuende, J. A. (2011). *Understanding the educational needs for parents of children with Clubfoot*. Orthopaedic Nursing, 30(4), 273–278. <https://doi.org/10.1097/nor.0b013e3182247c15>