Healthcare Data Management in Children with Cleft Lip and Palate

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An Interest in understanding and addressing the condition of Cleft Lip and Palate

The health condition that interests me as a data scientist is a craniofacial anomaly called Cleft Lip and Cleft palate. These are usually birth defects seen in babies and young children. This disorder is due to lack of tissue development during the prenatal stage. These can be unilateral or bilateral involving only lip, palate or both. There have been various theories that have been proposed to find out about the formation of clefts in lip and palate and one such factor is failure of fusion between median nasal process and maxillary process. They have multiple etiologies, they can be formed due to genetic factors, environmental factors, nutritional disturbances during development, defective vascular supply to the effective area, exposure to radiation, effect of certain drugs etc. These are relatively common congenital conditions as they affect thousands of children worldwide. As a data scientist I would understand the management of these conditions and improve them and find out if there are any correlations among these factors.

Management and diagnosis of Cleft lip and Palate in Healthcare Organizations

I chose the health care organization UPMC (University of Pittsburgh Medical Centre) for my research. In Healthcare organizations like these when a child arrives at a hospital or a healthcare organization a thorough case history and examination is conducted. A paper and an Electronic Health record is taken, The paper record consists of demographic data of the child, prenatal and birth history, medical and dental history, feeding history, speech and language development, developmental history and diagnosis and an initial treatment is recommended. The hospitals or organization's Electronic Health Record plays a critical role. Certain statistics show that cleft lip and palate is seen in 1 among 1600 babies and cleft palate is 1 among 1,700 babies. This data is sourced from National Institute of Health (NIH). EHRs in this case play a major role in recording these data. A case history is also noted in an Electronic Health Record; it also consists of the

diagnostic tests to be conducted like scanning and imaging tests, genetic testing and other specialized tests and the results are noted electronically.

The child with cleft lip and palate follows these steps when enters a healthcare organization

Patient Admission and Diagnosis, Inpatient care and treatment, Data collection and storage, Discharge of patient and follow up and reimbursement.

Software and Database used to manage data

During my research I have found that the data for Cleft Lip and Palate are usually cited from (CDC) which is Centers for Disease Control and Prevention and (NBDPN) which is National Birth Defects Prevention Network according to (NIH) National Institute of Dental and Craniofacial Research.

IT and Softwares used

- Electronic Health records- These are mostly used to collect, store and analyze data. It is used for total patient care from admissions to discharge and follow up. EHR softwares that are commonly used are Cerner, Epic and Allscripts.
- Database managements can be also used like HIPAA which is mostly used in the United states. These databases should be secure and should be able to handle unstructured and structured data.
- UPMC is a large organization and it uses Epic which is an EHR system to record, store and analyze data. They also have data warehouses like Microsoft SQL and Teradata. The University of Pittsburgh Medical Center is also investing in a cloud based healthcare operating system.
- For all the imaging data UPMC utilizes systems like Picture Archiving and Communication System (PACS). It maintains multiple data storage systems and servers

and supports real time exchange of information and patient data. .

- To maintain healthcare regulations and compliance UPMC focuses on data security by implementing firewalls and access controls to protect patient data and also provides backup.
- UPMC also uses mobile device management solutions to store and interchange data. Telehealth and remote patient monitoring is also done for data transmission.

Standards during data capture

UPMC follows a set of standards during data capture in Electronic Health Record systems and in data interoperability in handling Cleft lip and Palate scenarios.

a. Components in EHR that are helpful in managing cases of cleft lip and palate

There are a set of components used in EHR within UPMC organization for managing case in this scenario:

- Registration module and patient demographics this captures patient identification, contact and insurance information. The Clinical documentation module has records of clinical notes, diagnosis and treatment plans specific to cleft lip and palate.
- Medical Images like CT- scans, X-rays and MRI are usually recorded in the imaging and radiology module. Document details of cleft lip and cleft palate surgeries, preoperative assessments and post operative care is done using the surgical records module.
- Other procedures and diagnostic tests are also noted in the Electronic Health Record system.

b. Standards and Technologies used for data capture and data interoperability for UMPC's Cleft lip and Palate cases

HL7 or Health level 7 is a standard electronic health information exchange system which contains demographics, clinical reports and data and laboratory results. Digital imaging and communications in medicine (DICOM) is also used as a standard system for propagating, segregating and sharing medical images. Systematized Nomenclature of Medicine- Clinical Terms (SNOMED CT) is a coding system used for precise medical terminology and capturing data. For facilitating interoperability laboratory and clinical observations (LONIC) Logical Observation Identifiers Names and Codes is identified as a standard system. ICD-10 classification is used for billing and data capture.

a. Benefits of Health Data Exchange that UPMC participates

- University of Pittsburgh Medical Center can participate in health data exchanges like RHIO (Regional Health Information Organization) to improve patient care by providing patient health information for comprehensive health care and improved diagnosis and treatment plan.
- It also ensures better care coordination and gives access to care teams with real time data which also reduces costs and improves patient satisfaction.
- It also reduces medical errors like misdiagnosis and improves accuracy for medications and allergy recognition.
- The RHIO provides data exchange methods for easy patient data transfer from different healthcare organizations or hospitals. The patients can also have access to their data ansd updates regarding it.

- They also collaborate with insurance companies for faster reimbursement and reduced administrative costs which can attract more patients and improve engagement.
- With organizations like UMPC they also support research and conduct data analysis enabling this organization to make data driven and statistical decisions.

b. Potential costs to be considered

The main factor to be considered is the initial cost of investment as participating in Regional Health Information Organization may require costs for investing in inventory and technological infrastructure like interfaces to exchange and connect data and meet its standards. There will be other costs involving security which should also meet the standard data and privacy regulations. It also has to ensure data quality and privacy of patient data and meet the expenses related to cybersecurity.

The return of investment calculation may be challenging at this stage as it depends on various factors like patient engagement and population, size of the organization, and the use of data exchange.

- The decision of participation in RHIO should be carefully analyzed by looking into their costs and benefits. I personally believe that an organization like UPMC should participate with (RHIO) Regional Health Information Organization.

Continuation to the scenario

In this article I have aggregated and collected the data related to Cleft lip and Palate using Electronic Health Records and also assessed the benefits of collaborating with (RHIO) Regional Health Information Exchange and aggregated patient data locally. This dataset has the potential to provide various types of analysis.

a.Types of analysis that can be performed on the data of Cleft lip and Palate

- An Epidemiological Analysis can be done to predict the number of cleft lip and palate cases within the region that can be covered by UPMC.
- An evaluation can be done to find out about the success rate in cleft lip and palate using different types of surgical interventions or treatment options. Postoperative complications and treatment errors and follow ups can also be noted.
- Cost analysis can be done to evaluate the cost-effectiveness of treatment options like surgical and nonsurgical approaches.
- Predictive analysis can be done to find out interaction between the etiological factors that cause cleft lip and palate.
- Quality and improvement analysis can be done in enhancing patient care.

b.Knowledge and Information that can be used for Future Discoveries

- Genomic data and information can be used to analyze and discover potential correction among etiological factors contributing to cleft lip and palate
- Telehealth and monitoring devices can be used to detect prevalence of these conditions in a region and provide telehealth services.
- Artificial intelligence and machine learning can be used and optimized to discover new treatment protocols and preventive measures.
- Research studies can be done to find out the effectiveness of treatment plans and compare them with success rates of older or newer treatments. By using these analyses UPMC can get deeper insights into cases related to Cleft Lip and palate which can lead to continuous improvement of patient care.

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