Centers for Disease Control and Prevention

The Art of Abstraction

Abstracting information from medical records for birth defects surveillance

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Presentation Outline

- Surveillance terminology
- Sections of a medical record
- Approach to abstracting a medical record
- Information to collect for defects potentially related to Zika virus
  - Types of diagnostic evaluations, laboratory testing, and subspecialty consults
  - What information to collect about diagnostic evaluations and defect diagnoses
  - Three examples

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Surveillance Terminology

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Surveillance Terminology

- **Case ascertainment**: The method used for case finding at data sources
  - Active case ascertainment: Intensive case finding by program staff at data sources
  - Passive case ascertainment: Case reporting from data sources to the program
- **Case definition**: Criteria used by a surveillance program to define a case
- **Data sources**: Hospitals, genetic clinics, cytogenetic labs, prenatal diagnostic centers, and other sources of data about birth defects potentially meeting the case definition
- **Case finding**: The process used at each data source to identify cases of birth defects that potentially meet the case definition
- **Case culling**: The process of reviewing records of potential cases to determine those that meet the case definition
- **Case abstraction**: The process of recording needed information about cases that meet the surveillance case definition

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Sections of a Medical Record

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Sections of a Typical Medical Record

Face sheet	Demographics, insurance, admitting physician information, may contain list of ICD-10-CM codes
History and Physical	Past medical history, current physical status, reason for admission
Problem List	List of past and present diagnoses
Coding list	List of ICD-10-CM codes corresponding to diagnoses relevant to the hospitalization
Discharge Summary	Completed by the discharging physician. Includes: admitting diagnosis, pertinent medical history, current problems, progress and treatments during hospitalization, follow up and discharge plans
Consultations	Reports form specialists asked to see the patient. Can provide diagnostic clarification through physical exams, diagnostic testing and recommended follow-up
Progress Notes	Health care provider notes on the patient's progress during the hospital stay
Radiology	Reports from x-rays, ultrasounds, CT and MRI scans, etc., done during the hospitalization
Labs	Results of laboratory tests (CBC, electrolytes, etc.). May include results of genetic testing.
Operative Reports	Description and findings from surgical procedures, including examination under anesthesia
Medications (MAR)	List of medications given, dose, how often, etc. (MAR=Medicine Administration Records)
Doctor's Orders	Physicians' orders specifying patient care, including tests, meds, diet, etc.
Pathology	Results of biopsy, autopsy, or other procedure. May include external exam of fetal death
Letters	Copies of letters to outside physicians, family, etc., specifying the patients' findings and care.
Miscellaneous	Contains anything that does not fit elsewhere

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Maternal Medical Records

- Additional sections of the maternal delivery medical record may include
  - **Labor and Delivery Record**: Often a standardized form that includes basic information about the labor and delivery and the infant. Can include nurses' notes, admission and pregnancy history, etc. Information about a fetal death, including disposition of the fetus, if an autopsy or genetic testing was performed, etc., is documented in the L & D record.
  - **Prenatal Records**: Often a standardized form from the obstetrician's office with information on the course of prenatal care, maternal history and prior pregnancies, results of labs, genetic screening, prenatal ultrasounds, amniocentesis, etc.

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Maternal Medical Records

- **Pathology:** Results of pathological exam of a fetal or immediate neonatal death is usually documented in the mother's record. Can be an external exam only, a limited autopsy excluding the brain, or a full autopsy, and may include genetic testing of tissue specimens. Can provide location of the autopsy if not done at the delivery hospital.
- **Consents:** Signed consent forms for medical/delivery procedures (C-section, fetal autopsy, etc.)
- **Birth Certificate Worksheet/Vital Records Information**: A worksheet filled out by the mother and/or hospital staff with information included in the vital record such as demographics, type of prenatal care, maternal risk factors, congenital anomalies in the infant, paternity, etc.

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Newborn Medical Records

- A separate newborn record is generated when a liveborn infant is admitted to the newborn/neonatal nursery. A separate record typically is not generated for fetal deaths or infant deaths occurring immediately after delivery.
- Additional sections of the infant medical record may include
  - **Newborn admission assessment:** Often a standardized form with information on birth weight, head circumference, length, Ballard/Dubowitz score assessing gestational age, etc.
  - **Physician's exam:** Can be a standardized form documenting presence or absence of abnormalities, including birth defects, on newborn exam. May be performed in the delivery room or newborn nursery.
  - **Nurses' exam:** A separate exam documenting the infant's status on admission to the newborn nursey, including vital signs, temperature, and physical abnormalities.
  - **Newborn discharge summary:** Often a standardized form summarizing the course of the newborn's hospitalization
  - **Miscellaneous:** Can contain documentation of newborn metabolic screening, results of newborn hearing screening, plans for follow-up, other information

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Anatomy of a Medical Record

- The organization of medical records is not standardized
  - Medical records at different facilities can have different sections
  - The same information may be filed in different sections at different facilities, or even among records at the same facility
  - Information may not be filed in the expected sections
- Electronic medical records may be organized differently than paper records
- Needed information may be found in unexpected places
  - Mother's race recorded on metabolic screening forms
- May need to ask that specific sections be included or made visible
  - Radiology reports, scanned consults, prenatal records, etc.
  - Some facilities have a separate labor and delivery documentation system and include only an L&D summary in the main medical record.
- May need to ask for all of the mother's records, not just the delivery of interest, to find the information needed

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Approach to Abstracting a Medical Record

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Abstracting a Medical Record

- Information needed to request a medical record at a data source
  - Name
  - Date of birth
  - Approximate time of admission
  - Medical record number
- Identify the person in the medical records department with the time and interest in helping you
  - May not be the medical records department director

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Abstracting a Medical Record

Where to Start?

- When at a new facility, start by going through the first few medical records from beginning to end to learn how they are organized
  - Need to learn each facility's system of organizing a medical record
- When using a new abstraction form/tool, start by filling it out in sequence for the first few abstractions
  - Once you are familiar with the form, it will be easier to enter information as it is encountered in the medical record
- Begin by locating the problem list, defect list, or ICD-10-CM code list in the record. Next, identify the related procedures, tests, consults, etc.
  - These may be listed on the face sheet, in the discharge summary, etc.

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Information to Collect for Defects Potentially Related to Zika Virus

Types of Diagnostic Evaluations, Laboratory Testing, and Subspecialty Consults

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Information to Collect for Defects Potentially Related to Zika Virus

Diagnostic Evaluation

- Diagnostic evaluation of the brain
  - Gold standard
    - Postnatal magnetic resonance imaging (MRI) or computerized tomography (CT) scan
    - Postnatal head/cranial ultrasound
    - Autopsy
  - Other
    - Prenatal Ultrasound
    - Fetal MRI
  - Abnormalities of the brain cannot be diagnosed by physical exam only
    - Neurologic symptoms may suggest a brain abnormality

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Information to Collect for Defects Potentially Related to Zika Virus

Diagnostic Evaluation

- Diagnostic evaluation of the eye
  - Gold standard
    - Ophthalmology exam/consult including examination of the retina/fundus - may require exam under anesthesia (EUA) in infants
    - Autopsy
  - Other
    - External eye abnormalities such as cataracts, microphthalmia, coloboma of iris may be diagnosed by physical exam

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Information to Collect for Defects Potentially Related to Zika Virus

Laboratory Testing

- Testing for Zika infection - Maternal, infant, fetal
  - All specimens, all tests (positive, negative, equivocal), dates of testing
- Testing for other congenital infections - Maternal, infant, fetal
  - Toxoplasmosis, cytomegalovirus (CMV)
  - All specimens, all tests (positive and negative), dates of testing
- Genetic testing
  - Karyotype - Normal 46-XX, 46-XY
    - Infant serum, fetal tissue, amniocentesis
  - Microarray – can detect:
    - Microdeletions, microduplications
    - Single gene disorders (gene mutations)

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Information to Collect for Defects Potentially Related to Zika Virus

Subspecialty Consults

- Neurology
- Ophthalmology
  - Retinal exam
- Genetics
- Infectious disease
- Physical or occupational therapy
- Audiology
- Otolaryngology (ENT)

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Information to Collect for Defects Potentially Related to Zika Virus

Information to Collect About Diagnostic Evaluations and Defect Diagnoses

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What Information to Collect
Diagnostic Evaluations

- For each diagnostic evaluation/procedure abstract
  - Exact type of procedure
  - Date of procedure, or patient's age at the time of the procedure
  - Verbatim result of the procedure (including the exact titer for viral testing)
- Some procedures will have a lengthy description of the results, followed by a shorter overall "impression"
  - If possible, abstract both sections
  - If the description of results is lengthy, abstract the impression

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What Information to Collect
Diagnostic Evaluations

- Some records will contain multiple tests of the same type (e.g., serial prenatal ultrasounds)
  - Abstract as many tests of the same type as possible
  - Always abstract the first, the last, and any tests of the same type that modify, change, or more clearly describe the abnormality being evaluated
- Ensure the results are for a diagnostic procedure and not a screening test, such as newborn screening for hearing loss.

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What Information to Collect
Defect Diagnoses

- Record all defects diagnosed in each infant whether potentially related to Zika virus infection or not
- For each defect diagnosis, record:
  - The correct diagnostic code (ICD-10-CM, CDC/BPA)
  - The defect label corresponding to that code
  - A short verbatim description from the diagnostic evaluations that best describes the defect
  - The most definitive procedure that diagnosed the defect
    - Prenatal diagnoses should be confirmed by postnatal evaluation if possible
    - Include only diagnoses that are certain, not described as possible or probable
    - Evaluations by postnatal CT, MRI, retinal exam, neurology or genetics evaluation, or pathology/autopsy are the most definitive

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What Information to Collect
Defect Diagnoses

- Examples:
  - Q04.0 – Congenital malformations of the corpus callosum
    Verbatim: Marked hypoplasia of the corpus callosum anteriorly, postnatal MRI
  - Q04.8 – Other specified congenital malformations of brain
    Verbatim: Multiple calcifications in the subcortical white matter, CT scan
  - Q22.1 – Congenital pulmonary valve stenosis
    Verbatim: Marked stenosis of the pulmonary valve

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Case Example #1

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Case Example #1
Diagnostic Code List

- Face sheet lists the following ICD-10-CM diagnostic codes:
  - Z38.00 – Single liveborn infant, born in hospital, delivered vaginally
  - Q03.9 – Congenital hydrocephalus, unspecified
  - Q04.8 – Other specified congenital malformation of brain
- Where do you look for more information about these diagnoses?
  - What exactly are the abnormalities?
    - Other specified and unspecified do not define the diagnosis
  - Were they diagnosed prenatally only or confirmed postnatally?
  - Are they certain or possible?
  - What diagnostic procedures were done?
  - Which subspecialists consulted on the child's care?
  - What were the final assessment and diagnoses?
  - Look for other causes of the defects (e.g., IVH)

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Case Example #1
Diagnostic Evaluations

- Prenatal ultrasounds
  - At 20 weeks gestation – Normal anatomy
  - At 40 weeks gestation – Cerebral ventricles at upper limit of normal size
- Newborn exam
  - Anterior fontanelle full, wide-spaced, and tense; PF open and full; HC 40 cm
  - Mildly low-set ears
  - Deep nasal bridge
  - Low skin over neck
  - Gr 1/6 murmur
  - Dimpling over scapulae
  - Sacral dimple with visible base
  - Contractures of wrists, overlapping 4th toe on lt foot, hyperextension of lower extremities
  - Question of clonic movements of upper extremities with tongue thrusting

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Case Example #1
Diagnostic Evaluations

- Head ultrasound on day of birth
  - Indication: 40 week 1 day infant; hydrocephalus
  - Findings:
    - Marked diffuse bilateral ventricular enlargement with severe thinning of the cortical mantle bilat
    - Lateral and 3rd ventricles appear dilated
    - 4th ventricle not well-visualized
    - Corpus callosum is present
    - Midline structures grossly unremarkable
    - Sulcation pattern WNL for age
    - Imaged portions of post fossa normal
    - No significant extra-axial collections
  - Impression: Severe hydrocephalus
  - Recommendation: MRI for further evaluation

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Case Example #1
Diagnostic Evaluations

- Head ultrasound on day after birth
  - Hydrocephalus with marked dilation of lateral ventricles and mild dilation of 3rd ventricle
  - Dysmorphic appearance of frontal horns
- MRI of brain on 2nd day after birth
  - Diffuse brainstem edema
  - Severe hydrocephalus with posterior predominance and significant posterior greater than anterior cerebral volume loss, may be aqueductal stenosis
  - Small hemorrhagic foci scattered throughout cerebellum and pons, no definite corresponding gradient echo dark lesions, likely small hemorrhages
  - Small cerebellum, vermis not definitely identified
  - Cleft vs. enlargement of infundibular recess in floor of ventricle
- No mention of a cardiac echo or other evaluation of the heart murmur

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Case Example #1
Defect List

- Q74.3 – Arthrogryposis multiplex congenita
  Verbatim: Contractures of wrists, hyperextension of lower extremities, physical exam
- Q17.4 – Misplaced ear
  Verbatim: Mildly low-set ears, exam
- Q30.8 – Other congenital malformations of nose
  Verbatim: Deep nasal bridge, exam
- Q03.9 – Congenital hydrocephalus, unspecified
  Verbatim: Severe hydrocephalus with thinning of the cortical mantle bilaterally, may be aqueductal stenosis, U/S, MRI
- Q04.8 – Other specified congenital malformations of brain
  Verbatim: Dysmorphic appearance of frontal horns, cleft vs. enlarged infundibular recess in ventricle floor, small cerebellum, MRI

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Case Example #2

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Case Example #2
Discharge Summary

- **Admitting Diagnoses**: Prematurity at 34 2/7 weeks, suspected sepsis, encephalocele, ear canal stenosis
- **History of Present Illness**:
  - **Pregnancy & Labor**: Infant was born at 34 2/7 weeks via SVD to a 30 y.o. G8P2 now 3, A5 mother. Prenatal labs: Blood Type A+, RPR NR, HbsAg neg, HIV neg, GBS unknown. The pregnancy was complicated by preterm labor, anterior skull mass diagnosed in utero. Mother also with history of CHTN and pre-eclampsia at time of delivery. EDC was 9/17/XX.
  - **Delivery/Resuscitation**: APGAR scores were 8/9. Resuscitation included BBO2.
  - **Admission Exam**: Wt 2261, Length 43 cm, OFC 33 cm. The PE was remarkable for large right frontal fluid-filled mass covering the right eye, 4 x 3.75 in. and narrowed ear canals bilat. Also remarkable for a murmur.

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Case Example #2
Discharge Summary

- **Hospital Course By Systems:**
  - **Respiratory**: Admitted to nursery in room air. He was started on caffeine on DOL 13 for periodic breathing episodes noted on his cardio respiratory monitor. He was also started on NC around the same time for poor PO feeds.
  - **Infectious Disease**: A sepsis evaluation was done secondary to preterm labor and unknown GBS status. Blood cultures were negative at 48 hrs and Ampicillin and Gentamycin were continued until DOL #3.
  - **Neurosurgery**: Peds neurosurg was consulted for management of frontal encephalocele. MRI showed large right frontal encephalocele, cortical migration anomaly, polymicrogyria, dysplastic corpus callosum, Chiari I malformation. Repair planned at about 9 months of age.
  - **ENT**: Otolaryngology was consulted for narrowed external auditory canals on exam. Exam under anesthesia confirmed EAC stenosis bilat. Myringotomy tubes were placed.
  - **Cardiology:** Normal echo.
  - **Consults**: Neurology, Neurosurgery, Plastic Surgery, ENT, Cardiology

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Case Example #2
Diagnostic Evaluations

- Prenatal Ultrasound/Anatomy Scan – Anterior skull mass per history. Prenatal records not available.
  - Is this consistent with physical exam?
- Physical exam on day of birth – Large right frontal fluid-filled mass (4 in X 3.75 in) covering right eye. High arched palate. Ear canals appear small bilat. Grade 1/6 systolic murmur.
  - Was the mass evaluated further?

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Case Example #2
Diagnostic Evaluations

- MRI on day after birth

  Large right frontal encephalocele containing the majority of the frontal lobe. The brain parenchymal contents of the encephalocele demonstrate an abnormal gyral pattern c/w the presence of a cortical migration anomaly. There is also vasogenic edema from venous occlusion vs. contusion, white matter tear, and multifocal hemorrhage. The encephalocele does not extend into the right orbit or the paranasal sinuses. There is polymicrogyria of the left frontal lobe. Dysplastic vs. absent corpus callosum observed. Posterior fossa s/w small and cerebellar tonsils have a conical configuration w/ extension into the foramen magnum. Small abnormally configured right basal ganglia are identified. Brain stem is distorted but intact. Hypertelorism is present. Tonsils low-lying vs. Chiari I malformation.

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Case Example #2
Consults

- **Pediatric Neurosurgery**
  - Reason: Frontal Encephalocele
  - Physical exam: One-day-old male infant with prenatal diagnosis of anterior skull mass. Physical exam WNL except for large mass overlying right frontal region to superior aspect of right eye. Mass crosses the midline and overlies the region of the AF. Mass feels full and relatively solid, No drainage.
  - Impression: Large frontal encephalocele
  - Recommendations: 1. MRI 2. Will attempt to repair at 9 months of age with dural closure followed by expansion craniotomy on lt side in order to place bone on the rt side. 3. F/U in neurosurg clinic for repeat MRI in 4-5 months.

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Case Example #2
Consults

- **Otolaryngology**
  - Reason: Narrowed ear canals on PE
  - Exam under anesthesia: Bilateral external auditory canal stenosis. Myringotomy tubes placed.
- **Cardiology**
  - Reason: Heart murmur
  - Physical exam: Gr 1/6 systolic murmur, o/w normal.
  - Echo: Structurally normal heart. No F/Up recommended.

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Case Example #2
Defect List

- Q01.0 – Frontal encephalocele
  Verbatim: Large right frontal encephalocele, exam, postnatal MRI
- Q04.3 – Other reduction deformities of brain
  Verbatim: Abnormal gyral pattern; cortical migration anomaly; polymicrogyria of the left frontal lobe, postnatal MRI
- Q04.0 – Congenital malformations of corpus callosum
  Verbatim: Dysplastic vs. absent corpus callosum, postnatal MRI
- Q04.8 – Other specified congenital malformations of brain
  Verbatim: Cerebellar tonsils low-lying vs. Chiari I; abnormally configured right basal ganglia, white matter tear, distorted brain stem, postnatal MRI
- Q75.2 – Hypertelorism
  Verbatim: Hypertelorism, physical exam
- Q16.1 – Congenital absence, atresia and stricture of auditory canal (external)
  Verbatim: Bilateral external auditory canal stenosis, exam

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Case Example #3

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Case Example #3
Problem List

- 30-week AGA infant born by C-section
- Problem list:
  - Q04.8 – Other specified congenital malformations of brain
  - Q15.8 – Other specified congenital malformations of eye
  - Q66.89 – Other specified congenital deformities of feet

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Case Example #3
Diagnostic Evaluations

- Newborn physical exam
  - Epicanthal folds
  - Right clubfoot
- Diagnostic procedures
  - Cranial ultrasound on the 1st day of life reported as normal.
  - Cranial ultrasound 3rd day of life shows grade 2 intraventricular hemorrhage on the right
- Consultations
  - Pediatric orthopedics – right clubfoot, follow-up as out-patient one month after discharge to evaluate for serial casting

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Case Example #3
Defect List

- Q15.8 – Other specified congenital malformations of eye
  Verbatim: Epicanthal folds, exam
- Q66.89 – Other specified congenital deformities of feet
  Verbatim: Right clubfoot, orthopedics

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Questions?

More information on Zika: **www.cdc.gov/zika**

For more information, contact CDC
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348 www.cdc.gov