## Pediatric Family History

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February 24, 2006

## Pediatric Family History

What information do we need?
How can families collect it?
When can providers talk about it?

#### Why do we collect family history?

#### "Medical Reasons"

- Establish patterns of inheritance
- Assist with medical diagnosis
- Identify risk
- Provide appropriate screening
- Target education & prevention efforts
- Pre-conceptive counseling

#### Why do we collect family history?

#### "Provider/Patient Reasons"

- Establish rapport with patient and family
- Establish health status of family
- Understand relationships between family members
- Understand social environment

- Alcoholism
- Allergies
- Anemia, including sickle cell
- Arthritis
- Asthma

- Bleeding disorders
- Cancer
- Congenital disorders
- Coronary Artery Disease

- Death before age 50
- Diabetes Mellitus
- Drug addiction
- Epilepsy

- Heart Disease
- Hypercholesterolemia
- Hypertension
- Kidney Disease

- Learning disabilities
- Mental illness
- Migraine
- Stroke

- Tuberculosis
- Obesity\*
- Leprosy\*
- Syphilis\*
- (\* DeGowin & DeGowin, 1976)

### Elements of Family History Provider training

#### Physical Examination textbooks

- DeGowin & DeGowin 1976
  - 24 conditions
- Bates Guide with Pediatric section 1991, 5<sup>th</sup>
   Edition
  - 17 conditions
- Bates Guide to Physical Exam & Hx 1999,
   7<sup>th</sup> Edition
  - 14 conditions

# Elements of a Family History Provider Training

## University of California, San Francisco School of Nursing

- Pediatric Database for Advanced Practice Nurses
  - Genogram: sex,age & health of family members
  - Familial & Communicable Diseases
    - 24 different conditions

### Elements of a Family History Provider Training

#### Stanford University School of Medicine

- The Medical Interview, Cohen-Cole, 1991
  - Health problems and treatments of all first degree relatives
  - Health problems that "run" in the family
  - Problems in family members similar to chief complaint of patient
  - Brief review of illnesses, as in past medical history

#### Elements of a Family History Provider Training

- Stanford University School of Medicine
- The Medical Interview, Coulehan & Block, 1987
  - Systematic exploration of the presence or absence of any illness in family that may have impact on current problem or impact risk of future disease

# Elements of a Family History Provider training

#### **Medical Textbooks**

- Nelson Textbook of Pediatrics, 2000
  - "At the initial well child visit, data about family medical history and the prenatal and perinatal history should be entered..." (p.21)
  - New patient interview should last 30-40 minutes (p.66)
  - Many familial conditions listed in index

### Elements of a Family History Provider training

#### **Medical Textbooks**

- Rudolph's 2003
  - FH of developmental problems/syndromes (p.15)
- Neinstein Adolescent Health Care 2002
  - Age & health status of family members
  - 10 conditions
  - Guidelines for Adolescent Preventive Services (GAPS) (p.87-98)

# Elements of a Family History Genetic Focus

## The Practical Guide To The Genetic Family History, Robin L. Bennett, 1999

- Start with the Family Tree →Pedigree
- First degree relatives: parents, siblings, & children
- Ideally includes grandparents, aunts, uncles, grandchildren (second degree relatives) and cousins (third degree relatives)

# Elements of a Family History Genetic Focus

- Age
- Health Status

or

- Cause of death for each relative
- Then review of systems for familial conditions

# Elements of a Family History Genetic Focus/Systems review

#### Head, face, neck

 Structure: unusual sizes (head), shapes (eyes/ears), colors (eyes, hair), & problems (teeth- missing, extra, fragile)

#### Skeletal system

 Structure: unusual shapes (chest, bones, hands, feet), height (short or tall), & proportions.

# Elements of a Family History Genetic Focus/Systems Review

- Skin
- Respiratory
- Cardiac
- Gastrointestinal

# Elements of a Family History Genetic Focus/Systems Review

- Renal
- Hematological
- Endocrine
- Immune System

# Elements of a Family History Genetic Focus/Systems Review

- Reproductive system
  - Pregnancy losses, infertility, complications, infant mortality
- Neurological/neuromuscular
- Mental functioning

# Elements of a Family History Genetic Focus/Additional Questions

- Occupation (possible environmental exposure)
- Birth Defects (heart, hands, feet, spine)
- Cancer (may not be revealed in ROS)

# Elements of a Family History Genetic Focus/Additional Questions

- Drug and alcohol abuse
  - maternal teratogens
- Unexplained or sudden death
- Ethnicity

# Elements of a Family History Shared Environments

- Exposure to infectious diseases
  - Tuberculosis
- Exposure to carcinogenic substances
  - Second hand smoke
  - Pollutants
  - Agriculture (pesticides)

#### Elements of a Family History Shared Environments

#### Cooking habits

- Smoked/cured foods
- High fat diet

#### Lifestyles

- Active family
- Couch potatoes

#### Challenges for Patients/Families

- Emotionally charged information
  - Mental illness
  - Non-paternity
  - Consanguinity
- Should address with families before initiating history search
- Patients/families may need emotional support during search

### Challenges for Patients/Families

- Adoption
- Family estrangement
- Incomplete or inaccurate information
  - "I think she died of stomach cancer or was it female cancer?"
- Aging or absent family historians
  - "My mother has Alzheimer's and can't remember anything"

# How can patients/families collect and record info?

- Internet
  - The U.S.Surgeon General's Family History Initiative
    - "My Family Health Portrait"
    - http://www.hhs.gov/familyhistory
  - CDC's Family History Website for the Public
    - http://www.cdc.gov/genomics/public/famhist.htm

#### How to collect Information

- Family gatherings
  - Reunions, holiday celebrations, graduations, weddings, vacations
- Family Records
  - Baby books, bibles, military records, old letters, obituaries, death certificates

# How can patients/families collect info?

- Request medical records
  - Death certificates
  - Autopsy reports
  - Medical records
    - Maternal prenatal history form
- Genealogical websites
- See Handout

# When can providers talk about FH? Insurance & Billing Issues

- Capitated Insurance
  - HMOs
  - Capitated payment is a monthly payment provider receives for all services rendered
  - Same amount received for one visit or ten visits in the same month
- This kind of plan "penalizes" provider for extra visits (e.g. to collect additional family history)

# When can providers talk about FH? Insurance & Billing Issues

- Preferred Provider Organizations (PPOs)/others
  - Providers receive payment for each visit
  - Diagnostic codes justify reason for visit
- require reason beyond FH for visit
  - a positive finding on first pass of FH could establish basis for additional visits

#### When can providers talk about FH?

- Family History considered part of visit
  - one of the key elements in a new/return physical exam visit
- Can have a separate visit if there is an identifiable problem
- Can use counseling codes if > 50% of visit is spent talking with patient/family (for collection of family history)
  - but must have "problem" to be reimbursed

#### Evaluation & Management Codes

#### Use E&M codes based on time

- >50% of total visit time spent in counseling
- Have to document in chart total visit time and time spent counseling\*

99201-99205 (New patients) 99212-99215 (Established patients)

\*Medicaid/MediCal patients must be present during counseling, even if patient is a small child or infant

### Diagnoses Codes

Use V Codes for specific Family History
 Information Examples

- V18.0 FH of Diabetes Mellitus
- V18.61 FH of Polycystic Kidney Disease
- V17.6 FH of other cardiovascular disease (not ischemic)
- V19.5 FH of Congenital anomalies

### Diagnoses Codes

## Health Care Financing Administration (HCFA) Documentation Guidelines; 1997

- Documentation guidelines for Evaluation and Management reflect typical adult visits
- Infants, toddlers & adolescents may have additional or modified information recorded in the history and physical exam.
- "FH will focus on congenital anomalies and hereditary disorders in the family" (p.8)

## Other Options

- Risk Factor Reduction
  - no disease yet present
  - E & M codes
    - 99401-99412

Have to check with insurance carriers for coverage

Less frequently Used

Less sure of reimbursement

### Challenges for Providers

- Get providers to take and update family history
  - <3 minutes for a new patient FH</p>
  - <2 minutes for returning patients</p>
    - AchesonLS et al 2000
- Have to work Family History into existing visits or schedule specific visit to focus on FH (see previous slide)

### Challenges for Providers

- Quality Improvement Audit
- Pediatric/Adolescent Clinic (0-21 years)
- Providers
  - 1 MD/6 NPs (PNP, FNP)
- Random Audit of 43 patient records
- Standard Forms used for charting
  - Initial Hx form (31 FH items) with blank section for genogram/pedigree
  - Annual update history form

### Challenges to Providers

- Results: the good, the bad, & the ugly
  - 98% charts had a completed FH
    - done by parent/patient &/or provider
  - 60% of FHs had provider notations
    - Comments/explanations/review
  - 26% had genograms drawn by providers
  - 42% of patients returning for an annual exam had an updated FH

# The Pediatric Advantage Newborns and Toddlers

- Many well or preventive visits in first 2 years of life
  - 10 visits if American Academy of Pediatrics (AAP) periodicity followed
- First 2 years of life can be spent collecting and refining FH
  - providing that patient comes for all visits, sees the same provider, and there are no major problems!

#### Challenge to Providers

#### Introduce families to resources at first visit

- Add FH links to office/clinic's webpage, if available
- Provide handouts with resource information
- Print out fact sheets from websites
- Publicize Thanksgiving Day as Family History Day
- For computer-savvy children, involve them in process, as appropriate

## Don't forget to Update

- Slogans to help providers/families remember
  - "Five Minutes for Family History"
  - "Don't Forget Family History"
- Add FH section to annual history form, if not already there
- If pedigree from "My Family Health Portrait" is in chart- update there and date changes/additions

## Closing Thoughts

- Provider Training
  - Approach Family History Collection in more systematic fashion
- Patients & Families
  - Engage families in the process, provide resources
- Clinical Application
  - Improve tools and resources for providers