Think BIG: How Big Data is Changing the Future of Pediatric Healthcare

Kristin Hittle Gigli, PhD(c), RN, CPNP-AC, CCRN
Children’s Health, Children’s Medical Center Dallas

Disclosures

• I do not have any financial relationships to disclose. I will not discuss off label use and/or investigational use of any drugs in this presentation.
• Some devices described have not been FDA approved by are undergoing research trials.

Learning Objectives

• Evaluate key definitions and components that make up the world of big data.
• Explore ways big data is being used to change pediatric healthcare.
• Identify roles of the pediatric-focused APRN in big data utilization.
• Discuss ethical challenges surrounding the use of big data in pediatrics.

How BIG is BIG DATA?

A Historical Perspective

- 300 B.C. - Library of Alexandria
- 1459 - Gutenberg Printing Press
- 1950s - Birth of computers
- 1986 - The power of the pocket calculator
- 2000 - 3% of all data is digital
- 2007 - Only 7% of data is analog
- 2016 - 92% of data is analog

Big Data, Mayer-Schönberger & Cukier
Take a byte

- 1 byte = a single character
- 2 kilobytes = 1 typed page
- 1 megabyte = a novella
- 2 megabytes = a high resolution photo
- 10 megabytes = Chest x-ray
- 1 gigabyte = pickup truck filled with paper
- 1 terabyte = all x-rays in a large teaching hospital
- 1.25 terabytes = a human's functional memory
- 2 terabytes = an academic research library
- 1 petabyte = the DNA of the US population - then cloned twice
  = 2000 years of continuously playing music
- Exabyte → Zettabyte → Yottabyte → Xerottabyte → Silentnobyte → Domegemegrotbyte

Big Data Defined

- Data of a very large size, typically to the extent that its manipulation and management present significant logistical challenges (Oxford English Dictionary)

  “The ability of society to harness information in novel ways to produce useful insights or goods of significant value” and “…things one can do at large scale that cannot be done at a smaller one, to extract new insights or create new forms of value.” (Big Data, Mayer-Schönberger & Cukier, 2014)

M-health or Big Data

- M-health: use of mobile technology to collect health data
  - Democratized data collection
  - Low barrier to entry and use existing devices

- Big data:
  - Requires an organizational commitment:
    - Equipment: health information system, data storage space
    - Personnel: coherent data collection, skills for analysis, regulatory oversight

M-health

- 16 million women 15-19 give birth each year - UN development goals
- In sub-Saharan African 1 in 4 women had unmet need for contraception
- 24% of Ugandan teenagers have a pregnancy – what are attitudes of this group regarding contraception

The 4 V’s of Big Data

<table>
<thead>
<tr>
<th>Volume</th>
<th>Variety</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scale of data</td>
<td>Different forms of data</td>
</tr>
<tr>
<td>- We know that the amount of data is increasing exponentially</td>
<td>- Computer use (traditional source)</td>
</tr>
<tr>
<td>- Social media: Facebook, Twitter, Instagram</td>
<td>- Wearable technology</td>
</tr>
<tr>
<td>Velocity</td>
<td>Veracity</td>
</tr>
<tr>
<td>Analysis of streaming data</td>
<td>Uncertainty of data</td>
</tr>
<tr>
<td>- How fast can you get data</td>
<td>- How accurate is the information and thus how useful is data</td>
</tr>
<tr>
<td>- Real time vs. batching</td>
<td></td>
</tr>
</tbody>
</table>
Other V’s of Big Data

- Variability
  - How reliable is the data

- Visualization
  - How we use images (charts and graphs) to look at data to show a meaningful message

- Value
  - Is what we learn helpful?

Uses for Big Data

1. Enhance awareness
   - Describes a phenomenon or event
2. Builds our understanding
   - Cannot explain why things are
   - Shows that events and conditions are associated
3. Forecasting
   - Predicting outcomes

Keys to “Good” Healthcare Big Data

1. Anonymization - HIPPA
2. Complete data – fragmented records are not helpful
3. Data is usable by patients/families, providers, policymakers, researchers and entrepreneurs
4. Ensure safety – prevent breaches
5. Capture preventative and disease specific outcomes

Big Data’s Break in Healthcare

  - Health Information Technology for Economical and Clinical Health (HITECH)
    - Accelerate adoption of health information technology (HER)
      - Meaningful use
- Patient Protection and Affordable Care Act (2010)
  - Value-based purchasing
    - Reduce costs with changes to payments
    - Measuring and reporting quality care

Approaches to Healthcare Big Data

- Health-systems Focused
- Disease Specific

Buntin, Jain & Blumenthal, 2010
How do we obtain big data?

How can we use big data?

What we know is limited!

**Big Data Sources - Wearables**

- Step counters and activity trackers
- Sleep trackers
- Asthma and environment monitors
- Seizure monitors

**Big Data Sources - Connected Devices**

- Importance of integration with mobile technology
  - Scales
  - Blood pressure cuffs
  - Temperature monitoring
  - EKG tracings
  - Pulse-ox monitoring
  - Serum glucose monitoring

**Big Data Sources - Electronic Health Record**

- Can different health record systems “talk”
- How do you find what you want
  - Clear goals, study aims
  - Partnership with IT personnel
- What is the quality of the data
  - Missing data
  - Different classifications (diagnoses)
- IRB approval
  - Availability of obtaining de-identified data

---

Using Wearables – Activity Trackers

Health Outcomes of Information System Use Lifestyles among Adolescents: Videogame Addiction, Sleep Curtailment and Cardio-Metabolic Deficiencies

- Schuman, 2015

94 patients recorded sleep data for 1 week
Study included blood work and exam findings

Videogame addiction associated with:
  - Less sleep, obesity, higher blood pressure, low HDL, high TG and high insulin resistance

Using Connected Devices and Wearable

Health Outcomes of Information System Use Lifestyles among Adolescents: Videogame Addiction, Sleep Curtailment and Cardio-Metabolic Deficiencies

- Schuman, 2015
Using the EHR

- Data since 2009
  - All pediatric diseases
  - All pediatric specialties
- Combines the population to examine pediatric research questions
  - 5.3 million patients
  - 37,709 diagnoses
  - 2.6 million admissions
  - 137 million outpatient and ED visits
  - 1990 payer plans

Using the EHR - PEDSnet

- Acute Diarrhea
  - If breastfed, was patient advised to continue breastfeeding if able to take po
- Asthma
  - Patients with medication change had a follow-up visit within 3 weeks
- Immunizations
  - All children have 1 MMR vaccination between 1-2 yr of age

Using the EHR – PEDSnet ImproveCareNow

- Crohn’s disease and ulcerative colitis
  - Data from 66 pediatric GI centers and ~35% of all children with IBD
- Patient and provider collaboration to share outcomes data, best practices, quality improvement, and stories
  - Used treatment data to change protocols and increased remission rates from 55 to 77 percent
  - 2012 prospective study 4,000 pediatric patients anti-TNFα

Using Registries - Pediatric Surgery

- 8,975 pediatric patients
  - Supracondylar humerus fracture fixation (2,274, 25.6%)
  - Posterior spinal fusion (1,894, 21.1%) *most complications
  - ~4% adverse events, infection and 2% 30-day readmission

Using Registries - Government Surveys

- National Survey of Children’s Health
  - 91,000-102,000 children 0-17 years old
  - Physical and emotional health, factors that may relate to well-being of children

- National Survey of Children with Special Health Care Needs
  - 2001, 2005/6, 2009/10, annual since 2016
  - 38,000-40,000 children with special health care needs 0-17 years old
  - Health status, medical home, insurance status and ability to access care, transition and shared decision making

Big Data Sources – Government Surveys

- National Survey of Children’s Health
  - 91,000-102,000 children 0-17 years old
  - Physical and emotional health, factors that may relate to well-being of children

- National Survey of Children with Special Health Care Needs
  - 2001, 2005/6, 2009/10, annual since 2016
  - 38,000-40,000 children with special health care needs 0-17 years old
  - Health status, medical home, insurance status and ability to access care, transition and shared decision making

Big Data Sources - Registries

- Gabriella Miller Kids First Pediatric Research Program
  - Centralized database of clinical and genetic sequence data
    - Cancer and structural birth defects
      - Cleft lip/palate, heart defects, limb anomalies, neural tube defects
    - Children’s Cancer Research Network
      - Convenience sample of Children’s Oncology Group institutions
        - 42% of predicted children with cancer: ~4,000 patients
        - Leukemia 59%, renal tumors 67%, neuroblastoma 37%
Using Government Data: National Survey of Children with Special Health Care Needs

State Medicaid Eligibility Criteria and Unmet Preventive Dental Care Need for CSHCN

- 37,931 children; 14,272 insured by Medicaid

Using Government Data: National Health Interview Survey Child Component

- 3714 children 2-17 years old that received an action asthma plan
  - 42% in 2002 → 51% in 2013
  - More likely to have if child was black, had private insurance and used a controller

Government Surveys

- National Health Interview Survey Child Component
  - Annual survey since 1957
  - ~10,000 families a year with children 0-17 years old
  - Socio-demographic, health status, health insurance coverage, access to care

Government Surveys

- Survey of Pathways to Diagnosis and Service (2011)
  - 4,000 children; 6-17 year olds with autism spectrum disorders, developmental delay or intellectual disability
  - Emergence of symptoms, diagnosis, current status and treatments

  - 8,000 children; 4-17 years old
  - CAM use, payment for CAM, providers, reasons for and benefits of CAM

Big Data Sources – Administrative Data

- Healthcare Cost and Utilization Project (HCUP)
  - Diagnoses, complications, mortality, length of stay, practice patterns, cost

- National (Nationwide) Inpatient Sample
  - Largest publicly available all-payer inpatient health database
  - 7 million pediatric and adult hospitalizations
  - 1,000 hospitals with ~20% of all discharges
  - Good for cost, variation in practices and

- Kids Inpatient Database
  - Enriched pediatric sample, 21 and under, every 3 years
  - 5,000 hospitals, around 2 million pediatric admissions
  - Uses ICD codes to track utilization, access, cost, quality and outcomes
Using Administrative Data: KIDS Database

**National Trends in Hospitalizations for Opioid Poisonings Among Children and Adolescents, 1997 to 2012**

- 13,052 admissions for opioid poisoning from 1997-2012
- Incidence increase by
  - 205% in children 1-4 years of age
  - 176% in 15-19 year olds
  - 165% across all ages

**JAMA Pediatrics | Original Investigation**

**Using Administrative Data: KIDS Database**

- 17,461 patients; 9,982 teaching hospital, 7,479 non-teaching hospital
- Length of stay, cost, mortality, and number of procedures were all higher in teaching hospital when controlling for severity of illness

**Administrative Data**

- **Pediatric Health Information System (PHIS)**
  - Inpatient, ambulatory, ED and observation unit encounters
  - 45 children's hospitals
  - Clinical care, cost, quality improvement: readmission, antimicrobial stewardship, guideline effectiveness

- **National Survey of Child and Adolescent Well-Being**
  - Longitudinal study of children and families that have been subjects of a Child Protective Services (CPS) investigation
  - Child and family well-being outcomes based upon experience with CPS and social and environmental characteristics

**Using Administrative Data: KIDS Database**

**Using Administrative Data: National Survey of Child and Adolescent Well-Being**

- 2165 children in 30 hospitals over 4 years
- 1/3 had an EEG, 2/3 were treated for seizures with medication

**Big Data Sources – Claims Data**

- **Medicaid Analytic Extract data (MAX):**
  - National Medicaid utilization and claims data
  - Person-level data on eligibility, enrollment, payment and type of service
  - Claims: inpatient, long-term care, other services and prescription drug

- **Prescriptions:**
  - Premier Perspective Database
    - Inpatient drug utilization
    - Billing and coding for
    - 45 million hospital inpatient discharges
    - 220 million hospital outpatient visits
  - Cerner Multum Drug Database
    - Proprietary database of prescription and nonprescription drug products

[Links to data sources and additional information provided.]
Using Medicaid Claims Data

- 36 states contributed data
- 1.2 million foster care adolescents
  - 6517 with morbid obesity (0.5%)
  - Higher in female, non-white – increased with age
  - Second generation antipsychotic increased risk

Using Prescription Claims Data

Proton Pump Inhibitor Prescribing Patterns in Newborns and Infants

What is our role in Big Data Research?

“I think one’s feelings waste themselves in words; they ought all to be distilled into actions which bring results.”

- Florence Nightingale

You do not have to be a researcher

- Use research
  - Stay updated on latest studies
  - Look for trends in how technology is being used
- Support others research
  - Encourage patients to participate in registries
  - Complete surveys to document your role as a provider
  - Try to keep updated medical records (Bowman, 2013)

A Word of Caution

50-80% of electronic health record projects fail (UN, 2015)

- National Children’s Study a $150 million project (Mervis, 2015)
  - 100,000 children from birth to 21 years of age
  - Monitor environmental and psychosocial factors
- Google Flu Trends (Lazer & Kennedy, 2015)
  - Accurate in 2008, not by 2013

Tips for Success

1. Engage leadership stakeholders
2. Allow for feedback to data entry participants
3. Use institutional history
4. Engage bedside providers
5. Involve patients and families
If you are or want to be a researcher...

- Creating unique data sets
  - Look for opportunities and partnerships
  - What existing resource can you use
    - Data abstraction
      - Source
      - What are the questions and pertinent data
    - Technology
      - Apps, wearables and connected devices
  - Data entry
    - Standardization of terms
    - Complete data

- Role of aggregated and disaggregated data

- Participate in existing data collection efforts
  - Who are the key study personnel
  - What are the institutional requirements
  - Consenting patients and de-identified records

“The future is already here—it’s just not evenly distributed.”
- William Gibson

- Using existing data sets
  - Learn about the user requirements
  - How large are the files
    - How are you going to access and store the files?
    - Do you have the computer power to run the analysis?
    - What program are you going to use to analyze data?
  - Does the data make sense
    - Missing data
    - Signal and the Noise, Nate Silver
  - Is all the care captured — do you have complete story?
  - Are you asking a question that provides new insights
    - What is your audience

- Standardization of terms
- Complete data

Data Security

- Security Threats
  - Employee negligence
  - Cyber attacks
  - Insecure cloud services
  - Malicious insiders
  - Identity thieves
  - System failures
  - Insecure medical devices

- Data Breaches
  - Criminal attacks
  - Lost/stolen devices
  - Employee action
  - Phishing attacks
  - Third-Party Actions
  - Technical glitches

- Connected Devices
  - Need security protection mechanisms
  - Audit logs to assess for malicious intent

- Employer Concerns
  - 96% worry about lost and stolen devices
  - 83% have experienced phishing and malware attacks
  - Biggest concern is employee negligence!

- Preventive Practices
  - Strong policies and procedures
  - Process to deal with lost and stolen devices
  - Employee education
  - Third-party actions
  - Updated technology to prevent technical glitches
**Ethics in Health Care Big Data**

- Confidentiality is protected by
  - HIPPA: permits secondary data use for research, public health, and other “public interests and beneficial activities” without patient authorization
  - HITECH
  - Genetic Non-Discrimination Act (2008)
  - World Medical Association Declaration of Taipei on Ethical Consideration Regarding Health Databases and Biobanks (2016)

**Declaration of Taipei on Ethical Consideration Regarding Health Databases and Biobanks**

- The purpose of the Health Database or Biobank;
- The risks and burdens associated with collection, storage and use of data and material;
- The nature of the data or material to be collected;
- The procedures for return of results including incidental findings;
- The rules of access to the Health Database or Biobank;
- How privacy is protected

http://www.ama.net/en/30publications/10policies/68/

**Confidentiality vs. Anonymization**

- Data use without authorization (HIPPA)
- Assumption that anonymization protects privacy
  - Expectations of patients
  - Transparency of health care field
  - How does data get used
- Cannot release patient HPI but can sell and transfer medical records
  - PEDSnet
  - Pharma company
  - Genetic data

**Is anonymization enough?**

- One in six patients withheld information, provided inaccurate information, doctor-hopped, paid out of pocket instead of using insurance, or even avoided care
- Over 80% feared that internet searches about healthcare would result in changes in insurance coverage or otherwise reveal their information
- 67% oppose releasing data to third-parties, including researchers, without patient permission

**Behavior Modifications**

- Personalized offers limit choices – Free Choice
- The Amazon effect
- How do we decide what behavior is desirable when we use big data to influence behavior
  - Activity tracking devices and messaging interventions
  - Role of the IRB in oversight

**Predictive Uses for Big Data**

- Predictive models (Cohen et al., 2014)
  - Acquiring data to build the model
  - Building and validating it
  - Testing it in real-world settings
  - Disseminating and using it more broadly
- Over-prediction of health events (Kaplan, 2014)
- Identification and disclosure of disease (Kaplan, 2014)
Summary

- Technology is changing how we understand our patients' health and healthcare delivery.
- Increasingly, we have more information available to us for analysis that can be used to influence our care and our patients' health. - How do we use this information?
- APRNs can easily engage in big data collection and utilization.
- There are new considerations and responsibilities for the protection of our patients in this era of big data.

Go out and use BIG DATA!

References


References