Meaningful Use of Data in Coordination of Care for Children with Complex Special Health Care Needs: The TeleFamilies Project

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Objectives

1. Briefly describe care coordination for children with special health care needs as a critical health care challenge.

2. Using the DIKW* Framework, define meaningful use of data in the context of care coordination and the nursing role.

3. Using the TeleFamilies study as an example, demonstrate the value of the APRN role and scope of practice in contextualizing data for meaningful use in care coordination.

*DIKW: Data, Information, Knowledge, Wisdom (American Nurses Association)
Care Coordination for Children with Special Health Care Needs

The Challenge
The Institute of Medicine (IOM) identified care coordination as one of its 20 national priorities for improving quality of health care, and a primary area for performance measurement.
Complex Special Health Care Needs
“Children with Medical Complexity”

- Characteristic patterns of family-identified health care service needs;
- Lifelong chronic conditions that are severe and/or associated with medical fragility;
- Functional limitations that may be severe requiring assistance from technology; and
- High utilization of health resources such as hospitalizations and/or the involvement of multiple subspecialists

Cohen et al. (2011)
Health Records for CSHCN

Compared to children with acute or single chronic conditions, children with special health care needs have:

- Multiple providers
- Multiple systems of care
- Frequent changes in health status
- Multiple medications/prescribers
- Fluctuating problem lists
Health Records for CSHCN

§ Fluid nature of data and information and accuracy of its representation on the EHR

§ Requires synthesis of historical and current data based on knowledge and wisdom

§ Multiple EHR platforms with limited interoperability

§ Complex system of communication within and between providers
Meaningful Use and the DIKW Framework

The framework
HITECH: Meaningful Use

The HITECH portion of the American Recovery and Reinvestment Act mandated that incentives should be offered for meaningful use of data and electronic health records.

Meaningful use of EHRs: “the ability to transmit information, use decision support, and generate information that is important to patients, health care practice, and public health”

Challenges in Meaningful Use

- Providers’ experiences do not match policy-makers’ expectations of the role of EHRs in care coordination.

- Assumption: meaningful use of data is independent of the practitioner’s role, educational preparation, and ability to use knowledge to manage human problems.
Challenges in Meaningful Use

Providers’ experiences do not match policy-makers’ expectations of the role of EHRs in care coordination.

Assumption: meaningful use of data is independent of the practitioner’s role, educational preparation, and ability to use knowledge to manage human problems.
**Wisdom**: the appropriate use of knowledge to manage and solve human problems between types of information

*In clinical practice, the application of experience, intelligence, creativity, and knowledge enables the nurse to make timely clinical decisions based on wisdom, recognizing which information is most important to the plan of care*

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Nurses are ideally prepared to manage and solve the human problem of coordination of care for CSHCN.

Advanced practice nurses add value to the care coordinator role through enhanced scope of knowledge and practice.
DIKW Framework (ANA)

§ **Data:** discrete facts that represent objects, events, and their properties as well as abstract concepts such as pain and spirituality

§ **Information:** data that have been processed into a form that is meaningful

§ **Knowledge:** information in context

§ **Wisdom:** appropriate use of knowledge to manage and solve human problems

American Nurses Association. Nursing’s social policy statement: The Essence of the Profession. Silver Spring, MD: nursesbooks.org; 2010
Exemplar: TeleFamilies and the APRN Care Coordinator Role

The Implications
TeleFamilies

- Randomized Controlled Trial
- 4-year project, in year 3
- Children’s hospital-based primary care clinic
  - Certified healthcare home
  - Children with complex health needs
- Does interactive telehealth-enhanced APRN care coordination improve outcomes for CSHCN?
Setting

Population

Design

Care Coordination

Care Coordinator Role Preparation

Children’s Hospital Primary Care Clinic

Health Care Home (Special Needs Program, SNP)

N=10,000

Children with Complex Special Health Care Needs

TeleFamilies

N=600

N=150

N=50

N=50

Randomization

Usual Care

TeleNursing Intervention

Licensed Practical Nurse (LPN) + RN Triage

Telephone

Advanced Practice Registered Nurse (APRN)

Telephone

Telephone + Video

N=10,000

N=600

N=150

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Video-enhanced Care Coordination

VI Families
Knowledge: information in context

How does the APRN contextualize information about CSHCN through care coordination?
2 Features of Professional Nursing (ANA)

§ integration of objective data with the patient’s subjective experience

§ application of knowledge to the processes of diagnosis and treatment through the use of judgment and critical thinking
Contextualization of Information by the APRN

A. Developing relationships over time
B. Technology-enhanced interactions
C. Enhanced scope of knowledge and practice
D. Enhanced functionality of EHR
Contextualization of Information

§ Developing relationships over time with families
  § Learn about family, their history, their story
  § What worked in the past is known

§ Technology-enhanced interactions
  § Access to family/child is timely, visual cues available

§ Enhanced scope of knowledge and practice (APRN)
  § Advanced assessment, diagnostic skills
  § Autonomous completion of episode of care

§ Enhanced functionality of EHR
  § Tailored templates, standardized processes
  § Time to review, update as information changes

Figure intentionally blurred for copyright reasons. Contact W Looman for more information on this model.
Summary

1. Care coordination for children with special health care needs (CSHCN) is a critical health care challenge.

2. The DIKW Framework provides a model for understanding meaningful use of data in the context of care coordination for CSHCN.

3. The TeleFamilies study is an exemplar of the value of the APRN role and scope of practice in contextualizing data for meaningful use in care coordination for CSHCN.

*DIKW: Data, Information, Knowledge, Wisdom (American Nurses Association)*
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