Evaluation of the Integration of Genetics and Genomics into Nursing Practice

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Definitions

• **Genetics** – study of individual genes and their impact on relatively rare single gene disorders

• **Genomics** – study of all the genes in the human genome together, including their interactions with each other, the environment, and other psychosocial and cultural factors
Genomics of Common Disease

There are *already* opportunities to use genetic and genomic information in healthcare for common diseases

- Risk Assessment
- Prevention
- Diagnosis
- Treatment
“All patients have genes.”
Eugene Rich, 2004
WHY? Cumulative Pace of Disease Gene Discovery
Extent of Genetic and Genomic Testing

• As of 9/21/2011, there are 2437 diseases with available genetic/genomic tests
  – 2175 clinical
  – 262 research

Genomics of Common Disease

ENVIRONMENTAL CONTEXT OF GENOMIC INFORMATION ASSESSMENT

- Physical
- Occupational
- Emotional
- Sociocultural
- Religious
- Other?
BUILDING BLOCKS

- NURSES are essential to applying genomic discoveries to patient care
- CHALLENGE genetic health literacy
Define essential genetic and genomic competencies for **ALL** nurses regardless of level of academic preparation, practice setting or specialty.

Prepare the nursing workforce to deliver competent nursing care in the genomic era of healthcare.
Specific Aims

• Determine nurses beliefs, practices and competency of integrating into practice genetic and genomics information related to common multi-factorial diseases.

• Assess knowledge of human genetic variation and the use of patient genetic information in therapeutic decision-making.
Study Purpose

• Online survey with ANA
• Benchmark practicing nurses genomic competency
• Assess clinician’s knowledge of human genetic variation
• Assess use of patient characteristics in diagnostic, treatment, and referral decisions
• Data was needed to justify and guide development of education interventions
Methods

Recruitment

- American Nurses Association
  - Posting on Nursingworld.org
  - Paper cover for The American Nurse (TAN)
  - Email announcements to subscribers of ANA daily SmartBrief and weekly Nursing Insider, the e-Newsletter.
Methods

• Online survey methodology
  – Survey Monkey - open for four months
    • 10/2009 – 1/2010

Statistical Analysis
Descriptive statistical techniques
Genetics and Genomics in Nursing Practice Survey (GGNPS)

- 620 nurses responded
- 60% were members of ANA
- 91.8% white; 95.9% female
- Age range 21-76, mean 51
- Highest level of education
  - 16% Diploma/Associate Degree
  - 39% BSN
  - 34% MSN
  - 11% PhD or DNP
How important do you think it is for the nurse to become more educated about the genetics of common diseases?
Please rate your understanding of the genetics of common diseases.
Integrating Genomics into Practice

• Advantage
  – 86% selected better decisions about recommendations for preventive services

• Disadvantage
  – 65% felt this would increase insurance discrimination indicating a lack of awareness of the federal protection legislation (GINA) passed in 2008
Survey Results

• 83% agreed/strongly agreed that family history should be a key component of nursing care
• However, 66% of nurses reported that they had rarely or never collected a family history in the past three months
• 99% appreciated the clinical relevance of genomic risk (as indicated by family history) for coronary heart disease
• However, 60% incorrectly stated that diabetes and heart disease are caused by a single gene variant
• Knowledge gaps exist for all nurses
Genetics Education

Essential Competencies
• 33% Have heard or read about the Essential Competencies

Genetics Education
• 60% reported that their nursing curriculum DID NOT include genetics content
• Resources identified as most helpful included:
  – 40.0% Workshops
  – 37.4% Mix of books and electronic/web-based
  – 36.4% Electronic and web-based self study
Summary

• Although most survey respondents thought genomics was important, the majority of nurses felt inadequately prepared to incorporate genomics into practice.

• 72% were interested in learning more and 81% would support a genetics/genomics awareness initiative.

• All nurses would benefit from a broad scale education intervention.
Next Steps

Survey

• American Nurses Association – June 2010 Paper survey administered to the ANA House of Delegates
  – Data analysis ongoing
  – Compare findings to online survey
• National Coalition of Ethnic Minority Nurse Associations
  – Online survey data collection ongoing

Education

• National Council State Boards of Nursing
  – Funded: “Expanding RN Scope of Practice: A Method for Introducing a New Competency into Nursing Practice”