

Realizing the potential of Nurses role in Genetics and Genomic health care – An Integrated Review of the Literature

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Abstract: Introduction: Nurses are expected to have the necessary knowledge to interpret genetic and genomic information and technology with translation into nursing care, as they have a great impact on the daily nursing care of our patients. A literature search was conducted in January 2014 to understand the knowledge of Nurses in genetics which can clearly imply their role in genetics and genomic health care. **Methodology:** A literature review of abstracts and articles discussing the study aim on role of genetics in nursing, written in English, and published between 2007 and 2013 were searched. Articles were identified from four data bases using CINAHL, Pub Med, Google Scholar, and Medline with Full Text. **Findings:** The results of this review clearly indicate that there is still insufficient evidence to enable us to make a judgment as to whether nurses are competent to offer relevant genetic health care to patients in a range of clinical settings. It is perhaps encouraging that nurses acknowledged their need to have more information. However, most studies done worldwide assessed nurses' perceived knowledge rather than their actual knowledge levels. **Conclusion:** Therefore, the development of educational programs for nursing knowledge and counselling as well as basic curriculum in genetic nursing at universities are essential in the near future. Furthermore, it is essential that research activity progresses to the design and performance of studies to test the efficacy of nursing interventions in genetic health care.

Keywords –Nurses role, genetics, genomic health care, potential.

I. Introduction

In the areas of genetics and genomics, scientific advances, changing demographics of patient populations, new care technologies, and patient access to health care information call for new ways of thinking and doing in health care. In Pre-genome era, healthcare providers used a “one size fits all” approach to treating individuals. Whereas in the Post-genome era, increasingly healthcare providers will be able to use genomic information to tailor treatments to the individual, and personalize their care.

Advances in genetics science and technology have subtle significance for health care. The growing importance and relevance of genetics for everyday nursing practice is increasingly recognized in this era, where there is an increased complexity of diseases with hereditary component attached to it. Human genome sequence was completed by NHGRI (National Human Genome Research Institute) in April 2003. Following the completion of this project, there has been an explosion of available genetic and genomic information that is essential for nurses to incorporate into their daily clinical nursing practice. It has become essential to train all the nurses in genetics and genomics, regardless of country or practice setting, in order to provide best practices for prevention, recognition and/or treatment of disease (Barr and Mc Conkey, 2006; Burton and Stewart, 2003; International Council of Nurses, 2003).

Background of the study:

NHGRI now has intensified its focus on research aimed at improving health and fighting disease. Nurses are expected to have the necessary knowledge to interpret genetic and genomic information and technology with translation into nursing care, as they have a great impact on the daily nursing care of our patients. It is imperative to include Genetics and Genomics in the baccalaureate, masters', and Doctor of Nursing Practice programs, after the 2009 publications of the Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics. Nursing faculty are even expected to include genetics and genomics content in their nursing programs at all levels. Nurses prepared at the master's and doctoral levels are at the position of amalgamating these advanced genetic and genomic information into the client care. As the public continues to become more aware of genetic and genomic contributions to health and disease, nurses will be even more on the front lines, addressing genetics/genomics questions and the ethical issues that go with them (Greco, 2009). Twenty nine percent of US schools reported no genetic or genomic curriculum content in 2005 (Prows et al., 2006), while 50% of UK post-registration programs reported no genetic content (Metcalf and Burton, 2003). Barriers identified that have precluded the integration of genetic/ genomic content in nursing are nursing faculty's lack of knowledge of genetics and a limited number of clinicians and faculty who view genetic/genomic content as relevant to nursing practice (Jenkins, 2005; Kirk, 2009).

While nurses have always been required to care for patients with rare inherited diseases, evidence of the genetic contribution to common conditions such as diabetes (Morahan , 2011), coronary heart disease (Roberts 2008), and cancer (Bancroft 2010, Lillie et al. 2011) has increased the focus on genomics in nursing. The potential influence of nurses in this area was demonstrated by Barnoy, 2010), who undertook a study indicating that patients regarded advice about genetic testing as equally valuable whether it was given by an expert nurse or an expert physician. This development has created a need for health care professionals, including nurses, to have a thorough understanding of genetic disorders and to be capable of communicating genetic information to patients and families about genetic testing, risks, management, and treatment. Keeping these significance aspects in mind, a literature search was conducted in January 2014 to understand the knowledge of Nurses in genetics which can clearly imply their role in genetics and genomic health care.

Purpose:

This paper reports a literature review exploring the role of genetics in nursing profession. As nurses are the back bone of the health care system and they form the largest health discipline in all areas, the aim was to define the valuable contributions they can make to shape the delivery of genetic health care.

II. Methodology

A literature review of abstracts and articles discussing the study aim on role of genetics in nursing, written in English, and published between 2007 and 2013 were searched. Articles were identified from four data bases using CINAHL, Pub Med, Google Scholar, and Medline with Full Text. Search terms included “role of nurse in genetics”, “Nurse and genetics”, “Knowledge of nurses in genetics”.

Inclusion criteria:

- Original research studies
- primary data with full text
- Studies including Nurses as participants
- Published in English between 2005 and 2013

Exclusion criteria:

- Unpublished manuscripts or doctoral dissertations
- Review or opinion articles about menopausal symptoms

The initial search yielded 200 articles and with full text online articles were 55 which were reviewed for duplication and ended with 30. Out Of 20 papers retrieved finally, 8 were eligible for inclusion which had relevant information about knowledge, skills and attitudes of nurses regarding genetics, but the rest of the articles were utilized for writing background information of the article(ref.fig-1).

Findings:

The findings are presented in a narrative format. The 8 articles included in the review were based on studies conducted in 6 countries like USA, UK, Ireland, Turkey, Taiwan and Canada. The results of this review clearly indicate that there is still insufficient evidence to enable us to make a judgment as to whether nurses are competent to offer relevant genetic health care to patients in a range of clinical settings. In none of the studies did nurses demonstrate adequate and appropriate levels of knowledge and/or skills to be able to fulfil the core competences. It is perhaps encouraging that nurses acknowledged their need to have more information. However, most studies done worldwide assessed nurses’ perceived knowledge rather than their actual knowledge levels. Research on the delivery of genetics education is limited, but the role of skills-based training, use of clinical Scenarios and importance of assessment have all been identified as factors that can promote learning.

III. Discussion

Whilst areas of good performance were revealed, many studies identified gaps in professional competence and/or education. Agreement on the relevance of genetics for nursing practice is extensive. Empirical evidence of the learning needs of practitioners highlights widespread deficits in knowledge and skills, and low confidence levels. The nurses have also expressed great interest in educating and counseling patients. Most studies did worldwide have assessed nurses’ perceived knowledge rather than the actual knowledge in genetics. Provision of nursing education in genetics is patchy and insubstantial across a number of countries, further hampered by lack of strategic development. Significant progress has been made in the identification of

learning outcomes for nurses. Research on the delivery of genetics education is limited, but the role of skills-based training, use of clinical Scenarios and importance of assessment have all been identified as factors that can promote learning. Nurses' knowledge of genetics is insufficient to provide comprehensive services to the patients. The American Academy of Nursing recommended in a position statement (Lea, 2002), that nursing programs adopt the genetic core competencies developed by the National Coalition for Health Professional Education in Genetics (2001). In 1998, the International Society of Nurses in Genetics together with the American Nurses' Association developed the Statement on the Scope and Standards of Genetics Clinical Nursing Practice [revised in 2008] which stated that "Nurses require genetic knowledge to identify, refer, support, and care for affected by, or at

risk for manifesting or transmitting, genetic conditions" (American Nurses Association, 1998). Lastly, the Essential Nursing Competencies and Curricula Guidelines in Genetics and Genomics (Essentials) was developed (Consensus Panel on Genetic/Genomic Nursing Competencies,

2006, 2009). The goal was to disseminate the genetic and genomic core competencies to two target groups, practicing nurses and nursing students via nurse educators (Trossman, 2006). These two populations were targeted as nurses need to be able to identify genetic issues and refer patients and their families to appropriate specialists. Nurses are expected to have a significant role in caring for patients with genetic predispositions or disorders. To carry out this role effectively and efficiently, they must be able to 1) identify hereditary, familial, environmental and lifestyle characteristics that increase individual and family members' risk for disease, 2) facilitate informed decision making, 3) promote behaviors that facilitate surveillance and reduce disease risks, 4) identify, refer and/or prescribe appropriate disease management strategies, and 5) advocate publicly and politically promotion of optimal health care, including genetic health care for all desiring it (Baltimore, 2002).

Clinical Implications:

In short, by carrying the roles of a counselor, technician, care manager, and teacher for patients and their families, nurses will have an opportunity to expand as well as to create new leadership roles in health care. Therefore, the development of educational programs for nursing knowledge and counseling as well as basic curriculum in genetic nursing at universities are essential in the near future. Validated tools to assess nurses' competence in genetics are needed to facilitate comparisons across settings and countries. More research is needed to assess nurses' competence related to ethical issues in genetic health care. Furthermore, it is essential that research activity progresses to the design and performance of studies to test the efficacy of nursing interventions in genetic health care.

IV. Conclusion

All nurses need to be fluent in the language of genetics and genomics so that they can provide effective nursing care. Efforts in transforming health care should focus on educating nurses to be competent in this new knowledge. Nurses need an understanding of the impact of current scientific, genetic, and genomic discoveries and a vision of future discoveries. Only with these understanding and vision can the translation of such knowledge ultimately benefit our patients, their families, and communities.

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Figure 1: Methodological flow chart:

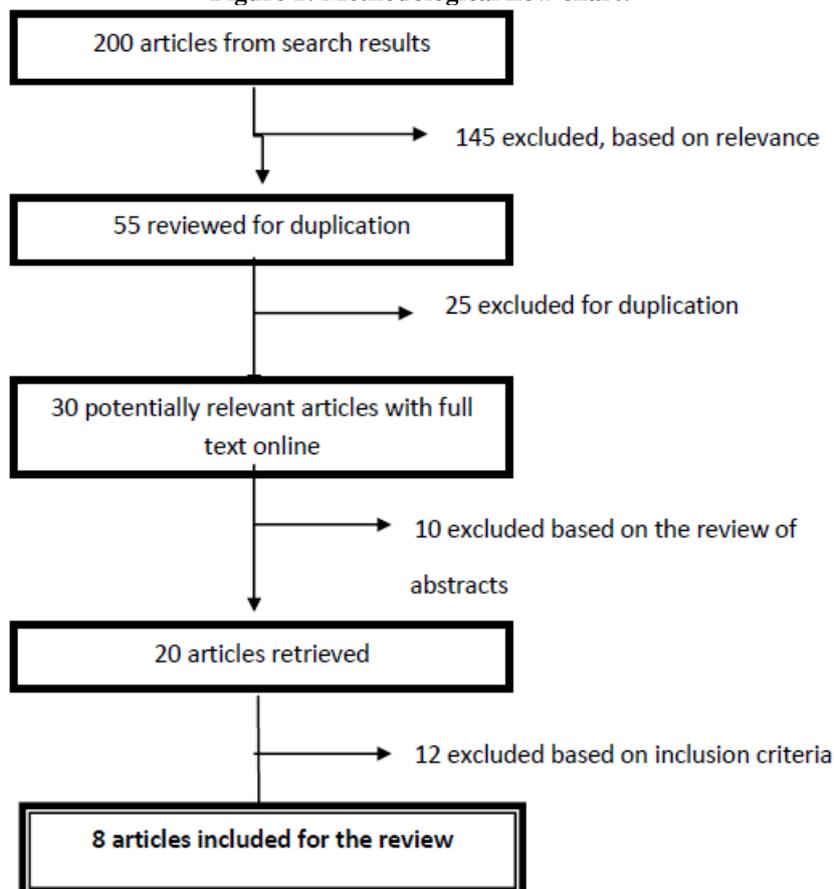


Table 1: Summary of the papers on Genetics and Nurses:

Tsornng-Yeh Lee et al.(2012)	To explore the knowledge level of human genetics among nurses and its correlation with characteristics of maternity and pediatric nurses.	A cross-sectional structured questionnaire was completed by 54 nurses who worked at a medical center in Taipei, Taiwan.	Descriptive and inferential statistics	The nurses’ correct answer rate in overall genetic knowledge was 66%.
Metcalfe et al. (2008, 2009)	To ascertain the views of hospice nurses re importance of genetics to their role and confidence to meet genetic care needs	Cross-sectional self-completion survey. 100 nurses from 14 hospices across the United Kingdom	Descriptive statistical tests and Dunnett’s C test	Majority of respondents were not at all confident about clinical and biological aspects of care, but fairly confident in respect of psychosocial activities
Spruill et al. (2009)	To assess interest, knowledge, and practice of African-American nurses, with respect to genetics Pilot study.	Cross-sectional self-completion survey. 77 African-American nurses from USA	Descriptive statistical tests	56% had poor knowledge of genetics. 86% knew how to complete a family health history. 78% thought genetic tests could be used to discriminate against individuals
Barr and McConkey (2006)	To explore the views of health visitors about their roles supporting parents of children referred to genetic services, their confidence about genetics and their ability to refer to genetic services	Cross-sectional self-completion survey, constructed by authors after a qualitative study. 194 caseload holding health	Descriptive and Inferential statistical tests	Health visitors reported low levels of activity and confidence related to referring patients to genetic services, obtaining genetic information, and discussing genetic test results with parents

		visitors working in 11 community health trusts in Northern Ireland		
Barr and McConkey (2006)	To investigate the views of health visitors regarding their educational needs around genetics	Cross-sectional self-completion survey, constructed by authors and reviewed by experts. Sample as above	Descriptive and nonparametric statistical tests	93.3–58.2% respondents stated they needed to learn more. 80.4–52.6% needed to learn more about eight genetics related skills
Bottorff et al. (2005)	To ascertain and compare knowledge, roles and confidence of physicians and nurses in providing genetic services for adult onset hereditary conditions and explore usefulness of educational programs	Cross-sectional survey. Data collected via postal, self-completion questionnaire. Random sample of 543/1425 physicians and 975/1425 practicing registered nurses invited in Canada	Descriptive statistics and non-parametric tests	On assessment of genetics knowledge, 35% nurses scored 4/5 and 14% scored 5/5. Mean level of confidence in providing genetics-related services was 2.30/5
Dogan and Sahinoglu (2005)	To assess and characterize the ethical framework and decision-making rationales at organizational level regarding fetuses with neural tube defects	Appears to have been a structured cross-sectional survey with qualitative and quantitative components, administered via interview. Ten nurses and 15 physicians working in perinatal units of Turkey	Analytical method poorly described	Nurses were not involved in decision-making discussions when a fetus with NTD was diagnosed. All nurses stated they respected the decision of the mother to refuse
Tomatir et al. (2006)	To ascertain nurses knowledge of and approaches to human genetics	Cross-sectional self-completion survey. 86 public health nurses recruited from 26 centers in Turkey	Descriptive statistics	4.2% of nurses felt they were knowledgeable about genetics topics. No nurses were knowledgeable about genetic counselling or ethics of human genetics