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Nursing genetics and genomics: The International Society of Nurses in Genetics (ISONG) survey

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Abstract

Background: The International Society of Nursing in Genetics (ISONG) fosters scientific and professional development in the discovery, interpretation, and application of genomic information in nursing research, education, and clinical practice.

Objectives: Assess genomic-related activities of ISONG members in research, education and practice, and competencies to serve as global leaders in genomics.

Design: Cross-sectional survey (21-items) assessing genomic-related training, knowledge, and practice. Settings: An email invitation included a link to the anonymous online survey.

Participants: All ISONG members ($n = 350$ globally) were invited to partake.

Methods: Descriptive statistics and Wilcoxon Rank Sum Test for between-group comparisons.

Results: Respondents ($n = 231$, 66%), were mostly Caucasian, female, with a master's degree or higher. Approximately 70% wanted to incorporate genomics in research, teaching, and practice. More than half reported high genomic competency, and over 95% reported that genomics is relevant the next 5 years.

Conclusions: Findings provide a foundation for developing additional educational programs for an international nursing workforce in genomics.

Keywords

Education; Genetics; Nursing; Research

1. Introduction

The National Institute of Health (NIH) defines *genetics* as the “study of genes and their roles in inheritance of disease,” while *genomics* involves “the study of all of a person’s genes, including the interaction of genes with each other and with the environment” (National Institute of Health, 2016). The importance and relevance of *genetics* and *genomics* (hereafter *genomics* for both terms) in nursing research, education, and clinical practice are becoming increasingly evident (Calzone et al., 2010; Calzone et al., 2013a,b,c; Genomic Nursing State of the Science Advisory Panel et al., 2013; Kirk et al., 2011; Williams, 2015). Nurses work at the forefront of translational science and can develop, lead, and implement genomic-based innovations in research, education, and practice (Tully and Grady, 2015). However, nurses need training and confidence in engaging with genomic-based techniques before they can contribute to precision medicine.

Given the exponential increasing pace of genomic research, it remains difficult for many nurses to stay up to date with current science. A U.S. national survey of the nursing workforce, reported that 57% of nurses believed that their genomic knowledge base was fair or poor (Calzone et al., 2013a,b,c). This statistic speaks to the significant gap regarding the preparation of the nursing workforce for the future of personalized healthcare. With the advent of the Precision Medicine Initiative, genomic innovation and its application to clinical care, are at the forefront of moving healthcare from a “one-size-fits-all” approach to considering individual differences, environmental influences, and responses to treatment to optimize disease and symptom management. Nurses are critical members of the healthcare workforce and with appropriate education and training in genomics, are can engage in practice and research that greatly contributes to realizing the potential of precision medicine (Williams, 2015).

The International Society of Nursing in Genetics (ISONG), an international professional organization charged with fostering scientific and professional development in the discovery, interpretation, application, and management of genomic information for the health of people worldwide (International Society of Nurses in Genetics, 2010). ISONG membership spans multiple areas of professional expertise; for over 25 years, members have made significant contributions to genomic science through innovative research, translation of research findings into clinical practice and development of innovative training programs for future nurses (Alexander, 2015). By identifying obstacles in educating the nursing workforce in genomics, ISONG serves as a mechanism for additional training in genomic competencies through an annual international conference and multiple free webinars and other educational resources. Given that ISONG promotes engagement in genomic-related activities, we evaluated the extent that members are involved in such activities. The overall purpose of the study was to assess ISONG’s contribution to the Precision Medicine Initiative by surveying its members about their genomic-related activities and their experiences regarding the integration of genomics in the nursing profession. The ultimate goal is identifying areas of research, education, and practice that merit improvement within ISONG and the nursing workforce.

2. Background

2.1. Genomic Nursing Education

Nursing education needs to evolve in order to integrate state of the art genomic science, such as complex biostatistics methods, into nursing education, boost the application of research findings from bench to bedside, and the translation of this knowledge into areas of clinical importance. A core element of the National Institute of Nursing Research (NINR) Strategic Plan is the genomic education of nurses, and the integration of this knowledge into nursing science, so that nurses can spearhead investigations with omics underpinnings (NINR, 2011).

There have been significant efforts to address gaps in genomic knowledge of the nursing profession. An important milestone was the establishment of the NINR Summer Genetics Institute (SGI), which for 15 years has been providing intensive hands-on training in molecular genetics at the bench with application to clinical practice and train the next generation of nursing scholars. Many graduates work on the customization of healthcare to the individual-, family-, and community-level, and are actively engaged in genomic research on topics and areas across the life span. Another important milestone was the development of the essential nursing competencies in genetics and genomics (Calzone et al., 2007; Consensus Panel on Genetic/Genomic Nursing Competencies, 2009; Calzone and Jenkins, 2011). The Genetics/Genomics Competency Center (www.g-2-c-2.org) provides high quality web-based genomic educational resources by healthcare educators and practitioners. The American Association of Colleges of Nursing (AACN) endorses the *Essentials of Baccalaureate Education for Professional Nursing Practice and the Essentials of Master's Education in Nursing*, and emphasizes the importance of genomics in the advancement of nursing education. The *Essential Competencies of Genetics and Genomics for Nurses with Graduate Degrees* include 38 core competencies in practice and research, and identify genomic knowledge that graduate level nurses are assumed to have achieved. Some of these competencies include risk assessment, analyses of family pedigrees to identify inherited disease, obtaining informed consent for genetic testing, and providing genetic counseling (Greco et al., 2011).

However, these essential genomic competencies are neither sufficiently integrated into nursing education, nor included in regulatory standards (Kirk et al., 2011). There are many system-level barriers for the adequate omics preparation of nurses and the integration of emerging areas of nursing science into PhD nursing programs (Conley et al., 2015; Henly et al., 2015a,b, Henly et al., 2015c; Wyman and Henly, 2015). Many U.S. schools of nursing incorporate these competencies into their undergraduate and graduate curricula, but in many cases this is limited to isolated lectures and lacks hands-on laboratory training. Many nursing schools do not have wet-laboratory space built into their facilities. Solutions involve cost sharing or collaborating with basic science or medical schools to cross-list of laboratory-based courses and research.

2.2. Genomic Applications in Clinical Practice

To enable integration of genomics into the nursing profession, it is important to recognize its applications and relevance into nursing clinical roles. Nurses at all educational levels should recognize “red flags” that might be associated with inherited conditions. Nurses with graduate degrees should be able to collect an accurate family history, be aware of how to incorporate genomics into the diagnosis, treatment, and care of patients, and how best to communicate this information to patients and families (Hickey et al., 2017).

Understanding the implications of genetic testing is complex and challenging for patients and families because the information that may or may not be available from test results varies among conditions. Presenting genomic information to patients requires knowledge of how to personalize and effectively communicate the application of this information into maintaining or improving health and quality of life. Cultural attitudes and beliefs toward genomics should be considered when providing personalized care to patients of multicultural backgrounds and when responding to questions about genomic profiles and healthcare choices (Singer et al., 1999, 2004, 2005, 2008; Taylor et al., 2013). The availability of Direct to Consumer genetic testing challenges nurses to become proficient in reading, interpreting and counseling patients about their genetic profiles. Nurses in clinical practice must be equipped to address these challenges as key members of interdisciplinary teams and help facilitate genomic literacy, misunderstandings about genomics, and informed decision-making that may influence healthcare choices (Klitzman, 2010).

In summary, there have been significant efforts to promote nursing involvement into genomics and nursing contributions to the Precision Medicine Initiative. Ongoing and systematic integration of genomic knowledge in nursing research, education, and clinical practice are needed. This study was designed to address this gap. The specific aims were to describe ISONG members’ confidence in genomic knowledge and its application; investigate specific areas of genomic-related activities of ISONG members; describe how ISONG can help advance genomic training of nurses; and identify additional areas of inquiry and improvement in genomic nursing.

3. Methods

This is a prospective, cross-sectional, descriptive, web-based survey. The Columbia University Institutional Review Board (IRB # AAA01768) and the ISONG research board approved the study protocol; the latter also granted access to potential participants’ email addresses. A disclaimer stated that this was an independent investigator-initiated study, explained its purpose and that participation was voluntary, and ensured confidentiality of responses. Participants’ contact information was not released to ensure confidentiality. The target sample included all ISONG members at the time of the study ($n = 350$).

An online anonymous survey assessed information on demographic characteristics, nursing and genomic training, details regarding nursing practice, self-reported genomic knowledge, and the application of genomics to research, education, and clinical practice. This survey is as an effective tool for administering and collecting data (Valentin et al., 2009; Agha et al., 2016a,b). A nursing panel with expertise in genomics and survey design reviewed the survey

to ensure clarity and face validity. Vague questions were revised, redundant items were removed, and new items were supplemented. The final survey contained 21 items arranged in demographics, nursing education, genomic training, workplace characteristics; confidence in genomic knowledge and its application; professional activities in which participants incorporate genomics in research, education, and patient care; recommendations of how ISONG can help advance genomic training of the nursing workforce; identify additional areas of inquiry and improvement in genomic nursing.

All ISONG members were invited to partake in the survey via an email, which directed them to a secure link and enabled access to the online survey. Email contact with participants took place three times over a period of three months: the initial email and two similar reminder and/or thank you emails. The final email reminder was sent one week prior to the annual ISONG World Congress Scientific Meeting. Participants were asked to respond to all questions. No email invitations were undeliverable due to invalid email addresses.

SPSS (version 15.0; SPSS, Chicago, IL, USA) was used for data analyses. Descriptive statistics (means, frequencies, percentages) were used for demographic data analyses. Wilcoxon Rank Sum Test was used for between group comparisons of non-normally distributed variables.

4. Results

Out of 350 ISONG members, 231 completed the survey (response rate 66%). Respondents were predominantly female (92.1%), Caucasian/White (91.7%), most between 40 and 65 years old (Table 1). Most (54.6%) held a PhD in nursing and another 35.8% held a master's degree. The majority (78.2%) was employed full-time; percent effort (% FTE) was almost equally divided in research, teaching, and clinical care. Participants with a doctorate in nursing spent a greater proportion of %FTE in research (two-sided P $|z|$ 0.0004), in teaching (two-sided P $|z|$ < 0.0001) and in administration (two-sided P $|z|$ 0.0264), but less time in direct patient care (two-sided P $|z|$ < 0.0001). The majority ($n = 199$, 86.2%) reported formal training in genomics, often at the NINR SGI (24.0%); other commonly mentioned organizations were the University of Cincinnati Children's Hospital; City of Hope; Fox Chase Cancer Center; King's College; Oncology Nursing Society, and the ISONG Annual World Congress.

4.1. Confidence in Knowledge and its Application in the Future

Respondents were asked to rate their genomic knowledge on a 5-point item, with responses ranging from 1 "Very Low" to 5 "Very High." Thirty five respondents (17.6%) rated their knowledge as very high and 102 (51.3%) as high, while 62 (31.2%) rated their knowledge as moderate, low, or very low. Participants were asked about the application of genomics in the future with three 5-point items and responses ranging from 1 "Strongly Disagree" to 5 "Strongly Agree." The majority (85.9%) agreed or strongly agreed that genomics is likely to be relevant to nursing research, education, and practice in the next 12 months, while 96.9% agreed or strongly agreed that genomics is likely to be relevant to nursing research, education, and practice in the next 5 years. Finally, 96.5% agreed or strongly agreed that the promise of genomics for healthcare has yet to reach its full potential.

4.2. Professional Activities Involving Genomics

Activities involving genomics in research and scholarship, education, and patient care were assessed with 5-point items, ranging from 1 “*Very Unlikely*” to 5 “*Very Likely*.” The majority indicated they are likely or very likely to incorporate genomics into their research and scholarship (87.4%), teaching and educational roles (91.4%), and clinical practice (86.6%) (Fig. 1). However, nurses with doctorate degrees were less likely to respond that they will incorporate genomics in their clinical practice (two-sided $P = 0.0116$).

Finally, 59.3% of respondents explicitly noted that ISONG had a leading role in nursing education and expressed a need for continued education on topics such as next generation sequencing and whole exome sequencing. Further recommendations for continuous education included integrating genomic content in nursing curricula at the undergraduate level; all nursing students should complete a full-semester course in genomics with a laboratory and data analytics component prior to entering a Master’s program; PhD nursing students should have relevant omics coursework provided by specialty genomics-based nursing courses or courses from other departments. Nurses working in healthcare or academic settings were more likely to seek additional training in genomics, compared to those working in industry or private practice.

5. Discussion

This survey of ISONG members provides unique information about global practices of nurses in genomics. It was hypothesized that ISONG members would be more likely to have already acquired advanced training in genomics, and to incorporate this knowledge into many different areas of research, education, and clinical practice. Results suggested that ISONG members who participated in the survey had advanced degrees and additional training in genomics. Participants also reported that the integration of this knowledge into diverse professional roles is of high value. These findings are congruent with a survey of nurses who attended the NINR SGI (Hickey et al., 2013). Among $n = 95$ SGI graduates, 70 had doctorate degrees and 66 were advanced practice nurses; they reported incorporating this knowledge into their practices after SGI training. Moreover, 72% reported being involved in genomic focused research, 52% reported active research funding at the time of the survey, and 79% provided genomic education as part of their nursing role. However, only 32% of SGI graduates reported incorporating genomics into patient care, as opposed to 68% of nurses responding to the ISONG survey. This discrepancy may be due to the international sample included in this survey and differences in scope of professional roles. However, there are still several ISONG members who considered possessing only moderate, low, or very low genomic knowledge. Participants also suggested integrating genomic content at all levels of nursing education.

Participants were predominantly Caucasian, indicating a lack of representation from ethnic minority nurses in genomics. This finding is not surprising, given the difficulties in retaining faculty from a minority racial/ethnic background in academic nursing (Hamilton and Haozous, 2017). A previous study reported that among 389 minority nurses 79% reported that education in genomics was important; while 94% reported an interest in learning more about genomics, only 30% reported taking a relevant course since licensure (Calzone et al.,

2013a,b,c). Although 39% held a master's degree and 42% worked in direct patient care, 50% reported a fair/ poor understanding of genomics of common diseases, e.g., that a single gene variant causes heart disease and diabetes. Among 77 nurses participating in a survey of the National Black Nurses Association, > 50% responded that their genomic knowledge was poor, but 93% wanted to expand this knowledge (Coleman et al., 2014). The desire of minority nurses to expand their genomic knowledge can serve as a catalyst for developing programs targeted toward underrepresented groups and creating a pipeline for the next generation of nurse scholars, well positioned to tackle topics such as health disparities and integrating genomics into culturally, linguistically, and educationally diverse communities. These findings have significant implications considering that chronic diseases such as heart disease and cancer are the most common morbidity and mortality reasons among ethnic minority groups in the US (CDC. National Center for Health Statistics, 2015, 2017).

A multi-layered approach provides a solid foundation for nurses to integrate genomic knowledge in their professional roles, participate and eventually lead omics investigations, with an emphasis on the recruitment, training, and retention of minority faculty and students (Conley et al., 2015). As a premier founding organization, ISONG includes the involvement of nurse opinion leaders, which may be one avenue to enhance engagement of more nurses in the integration of genomics in clinical practice and other professional roles (Andrews et al., 2014). This educational approach might further engage and enhance the continued education of the nursing workforce to keep pace with the rapidly changing genomic advancements.

It is essential to have an international nursing workforce trained in genomics who have achieved a minimum set of core competencies (Skirton et al., 2010). Differences between professional education and regulation vary from one European country to another, thus setting standard curricula would not be practical (Skirton et al., 2010). An expert working group under the auspices of the EuroGentest project and European Society of Human Genetics Education Committee established common education standards for clinical practice and education in genetic healthcare (Skirton et al., 2010). An extensive process involving health professionals, patient groups, and national educational experts helped set a core set of competencies for practitioners in primary, secondary and tertiary care settings. These competencies could be a framework that transcends national boundaries and can improve global genomic healthcare provided by nurses and other practitioners. In the US, NINR offers training on a variety of omic-based approaches. New centers of excellence can train and educate the next generation of nursing scholars in highly collaborative interdisciplinary environments (NINR, 2014).

For 25 years ISONG offers online webinars and an annual meeting that brings together international audiences, fosters collaborations and the exchange of ideas, helps train the next generation of transdisciplinary nurse scientists, provides exposure to genomic nursing research, new approaches to genomic education, and fosters advances in clinical practice. Collaborative work between ISONG and other organizations, including the American Association of Colleges of Nursing, the American Nurses Association, and the European Association of Nurses foster engagement of the entire nursing workforce to genomics.

5.1. Limitations

ISONG members are overall highly educated, highly motivated, and committed to professional development in the area of genomics; thus, they are not representative of the nursing workforce. The survey was brief and limited to specific questions. Findings cannot be generalized to the nursing workforce at large due to limited representation of minority and male nurses, and lack of information about the global outreach of the survey. Despite these limitations, responses reflect the characteristics and practices of this uniquely trained group of professional nurses.

6. Conclusions

There is substantial evidence regarding the wide contribution of ISONG members to genomic research, education, clinical practice, and public health (Alexander, 2015; Andrews et al., 2010; Calzone et al., 2013a,b,c; Katapodi et al., 2017; Kirk et al., 2011; Musunuru et al., 2015; Hickey and Rezzadeh, 2013; Hickey et al., 2014a,b; Wung et al., 2013). The rapid incorporation of genomics on disease prevention, health promotion, disease and symptom management, education of the next generation of nursing scholars, and public health interventions supports the importance and necessity of genomic nursing in improving health. There is a great opportunity and interest among nurses to continue increasing their genomic education and stay abreast of current advancements in the field. The formation of a diverse task force of nursing experts from ISONG, NINR, The National Human Genome Research Institute (NHGRI), the American Academy of Nursing, American Heart Association, Oncology Nursing Society, the member associations under the National Coalition of Ethnic Minority Nurse Association, the Robert Wood Johnson Foundation, with additional support from schools of nursing and other academic organizations would be one approach to ensure that genomic nursing is integrated into the precision medicine initiative.

It is essential that nurses expand their genomic knowledge as members of novel, diverse interdisciplinary teams. Strategies to inform the nursing community about incorporating genomics into practice include creating a network of genomic experts as points of contact (Leach et al., 2016). Nursing involvement in genomics is also expanding in Japan and the UK due to the implementation of relevant programs and the establishment of new nurse competencies (Skirton et al., 2006). Nurses are uniquely positioned to utilize genomics in their practice and break down barriers of genomic literacy (Lea et al., 2010; Calzone et al., 2010; Mital et al., 2016; Williams et al., 2004, 2015). These new practices can educate patients and families on the impact of genomics on healthcare, and contribute to the growing movement toward precision health. Precision medicine provides great opportunities for nurses to examine complex genomic relationships that influence health and quality of life, allows nursing science to contribute to personalized health across the lifespan, and promotes engagement in personalized healthcare where nurses can make positive and meaningful contributions.

As genomics integrates into practice and extends globally into health promotion, disease prevention, and diagnostic strategies, ISONG and other nursing organizations are essential in ensuring educational efforts aimed at achieving nursing genomic competencies worldwide. Results from this survey support that members of ISONG have successfully assimilated

genomics into their professional roles and have the responsibility to serve as opinion leaders (Alexander, 2015). ISONG plays an integral role in educating nurses and deepens understanding of the role of nursing in improving the health and well-being of patients, families, and communities globally.

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Fig. 1.
Likelihood of incorporating genetics and genomics in nursing professional roles.
*n does not equal 231 due to missing responses.

Table 1

Sample characteristics.

Age (mean $\pm$ SD ^a)	53.1 $\pm$ 10.8
Years in Nursing (mean $\pm$ SD ^a)	27.6 $\pm$ 12.2
Years since highest degree was completed, (mean $\pm$ SD ^a)	12.4 $\pm$ 10.3
Gender (<i>N</i> , % ^b)	
Female	210 (92.1%)
Race (<i>N</i> , % ^b)	
African American/Black	9 (4.0%)
Asian	5 (2.2%)
Caucasian/White	209 (91.7%)
Native American	3 (1.3%)
Pacific Islander	1 (0.4%)
Other	1 (0.4%)
Ethnicity (<i>N</i> , % ^b)	
Non-Hispanic	221 (96.9%)
Nursing education (<i>N</i> , % ^b)	
Diploma	1 (0.4%)
Bachelor's	21 (9.2%)
Master's	82 (35.8%)
Doctorate	125 (54.6%)
Income (<i>N</i> , % ^b)	
\$49,999	13 (6.6%)
\$50,000–\$99,999	45 (22.8%)
\$100,000–\$149,999	62 (31.5%)
\$150,000	55 (27.9%)
Prefer not to answer	22 (11.2%)
Marital status (<i>N</i> , % ^b)	
Married/Life partner	148 (75.1%)
Divorced	4 (2.1%)
Single	27 (13.7%)
Widowed	18 (9.1%)
Employment (<i>N</i> , % ^b)	
Full time	176 (78.2%)
Part-time	29 (12.9%)
Student	12 (5.3%)
Retired	8 (3.6%)
Professional activities (% FTE) (mean $\pm$ SD ^a)	
Research	27.7% (29.2)

Education/teaching	23.8% (28.4)
Patient care	28.4% (35.5)
Administration	11.0% (17.3)
Other ^c	9.0% (21.2)

^aStandard deviation.

^bValid percentages.

^cService to University and/or profession; genetic counseling.