Resources to Increase Genetics and Genomics Capacity of Oncology Nurses

Lisa B. Aiello, RN, MSN, AOCNS®, APN-C

Since the completion of the Human Genome Project (HGP) in 2003, the understanding of genetics and its influence on disease, particularly cancer, has increased dramatically. The initial focus after the completion of HGP was on identifying single-gene disorders, such as many hereditary cancer syndromes (e.g., BRCA1, BRCA2, HNPCC). As research continues, the major impact that genetics and genomics have across the healthcare continuum is only beginning to become clear (Pestka, Burbank, & Junglen, 2010; Thompson & Brooks, 2011). More specifically, genetics and genomics play a role in disease risk and prevention, carcinogenesis, diagnosis, prognosis, treatment selection, use of targeted agents, pain management, and end-of-life care. The implications of pharmacogenomics and cytochrome P450 (CYP) enzymes have yet to be fully understood. Oncology is one of the clinical specialties that has integrated genetics and genomics into clinical care. Therefore, oncology nurses must also include genetics and genomics into their nursing practice to provide competent, evidence-based care and to potentially improve patient outcomes (Jenkins, 2011).

Need for Knowledge

To provide competent, evidence-based care, oncology nurses need to have a baseline understanding of genetics. Competent care includes taking a family health history, constructing a pedigree, identifying red flags for those at increased risk, providing appropriate patient education and counseling, referring patients to a genetics professional when appropriate, supporting patients through the informed decision-making and consent processes, and advocating for competent genetics services for patients. However, current research has identified a continued lack of competence regarding genetics and genomics care among nurses at all levels of care (Calzone & Jenkins, 2011; Edwards, Maradiegue, Seibert, Macri, & Sitzer, 2006; Prows, Calzone, & Jenkins, 2006; Thompson & Brooks, 2011).

Policy initiatives have occurred to direct the genetics and genomics education of nurses. Nursing competencies pertaining to genetics and genomics were first published in 2006, providing the essential competencies required of all nurses; outcome indicators were added in 2008 (Consensus Panel on Genetic/Genomic Nursing Competencies, 2009). The American Association of Colleges of Nursing’s [AACN’s] Essentials of Baccalaureate Education for Professional Nursing Practice has also made genetics and genomics a requirement of baccalaureate nursing education.

Available Resources

Many resources are available to educate oncology nurses about genetics and genomics and their integration into practice, as well as to assist nursing faculty in the incorporation of genetics and genomics content into curricula (Tonkin, Calzone, Jenkins, Lea, & Prows, 2011) (see Table 1). Only a few of the numerous existing genetics and genomics resources are mentioned in this article, and they include the following web-based resources.

Genetics Education Program for Nurses: Developed by the Cincinnati Children’s Hospital Medical Center, the Genetics Education Program for Nurses is a resource that provides continuing education for nurses, as well as faculty support for curriculum development. This resource offers independent, self-paced modules and web-based courses.

Genetics/Genomics Competency Center: Funded by the National Institutes of Health’s National Human Genome Research Institute (NHGRI), the Genetics/Genomics Competency Center is, in essence, a warehouse of educational materials that can be used for nurse education or self-directed learning. Resources specific to nursing practice can be identified, but transdisciplinary resources are also available. Resources are available by topic; among the available topics are basic genetics concepts, cancer genetics, risk assessment, and pharmacogenetics and pharmacogenomics.

Global Genetics and Genomics Community: The Global Genetics and Genomics Community provides web-based genomic healthcare simulations. The user has the opportunity to interview patients through the use of prerecorded interviews, interpret family histories, identify risks, and apply guidelines to patient care. This resource provides an opportunity for the user to assess his or her genetics competency, as well as to access supplemental educational materials and activities for continued learning. Case studies include patients with many diagnoses, including cystic fibrosis, post-traumatic stress disorder, and pharmacogenomics issues. Many case studies are specific to oncology and include patients and families with known mutations in the BRCA2, EGFR, and MLH1 genes; a patient with multiple colon polyps; and a patient with a family history of breast cancer.

International Society of Nurses in Genetics: The International Society of Nurses in Genetics (ISONG) provides webinars on topics geared toward practicing nurses and nursing faculty. ISONG, in collaboration with the American Nurses Association, has published the scope and standards of practice for genetics and genomics nursing (ISONG, 2007).
National Cancer Institute: Among the many resources offered on the National Cancer Institute’s website is an in-depth guide, Cancer Genetics Overview (PDQ®), that covers topics including genetics counseling, hereditary cancer syndromes, genetics testing, and technological advancements.

National Comprehensive Cancer Network: The National Comprehensive Cancer Network has developed guidelines specific to genetic and familial risk assessment for breast and ovarian cancer, as well as for colorectal cancer. Each site-specific treatment guideline includes information regarding how genetics and genomics may affect diagnosis, prognosis, and treatment.

Oncology Nursing Society: The Oncology Nursing Society (ONS) offers many courses, articles, and books that provide education about genetics and genomics. It also provides a position statement on the role of oncology nursing in genetics and genomics across the oncology care continuum (ONS, 2014).

Talking Glossary of Genetic Terms: Created by the NHGRI, this glossary provides definitions of terms related to genetics and genomics, as well as relevant audio descriptions, animations, images, and additional links. It is available in English and Spanish, and as a download for a mobile device.

Telling Stories: Understanding Real Life Genetics: This website provides many real-life stories, told via text or video, that can be used as learning tools to promote understanding of genetics and its real-life implications. The stories are organized by themes and topics; therefore, oncology-specific stories can be quickly identified. The website was developed by the United Kingdom’s National Genetics and Genomics Education Centre, which is part of the National Health Service.

Conclusion

The resources provided in this article are by no means inclusive of all of the resources available. Many of these resources provide developed, interactive educational activities for the nurse, with a number of them being specific to oncology. Additional resources include topics such as family health histories and pedigrees; ethical, legal, and social issues; and the Genetic Information Nondiscrimination Act of 2008.

All nurses must achieve competence in genetics and genomics care. Oncology nurses are at the forefront of this endeavor. As genetics and genomics are integrated further into nursing practice, the patient may be the one to benefit. For example, patients could be identified as having an increased risk of cancer development, be provided with comprehensive risk reduction or early detection plans, and receive a more thorough prognosis and more appropriate, personalized treatments. In the long term, these interventions have the potential to improve health outcomes (Calzone & Jenkins, 2011; Greco & Mahon, 2012).

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Key words: genetics, genomics, competencies

Table 1. Genetics and Genomics Educational Resources for Nurses

<table>
<thead>
<tr>
<th>Resource</th>
<th>Website</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Essentials of Baccalaureate Education for Professional Nursing Practice</td>
<td><a href="http://bit.ly/1ws42y1">http://bit.ly/1ws42y1</a></td>
<td>Requirements for baccalaureate nursing curricula</td>
</tr>
<tr>
<td>The Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines, and Outcome Indicators (2nd ed.)</td>
<td><a href="http://1.usa.gov/1L4UrW">http://1.usa.gov/1L4UrW</a></td>
<td>Defines competencies and outcome indicators for all nurses, regardless of specialty or practice level</td>
</tr>
<tr>
<td>Genetic Alliance: “Family Health History”</td>
<td><a href="http://bit.ly/1CIQwCP">http://bit.ly/1CIQwCP</a></td>
<td>How to perform a family health history</td>
</tr>
<tr>
<td>Genetics Education Program for Nurses</td>
<td><a href="http://bit.ly/1CJLbTL">http://bit.ly/1CJLbTL</a></td>
<td>Web-based, self-paced educational resources</td>
</tr>
<tr>
<td>Genetics/Genomics Competency Center</td>
<td><a href="http://www.g-2-c-2.org">www.g-2-c-2.org</a></td>
<td>Warehouse of educational materials</td>
</tr>
<tr>
<td>Global Genetics and Genomics Community</td>
<td><a href="http://www.g-3-c.org">www.g-3-c.org</a></td>
<td>Web-based simulations</td>
</tr>
<tr>
<td>National Cancer Institute: Cancer Genetics Overview (PDQ®)</td>
<td><a href="http://1.usa.gov/1CJLhv">http://1.usa.gov/1CJLhv</a></td>
<td>Education on multiple topics, including methods of genetic analysis and gene discovery, and resources</td>
</tr>
<tr>
<td>National Human Genome Research Institute: Talking Glossary of Genetic Terms</td>
<td><a href="http://www.genome.gov/glossary">www.genome.gov/glossary</a> (English); <a href="http://www.genome.gov/GlossaryS">www.genome.gov/GlossaryS</a> (Spanish)</td>
<td>Interactive dictionary, available in English and Spanish, and downloadable to mobile devices</td>
</tr>
<tr>
<td>Oncology Nursing Society</td>
<td><a href="http://bit.ly/1yMAk7l">http://bit.ly/1yMAk7l</a>; <a href="http://bit.ly/15I2vU1">http://bit.ly/15I2vU1</a></td>
<td>Courses, articles, and position statements, among other resources</td>
</tr>
<tr>
<td>Surgeon General: “My Family Health Portrait”</td>
<td><a href="http://1.usa.gov/1xDsG4p">http://1.usa.gov/1xDsG4p</a></td>
<td>How to perform a family health history</td>
</tr>
<tr>
<td>Telling Stories: Understanding Real Life Genetics</td>
<td><a href="http://www.tellingstories.nhs.uk">www.tellingstories.nhs.uk</a></td>
<td>Real-life stories via text or video</td>
</tr>
</tbody>
</table>
References

Genetics & Genomics
This feature aims to educate oncology nurses about the emerging role of genetics and genomics in cancer care. Possible submissions include, but are not limited to, application of genetics and genomics in clinical practice, screening and surveillance, case studies to present new ideas or challenge current notions, and ethical issues. Manuscripts should clearly link the content to the impact on cancer care. Manuscripts should be 1,000–1,500 words, exclusive of tables and figures, and accompanied by a cover letter requesting consideration for this feature. For more information, contact Associate Editor Lisa B. Aiello, RN, MSN, AOCNS®, APN-C, at lba34@drexel.edu.