

# Adapting Genetic Counseling Training to the Genomic Era: More an Evolution than a Revolution

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Received: 30 December 2013 / Accepted: 9 January 2014 / Published online: 28 January 2014  
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Genetic counselors, like other healthcare professionals, are continually challenged to keep abreast of up-to-date, evidence-based information regarding their practice. In particular, we are tasked with trying to keep pace with technological advancements in genomics. Without a doubt, the content covered in our graduate and continuing education curriculum with regard to genetic screening and testing has significantly changed over time. In 20 years, we have seen maternal serum screening for aneuploidy transition from a single analyte second trimester blood test to a multi-analyte first and/or second trimester test that can include a nuchal translucency measurement to DNA-based non-invasive prenatal screening. We have seen cytogenetic analysis move beyond the identification of aneuploidies and large structural defects to comprehensive chromosomal microarray analyses. Testing for relatively common single gene disorders like Fragile X syndrome, Huntington disease, and cystic fibrosis has changed dramatically. Furthermore, gone are the days of having to wait months for the results of the Sanger sequence analysis of a single gene. Now, next-generation panel tests can provide a plethora of information in just a few short weeks. The introduction of each of these technological advances required adjustments to our genetic counseling curriculum and continuing education programs. But one of the strengths of our profession is that we are trained in fundamental core genetic counseling competencies that can be applied across diverse practice settings and readily adapted to changes in practice brought forth by new

technologies. As a result, even in the face of these rather significant changes, the four domains that define the competencies of genetic counselors: genetics expertise and analysis; interpersonal, psychosocial, and counseling skills; education; and professional development and practice (Accreditation Council of Genetic Counseling 2013a, b) have remained largely the same.

As new technology is adopted, it is critically important for program directors and practicing professionals to evaluate whether fundamental changes in genetic counselors' knowledge, skills, and attitudes, and ultimately genetic counseling practice, are required. In this issue Hooker et al. (2013) discuss the significant challenges of integrating genomics into the training of genetic counseling students and practicing professionals. We agree with many of the points made by the authors, however, we assert that these are no more significant than the other challenges we have faced with incorporating new content in the program curriculum. In addition, Hooker et al. discuss that large-scale, clinical genomic sequencing results in a paradigm shift in the practice of medical genetics. We struggle with the term "paradigm shift" given that the definition of a paradigm shift is "a radical change in underlying beliefs or theories," (Collins English Dictionary 2014). The scale of information provided by genomic sequencing definitely poses challenges in areas such as pre-test informed consent as well as interpretation and disclosure of test results. But do these challenges truly constitute a paradigm shift or are these just the same issues we have faced in the past but on a much larger scale and in a slightly different context? We believe that it is the latter.

Anytime new technology is implemented in clinical care, new content must be added to the existing training curriculum and continuing education programs. It may be important to expand specific topics, change the emphasis, and/or present information from a different frame of reference, but the foundation to do so should already be in place. For instance with

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regard to understanding the bioinformatics filtering processes and subsequent steps in variant calling, genetic counselors have been assessing variant pathogenicity since the advent of genetic testing. They have also long been involved with helping individuals cope with variants of uncertain significance and find personal meaning in their results. The issues surrounding genomic sequencing are about learning how to use an expanding array of bioinformatics tools and dealing with a larger number of variants rather than needing to develop a new set of skills to do so. Thus to us, this does not constitute a major challenge in educating genetic counselors or students.

The three main challenges we see facing our profession are managing the increased volume of test results, developing new reimbursable service delivery models and ensuring an adequate workforce. With regard to the volume associated with genomic test results, the challenge lies in determining which results to return and how and when to return them. Hooker, et. al. address the issue of return of results and the need to focus on client-centered counseling. If there are genetic counselors still resistant to client-centered counseling then this may be the tipping point that pushes them to adopt this approach. Conversely, the volume of information that comes from a genomic sequence may reinforce the use of a primarily education-based model with little emphasis on assessing and addressing psychosocial impact. The justification for using the education-based approach may be that there is even less time to cover all the information that “needs” to be conveyed in a single session. As such, genomic testing further challenges us to critically evaluate how we deliver our services. Do we give all results in one counseling session or is timing of the results disclosure driven by a combination of client preferences and their stage in the lifecycle? How do we appropriately filter genomic test results so as not to burden the client with unnecessary information yet still promote client autonomy? The issue may not be what genetic counselors need to know about genomic testing, bioinformatics, results interpretation, uncertainty, and informed consent in the genomics era. Rather, the bigger challenge to our profession may be to produce a larger body of outcomes-based research and use the results of such studies to identify the best way to impart the volume of information provided in a way that promotes better adaptation to risk, familial communication, and health outcomes. If, for example, such research were to show that client centered counseling approaches are more effective than the more predominant educationally-focused approach to genetic counseling (Meiser et al. 2008), this would require a change in the broader genetic counseling culture.

Another challenge will be to creatively adapt genetic service delivery models and to develop new ones to serve a larger community. Integration of genomics into mainstream medicine will be dependent upon our ability to work effectively

with primary care providers and to serve as consultants as well as provide direct patient care. Genetic counselors are already using service delivery models beyond the traditional in person direct patient care model (Cohen et al. 2013). However, in the absence of adequate reimbursement across all service delivery models we may still fall short of ensuring broad access of genetic counseling services.

Perhaps one of the biggest challenges of true integration of genomics into healthcare is to ensure that we have a sufficient genetic counseling workforce. To our knowledge, no one has formally assessed whether or not there is a shortage of genetic counselors at the present time. But as genomic testing becomes more widespread, if there is a concomitant increase in demand for services, there may be a shortage. To this point in time, we have not been able to grow our profession in the same way other healthcare providers have. Our attention should be focused proactively on the model of *how* we train genetic counselors and what changes can be implemented to increase the number of counselors trained. In addition, funding of training programs is a critical issue that needs to be addressed not just by our profession but by the larger healthcare community on a national level. By focusing on both aspects, how we train and fund training, we can ensure that we, and our geneticist colleagues, are able to fulfill the anticipated needs of individuals who will benefit from meeting with a genetic counselor and continue to be a resource to non-genetic healthcare providers.

In summary, implementing genomic sequencing in clinical practices requires a high level of competency in medical genetics, education, counseling, and ethics; the core competencies of the genetic counseling profession. We believe that our genetics expertise and counseling skills will evolve and adapt to the new environment of whole genomic sequencing just as we have done in response to other technological changes in the past. Certainly graduate and continuing education programs need to keep pace with the evolving genomic landscape. The biggest challenges to our profession will be to adapt our methods of providing genetic counseling, develop innovative service delivery models that ensure timely access and are adequately reimbursed, and modify how we train graduate students to grow the genetic counselor workforce.

**Conflict of Interest** Catherine Wicklund: I declare that I have no conflict of interest.

Angela Trepanier: I declare that I have no conflict of interest.

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