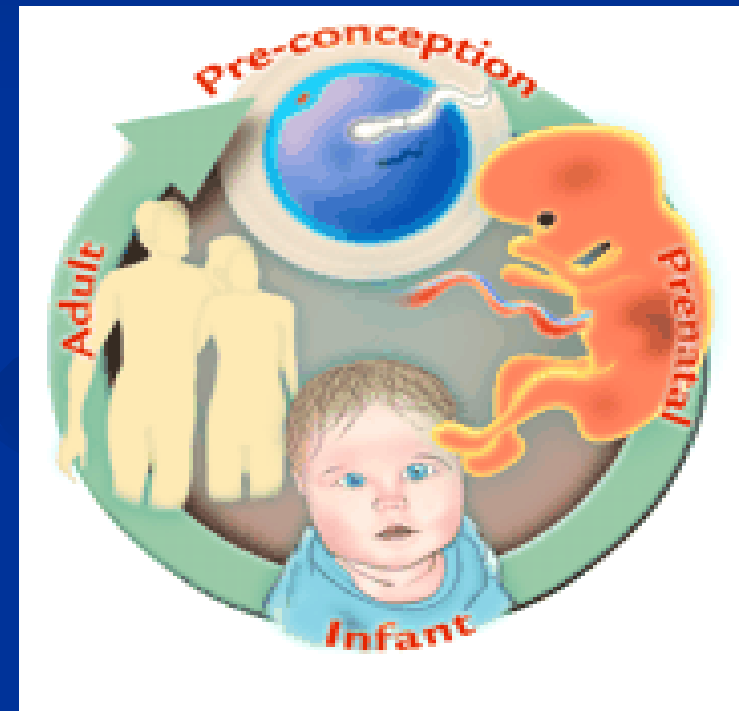


**Increasing the public's knowledge
about genetics:
Utilization of genetic counselors as
health educators**

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Why study genetic counselors?

- With the completion of the Human Genome Project, genetic testing will become more common.
- With this, will come greater demand for genetic services.
- Genetic Counselor is an important part of genetics team.
- Genetic counselors interact the most with patients regarding genetic decisions.



Methodology

- Extensive literature review of genetics and genetic counseling
- 38 Interviews with Genetic counselors, Clinical Geneticists, Obstetricians, and Key informants in the genetics field.
- Qualitative Analysis using Atlas.ti of all transcripts

What were they asked?

- Role of Genetic Counselor
- Views on genetic counselors as a profession
- Major stakeholders in the profession
- What are the problems in achieving autonomy
- Payment issues
- Technological influences
- Future of genetic counseling
- Relationships between other medical professionals

What is a genetic counselor

“A genetic counselor basically helps patients and families understand genetic disease, or the risk of having a genetic disease, or having a child with a genetic disease and options that might potentially available to them for testing and counseling and services that they might need” (K. Valverde, Director of Genetic Counseling Program, Arcadia University).

What is a genetic counselor

“people who are trained to work with individuals and families grappling with the human issues that surround genetic disease, genetic risks, and also the issues of genetic technologies, diagnostic technologies mostly. Really, helping people cope with, adapt to, and understand how genetics can benefit their health and their lives and somebody who can competently champion those issues on a bigger picture basis.” Judith Beckendorf, ACMG

Defining the profession: Issues Raised

- Easily transferable skill set or specifically delineated clinical occupation?
- “Physician extenders” or autonomous profession?
- Where else do genetic counselors fit in?

Media and Genetics Education

- Often leaves out important facts
- Leads to misconceptions about how genetics research can be applied
- “I have this series of slides if you look like at Newsweek and Life magazine over the past years. The things that are on the cover are amazing. It looks like genetics knows everything, can predict everything, can fix everything. And then you get to the article, and the article is like, no you can't. But people don't get to the article. They just look at the cover” (B. Leroy)



Public understanding of genetics

“My sense about genetics as a whole, particularly now, is that the majority of people, even with all the publicity there has been about the human genome project and how medicine has changed with the sort of geneticization of medicine, people still don’t understand what genetics really means” – Caroline Leiber, Director of the Human Genetics Program, Sarah Lawrence College



The need for genetic counselors

The medical community will need genetic services, and specifically genetic counselors, to translate and make sense of complicated information about risk and susceptibility that will result from these genetic tests

Genetic counselors as educators

- Have the skill set that “allows them to take very complicated scientific information and put it into language that they can tailor to whatever their audience is” (C. Leiber)
- “What genetic counselors do is they translate, but they also educate. And they do it on a daily basis. They do it a cocktail party. They do it in a grocery store. They do it all the time” (C. Leiber)

Genetic counselors as educators

“Genetic counselors need to be educators. They need to go out into the public, into the communities...to the communities that maybe don't have any idea what genetics is and aren't going to go to an educational talk or read something about genetics in the newspaper, or watch the big piece on genetics on a public TV station or whatever...to get them interested in genetics...to give them the information they need if they have questions, they should be able to call a number, or go to a website or have a pamphlet mailed to them...it's up to the profession to keep on top of that and to keep pursuing that. But it is also up to the profession to try to find some time in their busy schedules as seeing patients or whatever they do to still educate the public in just however they can – whether it is being involved with other doctors in grand rounds, or going out to communities to give talks” (GC6MB).

Defining Scope of Genetic Services

“We need to deal with some of the scope of practice issues and haven’t. I think there are a lot of gaps in the way we deliver our services and gray zones that exist among the various providers of services that confused people looking in about what we are and who does what...it leads to payers not understanding you and therefore not knowing how to use you, when to use you. It leads to government not doing what it should and the definitions of specialities and things of that kind. It leads to a world of problems”

- Michael Watson, Executive Director, American Board of Medical Genetics

Implications and Recommendations

- Creating a consistent vision of what the profession needs to look like through strong and clear leadership.
- Lack of consistency as to where genetic counselors exist within the current medical system
- Not just a problem pertaining to genetic counselors, but to the genetics field as a whole.
- Build awareness of genetic services among the public.
- As genetics becomes a more pervasive part of medicine, it will be important to for genetic counselors and the public health community to educate the public about the new challenges and questions people will face because of genetic testing technology and to ensure that genetic services are properly utilized.