

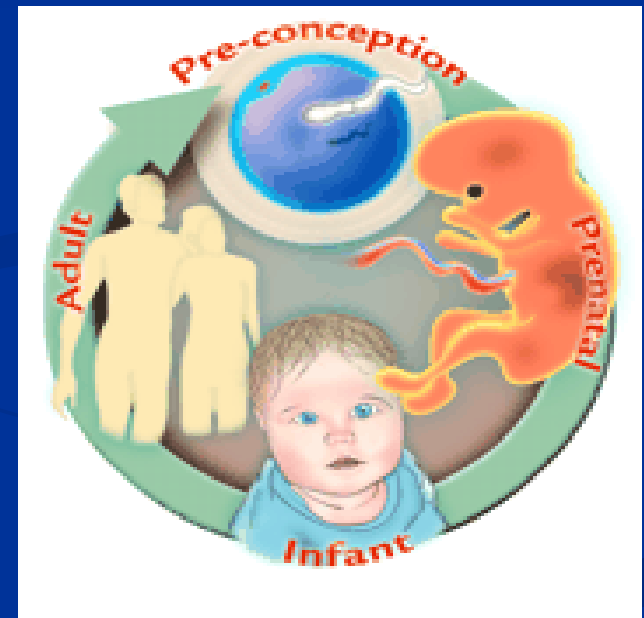
# The Role of Genetic Counselors and Genetic Services in Medical Care

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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.



# Why study the role of genetic counselors?

- Very little literature on the genetic counseling profession.
- Becoming more important to define the purview of the profession and where it belongs in medicine and healthcare.
- Young profession whose history can be studied since it is still evolving.



# 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 made key informants “key informants”?

- Senior genetic counselors who helped establish the profession and were critical in deciding how the profession would take shape.
- Directors of Genetic counseling programs throughout the country, who decide how to train future generations of genetic counselors.
- Key figures in professional organizations such as NSGC, ACMG, ABGC.
- Researchers and medical professionals in the field of genetic counseling and genetics that gleaned a broader perspective of the field.

# 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

# RESULTS

## Major Themes:

- Problems in defining the profession
- Jurisdictional issues between clinical geneticists, nurses, and other physicians
- Defining the scope of genetic services in medical care
- Licensure/Payment
- Respect/Recognition of profession
- Public understanding of both genetics and genetic counseling



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# Defining the Profession

“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 be available to them for testing and counseling, and services that they might need.”

– Kathy Valverde, Director of Genetic Counseling Program, Arcadia University

## Components of the Genetic Counseling Process

1. Information gathering
2. Diagnosis
3. Risk assessment
4. Information giving
5. Psychological assessment and counseling
6. Help with decision making
7. On-going client support

*[Modified from: AP Walker (1997)]*

# 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?

# Claiming jurisdiction

- Struggle for control of ability to provide genetic counseling services
- Nurses and physicians often feel that they are able to provide genetic counseling services to patients
- Significant problem in a profession that is small and that provides a service that is in high demand.

# 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

# Licensure

- Major issue in the profession that was discussed in every interview.
- Without licensure, cannot get malpractice insurance, and therefore cannot get CPT codes that would allow genetic counselors to bill payors.
- Only people who encounter patients in the hospital who are not licensed.
- Opposition faced by nurses and clinical geneticists.
- “If you are not a licensed health professional, who the hell are you?” – Bonnie LeRoy, Director of Genetic Counseling Program, University of Minnesota



# Recognition/Respect

- “ I do feel like we’re seen as a second rate health care provider.” – GC2RF
- Many in the medical community are not familiar with genetic counselors and do not recognize and respect them as a healthcare profession.
- Physicians lack of knowledge of genetics and genetic counseling is of detriment to not only the genetic counseling profession but also to the patients.



# 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



# What did we learn?

- What is the role of the genetic counselor within the genetic services model?
  - 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.



# What did we learn?

- Why has genetic counseling not developed into a fully autonomous profession?
  - Licensure as a major obstacle for establishing direct payment for services.
  - Inability to bill for services makes genetic counselors rely on other medical professionals to include them in their billing.
  - Lack of support from medical community .
  - Major obstacles in establishing clear cut jurisdiction

# Limitations of study

- Judgment sampling
- Underrepresentation of certain perspectives
- Validity
- Interviewer bias

# Implications and Recommendations

- Creating a consistent vision of what the profession needs to look like through strong and clear leadership.
- Obtain licensure, working in each state to gain support of nurses, physicians, and patients.
- Build awareness of genetic services among the public.