

Methods for Developing a New Genetic Counseling Position in a Specialty Clinic

Jennifer Hardt, Carrie Gill, MaryAnn W. Campion, Allison Cirino

Boston University School of Medicine, Boston, Massachusetts

Genetic counselors have been expanding their role from the traditional areas of prenatal, pediatrics, adult and cancer counseling into a growing number of specialty areas over the past years as we continue to learn more about the genetic contributions to disease. For example, there are increasing numbers of genetic counselors working in Cardiology, Neurology, Psychiatry and Assisted Reproductive Technologies (ART)/Preimplantation clinics throughout the US and Canada. The purpose of this study is to develop a model for creating a new position as a genetic counselor in a specialty area by compiling and analyzing different techniques and methods previously used by genetic counselors. These genetic counselors have successfully established or continued to develop a position in a specialty area. We used a descriptive qualitative approach and conducted semi-structured phone interviews with genetic counselors that have either created a new genetic counselor position or are the second genetic counselor in a recently established genetic counseling position in a specialty area. The interviews were recorded and transcribed, and the transcripts were subject to thematic analysis. This study did reveal similar themes as those previously identified by the Cancer Genetic Counseling Special Interest Group (SIG). However, it also demonstrated key differences and provided new information surrounding the development of a new specialty genetic counselor position. Many genetic counselors in this study developed their specialty position because of the desire to start something new and exciting. Likewise, most participants reported having the freedom to continuously evolve their position. Only one of the fifteen participants made a formal proposal with justifications for the addition of a genetic counselor to the specialty clinic, not allowing this study to outline specifics of a proposal for a new position. However much information was provided for ways to approach physicians in the specialty and promote the role of a genetic counselor. The cancer SIG elaborated on justifications for including a cancer genetic counselor in a clinic such as financial incentives and volume or how to work with insurance companies, which were not highlighted by the participants of this study. Many participants emphasized the need and utility of educating coworkers and potential referring providers about the availability and role of the genetic counselor in the specialty. This majority of the participants in this study had no graduate training specifically for their specialty, which makes it a unique subset of genetic counselors in the field. Key findings from this study may be used to assist other genetic counselors interested in developing a new genetic counselor position in a specialty clinic.