

A Master of Science in Genetic Counseling Program in the Philippines

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ABSTRACT

In the Philippines, there is an urgent need to expand the clinical services for diagnosis, management and emotional support for patients with genetic conditions and their family members. Despite the lack of trained health care providers with specialization in genetics, public health-related genetics programs are continuously being implemented. To address these current demands, strategic planning began in 2009 between local medical geneticists and international genetic professionals to develop the curriculum for an advanced degree in genetic counseling program. The Board of Regents at the University of the Philippines approved the proposed curriculum in January 2011, and training of the Philippines' first cohort of genetic counseling students commenced in June 2011. The successful implementation of the MS in Genetic Counseling program will provide the opportunity to incorporate the much needed genetic counseling services in the country.

Key Words: Genetic Counseling, Philippines

Introduction

Currently, there are only seven available clinical medical geneticists serving the needs of approximately 92 million people in the Philippines.¹ The implementation and expansion of public health-related genetics programs such as the National Comprehensive Newborn Screening Program, Birth Defects Surveillance Project, Telegenetics Referral System and the Philippine Genome Center add urgency to have additional professionals specifically trained in genetic counseling in the country.²⁻⁵ To illustrate, the expansion of the Philippines' Newborn Screening Program continues to

identify affected newborns recommended to follow a specialized medical management protocol and strict dietary supplementation plan.⁶ Thus, additional health care providers are needed to provide education for parents to understand the importance of compliance to prevent adverse health outcomes.

The establishment of the MS in Genetic Counseling training program at the University of the Philippines Manila serves a vital role in the access, delivery, and expansion of medical genetics, not only in the Philippines but also in the Asian region. Historically, the first graduate training program in genetic counseling was established in Sarah Lawrence College, New York in 1969 following the request to have trained non-physician health care professionals as part of the delivery of clinical medical genetics.⁷ At this time, there are over 30 genetic counseling training programs in North America and several other programs in other parts of the world.⁸ In Asia, a graduate level training in genetic counseling is offered in Australia, Japan, Taiwan and Indonesia.

Briefly, genetic counselors are health care providers with specialized training in genetics and psychosocial counseling of patients and members of their families with risks for genetic disorders. Sheldon Reed initially defined the genetic counseling process as "a kind of social work done for the benefit of the whole family entirely without eugenic connotations".⁹ In 2005, the National Society of Genetic Counselors, a US-based organization, expanded the definition of genetic counseling as "a process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease".¹⁰ Genetic counselors work closely with the medical geneticist who provides the clinical diagnosis and management of a patient. They also work with a team of other health care providers (e.g., social workers, nurses, nutritionists, and other specialized medical professionals) to provide genetic counseling and support in pediatric, metabolic, cancer, prenatal, neurology, cardiovascular and various high-risk specialty clinics. Competent genetic counselors are able to serve the population by having a broad range of skills, knowledge, and attitudes pertaining to genetic counseling.

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Guidance to develop the curriculum in order to effectively train the Philippines' genetic counseling professionals was obtained from already established specific competencies developed by organizations such as the American Board of Genetic Counseling,¹¹ and expert opinion advice from international colleagues in the medical genetics and genetic counseling specialty. A review of the already existing curriculum from various training programs in other countries (e.g., United States, Canada, and Australia) was done to determine the type of training and skill development for the Philippines' genetic counselors that is most appropriate to meet the needs of the Filipino patient population.

Genetic Counseling Training Program in the Philippines

In January 2011, the University of the Philippines Board of Regents approved the curriculum for the MS in Genetic Counseling. The curriculum was created with participatory inputs from various specialties (e.g. public health, epidemiology, biostatistics, medical anthropology and bioethics). They will have the expertise to guide patients and their families to make their own informed choices. With the required courses in genetics and genetic counseling, the students will also have the foundational knowledge in each of these specialties to ensure sustainability and successful incorporation of the genetic counseling field in the public health care system in the country. Students will have an in-depth understanding of the various genetic conditions, their clinical management, inheritance pattern, and prognoses. As the students complete the two-year program, they will gain competency in providing psychosocial support to the patient and members of their families. Their training will allow them to (1) apply the basics of human genetics and the principles of medical genetics and genetic counseling to given clients; (2) provide supportive genetic counseling to families, serve as patient advocates, and refer individuals and families to community and/or local government support services; (3) serve as educators and resource for other health care professionals and for the general public; and (4) plan, develop and evaluate genetic services programs.

Student-preceptorship collaborations are arranged with experienced certified genetic counselors practicing in the United States and Canada to enhance the training and development of the genetic counseling students. In addition, a joint partnership with the Stanford University MS in Human Genetics and Genetic Counseling as "sister programs" was created to share educational resources and to promote cross-cultural genetic counseling awareness.¹² This agreement entails bi-monthly video case conference for students and faculty members to share challenging genetic counseling patient cases. Telecommunication is conducted via secure video and web interface platforms to ensure the protection of patient confidentiality and privacy.

Current and Future Demands of Genetic Counselors

In the near future, it is foreseeable that the role of the genetic counselor in the Philippines will expand to serve as research coordinators, as project development officers, and as members of faculty for the genetic counseling program. It is envisioned that there will be at least 1 genetic counselor for each of the 81 provinces of the Philippines. The initial 81 job openings are in response to the articles stipulated in the Newborn Screening Act of 2004 and its Implementing Rules and Regulations.¹³ In compliance with the aforementioned articles, the Newborn Screening Reference Center and the Department of Health are both pushing for the requisites of the establishment of Referral Centers that will be responsible in the management of cases diagnosed to have any of the disorders included in the newborn screening panel. Due to the urgency to train genetic counselors in the country, scholarships are available, though still limited in number.

Conclusion

The newly established MS in Genetic Counseling program at the University of the Philippines Manila is a momentous achievement to meet the demands of the increasing applications of genomics to improve health. As patients and members of their family seek better understanding on the medical and scientific explanation of the identified genetic diagnosis, they also yearn for the empowerment support from medical geneticists and genetic counselors for personal and social acceptance. In addition to providing the needed support to patients and members of their family, graduates of the genetic counseling program are foreseen to be able to recommend appropriate policies to improve and expand clinical and research genetic services in the country. In alignment with this commitment, awareness and acknowledgement of the various ethical, legal, and social implications are also recognized. This is of utmost importance given the significant contribution of the field of genetic counseling in the local, national, and international level.

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Resources

For more information on the MS in Genetic Counseling program, please contact:

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Email: ngohs@post.upm.edu.ph

Website: www.ngohs.upm.edu.ph

For more information on genetic services and patient support groups:

Institute of Human Genetics, National Institutes of Health, University of the Philippines Manila

Website: <http://ihg.upm.edu.ph/>

References

1. Institute of Human Genetics National Institutes of Health, University of the Philippines Manila [Online]. 2011 [cited 2011 Dec]. Available from <http://ihg.upm.edu.ph/>
2. Padilla CD, Basilio J, Oliveros Y. Newborn Screening: Research to Policy. *Acta Med Philipp*. 2009; 43(2):6-14.
3. Philippine Genome Center University of the Philippines [Online]. 2011 [cited 2011 Dec]. Available from <http://pgc.up.edu.ph>.
4. Padilla CD, de la Paz EC, Cavan B, Abarquez C, et al. Birth Defects Surveillance in the Philippines. *Acta Med Philipp*. 2011; 45(4):
5. Padilla CD, Krotoski D, Therrell BL Jr. Newborn screening progress in developing countries--overcoming internal barriers. *Semin Perinatol*. 2010; 34(2):145-55.
6. Newborn Screening Reference Center [Online]. 2011 [cited 2011 Dec]. Available from <http://www.newbornscreening.ph>.
7. Scott JA, Walker AP, Eunpu DL, Djurdjinovic L. Genetic counselor training: a review and considerations for the future. *Am J Hum Genet*. 1988; 42 (1):191-9.
8. The National Society of Genetic Counselors [Online]. 2011 [cited 2011 Oct]. Available from www.nsgc.org.
9. Reed SC. A short history of genetic counseling. *Soc Biol*. 1974; 21(4):332-9.
10. Resta R, Biesecker BB, Bennett RL, et al. A new definition of Genetic Counseling: National Society of Genetic Counselor's Task Force Report. *J Genet Couns*. 2006; 15(2):77-83.
11. American Board of Genetic Counseling [Online]. 2011 [cited 2011 Oct]. Available from www.abgc.org.
12. Stanford University Master's Program in Human Genetics and Genetic Counseling [Online]. 2011 [cited 2011 Oct]. Available from <http://med.stanford.edu/genetic-counseling/>.
13. Newborn Screening Act 9288 [Online]. 2011 [cited 2011 Oct]. Available from <http://www.doh.gov.ph/ra/ra9288>.