INTRODUCTION & BACKGROUND

Genetic counseling service is widely available in developed countries; however, this is not so in most developing countries due to limited resource (WHO, 2015).

Challenges to Genetic Counseling Services in Southeast Asia (SEA)

- Patient and provider access to genetic counselors is limited in Southeast Asia (SEA).
- The limited reproductive services available through the public health system has resulted in an increase in the development of reproductive tests offered by private companies or medical (Lee & Thong, 2013).
- There is an urgent need to establish genetic counseling as a profession in SEA, to develop certification and training possibilities for genetic counselors (Olga et al., 2014).
- There is a major shortage of Asian genetic counselors. Currently, there are limited number of accredited genetic counselors in practice in Malaysia, Singapore, Hong Kong, Indonesia and Philippines (Olga et al., 2014).
- Most genetic counselors were trained in developed countries and return to their native countries to work with public genetic health services.
- Three main factors emerged as having an impact on genetic counseling in SEA which are language, religion and culture (Olga et al., 2014).
- Local training programs can increase the number of culturally competent genetic counselors who are able to identify and overcome cultural barriers in genetic counseling through an individualized approach based on their language or dialects used, culture, religious beliefs, legal and health care system (Barlow, 2011).

Increasing Genetic Counselors in Commercial Genetic Testing Laboratories

- Recent literature in the U.S. show an increasing number of genetic counselors employed by private commercial laboratories due decreasing costs of biotechnology and bioinformatics.
- Roles of genetic counselors include data management, result interpretation and reporting, and guidance of other healthcare providers (Zetzsche, Kotzer & Wain, 2014).
- In SEA, there is also a growing number of new commercial genetic testing companies established but some do not offer genetic counseling support which may be due to the limited number of experienced and certified genetic counselors.
- The demand for genetic counselors in commercial laboratories provide a new career pathway for genetic counselors in SEA.

Genetic Counseling: Challenges and Opportunities

Asia Genomics (AG), the First Molecular Diagnostics Company to Address Need for Genetic Counseling

- AG was established in Singapore in May 2014, with a vision to offer cutting edge tests that has significant role to improve healthcare, increase access to latest genetic tests and to offer lower cost of genetic testing in SEA.
- Current tests offered include non-invasive prenatal testing, carrier screening panels, hereditary cancer genetic testing and access to larger syndromic and single gene genetic test catalogues.
- AG stands out in a competitive market because they are the first to offer genetic counseling support within their services in SEA. Hence, addressing the pre-existing challenge of limited access to genetic counseling services and clinical genetic access across SEA.
- AG recognizes the importance of patient and provider education, the need for pre- and post-test genetic counseling and access to genetics specialists as key areas in providing a holistic customer service and adherence to high standards of service delivery.

METHODS

Active Recruitment and Employment of Genetic Counselors

- Two Genetic Counselors (GC) were employed by Asia Genomics in 2014.
- One Malaysian full-time GC certified by the Human Genetics Society of Australasia.
- One American part-time GC certified by the American Board of Genetic Counselors.
- Actively seeking to employ additional GCs to expand the genetic counseling team.

Development of Genetic Counselor’s Role in the Company

- Limited models or guidelines for the role of genetic counselors in commercial laboratories.
- Many are involved in customer support to providers.
- Less often involved in direct to patient genetic counseling.
- Various genetic counseling support needs were assessed by genetic counselors and the management team that include considerations of provider and client needs, patient support and intervention, internal marketing, sales and company development strategies, genetic testing technical support and principles of genetic counseling, practice and professional ethics.

ROLE OF GENETIC COUNSELORS

Genetic Counseling Support To Providers

- Review of test requisitions forms especially on indication for testing.
- Liaison with providers and partner laboratories if additional information is needed or concerns are raised on a specific test ordered.
- Develop protocols and document for genetic counseling service to providers and patients
- To initially offer post-test genetic counseling for abnormal test results
- Limit options for direct patient counseling
- Post-test genetic counseling support for providers and upon request, to include patient contact
- Provide access to genetic counselors with genetic counseling on testing
- Assessment of genetic tests request
- Assist in answering questions by providers

Pre-Test

- Product update for medical providers
- Answer providers questions, FAQ’s
- Genetic resources – Flipbooks, leaflets

Test Request

- Request form assessment
- Further pre-test support to patients (upon request)

Post-Test

- Direct contact to providers for abnormal results
- Available for additional patient counseling for abnormal results
- Written genetics resources available through Asia Genomics

GENETIC RESOURCES

Develop Genetic Resources & Educational Materials for Providers and Patients

- Develop patient and provider education and marketing materials.
- Information is in English and translated into local languages using sensitive language, based on genetic counseling literature and current medical practice guidelines.
- Designed for providers to use in conjunction with patients (flipbook and brochures).
- Develop online access to genetics resources through AG website.
- Fact sheets available on basic genetic concepts, genetic screening/testing and genetic disorders especially for patients with abnormal results.
- Collaborate with local genetic patient support groups and to include links useful to patients.

Private Genetic Counseling Clinic

- Private-public partnerships (PPPs) can be implemented in genetic services especially in countries with low and middle incomes (Meier, Schöffski & Schmidtke, 2013).
- AG is the first to setup a PPPs with a prominent consultant clinical geneticist to offer private clinical genetics clinic in Kuala Lumpur, Malaysia.
- Most clinical genetic services are mainly available in the public health setting (Lee & Thong, 2013).
- Increasing demand for genetic counseling among public and private healthcare practitioners.
- Pre-test and post-test counseling conducted by genetic counselor and clinical geneticist.
- Affordable consultation fees applicable to patients for medical consultation and genetic counseling.
- If AG test is ordered for the patient, genetic counseling fee will be reimbursed to patients and the fee would be absorbed by AG as part of the added value service provided.

Education and Training for Providers and Internal Staff

- Organize internal staff training for:
  - Sales and marketing team on genetic screening and diagnostic tests offered.
  - Review of new genetic tests to be considered under AG panel testing.
  - Conduct talks in external programs, training workshops and continuing education for providers.
  - To present in grand rounds and educational events.
- Topics include updates on genetic testing offered by AG.
- Genetic counseling support services and resources available through AG.

Research and Professional Development Activities

- Participation in presentations and publications at regional genetics or medical conferences
- Conduct research related to genetic counseling services
- Professional networking, contribute to genetic counseling training and development in Southeast Asia
- Supervise genetic counseling students posted for internship.
- Cross-training for genetic counselors in SEA.

SUMMARY & CONCLUSION

- As access to genetic testing increases, there is also a growing need for genetic counseling. However, there are not sufficient genetic counselors in SEA to support the growing demand for genetic counseling.
- Genetic counselors have a significant role within the commercial companies.
- Asia Genomics plans to expand the genetic counseling team, hence, creating career opportunities for genetic counselors which was previously limited in SEA.
- Efforts are in progress to create a professional network of genetic counselors and developing partnerships with existing genetics professionals to further improve the quality of genetics-related healthcare services in SEA.
- Future research includes assessing the uptake and utilization of various genetic counseling services and psychosocial issues among the Asian community.

REFERENCES

3. Map of Southeast Asia and countries in which ag is present. [Map]. Retrieved from: https://www.freemaps.com/asia-southeast-map-
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