

Genetic and Genomic Nursing Development: First Experience in Queen Mary Hospital of Hong Kong

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INTRODUCTION

Rapid advances in the field of genomics are affecting nearly all areas of healthcare. Genetic and genomic medicine plays a pivotal role in personalized care treatment. The global trend of healthcare systems is moving towards integrating genetics and genomics into mainstream clinical practices to facilitate personalized and precision medicine. Development in genomics and its implementation in the healthcare system worldwide has been steadily increasing [1,2]. Although knowledge of the clinical application of genetic and genomic practices is widely practiced, the knowledge practice gap towards genetic and genomic practices is known [3]. In this regard, the Hospital Authority (HA) will work towards achieving the following vision. The HA Strategic Service Framework for Genetic and Genomic Services underpins the guiding, planning, and development of human genetic and genomic services in HA over the next five to ten years. It aims to improve the service quality by building up of a service model to outline the directions and strategies for genomic medicine [4].

Queen Mary Hospital (QMH) of the Hong Kong West Cluster (HKWC) is the only cluster in HA with well-established two clinical genetic comprehensive services for breast and colorectal hereditary disease. In 2018, being one of the partnering centers with the Hong Kong Genome Project (HKGP), the HKGP catalyzed to advance further development and paved the way for clinical implementation of genomic medicine in QMH as well as Hong Kong. In alignment with the HA strategic planning on genetic and genomic service, and to maximize the patient's benefit from the widespread genetic / genomics science, nurses must be competent to obtain comprehensive family histories or identify the family members at risk [4]. It isn't just specialist nurses who are, and will be dealing with genomics, all nurses need to have an understanding of genomics and the enhanced standard of proficiency and competency [5,6]. Hence, a commissioned training program is needed in the Hong Kong West Cluster to nurture a skilled and competent genetic and genomic workforce and to address widely acknowledged deficits in nurses' genomic literacy [7,8].

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Aims

This study aims to describe how we develop and train nurses in genetic and genomic medicine and also explain the role of providing an understanding of the fundamentals of genetics and genomics medicine and provide training for nurses to equip them with the knowledge and skills required to keep up and get ahead to the expanding field of precision medicine.

TRAINING METHODS

A local training program was organized by the Central Nursing Department of HKWC followed by a virtual overseas genetics program. A two-day Commissioned program on the introduction of Genetics and Genomic for Nurses and a six-day virtual overseas genetic program was organized. A total of 36 nurses completed the training and they were working from different clinical specialties or primary care settings including pediatrics; oncology; cancer; antenatal; newborn screening; gynecology; genetic counseling unit; orthopedic; palliative care; renal unit; medicine and surgery, etc. Training components included lectures, theories, scenario discussions, and case studies. Distinguished and renowned speakers and training centers from genetic fields were invited to deliver the courses.

Practical training was provided by the Hong Kong Genome Institute that prepared nurses for the role as a genetic counselor. The Hong Kong Genome Institute provided a series of training to the Hong Kong West Cluster (HKWC) which included briefing on the Genomic Program, alignment of practice training, and sharing of standardized pedigree journal. We selected and recruited 9 nurses out of the 36 nurses who worked in oncology and pediatrics specialties in the Genetic Counsellor talent pool of HKWC after they had completed additional training from the Hong Kong Genome Institute. Moreover, both local and overseas training programs will be arranged annually as our long-term professional development strategies.

The quality assurance was monitored by the Genomic Project Team of Hong Kong West Cluster. The Genomic Project Team in Hong Kong West Cluster (HKWC) started its work in July 2021 to recruit patients from various cluster hospitals, at the recommendation/referral of doctors, to participate in the Hong Kong Genome Project (HKGP). The genetic service was implemented in the pilot and main phases. Initially, the recruitment service was only done at the 'Genetic Office'

which was located at the S1 clinic of Queen Mary Hospital (QMH). However, due to the risen trend of patient demands, mobile team outreach services to cluster hospitals were established. They were Grantham Hospital, The Duchess of Kent Children's Hospital, and followed with Tung Wah Hospital. The mobile teams were able to provide further networks for patients suffering from diseases of a specific nature at those hospitals.

RESULTS

From July 2022 to December 2023, 3230 participants from 2251 families were referred to nurse genetic counseling. Clients were interviewed and indications of genetic testing, potential benefits, limitations of whole genome sequencing, and consent information were carefully explained before signing up. The genetic nurse counselors obtained: comprehensive family histories for pedigree drawing, and identified family members at risk for genomic-influenced conditions. Patients referred for genetic testing came from different clinical specialties and diagnosis such as retinal pigmentation, retinoblastoma, eye degeneration disease; global development delay, autism, attention deficient hyperactive disorder; cardiac disease such as Brugada syndrome, ischemic/dilated cardiomyopathy/ arrhythmia problems; immune; endocrine or various cancers or orthopedic disorders, etc.

DISCUSSION

Genomic education and training are very important for nurses but are lacking. Being the largest professional group in the health care system and as a primary contact with patients, nurses have a pivotal role in the genomic data interpretation and care of patients (World Health Organization 2016). The nursing profession is a pivotal provider of quality healthcare services and is intimately involved in the ongoing treatment and management of disease conditions. Nurses are well-positioned to incorporate genetic and genomic information and make unique contributions to the field of genetics and genomics. The acquisition of genetic and genomic knowledge allows more patients to benefit from widespread genetic and genomic medicine. Nurses must be competent in obtaining comprehensive family histories, identifying family members at risk for genomic-influenced conditions, and helping them to make informed decisions to understand their situation and take appropriate action or care [9].

However, nurses' genomic literacy and knowledge practice gap affected the clinical application of genomic practice. The lack of confidence to apply genomic knowledge to their clinical work is a common phenomenon. There is an urgency for nurse education in the field of genetics especially when there is lacking of official training in the nurse training curriculum. Nurse educators should proactively review and develop and revise the specialized nurse training in university or nurse training schools [10]. A well-designed and effective genetic and genomic educational program and an updating the nursing curricula are in need. Appropriate genetic-genomic education will enhance nurses' collaborative work with multidisciplinary healthcare professionals, including genetic [11].

The success of nurse genomic education or training required tremendous support from top management. Many challenges encountered by the Project Team of HKWC to meet the recruitment target during the initial pilot phase have been overcome with great effort by hospital management in streamlining the recruitment workflow, the implementation of mobile services with engagement and enormous support from clinical teams was also crucial. Developing existing and future workforce and meeting the demands of a rapidly expanding service is important for the integration of genomic medicine. It is expected that precision medicine and effective treatment and optimized medicines will be driven by the use of genomics.

Nowadays, the engagement of nursing with genetics/genomics is limited. The nursing profession is a pivotal provider of quality healthcare services and is intimately involved in the ongoing treatment and management of disease conditions. Increasing awareness of the impact of nursing in genetics/genomics, adopting competency standards, and curricular integration are key if nurses' roles in genetic healthcare are to be realized. The nursing leaders need to be aware and recognize and implement policy or training to include the genetic /genomics practice in nursing [12]. The introduction of the concept of genetic and genomic nursing and basic counseling skills should be promulgated in different clinical settings. It would be expected that genetics and genomics to be included in the nursing curriculum soon. Nurses are at the forefront of the integration of genetics and genomics into clinical practice. Barriers such as limitation

of genetics knowledge and skill, low confidence in initiating genetics discussions, lack of resources and guidelines, and concerns about discrimination and psychological harm [13]. Building and developing the capacity of the current and next generation of nurses to integrate genetics and genomics into usual clinical practice is essential.

CONCLUSION

Given its importance, the Hong Kong West Cluster is delighted to develop nurses in genetic and genomic clinical practice and serve as a good starting point for the development of nurse genomic practice. The genetic service not only provides clinical information to the medical team for precise diagnosis and tailored treatment plans of individual patients but also expands the care to the whole family to know their risks in advance, if any. Relevant screening or treatment could be carried out in advance. Therefore, we are also dedicated, determined, and proactively striving for nurse competencies in genetic and genomic practices to create a healthier future for the people of Hong Kong through better care prevention, developing precise medicine, and personalized individual treatment.

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