The role of nurses in genetics

Nursing in genetics and genomics still do not have much visibility in Latin America. There have been some success efforts, especially in Brazil, Colombia, Cuba and Mexico. However, the majority of students and professors of undergraduate and graduate nursing programs still having a very conservative view of genetics and genomics, probably due to the content of current programs, which in general are uninformative about the attributions of nurses in this scenario and the absence of a specific direction for professional practice. A political-pedagogical and clinical transformation is needed, to ensure that nurses would have enough skills and competencies to integrate genetics and genomics at all levels of healthcare.

In Brazil there are several reports of nurses' performance in genetics and genomics. In the 80’s nurses started their acting in prenatal counseling and later, in the 90’s, oncology and geneticist nurses started to delivery genetic counseling in oncology settings. Nursing practice in genetics and genomics in Brazil is focused on the recommendations of the “Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics”, according to the regulations of the Law Nº. 7498 of June 25, 1986, that guides Brazilian nursing practice, and on the Brazilian Code of Ethics of Nursing Professionals.

The activities performed by Brazilian nurses are related to care, to education, management and research, and include: a) holding nursing consultation (for example, the collection, recording, updating and validation of the family history, to the empowerment for informed decision-making for genetic testing); b) participation on clinical case discussions with the multiprofessional team; c) planning and implementation of educational actions for health professionals to identify patients and families with or at risk for genetically determined diseases (ex.: early detection of inborn errors of metabolism and hereditary neoplastic syndromes), d) identification of issues and research hypotheses, and development and implementation of research projects; e) implementation and articulation of knowledge related to ethical and legal aspects involved in genetics and genomics health care; f) attention to various subjective experiences of patients regarding genetic disorders and integration of subjective and objective data to understand the context, and prescribe and implement a personalized care plan.

The need for nurses, in an informed and competent way, to become intimately involved with health care based on genetics and genomics results from the emerging need to optimize health outcomes in the light of powerful tools able to resolve the real health needs of population. This need has in view not only the epidemiological transition model already known, but it also has in view the political changes in the health sector, such as the recent approval of the National Comprehensive Care Policy for People with Rare Diseases in the Unified Health System(called SUS) in Brazil. Recently, it has been recognized the need to structure at SUS a network of regionalized and hierarchical services that can offer the possibility of comprehensive care for people with rare diseases with or without genetic predisposition. In order to meet this need, the Brazilian Ministry of Health, through Ordinance Nº. 199, of January 30, 2014, established and approved the National Policy on Comprehensive Care for People with Rare Diseases in SUS. The organization of this policy is supported by lines of care for users ranging from primary care to the specialized care An important contribution of this Policy is the need for training professionals with genetic and genomic knowledge, able to perform genetic counseling.
In June 2015 was established the Brazilian Society of Nurses in Genetics and Genomics (Sociedade Brasileira de Enfermagem em Genética e Genômica – SBEGG), with the mission of being a Latin American organization to gather and divulge the activities of nurses working in different areas of genetic and genomic care.

References: