



International Society of Nurses in Genetics

Informed Decision-Making and Consent: The Role of Nursing

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Brief Statement of Need/Importance

Genetic technology, such as molecular genetic testing can now be used for screening and diagnosis; and to guide treatment, health and reproductive decision-making; and research. The benefits of genetic testing range from early detection for treatable disorders to prevention by health planning before the onset of symptoms for those who are at risk for a genetic disorder or for enabling parents to make reproductive choices. Consumers of genetic technologies may also value the psychological and social benefit of knowing their genetic status. Potential adverse effects of genetic testing can include: psychosocial distress, altered family functioning, misunderstanding of meaning of the results, discrimination and unnecessary healthcare resource use. Nurses, as the omnipresent health care providers, have a central role in providing sufficient and accurate information and support to clients in the multiphase process of genetic testing. With genetics knowledge, nurses can advocate, educate, counsel and support clients during their decision-making process.

It is the Position of ISONG that nurses be responsible for:

- Alerting clients before genetic testing of their right to make an informed decision
- Advocating for client autonomy, privacy, and confidentiality in the informed decision-making process
- Ensuring that the informed decision-making process involves discussion of benefits and risks including the potential psychological and societal injury by stigmatization, discrimination, and emotional stress, in addition to, if any, potential physical harm

- Being aware of the clinical and personal utility of genetic testing, such as positive predictive value, penetrance rates, background populations and affected percentages and advising clients of the meaning of the testing and results
- Advising clients on the difference between research versus clinical use of genetic testing, return of results, clinical utility and defining the status of a specific test for that individual
- Augmenting the informed decision-making process by assisting the client in the context of the client's specific circumstances of family, culture, and community life
- Integrating into their practice the guidelines for practice (e.g. privacy and confidentiality, truth telling and disclosure, and non-discrimination) identified by national nursing organizations such as the American Nurses Association and the Australian Nursing and Midwifery Council guidelines
- Acquiring appropriate education in preparation for providing genetic services that includes knowledge of the implications and complexities of genetic testing, ability to interpret results, and knowledge of the ethical, legal, social, cultural and psychological implications of genetic testing
- Being aware of genetic health professionals and services with whom they can collaborate to maximize the ability of the client to make an informed decision.

Summary

ISONG supports a collaborative process of genetic testing with an emphasis on the informed decision-making authority of the client to choose to accept or to reject testing. Pivotal to accomplishing this process is a dialogue between the client and the providers in a joint endeavor to facilitate informed decision-making through open discussion and an honest exchange of relevant information at the level of language comprehensible to the client. The dialogue includes encouraging clients to seek information and identify concerns before undergoing genetic testing. The nursing process can be universally utilized to assist clients contemplating any type of genetic testing and to ascertain whether essential information is understood and is part of the decision-making process. This position statement applies to the use of genetic testing that is prescribed by a healthcare provider within the healthcare context. Direct to consumer and other forms of genetic testing are beyond the intended scope of the statement.

References

1. American Nurses Association (2001). Code of Ethics for Nurses with Interpretive Statements. Washington, DC: Author.
2. ISONG/ANA (2007). Genetics and Genomics Nursing: Scope and Standards of Practice. Washington DC: American Nurses Association.
3. Australian Nursing & Midwifery Council (2005). National Competency Standards for the Registered Nurse. http://www.anmc.org.au/userfiles/file/competency_standards/Competency_standards_RN.pdf. Retrieved June, 28, 2011.