



International Society of Nurses in Genetics

Genetic Counseling for Vulnerable Populations: The Role of Nursing

(Approved: October 10, 2002, Revised: January 29, 2010)

Background

The explosion of genetic discoveries resulting from human genome research is creating new health care provider practice roles and expanding health opportunities for clients worldwide. Genetic testing is increasingly being used in the screening, diagnosis and treatment of rare and common diseases. These tests not only are used for clinical decisions, but also may identify genetic susceptibilities to common disorders and other personal traits. Genetic tests and the use of other genomic technologies have the potential to be used to design personalized plans to minimize the risk to develop common diseases, and improve the overall health of individuals, families and populations. (National Human Genome Research Institute, 2009). As a result, clients are increasingly seeking genetic information and counseling services. Nurses will use patient and public education, counseling, and case management skills to assist clients in this new era of genomic-based health care.

The expansion of genomic health information is marked by increasing numbers of new technologies for diagnosis of genetic illness or increased genetic health risks. Vulnerable populations may not have access to such technologies directly. The ethical principle of justice (International Council of Nurses, 2006), notes the mandate of all health care professionals to seek equality of health services for all patients. This ethical requirement extends to nurses working in genomic health, who must take actions to see that their patients have access to appropriate genetic testing technologies, information, and counseling. Nurses are reminded to work through their organizations and policy-making units to achieve these therapeutic ends.

Optimum ways to provide genetic counseling are needed to address all clients' genomic-based health care needs. This is especially important for vulnerable populations. The International Society of Nurses in Genetics, Inc. (ISONG), as outlined in the Scope and Standards of Practice (ISONG, 2007) supports a broad interpretation of vulnerable populations. The ISONG Scope and Standards of Practice identifies vulnerable populations to include: children, individuals with hearing and language deficits or conditions limiting communication (for example, language differences and concerns with reliable translation), cognitive impairment, psychiatric disturbances, persons from minority populations, clients experiencing high levels of stress,

those without financial resources; clients with acute or chronic illness or pain and/or in end-of-life, and those in whom medication may impair reasoning. Such an expansion may be warranted because of the contribution genetics makes to such underlying conditions.

The ISONG definition of vulnerable populations expands on the definitions provided by the World Health Organization, the Centers of Disease Control Office of Minority Health, and the American Society of Human Genetics (World Health Organization, Centers for Disease Control, American Society of Human Genetics, 1995). Traditional genetic counseling strategies focus heavily on the exchange of factual information. Standards of practice for providing genetic information are based on the average person's needs, modified by the individual's needs or desires, as determined through discussion. The intended result is informed decision-making and a change in knowledge and/or behavior (Finucane, 1998). Issues of concern to vulnerable clients are likely to be similar to those of other clients; however the process of receiving and acting on health information may differ. When considering genetic counseling with vulnerable populations, outcomes such as satisfaction with the need for certainty and satisfactory achievement in the client's psychological adaptation to the genetic condition/issue in the family should be tailored to each specific client situation (Skirton, 2001). These principles apply to the full range of nursing interventions including patient teaching, decision-making support, and case management.

Nurses in all practice settings have a role in delivery of genetics services to vulnerable populations. At the basic practice level, nurses advocate for the vulnerable client by facilitating access to genetics resources; and providing or reinforcing information about a genetic condition/concern. At this level, nurses advocate for and support vulnerable clients by ensuring that they have access to genetic counseling services that meet the clients' desired outcomes. Furthermore, according to the Essential Competencies, all nurses must tailor genetic and genomic information and services to clients based on their culture, religion, knowledge level, literacy, and preferred language (Consensus, 2008).

At the advanced practice level and with expanded skills, nurses themselves provide genetic counseling to vulnerable clients. This includes:

- Assessing vulnerable clients' physical, cognitive and developmental levels, genetic literacy, and expressed interest in genetic information.
- Identifying outcomes that are appropriate to the client's goals, selecting interventions, including genetic counseling to achieve these outcomes.
- Evaluating outcomes of the care in collaboration with the client and a multidisciplinary team.
- Participating in and/or initiating research in nursing interventions including genetic counseling and education strategies and methods and evaluation of such for vulnerable populations.
- Participating in and/or conducting nursing research in genetic services.

Genetic Counseling of Vulnerable Populations: The Role of Nursing

The International Code of Ethics for Nurses (ICN, 2007) states that all nurses ensure that the individual receives sufficient information on which to base consent for care and related treatment. This includes the right to be given accurate, complete and understandable information in a manner that facilitates an informed judgment; to be assisted with weighing the benefits, burdens, and available options in their treatment, including the choice not to pursue treatment (ANA, 2001). Nursing support of this right includes the opportunity for the individual to make decisions together with family and significant others and access to advice and support from knowledgeable nurses and other health professionals. Nursing responsibility may extend, with the client's consent, to communication with other health or social care professionals on behalf of or in conjunction with the client, to ensure that the client's needs are met. The ICN Code of Ethics for Nurses (2007) further addresses the nurse's responsibility (shared with society) for initiating and supporting action to meet the health and social needs of the public, including those of vulnerable populations. In particular, as advocates and caregivers of vulnerable clients, nurses promote provision of genetic counseling with a focus on genetic issues of concern to the client and that includes family and/or legal guardian when needed.

It is the position of ISONG that professional nurses will:

- Incorporate a broad definition of vulnerable populations receiving genetic counseling services.
- Evaluate the extent to which individual factors contribute to a client's status as a member of a vulnerable population.
- Advocate for optimum genetic counseling outcomes for vulnerable clients, including advocating for appropriate and reliable translation of genetic information in situations when language differences are present.
- Communicate (after consultation with and consent of the client) with other health and social care professionals on behalf of or in conjunction with the client to ensure that the client's needs are met.
- Adopt into practice, guidelines for ethical practice, such as the International Council of Nurses, The ANA Code of Ethics for Nurses or similar guidelines that identify the patient's right to self-determination, and the nurse's responsibility to meet the health and social needs of vulnerable populations.
- Understand that formation of a personalized relationship between the client and genetics staff significantly enhances understanding and lowers anxiety thereby influencing the central outcome of genetic counseling.
- Recognize that important outcomes of genetic counseling for all clients, especially vulnerable populations, include:
 1. a client's lay knowledge of a genetic condition, ,
 2. determination of decisions regarding testing or management with respect to a genetic condition or risk for a genetic condition that includes patient preferences and informed decision making, and
 3. the client's successful adaptation to the genetic condition in the family.
- Incorporate into genetic counseling services for vulnerable populations, methods to evaluate and promote understanding in the client.

References

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