

Position Statement:

Genetic Counseling for Vulnerable Populations: The Role of Nursing

Background/Definitions

Sequencing of the human genome has led to enormous growth in our abilities to screen, diagnose, and treat both rare and common diseases. Genetic tests are used as part of clinical decision-making to identify susceptibilities, reduce disease risk, and develop personalized treatment plans to improve the health of individuals, families, and populations. Nurses use counseling and case management skills to assist people who seek to know their genetic information in this era of omics-based healthcare.

Vulnerable populations. The International Society of Nurses in Genetics, Inc. (ISONG) adopts an expansive interpretation of vulnerable populations that includes those at extreme ends of the lifespan, specifically conception and older adulthood; those of all ages who may be unable to provide informed consent independently; indigenous populations; ethnic and political minorities; immigrant and refugee communities; medically underserved and/or those underrepresented in research studies; sexual and gender minorities; rural populations; people with low health and/or genetic literacy or who are otherwise educationally disadvantaged; pregnant women; prisoners; populations of those with acute or chronic medical conditions; populations affected by communication barriers (i.e., due to hearing or language deficits or lack of reliable interpretive services); cognitively-impaired populations (including those with psychiatric disturbances, increased anxiety, or medication use) (American Nurses Association, 2008, 2015; ANA & International Society of Nurses in Genetics, 2016; Centers for Disease Control and Prevention, 2020; International Council of Nurses, 2019; National Human Genome Research Institute, 2017a, 2017b; Tangcharoensathien et al, 2016; Tluczek et al., 2019; United States Department of Health and Human Services, 2021).

ISONG recognizes that this is not an exhaustive list of examples and that the definition of vulnerable populations may be situationally specific or evolving over time, such as marginalized populations needing response assistance in a disaster or emergency (CDC, 2020; Tangcharoensathien et al., 2016; US DHHS, 2021).

Access. Vulnerable populations may not have access to genetic technologies directly (Prabarna, 2019; US DHHS). The ethical principle of justice mandates that healthcare professionals seek equity of health services for all people (ANA, 2008, 2015; American Society of Human Genetics, 2020; ICN, 2019). Thus, nurses must advocate and work through their organizations and policy-making units to ensure people have access to appropriate genetic testing technologies, information, and counseling according to each person's culture, religion, omics knowledge level, literacy, comprehension abilities, and preferred language (CDC, 2020; NHGRI, 2017b; Tangcharoensathien et al., 2016; Tluczek et al., 2019).

Genetic counseling. Traditional genetic counseling has focused on the exchange of information based on the average person's needs, modified by their moral principles (personal beliefs, values, and attitudes), determined through discussion, and resulting in informed decision-making and a change in knowledge and/or behaviors (National Cancer Institute, 2021; Skirton, 2001; Tluczek et al., 2019). Issues of concern to vulnerable populations are likely similar, although methods of addressing these concerns may differ.

Each encounter and nursing intervention should be tailored to each specific situation, including patient teaching, decision-making support, advocacy, and case management to include facilitation of informed consent for genetic testing, meetings with appropriate healthcare professionals for discussions of risk management or family planning, and referrals when needed (ANA 2008, 2015; ASHG, 2020; ICN, 2019; NHGRI, 2019). When one individual gets tested, there are confidentiality issues for generations before and to come in the person's genetic family history, and due care must occur in order to educate tested individuals about this relationship to their relatives.

Case management. Case management is a collaborative process involving coordination of and advocacy for all support required to effectively care for a person and their family (Case Management Society of America, 2020). This process may include, but is not limited to, the assessment, planning, facilitation, and evaluation of options and services to meet a person and their family's comprehensive health needs through communication and available resources. This process promotes patient safety, quality of care, and cost-effective outcomes (ANA, 2008; CMSA, 2020).

Informed consent. Nurses ensure that each person receives sufficient information to make informed decisions for healthcare, personal and family planning, and related treatment consent (ANA, 2008, 2015; ICN, 2019). This includes accurate, complete, understandable information in a manner that facilitates informed judgement, including benefits and risks, available options for treatment, and the choice not to pursue treatment (ANA, 2008, 2015; ASHG, 2020; ICN, 2019). Nurses support patients' rights to confer with family and significant others, as well as to obtain advice or support from others. With the patient's consent, the nurse may communicate with other health or social care professionals to ensure the patient's needs are met. Nurses' societal responsibilities to meet the health and social needs of the public include the needs of vulnerable populations and include the provision of genetic counseling (ANA, 2008, 2015; ICN, 2019; Tluczek et al., 2019).

It is the position of ISONG that professional nurses will:

- Incorporate a broad, inclusive definition for vulnerable populations who require genetic counseling services in their practices.
- Evaluate the extent to which individual factors contribute and culminate to achieve a person's status as a member of a vulnerable population.
- Advocate for optimal genetic counseling outcomes for vulnerable persons, including communication with other health and social care professionals on behalf of the person, with their consent, and with consideration of appropriate cultural considerations and reliable interpretive services as needed.
- Support guidelines for ethical practice regarding personal rights of self-determination and nursing's responsibility to meet health and social needs of vulnerable populations.
- Support the formation of a trusting relationship between consumers/patients and genetics staff to significantly enhance understanding and lower anxiety.
- Incorporate important outcome goals of genetic counseling for all people including:
 - a person's lay knowledge of a genetic condition,
 - determination of decisions regarding testing or management with respect to a genetic condition or risk for a genetic condition that includes personal preferences and informed decision-making, and
 - adaptation to the genetic condition in the family.
- Incorporate methods to evaluate and promote understanding as part of genetic counseling services for vulnerable populations, to include participation in and/or initiation of research involving nursing interventions, e.g.: genetic counseling, education strategies, as well as evaluation of such for vulnerable populations.

- Utilize expanded skills to:
 - assess a vulnerable person's physical, cognitive and developmental levels, omics literacy, and expressed interest in genetic information,
 - identify outcomes,
 - select and evaluate appropriate interventions including genetic counseling, and
 - achieve these outcomes in collaboration with a multidisciplinary team.

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Original position statement prepared by: The Ethics and Public Policy Committee and approved by the ISONG Board January 2010.

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Approved by: ISONG Board of Directors, November 18, 2021