

Role of Nurse in Prevention of Congenital Malformation

Lekshmi Sudhish Nair

Author Affiliation: Assistant Professor, Department of Obstetrics and Gynecology, Krishna Institute of Nursing Sciences, Karad, Satara, Maharashtra 415539, India.

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Abstract

Genetic diseases may seem esoteric to nurses, but knowledge of genetic disorder will help nurses to recognition and assessment of possible genetic disease, to obtain comprehensive family histories, identify high risk for developing malformation, help people to make informed decisions about and understand the results of their genetic/genomic tests and therapies, and refer at-risk people to appropriate health care professionals and agencies for specialized care. Nurses should have independent knowledge on genetics and disorders rather than depending on medicine professionals. Controls of Occupational hazards are another key component in prevention of malformations. Occupational nurses can advice to clients to avoide of exposure to teratogens (e.g. alcohol, recreational drugs, and certain chemicals and infectious agents) during pregnancy. Nurse administrator can design a policy Guidelines to facilitate the integration of various departmental staff to provide comprehensive nursing Care package for patients and family with congenital malformation.

Keywords: Role of Nurse; Prevention; Congenital Malformation.

Introduction

Genetic diseases may seem esoteric to nurses, but knowledge of genetic disorder will help nurses to recognition and assessment of possible genetic disease, to obtain comprehensive family histories, identify high risk for developing malformation, help people to make informed decisions about and understand the results of their genetic/genomic tests and therapies, and refer at-risk people to appropriate health care professionals and agencies for specialized care. The main aim of the genetic services includes “help people with a genetic

disadvantage to live and reproduce as normally and responsibly as possible” (WHO, 1985). In order to ensure the successful implementation of a genetics services it is recognized that the training of community-based nursing staff is of the highest priority, and that the common genetic disorders and birth defects recognized as part of the Services are appropriately managed.

Nursing services

Primary care providers, including nursing professionals regardless of their department

Corresponding Author: Lekshmi Sudhish Nair, Assistant Professor, Department of Obstetrics and Gynecology, Krishna Institute of Nursing Sciences, Karad, Satara, Maharashtra 415539, India.

E-mail: nairlekshmi86@gmail.com

and specialty, will be increasingly challenged to integrate theoretical genetic knowledge into their practice in order to ensure that patients and families affected with genetic-related health conditions receive adequate preventive and health promotive health services in clinical and community health area. Nurses should have independent knowledge on genetics and disorders rather than depending on medicine professionals.

Preconception and prenatal settings

In preconception and prenatal settings, nurses have an opportunity to help newly married couples to plan their pregnancy with appropriate decision on time. It includes explaining the rationale behind screening for numerous genetic diseases, counseling to explaining the benefits of genetic treatment modalities for a specific disease.

Knowledge of congenital malformation helps nurse to:

- Identify risk factors such as hereditary, familial, environmental and lifestyle characteristics that increase chances of malformation.
- To Helps to make appropriate decision making.
- To promote behaviors of couples and family members to facilitate surveillance and reduce disease risks.
- To identify, refer and/or prescribe appropriate disease management strategies, and
- To advocate publicly and politically promotion of optimal health care in community.
- Nurses emphasized involvement in counseling, education, supervision more than diagnosis and testing. Nurses recognized the importance of follow-up care in order to prevent genetic diseases in patients.

Diagnosis of birth defects have enormous emotional, psycho-social and financial impact on family, and are important causes of ill health and human suffering. Some birth defects can be treated, but management is usually costly and often only partially successful. Other abnormalities, however, may be wholly preventable by dietary means, prenatal diagnosis, selective termination of pregnancy, or even by early diagnosis and treatment.

Role of nurse in prevention of malformation

Primary prevention of congenital malformation includes health education to couples regarding reducing risk factors. These included,

- Down syndrome can be prevented by avoiding pregnancy in women over 35 years of age),
- Avoiding neural tube defects by encouraging folic acid consumption peri-conceptual period.
- Fetal alcohol syndrome can be prevented by discouraging the drinking of alcohol during pregnancy.
- prevention of disease complications, e.g. eye and skin care for persons with albinism,
- Mental stimulation for children with Down syndrome, and encouraging women to procreate at the ideal reproductive ages (20 – 35 years) to reduce the risk of chromosomal abnormalities;
- Provision of psycho-social support to affected individuals and their families.

Community health nurses can play an important role in creating awareness on improvement of health, nutrition, education and self reliance, particularly of women; avoidance of unintended pregnancies, and proper birth spacing through access to contraception and other methods of family planning and quality of, pre-natal care and genetic counseling, Improved quality of birth care also helps in avoiding complication during delivery by means of which many deformities could be prevented.

Role of industrial nurse

Controls of Occupational hazards are another key component in prevention of malformations. Occupational nurses can advice to clients to avoid exposure to teratogens (e.g. alcohol, recreational drugs, and certain chemicals and infectious agents) during pregnancy.

Secondary level prevention

Secondary prevention arises when there are symptoms of any malformation or there is high risk such as family history of genetic disorders. Interventions includes in secondary preventions are voluntary pre-natal diagnosis and selective termination of pregnancy for genetic disorders and birth defects, e.g. anencephaly, Trisomy 18, Trisomy. Other Strategies for secondary prevention include identification high risk group/ mother such as identification of pregnant women aged 35 years or more; pregnant women exposed to teratogens, e.g. alcohol, recreational drugs, infections (e.g. rubella, syphilis), medicines (e.g. phenytoin) or chemicals; ultrasound evaluation for all pregnant women for

accurate gestational aging in order to detect fetal defects; amniocentesis or chorion villus biopsy in appropriately-selected pregnancies, e.g. previous chromosomal abnormality; and termination of pregnancy for serious genetic disorders or birth defects.

Commonly-neglected component of congenital defect care is concept of Tertiary care which includes mainly rehabilitation aspect. It involves correction of genetic disorders or birth defects in order to restore normal function, e.g. repair of cleft-lip/palate, orthopaedic management of club feet, and cardiac surgery for children with Down syndrome.

Other rehabilitative interventions included anticipatory guidance (e.g. prevention of obesity in Down syndrome); proper intervention to avert complications (e.g. laminectomy to alleviate spinal cord compression in achondroplasia); rehabilitation of disabilities (e.g. speech therapy, hearing aids in hypoacusia, physical therapy in neuromuscular diseases); and psycho-social support of affected individuals and their families.

Nurses role at Antenatal clinic

In antenatal clinic nurses has to focus on observing Regular ante-natal care, Early identification of pregnant women of advanced maternal age, assessing of genetic risk based on a family history, Identification of women who have been exposed to teratogens, Continuation of folic acid supplementation, Identification of high-risk pregnancies, e.g. diabetic mothers and Offering of appropriate diagnostic tests.

Nurses role in intranatal period

Intranatal period is vital time in which nurse can do Physical examination of the neonate for genetic disorders and birth defects, Physical examination and investigation of the stillborn baby, Parental referral for genetic counseling and Patient referral for medical care.

Role of nurses in postnatal services

During postnatal period nurse can encourage couple to attend at well-baby clinics, Monitoring of growth and development, Identification of late-onset genetic disorders and birth defects and Referral for appropriate care and genetic counseling

Community health nurse can plan community activity such as Creation of awareness of risks associated with advanced maternal age,

Ascertainment of genetic risk based on a family history, Discouragement of exposure to teratogens, e.g. alcohol, tobacco, rubella, Encourage folic acid supplementation to reduce the risk of neural tube defects, Creation of awareness of medical conditions that predispose to birth defects, e.g. epilepsy, diabetes mellitus and Identification of women who have had multiple miscarriages.

Nursing Education

Nursing professional must have knowledge on human genetics, genetic testing for congenital malformation, and the associated ethical, social and legal issues in examination as well as in their treatment because they are at the forefront in identifying, assessing, and counseling patients and families with congenital malformations. Nurses plays major role in counseling, education, supervision, follow-up care more than diagnosis and testing in order to prevent genetic diseases in patients.

Genetic knowledge now has implications for all areas of health and disease management and nursing practice. Previously genetics is taught in prerequisite natural science courses such as in pathology, anatomy, and physiology. At present Indian nursing council prescribed curriculum on genetics has limited knowledge on congenital malformation and its implementation in clinical area which altimetry does not prepare nurses adequately for their evolving role in present clinical challenges in genetic disorders ant its caring strategies. Therefore it has been strongly suggest that knowledge of genetic disorder to be considered as a basic and an important part of the obstetrical and child health nursing practice. Not only nurses but also all health professionals must have adequate knowledge on revolutionary advances in genetics and genomics so as to assure that they can provide base line care to patients and families of congenital malformation. Globally also there has been created a need to explore the knowledge of nurses as Anderson(1996) stated that, from 1976 to 1994, only 9 studies were conducted to explore nurses' knowledge and usage of genetic information for caring patients. Another study by Scanlon and Fibison study (1995) also shows the same impressions adding to it they stated that most of the respondents who are acquiring genetic knowledge pointed that their knowledge comes from the mass media. So, authors stressed that genetic knowledge should be obtained as professional knowledge rather than common sense. Its created the need of an hour's to think about the necessity of inclusion

of genetics in every education curriculum for nurses so that in the present condition a competent Nurses can be prepared to meet changing needs in health care delivery, to support and care for patient affected by genetic disease. It should also include sufficient exposure to clinical experiences with genetic defects/diseases their programs. Genetic knowledge and skills need to be integrated into student clinical experiences across the life span and throughout the health and illness spectrum.

Furthermore Nursing education programs and curricula must be prepared in such a way that it should increase emphasis on the cultural, language, family values, traditions, health beliefs and religious perspectives that impact access to and use of genetic/genomic information, technology and services.

Nursing Research

Research on the clinical nurses' perception of their role and their knowledge in genetics is important as nursing profession is a pivotal provider of quality health care services and is essential to closing the gap between research discoveries that are efficacious to health care and their successful adoption to optimize health. Basically there is need for nursing research to provide important insights about how nurse' knowledge in genetics disorders can optimize patient outcomes.

The goal of nursing research in clinical genetics and genomics is to improve the quality of health care for patients and families. Application of nursing research on health disparities to research on genetic and genomics and health outcomes for patients and their families is to be considered during planning for research.

Nursing research in the field of congenital malformation aimed at providing a foundation of content for maintaining wellness through prevention and health promotion to patient and family care. Much research is needed to explore how family members access, use, and cope with genetic/genomic information that can influence the achievement of present and future health goals. Institutional as well as governmental organization has to provide increased funding for nurse researchers to conduct basic, clinical and translational genetic research.

Genetics offers many opportunities for nursing research, ranging from basic genetic theory in curriculum to its application in nursing practices. Research nurse can select topic on.

- Biopsychosocial factors in congenital malformation and its application in health and illness,
- Managing and diagnosing cardinal symptoms of malformations.
- Holistic and community approaches in caring child with malformation.
- family education and counseling aspects of genetic disorders
- Genetic disorders Health promotion and disease prevention, and rehabilitation.
- biopsychosocial intervention and counseling related to genetic disorders.
- The multidisciplinary collaboration of in nursing research with respect to genetic disorders is much more important for developing treatment strategies as well as preventive policies in public and private sector clinical practices.
- Nursing research along with psychologist and psychiatrist helps to develop models for treating psychological aspect of genetic disorders.

Nursing Administration

Nurses administrator can approach to higher authorities in the health care system To integrate medical genetics services into primary, secondary and tertiary levels of care as part of the comprehensive health care system with an appropriate referral network. Administrator can organize workshops to train other health care staff. The contents of the workshop would be standardized, and lectures would be given by trained nursing staff, genetic counselors and medical practitioners trained in Genetics.

The current national situation with regard to genetic staffing is critical and requires urgent attention. There should be separate department in each training hospital with full-time clinical geneticists and genetic nurses, genetic counselors / trained nursing staff, cytogenetic, molecular and biochemical technologist to deliver a comprehensive genetic service equitably to all.

- Effective continuing education programs will prepare practicing nurses to consider influencing variables related to the use of genetic/genomic services.
- There is an even greater knowledge gap associated with the sensitivity, specificity and clinical utility of the broad array of genetic tests available to the public. This gap can be

closed through education about the relevancy of these discoveries and the translation to practice, education, and policy.

- Nurses requires financial support to develop and update continuing education programs; to create workshops; and build, maintain, and update an educational portal that facilitates access and use of all available genetic educational resources.
- There should be separate position in clinical setting as “Genetic Nurse” who must be specially trained and had knowledge on congenital disorders and its prevention along with health promotional skills.
- It’s also important to train nurses who are already working in the patient care area who themselves have not had this new science in their training. This can be achieved by more publications on genetic disorder to promote awareness; development of educational programs to prepare faculty and researchers; and tools to assist faculty in curriculum integration of genetics and genomics.
- The leadership nursing has provided in the area of competencies and education can serve as models to inform the work of other health care professionals.
- Relevant genetics content is needed across nursing continuing education programs to assure quality care.
- Nursing education programs must emphasize the genetic concepts and skills needed to assure quality care.
- Resources to prepare faculty and to support ongoing changes are needed to assure that all faculty are able to implement and sustain the integration of genetic/genomic content throughout all nursing programs.

Administrator can plan interventions in such a way that services should be integrated nursing genetic services into primary, secondary and tertiary levels of care as part of the comprehensive health care system with an appropriate referral network. Genetic Education Manual would be offered for nursing staff, particularly those involved in maternal, child and women’s health, who wish to undertake further training in medical genetics. To develop a nursing genetic component of health services through capacity building, re-orientation of health professionals, training of PHC workers particularly midwives, nurses and others concerned with Maternal, Child and Women’s Health is important.

A short genetics course which should be practically-orientated in Genetic nursing can be offered to nursing and midwifery staff those have completed the diploma nursing programme. Topics to be covered would include the diagnosis and management of common genetic disorders and birth defects; laboratory procedures; principles and practice of genetic counseling; psychosocial support; and the collection and collation of statistics more importantly nursing assessment and accurate interventions in dealing with various malformations.

Yearly in-service training programmes should be conducted to ensure that nurse can develop good knowledge and skill to maintain their level of education, and to keep abreast of current developments. Nurse administrator can design a policy Guidelines to facilitate the integration of various departmental staff to provide comprehensive nursing Care package for patients and family with congenital malformation.

Conclusion

Risks to the fetus caused by maternal exposure to specific risk-factors can be decreased if the mother is aware of such factors because such knowledge leads to preventive behavior. It is, therefore, important that mothers accept that congenital abnormalities can occur and adopt effective measures to avoid them, although the road to such measures, which should be taken by every couple who wants to have a baby, is usually filled with uncertainties.

The nurse’s roles of a counselor, technician, care manager, and teacher for patients and their families, will have an opportunity to expand as well as to create new leadership roles in health care.

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