



Role of Pediatric Nurse in Management of Child with Genetic Disorders

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Nurse's Management

Role and Responsibilities

- Pediatric nurses will have to be vigilant as she has to encounter children with genetic disorders of any type in every clinical specialty area in which she works, including clinics, hospitals, schools, and community-based centers
- Genetic counselling plays a very effective role and this role is to be played by a pediatric nurse with best out of abilities.
- Talking with parents who have recently been diagnosed with a genetic disorder or whose gave birth to child with congenital anomalies is very difficult but pediatric nurse can arrange follow up meetings with the parents and can talk to them at different sessions.

Nursing implications

Pediatric nurse has to be alert and must remember the followings things in the entire procedure:

- Explain the positive as well as negative effects of any genetic test.
- The information is to be given to the parent or the close concerned member.
- Pediatric nurse should always remember that the genetic diagnosis is a family diagnosis and this is needed to be handled very delicately.
- If we are dealing with the adolescent who is carrier, we must make individual fully understand about the reproduction.
- Pediatric nurse must fully and critically educate the parents about that disease connected with parents and make them clear that the frequency is a new gene mutation and has no connection with the parent gene.
- Make sure of the availability of resources and ensure the appropriate resource providers for them.
- Always offer to help the family connect to a support group for the relevant diagnosis.

Nursing Process Overview for the Child with a Genetic Disorder

• Assessment

- » Health history: complete history which include family history, pregnancy history of mother, childhood history etc.
- » Physical examination; It includes Inspection and observation, Auscultation, Palpation.
- » Laboratory and diagnostic testing.

• **Nursing diagnoses:** Appropriate nursing diagnosis, goals, interventions, and evaluations.

Nursing management

Due to the increasing incidence of Genetic disorders and the complex medical and nursings needs of these children, most pediatric nurses are likely to care for these children in their practice. Nursing management focuses on providing supportive measures from which few are mentioned below such as:

- Promotion of growth and development.
- Preventing complication.
- Promoting nutrition.
- Providing support and education to child and family.

Promoting Growth and Development

- Pediatric nurses can help the families with appropriate resource facilities which can promote and facilitate the child's growth and development.
- Most of the interventions should begin as early as possible for the betterment of the child.
- Various therapist can be collaborated so that they can provide necessary therapies for the affected child such as Speech and language therapy, occupational therapy and physical therapy, these all are very important in promoting the child's growth and development.
- Special education should be provided at each developmental level and should fit the child's individual needs, and the child should be integrated into main stream education whenever possible.

Preventing Complications

Nurses also play a key role in educating parents and care givers about how to prevent the complications of the child with genetic disorders.

For Example

Child with Down's syndrome. Their are certain teaching guide lines which can be followed:

- Pediatric nurse has to evaluate and monitor the child and she should ensure to evaluate child by pediatric cardiologist before child is 3 months of age.
- Child should be routinely monitored for vision and hearing.
- Educate the parents about the daily exercise.
- Make sure the child follows the regular and healthy dietary patterns.
- All the family members should be educated for maintaining proper hygiene in order to prevent infections.
- Educate the parents of importance of regular medical follow up care.
- Pediatric nurse has to monitor for signs and symptoms of respiratory infections, such as pneumonia and otitis media.

- Educate the parents regarding child's dental hygiene and after every 6 months the child should visit to a dentist.
- Make sure the child gets cervical X-ray between 3 to 5 years of age to screen for atlanto-axial instability.

Promotion of nutrition

Child with genetic disorder is very importantly taken care of nutritional requirement. Many children with genetic disease have problem in feeding so activities promoting their nutrition should be promoted.

For Example

Children with Down syndrome have lack of muscle tone which may result in difficulty sucking and feeding. They tend to have small mouths, their tongue is large, flat and smooth and have chronically stuffy nose which is result of under developed nasal bone. This may lead to poor nutrition intake and problems with growth. These problems usually decrease as the child improves control on tongue.

- Maintain proper position of the infant while feeding.
- Frequently change the position of the infant.
- Use bulb syringe for feeding.
- Promote breast feeding to the baby as antibodies present in the milk helps the child to fight against the infections.
- Educate the parents and family that during feeding additional support should be provided.
- Nurse should collaborate with the speech therapist which may help in strengthening of the muscles.
- Promote balanced diet and high-fiber diet which helps in increasing gastric motility thus preventing constipation.

Providing support and education to child and family

Provide support to the family members and provide elaborated education about the disease conditions.

Example in:

Down syndrome

- From the time of diagnosis the family should be educated regarding its life long implications of health problems, so family should be involved in the care from the very beginning.
- Educate the parents about how to take care of their child in routine basis.
- Nurse should involve parents and other family members in planning interventions for the child.
- Educate the entire family about the needs of the child at different developmental stages.
- Make the family equipped with the resources available.
- Team up with other services at national and international level to help the child and families.

Klinefelter's syndrome

- Counseling about infertility is important to the family with child suffering for klinefelter syndrome.
- Educate the client as well as family regarding possible sexual relationships.
- Explain the alternatives for reproduction and new technology available for infertility.

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