



PARENTING AND CARE : A COMPLEX ROLE IN CHILDREN WITH NEUROMUSCULAR DISORDER

Vd Kiran P. Nandeshwar*

PhD Scholar, Department of Kaumarbhritya Government Ayurved College, Dharashiv, Maharashtra, India *Corresponding Author

Dr Anil B. Kale

Professor & Head of Department, Department of Kaumarbhritya R. A. Podar Ayurved Medical College Worali Mumbai, Maharashtra, India.

Dr Tirunagry Y. Swami

Professor & Head of Department, Department of Kaumarbhritya Government Ayurved College, Dharashiv, Maharashtra, India

ABSTRACT Parenting is a crucial responsibility that demands bringing up a child mentally, physically and socially in the best possible way. It is difficult task for parents as well as single parent. Neuromuscular Disorder (NMD) are a heterogeneous group of condition caused by underlying genetic mutation leading to diseases arising from different parts of the lower motor neuron units. NMD causes orthopaedic, respiratory, cardiovascular, nutritional and gastrointestinal complications. A child with a NMD presents a complex challenge to the parents and whole family. When a neuromuscular disease diagnosis is made, parents may leave in shock. Acceptance can be difficult, it may feel overwhelming. Parents will need to understand both the disease and how their lives will change. This paper will evaluate parenting a child with a neuromuscular disorder and teach them how to provide the required care, master sophisticated in home medical equipment and navigate both the social and medical environment to ensure optimal care and quality of life of their child. The parents and child's health and emotional well-being will impact quality of life. The ability to survive will matter more than disease severity.

KEYWORDS : Neuromuscular Disorders, Parenting, Ayurveda, Quality of life.

INTRODUCTION

Neuromuscular disorder (NMD's) covers all diseases that affects one or more components of the 'motor unit', composed of the alpha motor neurons, spinal nerve roots, the peripheral nerves with their axons and myelin sheaths, the neuromuscular junction and lastly the muscle fibres, sensory fibres and the final ganglia can also be affected. Prevalence in children and adolescents is 60-70/100000.^[1] Diagnosis of NMD is burdensome and psychologically stressful situation for the patients and their families. Parenting is a process of promoting and supporting the physical, emotional, social and intellectual development of a child from infancy to adulthood.^[2] In NMD's there is functional impairment, weak muscle strength, dependency increases, low activity of child. There is need of quality of care, adjusted expectation and most importantly acceptance. Disable child leads to loneliness and isolation. Positive parenting can result in positive feelings in those children who have devoted caregiver and healthy home environment.^[3] Ayurveda is an ancient Indian science which emphasis on importance parents to raise a healthy child and care of child even before the intrauterine life. There is need of more understanding and love from parents and feel happier at home in NMD's children.

Neuromuscular Disorder

Neuromuscular diseases affect the lower motor neuron of the nervous system, which may include the muscles, nerve or the junction between muscles and nerves (known as neuromuscular junction.) A familiar group of neuromuscular disorder is known as muscular dystrophies, but there are many other kinds of neuromuscular disorders.

Causes

There are many different of paediatric neuromuscular disease type. These may include inherited neuropathies, muscular dystrophies such as Duchene, congenital myasthenic syndromes and congenital myopathies. Through genetic testing and counselling, patients and their families can better understand how disorders are inherited and the roles that genes play in certain diseases. Some neuromuscular diseases are caused by an immune imbalance. They may have markers in the blood that can be tested, such as an electromyogram[EMG] to confirm diagnosis.

Symptoms

Children with neuromuscular diseases symptoms may have :-

- low muscle tone (hypotonia)
- delayed motor milestone like delayed walking or abnormal gait
- muscle weakness, atrophy, twitching or rippling.^[4]

Parenting

Parenting is the labour of love. Parents play a major role in moulding the satva of little one. According to Sushrut when a child is taken good

care, child will accomplish nityamadagrasatwa(stable mind), niroga(healthy), suprasanna mana (mental wellbeing). Children who diagnosed with NMD having symptoms of anxiety, depression and psychological maladjustment. They need advanced care, palliative and psychological support.

Types of Parenting :- There are 4 types of parenting

1. Authoritative
2. Permissive
3. Neglectful
4. Authoritarian^[5] – Authoritative parenting useful in NMD's children.

Parental Quality of Life and Lived Experience with NMD Children:-

When a family receives neuromuscular diagnosis, there will be many unpredictable challenges along the way and unfortunate circumstances that the entire family must adapt to in order to thrive. It can be a devastating blow for parents which may leave them feeling inadequate and hopeless. Parents are profoundly affected by their child's condition.^[6] Isolation, loneliness, stress, anxiety, anger, exhaustion and depression are reported to impact quality of life for parents of children with NMD. Parents often have little to no personal time, neglect hobbies and interests, limit family, and social outings and their relationship may suffer. The home may need renovation to meet present and future needs. Family may decide to move to a more assessable home. Some may move closer to their family of origin to have ready access to willing helpers. The financial burden on the family can be tremendous. Parents worry about their child being in pain, disfigured, rejected by peers, isolated and unhappy. Father experience psychosocial, familial and economic difficulties still need to strong for the family. Mother is particular tend to leave the workplace in order to care for their child with NMD.

Families need access to external resources, such as respite or financial aid and greater participation in social activities that are meaningful to them in order to experience an improved quality of life.^[7] Parents have a natural inclination to cure their child as a part of their desire to protect, provide and problem- solve. Parental confidence in the ability to provide excellent care must be supported by clinicians and can lead to better outcomes for the child.^[8]

Parenting and Ayurveda :-

Ayurveda regards child care as it must start from the care of women from the first day of Menstrual period to the period during and after gestation.^[9] According to Chakrapani, the achara (behaviour) followed by garbhini stree (pregnant lady) is one of the contributing factors in garbhavrudhi (development of a child).^[10] As Kashyapa says " Garbhe

api prabhuruthi baleshu” one has to take care of child since fetal life.^[11] Satwavajaya chikitsa described in Ayurveda can help the parents of NMD's child to bring out the best in their child life. According to Manusmriti, parents are referred as 'Guru'.^[12]

Abhiyukthaha Sadachara :- Parents should be faithful with good conduct and healthy habits, should have affinity towards child care. Parents must follow a Satvik life style with good sense of hygiene, talks politely with respect. Child nurtured with such kumaradhara, adopts a similar behaviour in life as it learns a lot by observations.^[13]

Satwavajaya in Parenting^[14] :-

Jnana- adhymujnanam – Knowledge about self and knowing self. It's about helping the parents to self evaluate and handle their emotions in front of children. This also helps to connect with the children.

Vijnana – Shastrajananam – It's about educating the parents regarding parenting, various type of parenting and consequences of bad parenting.

Dhairya- Anumatischethasaha - In Permissive type of parenting helping the parents to overcome their fears in putting rules to their children is very important. It will built confidence in parents to discipline and care their child in right way.

Smrithi – Anubhutharthasadhanam – It's about probing into the past of parents to know how they were brought up and help them to let go of negative inputs about parenting

Samadhi :- Vishayebhyonivarthanthe mananiyamana – It's about advising parents to read books to know more about spirituality so that they become stress free in NMD conditions. Pranayam, dhyana etc. help the parents to keep their mind stable and raise their child in a healthy way as mind of a child have a great influence by parents mentality.

In Neuromuscular Disorder Children , It Needs To Be Treated In Accorded With Recommended Practice Guidelines.

There are parenting groups that are helpful for parents who have been maltreating their children, these focus on child development, education, disciplinary style as well as technique for anger, frustration, anxiety, depression management.^[15] In NMD, it is important to provide emotional support, encouragement to children and parents in learning to plan for upbringing the child and to resolve their own inner psychic conflicts.

Parents and therapist collaborate to maintain the variables in child's environment and family system, to develop plan to change parental behaviours when necessary and to rearrange contingencies in the immediate environment to foster the child recovery.

Reinforcing and praising the child's efforts at copying, no matter how small, is essential for parents to learn.

In Ayurveda Panchakarma therapy described by all acharyas which is useful in NMD for better quality of life. Snehan, Swedana treatment useful for muscle tone, spascity, etc. Parents should learn it from therapist and practice at home as they are the primary managers of their children's diseases.

DISCUSSION

Diagnosis of neuromuscular disorder in children is overwhelming experience for even the strongest parents. But parents should have patience out their child. They should learn about diseases and their management. As they are first caregiver of child, psychological, emotional support and positive attitude is must in parents of NMD's children. Parents have godly position in children's life; parenting is skill that must be learnt by gaining knowledge and experiences. Good and calm parenting can improve children quality of life and can bring them back to track and prevent further damage to the child's mind. Ayurveda explain how to build healthy and stress free environment for the children.

CONCLUSION

Parenting has vital influence over the complete physical and mental health of children. Ayurveda gives various norms of behaviour like sadvritta, achararasayana, dincharya, rutucharya to take care of child's satva and also mentions how to behave with child to take care of his/her satva. In ideal parenting one can improve the quality of life and mental health in children with neuromuscular disorder. Parenting a child with a neuromuscular disorder involves a multitude of emotions, responsibility and decisions from diagnosis to end of life. Obtaining a genetic diagnosis living with chronic neuromuscular disease, advance care planning and preparing for death are significant milestones that

parent may experience during their child's lifetime.

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