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Inclusive Education and avenues of learning for learners with Muscular Dystrophy: A Case Study

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ABSTRACT--*Muscular Dystrophy is a group of diseases that cause progressive weakness and loss of* ***muscle*** *mass. In muscular dystrophy, abnormal genes (****mutations****) interfere with the production of proteins needed to form healthy muscle. Consequently, with time, the afflicted loses the ability to even carry out an elemental function like body movements. It is an agonisingly painful phase in the patients' life as they battle with the disease that threatens to choke their chances of sustenance with each passing day. Even more dismal is the lack of awareness regarding the disease, hence, the possibilities of creating appropriate scaffolds to facilitate the well-being of people afflicted with muscular dystrophy is minimal at present. This lacuna is more entrenched in education. It is pertinent to refer to the Rights of Persons with Disabilities Bill – 2016, in this context. With the amendment now, the Government of India has extended the ambit of Disabilities from 7 to 21, with muscular dystrophy indicated as separate class of specified disability. Given this premise, it is imperative to note that it is now a mandatory clause for all the government funded educational institutions as well as those recognized by the government to proffer inclusive education to such learners. In this contextual frame, this study attempts to present 5 case studies pertaining to learners with muscular dystrophy. The author has personally witnessed a lack of information among the parents and, therefore, their inability to help their children affected with muscular dystrophy, especially in the case of Duchene muscular dystrophy. Hence, as a long-time personal goal, she developed this study to address this lacuna. Case studies are based on semi-structured interviews which were conducted with five parents. Analysis of the interview data indicated the willingness of these parents to share information to empower others like themselves. The study etches conclusions that recommend a host of solutions aimed at redefining pedagogies to empower the learning abilities of students with muscular dystrophy.*

Keywords-- *Muscular dystrophy, Duchene muscular dystrophy, awareness of parents, inclusive education.*

I. INTRODUCTION

In 2016, The Indian Legislative Houses passed yet another pivotal Bill which was "The Rights of Persons with Disabilities Bill". This Bill was intended to replace the existing Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, which was enacted **21** years ago. Further, the Act committed to fulfil the obligations of the United National Convention on the Rights of Persons with Disabilities to which India is a signatory. The **Act** came into force during December, 2016

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The number of recognized **disability** conditions was increased from 7 to 21 in the **RPWD Act 2016**. In the RPWD Act now enlists: "cerebral palsy, dwarfism, muscular dystrophy, acid attack victims, hard of hearing, speech and language disability, specific learning disabilities, autism spectrum disorders, chronic neurological disorders like multiple sclerosis and Parkinson's disease, blood disorders (haemophilia, Thalassemia), and sickle cell anaemia, and multiple disabilities. The nomenclature mental retardation is replaced by intellectual disability which is defined as a condition characterized by significant limitation both in intellectual functioning (reasoning, learning, problem-solving) and in adaptive behaviour which covers a range of every day social and practical skills including specific learning disabilities and autism spectrum disorders.*"*

Muscular dystrophy, as defined in medical ambit**,** is a, "group of genetic diseases characterized by progressive weakness and degeneration of the skeletal or voluntary muscles which control movement. The muscles of the heart and some other involuntary muscles are also affected in some forms of muscular dystrophy. The disorders differ in terms of the distribution and extent of muscle weakness, age of onset, rate of progression, and pattern of inheritance. The symptoms of muscular dystrophy are the result of a deterioration of the body's muscles". Some types of muscular dystrophy affect only males. Some people with muscular dystrophy enjoy a normal life span with mild symptoms that progress very slowly; others experience swift and severe muscle weakness and wasting, dying in their late teens to early 20s. Severe breathing and heart problems mark the later stages of the disease. The disease renders its victims in a hapless condition which worsens with the passage of time. There are different kinds of muscular dystrophy as defined in the medical nomenclature**:**

- Duchenne muscular dystrophy **(DMD)** is the most common form. It mainly affects boys, and starts between ages 3 and 5.
- Becker muscular dystrophy is like Duchenne, except milder. It also affects boys but the symptoms start later- between the ages 11 and 25.
- Myotonic muscular dystrophy is the most common form in adults. People who have it cannot relax their muscles after the muscles contract. It can affect both men and women, and it usually starts when people are in the age group of 20s.
- Congenital muscular dystrophy starts at birth or shortly afterwards. Limb-Girdle muscular dystrophy often starts in a person's teens or at/after the age of 20 years.
- Facioscapulohumeral muscular dystrophy affects the muscles of the face, shoulders and upper arms. It can affect anyone from teenagers to adults in their 40s.
- Distal muscular dystrophy affects the muscles of the arms, legs, hands, and feet. It usually comes on later in life, between ages 40 and 60.
- Oculopharyngeal muscular dystrophy starts in a person between the age group of 40 or 50. It causes weakness in the muscles of the face, neck, and shoulders, and droopy eyelids followed by difficulty swallowing (dysphagia).
- Emery-Dreifuss muscular dystrophy affects mainly boys, usually starting around the age of 10. People with this form often have heart problems along with muscle weakness.

Out of the above specified childhood muscular dystrophies, DMD is one of the most common ones. DMD is an inherited disorder (X-linked recessive) with progressive degeneration of muscle; onset is generally before the

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age of 6. People with DMD lose muscle all their lives, but it is usually not noticed until a parent or the caregiver finds unusual walking and/or talking around the age of 3. About 1 in every 3,500 boys is born with Duchenne muscular dystrophy. Although the statistics show that the girls rarely get this disease, females can still have some of the symptoms like weaker muscles in the back, legs and arms that fatigue easily. Some may need a wheelchair or other mobility aids. Carriers may have heart problems, and can have shortness of breath or failure to do moderate exercise. The heart problems, if untreated, can be quite serious, even life-threatening. As stated in the health records, people affected by DMD often suffer from the failure of the heart muscle and the death usually occurs by the age of 25. Symptoms of Duchenne muscular dystrophy include**:**

- Muscle weakness that begins in the hips, pelvis, and legs and difficulty in standing.
- Trouble in sitting independently, climbing stairs, walking and waddling gait. By the age of 10, the person may need braces for walking. Ability to walk may be lost by the age of 12 and most patients are confined to a wheelchair.

II. CAUSES OF DUCHENNE MUSCULAR DYSTROPHY

The Muscle-Fiber Membrane Muscles are made up of bundles of fibres. A group of interdependent proteins along the membrane surrounding each fibre helps to keep muscle cells working properly. When one of these proteins, dystrophin, is absent, the result is Duchenne muscular dystrophy. DMD is caused by a mutation in the gene that produces an important muscle protein called dystrophin, which is not produced.

III. TREATMENT OF DUCHENNE MUSCULAR DYSTROPHY

An embryonic stem cell transplant is one possible treatment amongst few others. It is hoped that injecting healthy, non specialized stem cells into DMD victims will cause the stem cells to specialize and produce structurally and functionally correct dystrophin. If dystrophin can be produced, it may slow the progression of the disease, or cure it altogether.

With this existing repository of outsourced information, this study is intended at meeting the following

IV. OBJECTIVES

1. To identify the tribulations of the parents whose children are afflicted with DMD and understanding of the various inventive learning aids that have been incorporated to facilitate inclusive education in the wake of RPWD Act-2016.

2. To bring to focus the efforts that have been reached in pedagogical approaches for benefitting children with DMD.

3. Etching further possibilities to provide learning scaffolds and empower the learners with DMD with inclusive education.

Case Analysis of three case studies has been detailed which is an attempt to reach the First Objective of this study. Each Case study is profiled in three analytical aspects which are: (1) Health Condition of the Learners' with

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DMD; (ii) Educational Needs of the Learner; (iii) Parents' Response. To collate a more specific data, parents' response should further address three queries-

a. Are parents and teachers of the school aware of RPWD Act- 2016 and did they receive the right scaffolds from school and teachers in this context?

b. Were special learning aids and changes in learning pedagogies included in to facilitate the learning?

c. Did the parents liaison with medical and social counselling to help their child.

V. WITH THIS AS THE GROUNDWORK OF THOUGHT, THE FOLLOWING CASE STUDIES ARE ENUNCIATED

Case Study I:

- Patient's Name: Raghvendra
- State: Uttar Pradesh
- City: Lakhimpur
- Education Achieved: Not formal education but he achieved informal education at home because his father is highly qualified.
- School Student of: No
- Family status: Upper class
- ***Health Condition***:

Raghvendra was diagnosed with DMD at the age of 3 and battling with the degenerative aspect of the disease, he succumbed to it at the age of 18 with the cause of his death being the failure of his respiratory system. His medical records stated that beginning at about 10 years of age, the diaphragm and other muscles that operate the lungs weakened, making the lungs less effective at moving air in and out. Problems that indicate poor respiratory function included headaches, mental dullness, difficulty concentrating or staying awake, shortness of breath at times and nightmares. Weakened respiratory muscles made it difficult to cough, leading to increased risk of serious respiratory infection. A simple cold could also lead to pneumonia.

Educational Needs of Raghvendra :

Parents' Response:

- For the Query- A.:-Parents were aware of RPWD Act- 2016 and School not allow to continue the study for such type of patient.
- For the Query- B. :- focus the efforts that have been reached in pedagogical approaches for benefitting children with DMD at home because father provide all the teaching ,learning equipment provide to Raghvendra
- For the Query- C.:- yes parents liaison with medical and social counselling to help their child

Case study II:

- Patient's Name: Piyush
- Present age: 12 years

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- State: Uttar Pradesh
- City: Barabanki
- Education Achieved:
- School Student of:
- Family status:Middle class

Health Condition:

Piyush was diagnosed with DMD at the age of two and battling with the degenerative aspect of the disease, he succumbed to it at the age of 12 with the cause of his medical records stated that beginning at about 10 years of age, the diaphragm and other muscles that operate the lungs weakened, making the lungs less effective at moving air in and out. Problems that indicate poor respiratory function included headaches, mental dullness, difficulty concentrating or staying awake, shortness of breath at times and nightmares. Weakened respiratory muscles made it difficult to cough, leading to increased risk of serious respiratory infection. A simple cold could also lead to pneumonia.

- ***Educational*** Needs ***of Piyush***: Not enrolled in school.
- ***Parents'*** Response***:*** For the Query- A.:-Parents of Piyush were aware of RPWD Act- 2016 and School not allow to continue the study for such type of patient.
- For the Query- B. :- focus the efforts that have been reached in pedagogical approaches for benefitting children with DMD at home because Parents are no highly qualified so they not provide all the teaching ,learning equipment to Piyush.
- For the Query- C.:- No parents liaison with medical and social counselling to help their child

Case StudyIII:

- Patient's Name: Raj
- Type: Myotonic muscular dystrophy
- State: Uttar Pradesh
- City: Varanasi
- Education Achieved: achieved formal education
- School Student of:
- Family status:Upper class
- ***Health Condition***:
- Raj was diagnosed with Myotonic muscular dystrophy at the age of20. Muscle weakness that begins in the hips, pelvis, and legs and difficulty in standing.

Educational Needs of Raj: Not enrolled in school.

Parents' Response:

- For the Query- A.:-Parents of Raj were aware of RPWD Act- 2016 and

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- For the Query- B. :- focus the efforts that have been reached in pedagogical approaches for benefitting children with DMD at home because father provide all the teaching ,learning equipment provide so Raj
- For the Query- C.:- yes parents liaison with medical and social counselling to help their child

Case Study IV:

- Patient's Name: Mayank
- State: Uttar Pradesh
- City: Sitapur
- Education Achieved: No
- School Student of: No
- Family status: Lower middle class
- ***Health Condition***: very Poor health condition Mayank was diagnosed with DMD at the age of 3 Problems that indicate poor respiratory function included headaches, mental dullness, difficulty concentrating or staying awake, shortness of breath at times and nightmares. Weakened respiratory muscles made it difficult to cough, leading to increased risk of serious respiratory infection. A simple cold could also lead to pneumonia.

Educational Needs of Mayank:

Parents' Response:

- For the Query- A.:-Parents were not aware of RPWD Act- 2016 and School not allow to continue the study for such type of patient.
- For the Query- B. :- focus the efforts that have been reached in pedagogical approaches for benefitting children with DMD at home because parents are not educated so they do not provide any type of pedagogical approached.
- For the Query- C.:- parents liaison with medical and social counselling to help their child

Case Study V:

- Patient's Name: Ravi
- State: Uttar Pradesh
- City: Gonda
- Education Achieved: Highschool pass
- School Student of:
- Family status: Middle class

Health Condition:

- Ravi was diagnosed with DMD at the age of 4 and battling with the degenerative aspect of the disease, he succumbed to it at the age of 14 .His medical records stated that beginning at about 6 years of age, the diaphragm and other muscles that operate the lungs weakened, making the lungs less effective at moving air in and out. Problems that indicate poor respiratory function included headaches, mental dullness, difficulty concentrating or

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staying awake, shortness of breath at times and nightmares. Weakened respiratory muscles made it difficult to cough, leading to increased risk of serious respiratory infection. A simple cold could also lead to pneumonia.

1. ***Educational Needs*** of Ravi :Parents and educators focused on the physical access and safety around the school building.

Parents' Response:

- For the Query- A.:-Parents of Ravi were aware of RPWD Act- 2016 and School allow to continue the study for such type of patient.
- For the Query- B. :- focus the efforts that have been reached in pedagogical approaches for benefitting children with DMD at home because father and NGOs provide all the teaching ,learning equipment to Ravi.
- For the Query- C.:- parents liaison with medical and social counselling to help their child

Inferences: The collated data, when dissected and understood in the backdrop of inclusive education and its cause as underscored in RPWD Act- 2016, revealed that:

1. There was noticeable lack of awareness regarding the coping mechanisms while enabling the learning process of a child with DMD.
2. Special/itinerant teachers skilled in various disabilities were not part of the school's teaching fraternity. Teachers and caregivers need more sensitisation regarding the cognitive and behavioural capacities of children with DMD.
3. Learning pedagogies require a highly learner-centric and customised approach to educate the learners with DMD.
4. An interactive network of parents, health experts, social counsellors and educators to respond and cooperate while being the four core support groups for the child with DMD was found missing.
5. Few learning aids employed were:

VI. DISCUSSION & RECOMMENDATIONS

This study provides several implications for professionals who work with children who have Duchenne muscular dystrophy. Medical, educational, and other professionals can learn and benefit from the practical experience of parents who cope with Duchenne muscular dystrophy on a daily basis.

In addressing the learning needs of the children with DMD and their families, the role of the physical therapist varies by setting. As a team member in a multidisciplinary specialty clinic, the therapist may perform evaluations and make recommendations over extended periods of time. The school-based physical therapist may serve as consultant, educator, and coordinator, facilitating the provision of services to meet the student's educational needs and prepare for the transition to adulthood. The outpatient therapist may intervene for brief episodes of care after surgical interventions or to assist in the acquisition of and training regarding orthoses, wheelchairs, and other adaptive equipment. Home care may involve procedural interventions, patient/client-related instruction with the family, and recommendations for adaptive equipment and home modifications.

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The first issue that parents cope with is the diagnostic process. Most of the families in this study noticed atypical physical signs such as enlarged calf muscles, tip-toeing, the 'Gower manoeuvre', frequent falling, and fatigue when their sons began walking. Although parents did not want to believe that these symptoms indicated a serious condition, they were anxious to find an explanation. In some cases, the parents felt they had to convince the doctors to take them seriously and run diagnostic tests. Thus, the concerted efforts on part of medical practitioners, parents and educators to identify and immediately adapt to aids that will optimise the growth process of the child is of foremost priority.

Further, this study is committed to reorienting pedagogies that would make learning, at any age, for the patients with DMD both a mind engaging activity as well as enhancing their general well-being. Hence, the following recommendations must be underlined as possible course of action:

2. In aligning with the policy statement of RPWD, it must be a mandatory exercise for schools to identify, engage and offer the most inclusive means to educate the children with DMD. The trained teacher in the given ailment and the school-based physical therapist can play a crucial role in this regard. Constant monitoring and counselling of the parents and child will be the best scaffold.

3. An expert teacher can help in both the subject study as well as in imparting the knowledge of coping mechanisms to the child.

4. Inventing and inclusive lesson plans must be part of teaching activities. It is important to make a child with DMD feel independent and to listen to them. Best examples could be employing role plays, Do It Yourself modelling exercises, make-a-movie, word or number mapping. Learning through animated videos as well as outdoor leaning ambience will boost the interest levels.

5. Parents and educators need to focus on the physical access and safety around the school building.

6. Customised seating arrangements have to be availed of.

7. Teachers can make use of several aids such as computers or handouts to allow the student to keep pace with the rest of the class.

8. There is more adaptive equipment to improve mobility and quality of life. In this study also, parents reported that their sons successfully use canes, walkers, electric scooters and power wheelchairs to maintain their mobile independence.

9. The parents use modifications such as lifts, bars, shower chairs, modified vans, and ramps as aids to assist in caring for their children and teachers must ensure that such scaffolds are easily adapted to in the learning stratagem.

10. It should be mandatory to introduce the training on coping mechanisms as a part of B.Ed. curriculum in Indian Education especially on the 21 ailments identified as disabilities in the RPWD-2016.

VII. CONCLUSIONS

Through their life experiences and personal travails, parents in this study demonstrated their resilience and ability to develop effective coping strategies. After the diagnostic process, parents begin a new life with a son/child who has Duchenne muscular dystrophy. Although Duchenne muscular dystrophy progression varies from person

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to person, even those who are siblings or first cousins, as reported by the participants, were quick to adjust to and cope with increased weakness and dependency as the disease progressed. Parents indicated very clearly that they will do whatever is necessary to maintain normal lives for their children. Additionally, these parents are willing to readjust their attitudes to improve the quality of life for their sons with Duchenne muscular dystrophy and everyone else in the family. Education is the only empowerment that can enlighten and make the child with DMD feel emancipated enough to enjoy life is its totality. Towards gaining that power, educators need to shoulder maximum responsibility in training these young minds for an enabled future.

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