

## Counselling for Duchenne Muscular Dystrophy (DMD): Integrating Psychosocial Perspective

Ms. Kripa Arora<sup>1\*</sup>, Dr. Komal Uppal<sup>2</sup>, Dr. Somesh Kumar<sup>3</sup>,  
Dr. Sunil K Polipalli<sup>4</sup>, Dr. Seema Kapoor<sup>5</sup>

### ABSTRACT

Duchenne muscular dystrophy (DMD) is one of the most severe forms of muscular dystrophy and is associated with profound mobility and psychosocial disability. This article explores the psychosocial implications for individuals dealing with DMD, highlighting the significant influence that genetic counselors can have in managing different issues, fostering resilience to the emotional burden, enabling social positioning, and assisting families in ethical dilemmas. Further, the review notes the difficulties counselors experience in what can be an emotionally exhausting and ethically challenging role and the requirement for ongoing professional support. By presenting these viewpoints in collaboration, this paper emphasizes how genetic counseling may contribute to both psychiatric, social and quality of life outcomes, for individuals with DMD, and how such support may alleviate the profound psychological stress related to this disease.

*Keywords: DMD, Psychosocial, counseling*

Duchenne muscular dystrophy DMD is a severe genetic disorder characterized by progressive loss of muscle strength and functionality. While the physical symptoms of DMD including reduced muscle mobility and heart issues are prominent the drastic effect on the individual's psychological wellbeing is less publicized. The disease is associated with the new set of physical difficulties, with the need of performing medical treatments, and with the new emotional suffering of patients and their families.

DMD impacts on human behavior, whereby patients experience shock, denial, and anger about the disease. Some of the symptoms include grief and depression due to loss of physical functions and dependence among patients as the disease advances. The patients present with chronic pain that may be mild or severe accompanied by extreme fatigue and this may lead to hopelessness. Restricted mobility affects social interaction, and patients are

<sup>1</sup>Undergraduate Student

<sup>2</sup>Clinical Genetics Specialist

<sup>3</sup>Ph.d (Scientist)

<sup>4</sup>Ph.d (Cytogeneticist)

<sup>5</sup>Directory Professor, Department of Genetics

\*Corresponding Author

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left out of activities they used to engage in with friends and family leading to isolation and low self-esteem. These include anxiety, depression, change in mood and personality, cognitive decline, sleep disorders, and pain due to the progressive nature of the disease and concerns about the future.

In contrast to medical treatment that aims at regulating and curing the physical symptoms and prolonging the human life, the patients' emotional and psychological state is also crucial. The patient and families should be greatly availed of mental health support by the psychologists at each stage of this process. They express feelings of encouragement for the patient, model as well as explain methods used for coping with stressors and providing various psychotherapeutic treatment. Acknowledging the need for psychological treatment in addition to medical treatment can greatly improve the outlook of DMD patients and their families empowering them with the necessary resources to face the obstacles of the disease.

### **MEDICAL OVERVIEW OF DMD**

Duchenne Muscular Dystrophy (DMD) is an X-linked recessive disorder that occurs due to the mutations in the DMD gene; the affected population mostly being males. This genetic anomaly affects dystrophin which is a protein useful for the stabilization of muscle fibers. Therefore, if the reserve does not get used, the muscle tissue simply atrophies over a period of time in which it is replaced by fat and connective tissue.

DMD is characterized by muscle weakness that begins early, mostly in the early childhood between two to five years of age, and is manifested by gradual weakness in various forms of movement. The disease progresses and patients exhibit symptoms such as a waddling gait, calf pseudohypertrophy, as well as Gower's sign which involves using the hands to support the thighs when standing up from a sitting position.

Although there is no known cure for DMD, medical prognosis has been enhanced with enhancement of breathing and cardiac challenges in those affected along with being bound to a wheelchair. Hailed are the newest achievements and expectations for the enhancement of the patients' quality of life and life expectancy in spite of DMD diagnosis; crucial is the continuous strenuous care for DMD patients and their families due to multiple physical, social, and psychological issues.

### **PSYCHOSOCIAL PROBLEMS FACED BY PATIENTS**

Patients with Duchenne Muscular Dystrophy (DMD) face a multitude of psychosocial challenges that significantly impact their quality of life.

#### **Physical Limitations and Daily Life**

1. *Loss of Ambulation:* It is a progressive muscle disorder making patients wheelchair bound by early teenage years. The restriction of movement is a major psychological barrier because it alters the way they continue living their lives.
2. *Dependency:* As the disease likely unfolds, patients require the assistance of carers for basic everyday activities. It can also cause loss of control or even feeling helpless which are not desirable effects of the technology.

#### **Social and Educational Challenges**

1. *Educational Barriers:* Cognitive and physical disabilities that accompany DMD arrest learning and can compromise education. Many schools are poorly prepared to

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offer required adjustments that have implications on learning as well as peer interactions.

2. *Peer Relationships*: Social relationships are hindered by physical disability and resulting weakness and stigmatization making patients withdraw from society.

### **Emotional and Psychological Distress**

1. *Depression and Anxiety*: DMD is gradually progressive and often there are expectations of future disability and early death. The effects of understanding that a disease will progress in the future may bring about mental disorders including anxiety and depression, which should be treated and managed.
2. *Behavioral Issues*: In order to address their frustration and emotional suffering, patients can develop behavioral problems that may include aggressiveness, reclusive behavior, and refusal to adhere to medical instructions, altering their relationship dynamics and, therefore, introducing increased stress and conflict.
3. *Body Image Issues*: Physical changes and deformities coupled with muscle deterioration seen in DMD like scoliosis and contractures can significantly damage the body image and self-esteem. Such body image ideologies affect social interactions consequently, resulting in low self-esteem.

### **Impact on Independence and Future Planning**

1. *Loss of Future Opportunities*: Frustration occurs due to the understanding that the condition will only tend to deteriorate in the future, and this may lead to hope and hopelessness regarding the future. This can demotivate patients in terms of education or career paths hence leaving them with no direction or focus in life.
2. *Dependence on Others*: Therefore, there is burden formation due to the progressive dependence on caregivers. Such factors may include; self-perception as a burden to the family resulting from the fact that the patients may develop guilt of the inconvenience they cause to their families. This can have implications for their psychological health and relationship responsibilities, ultimately leading to dependency and unhappiness.

## **PSYCHOSOCIAL PROBLEMS FACED BY FAMILIES OF PATIENTS**

Duchenne Muscular Dystrophy (DMD) not only profoundly affects the patients but also imposes significant emotional, social, and financial burdens on their families.

### **Emotional Burden**

1. *Grief and Guilt*: Coping with DMD could be challenging for families of the patients, as they may experience stress, grief, guilt, and anger among others. The parents for instance may feel deep grief after learning of the fate of the child and the disease's advancement. They often experience feelings of guilt especially when thinking about passing on DMD to their children.
2. *Anxiety and Depression*: This level of stress not only increases the chances of developing anxiety and depression in the carers but also exposes them to other psychological complications (Peay and Hollin, 2013). Parents acting as primary caregivers stay anxious about their child's health, looking forward to their well-being and ongoing treatment challenges and coordinating medical, therapy and care schedules.

### Social Strain

1. *Caregiving Demands*: Due to the amount of care needed for DMD patients, families are left exhausted and sometimes experience burnout. Thus, the impact is felt by dependent relatives, who often have to scale down their work, or give up their occupations, to attend to the carer.
2. *Social Isolation*: The role of caregiving deprives families of their social support systems. Lack of time and energy to engage in related social interactions implies that caregivers become lonely because they cannot engage in friendship and other social activities.

### Impact on Family Dynamics

1. *Siblings*: Siblings of DMD patients may feel neglected due to the disproportionate attention given to the affected child. This can lead to feelings of guilt. Resentment and anxiety about their future (Firth et al. 2010). They may also struggle with their own emotional responses to the illness. Feeling overlooked within the family dynamic.
2. *Family Strain and Marital Stress*: Caring for a child with Duchenne Muscular Dystrophy (DMD) places significant emotional and practical burdens on the entire family. Parents often face marital strain. Due to constant stress, caregiving conflicts can weaken their emotional connection and destabilize the family.

### Economic Challenges

1. *Medical Costs*: The high cost of medical care including therapies, medications and adaptive equipment places significant financial strain on families. These costs can be overwhelming, particularly for families with limited financial resources.
2. *Loss of Income*: Parents often need to reduce their work hours or quit their jobs. This is to provide full-time care. This leads to a loss of income and financial instability. This loss can lead to a financial burden. It makes it difficult to afford necessary medical and psychological support (King et al. 2010).
3. *Access to Resources*: Families from economically disadvantaged backgrounds may struggle to access necessary medical and psychological support. This can hinder their ability to provide optimal care for their child.

### Coping with Uncertainty

1. *Future Uncertainty*: The progressive nature of DMD means families constantly face uncertainty about the future. This includes concerns about the patient's health. Financial stability and availability of new treatments are also worries (Firth et al. 2010).
2. *End-of-Life Planning*: Families must confront the difficult reality of planning for end-of-life care for their loved one which can be emotionally devastating. This planning involves various decisions about medical care. Legal arrangements are also needed. Emotional preparations are essential.

### ROLE OF COUNSELLOR

Duchenne Muscular Dystrophy (DMD) presents multifaceted challenges that extend beyond the physical symptoms of the disease. Patients and their families often face significant psychosocial issues. Counselors play a crucial role in addressing these challenges. They should provide comprehensive support. In the following ways:

### **1. Healthcare Information and Resource Coordination**

Essential aspect of the counselor's role is providing healthcare information and coordinating resources. Their job includes educating families about DMD including its progression and explaining treatment options along with information about potential complications. This information helps families make informed decisions and understand the disease better especially during OPD visits due to the lack of time with the medical professionals to provide in depth information.

### **2. Ethical and Decision-Making Guidance**

DMD often involves complex ethical decisions particularly concerning treatment options and end-of-life care. Counselors should help families navigate these decisions and discuss potential outcomes along with respecting the family's values and preferences. Counselors play a crucial role in discussing reproductive options and the implications of genetic testing, thus helping families make informed decisions about future pregnancies.

### **3. Addressing Mental Health Disorders**

The prevalence of mental health disorders such as anxiety and depression is high among DMD patients and their caregivers. Counselors have an essential role in identifying these disorders early, and provide appropriate interventions. They may offer individual therapy to address specific mental health concerns.

### **4. Emotional Support and Coping Strategies**

One of the primary roles of counselors is to offer emotional support to both patients and their families. The diagnosis of DMD can lead to an array of emotional responses such as shock denial, anger and grief. Counselors should help individuals navigate these emotions by providing a safe space for expressing fears and frustrations. For instance, cognitive-behavioral therapy (CBT) can help patients and their families reframe negative thoughts and develop healthier coping mechanisms along with assisting families in managing the chronic stress associated with caring for a child with a progressive disease.

### **5. Social Integration and Support Networks**

Physical limitations due to DMD often lead to social insecurity. Counselors play a pivotal role in mitigating this insecurity by facilitating social integration. They work to connect patients and families with support groups and community resources and provide non-directive counseling. This can provide a sense of belonging and offers mutual support thus helping reduce feelings of loneliness and enhancing social networks.

### **6. Professional Development and Self-Care for Counselors**

Counselors themselves face significant emotional demands in their roles. To provide the best care. It is crucial that they engage in continuous professional development which includes staying current with the latest research and attending relevant training.

## **CHALLENGES FACED BY GENETIC COUNSELLOR AND THEIR SOLUTIONS**

Genetic counselors dealing with Duchenne Muscular Dystrophy (DMD) have to handle a lot of challenges, like explaining complicated genetic stuff to patients and their families, making sure they understand, and being sensitive to different cultures and emotions.

### **1. Health Literacy Concerns**

One big challenge is helping patients and their families understand the medical terms and stuff that comes with DMD. Some families might not be good at reading and understanding

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medical stuff, so counselors need to explain it in a way that they can understand by using pictures and easy-to-understand words. It's also important for counselors to make sure the families actually get what they're saying by having them repeat it back and using terms they're comfortable with.

### **2. Cultural Sensitivity**

Counselors need to be aware of the different cultural backgrounds of their patients and families, and how these can affect their understanding of DMD and their decisions about treatment. Using interpreters or people who know about different cultures can help with this. It's important for counselors to listen carefully to what families have to say and show respect for their beliefs and traditions which will help build trust and make sure everyone is on the same page.

### **3. Emotional Burden**

Dealing with the emotions of patients and families can be tough for counselors. They might see people who are really sad or angry about their diagnosis and they need to find a balance between being empathetic and maintaining professional boundaries. It's important for them to take care of their own emotions too, so they don't get burnt out or lose their ability to help others.

### **4. Resource Limitations**

Resource constraints are another big deal when it comes to working with families affected by DMD. Not all families have equal access to medical care, support services, and money for stuff they need. Counselors need to navigate these limitations, trying best to connect families with available resources.

To help manage these resource limitations, a comprehensive list of local, state, and national resources that offer financial assistance, healthcare services, and support groups can be created. Teaming up with social workers and case managers can help build a stronger support network for families.

### **5. Ethical Considerations**

Ethical dilemmas are all over the place in genetic counseling for DMD. Counselors are constantly having to make tough decisions about stuff like confidentiality, informed consent, and how to share potentially upsetting information with families. The most appropriate way for this is to talk about ethics with peers and supervisors regularly.

When it comes to reproductive counseling, there can be some tricky conversations about the risks of passing on genetic conditions. They have to be sensitive and respectful of people's personal values and beliefs while having these talks. Having a clear plan for how and when to share information can help manage expectations and reduce anxiety.

## **CONCLUSION**

In conclusion boys and adolescents with Duchenne Muscular Dystrophy (DMD) face significant physical challenges which often lead to overlooked consequences in their learning, behavior and other psychosocial issues. Ensuring that boys with DMD receive equal opportunities for normal physical and social -emotional development is crucial. Effective psychosocial adjustment involves increased awareness of various issues faced by DMD patients and adequate support to accept and deal with those issues. Proper education

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and care given by family members, friends and professionals can help these patients adapt to the psychosocial issues.

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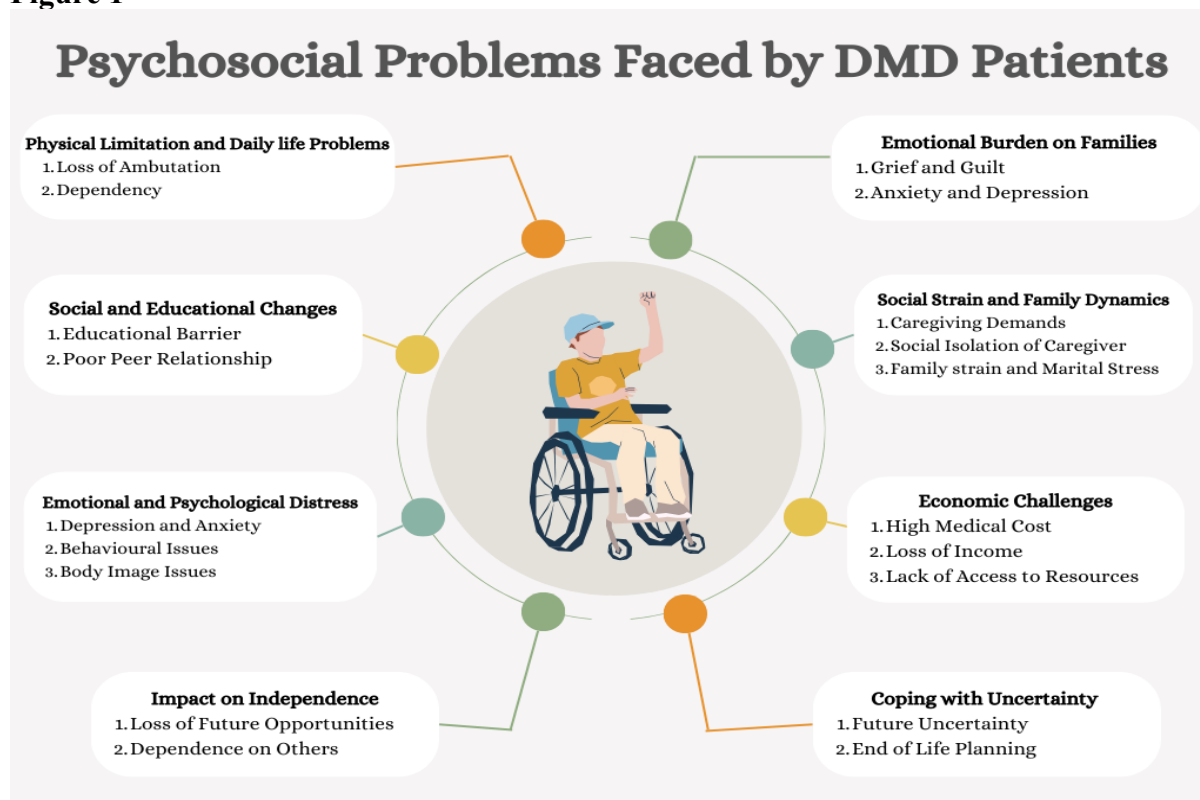
### Conflict of Interest

The author(s) declared no conflict of interest.

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### APPENDIX

Figure 1



## Counselling for Duchenne Muscular Dystrophy (DMD): Integrating Psychosocial Perspective

**Figure 2**

