

# From Diagnosis to Treatment of Muscular Dystrophy: Psychology Meets Medicine

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## Abstract

This paper will briefly discuss the condition of muscular dystrophy disease in Malaysia and will explore the potential of psychological approach in managing the muscular dystrophy patients in Malaysia. Muscular dystrophy is a hereditary and progressive degenerative disorder affecting skeletal muscles, and also often other organ systems. This term includes many conditions associated to the muscle wasting and weakness where all are still genetic but having different types due to different genes and differ in severity. It is estimated there are around 43 newborns are affected by muscular dystrophy each year in Malaysia. The real burden of muscular dystrophy in Malaysia is difficult to estimate, since the epidemiological data for each of muscular dystrophies and even for muscular dystrophies in collective are not available. There are not many researches focusing on muscular dystrophy in Malaysia. The few available researches related to muscular dystrophy in Malaysia are mostly revolving around the medical and genetic science aspects of it, not in the psychology and social sides of the disease.

**Keywords:** muscular dystrophy, psychological approach, health psychology, patient psychological care

## 1. Introduction

The muscular dystrophies are a group of inherited diseases in which various genes controlling muscle function are defective (Emery, 2008). This disease is not infectious or contagious in any way. There is also no evidence that everyday life activity can cause the disease or bring it on. All muscular dystrophies are genetic and are due to defects in the gene.

No matter what the particular type of dystrophy, the essential feature of this disease is muscle wasting and muscle weakness. The distribution of muscle weakness is different in different types of dystrophy. For certain types, muscle weakness can remain localised, as example, to the muscles of the eyes and face. For another types, the major muscle groups responsible for moving the limbs become mainly involved and may affect other muscles later on. The degree of severity also varies from one type to another type. The usual symptoms of muscular dystrophy besides the muscles weakness are decrease in dexterity (quickness, readiness and grace in physical activities), stiffness of grip, tongue and pharynx involvement may produce speech disturbances, increase in clumsiness and cardiac complications. With the development of diagnostics, it has become evident that muscular dystrophy is a heterogeneous entity composed of a large variety of neuromuscular disorders (Boström & Ahlström, 2005).

Medilexicon's medical dictionary (2012) defines muscular dystrophy as a general term for a number of hereditary, progressive degenerative disorders affecting skeletal muscles, and often other organ systems. This term includes many conditions associated to the muscle wasting and weakness where all are still genetic but having different types due to different genes and differ in severity (Emery, 2008).

Muscular dystrophy is not one type of disease. There are currently over 30 different types of muscular dystrophy have been recognized where some of these are very rare or only occur in certain parts of the world. Generally, there are 8 main types of muscular dystrophy; Duchenne muscular dystrophy, Becker muscular dystrophy, Emery-Dreifuss muscular dystrophy, limb girdle muscular dystrophy, facioscapulohumeral muscular dystrophy, distal muscular dystrophy, oculopharyngeal muscular dystrophy and congenital muscular dystrophy. The different muscular dystrophies are varied in who they affect and the symptoms of the specific type of muscular

dystrophy (Naff, 2011).

Some of muscular dystrophies can appear at birth or during childhood, while others can only be detected later in life. In all types of muscular dystrophy, the disease will become worse as the patient's muscles grow weaker. Most patients with muscular dystrophy will eventually lose the ability to walk, either in a very early age or later in their life. Some patients with muscular dystrophy have mild cases which worsen slowly, while other cases are more severe and disabling.

Currently, there is no cure for muscular dystrophy and the treatments for muscular dystrophy normally include physical therapy, speech therapy, orthopaedic devices, surgery and medications. Due to many limitations faced by the muscular dystrophy patients, this disease can cause medical and social problems among the patients. In addition, because it is a hereditary disorder, it may recur again in some families.

## **2. Overview of Muscular Dystrophy**

### *2.1 Rare Diseases*

The individual types of muscular dystrophy are examples of the rare diseases listed by National Human Genome Research Institute. Rare diseases are diseases that affect less than 2000 individuals in the European Union and at most one in 1250 in the USA population (Schieppati, Henter, Daina, & Aperia, 2008). According to WHO, more than 5000 disorders fit this definition. This is actually a big number. From the definition, the number of patients affected by a rare disease could be around 30 million in Europe and 25 million in North America.

There is no official definition for rare diseases in Malaysia. Nonetheless, the unofficial working definition for rare diseases in Malaysia is that the rare diseases are diseases which affect less than one in 4000 people in the population (Thong, 2011). There are about 3% of babies will have some serious birth defect worldwide. In Malaysia, there are around 600,000 births every year. Therefore, there would be about 18,000 babies will be born with birth defects every year. The patients of rare diseases are few because their diseases are so uncommon.

### *2.2 Muscular Dystrophy Statistics in Malaysia*

There is no specific statistic based on an exact data for muscular dystrophy in many countries including Malaysia because of the rarity of the individual types of muscular dystrophy and the lack of attention to it. However, from an extrapolation by the Right Diagnosis, it is estimated there are around 43 newborns are affected by muscular dystrophy each year in Malaysia.

Taking the lack of concrete statistics of rare diseases and muscular dystrophy in Malaysia into the perspective, the real burden of muscular dystrophy in Malaysia is difficult to estimate, since the epidemiological data for each of muscular dystrophies and even for muscular dystrophies in collective are not available.

### *2.3 Muscular Dystrophy Awareness in Malaysia*

Mostly, the general public is not familiar with muscular dystrophy disease. It is not just the public who are unfamiliar with this disease, there is time when even the doctors do not know enough to diagnose the patients. Sometimes, further confirmation tests and examinations are required because many of the conditions of the muscular dystrophies look alike to each other. It is very important to have an accurate diagnosis as it will affect any genetic counseling afterwards, especially for the quality of life and future reproductive choices.

The awareness of muscular dystrophy among the public is generally very low. There are many misunderstandings and sometime taboos among the Malaysians. For example, some people might think this disease is caused by the black magic, curse or bad karma. Some family members might blame the parents for doing something wrong during the pregnancy. Sometimes, the family ends up being ashamed of the child.

### *2.4 Dealing and Living with Muscular Dystrophy: Psychosocial, Behavioral & Emotional Issues*

The psychological and emotional effects of muscular dystrophy on the patients and their families are often concealed, suppressed and ignored. From Emery (2008), based on several studies, many Muscular Dystrophy patients actually have to face with the feelings of isolation, inadequacy and worthlessness. As a result, these inferior feelings may cause them to become depressed. The challenge in living with Muscular Dystrophy starts right from the moment of the disease diagnosis. Just like other life's major events, not everyone reacts to the Muscular Dystrophy disease in the same way; the response varies among the individual. Different people react differently to the diagnosis and different people cope differently with this disease. Many patients and their immediate families feel sad, shocked and angry upon hearing the diagnosis. Besides the emotional responses to the physical handicap and pain, there are also social induced emotional problems among the Muscular Dystrophy patients. Muscular dystrophy patients frequently have poor self esteem. They fear about the progressive nature of the illness and its prognosis.

While dealing with the underage patients, it is better not to discuss the whole picture and full implications of the disease with them. It is better to let the questions and curiosity arise naturally. It is suggested for the parents to answer any question according to the age and level of understanding. At the same time, parents should avoid from being too overprotective over their affected child as this will lead to frustration and stress for the child and the family in the long term. As for the adults, a thorough information and explanation can be provided right from the beginning. However, in order to avoid stress during the explanation process, the patient's questions and response should be taken into consideration. Normally, many Muscular Dystrophy patients give impression of being well adapted and already come to terms with their illness. This is probably true in some cases, but it is not right to assume that all Muscular Dystrophy patients are unaffected emotionally and psychologically.

It is very seldom to see the impact of Muscular Dystrophy disease to be limited to only the Muscular Dystrophy patients. Most of the time, psychological and social consequences of Muscular Dystrophy always involve other family members in various degrees. People who are suffering with the Muscular Dystrophy disease normally have unique disabilities which may cause social stigma and eventually may become an embarrassment to the parents or family. Certain parents of Muscular Dystrophy patients also often blame themselves for passing down the disease to their children (Abramovitz, 2008). Parents or caretakers who are taking care of the Muscular Dystrophy patients might end up neglecting other family members. As they centralise their focus on the patients under their care, they also might end up feeling isolated and overworked. As a result, relationships within the family might get affected negatively. Siegel (1999) strongly suggested that the parents or the primary caretaker must not neglect his or her own well-being while attending to the patient's need. If they are going to continue to help their loved ones at their very best, the caregivers have to care for themselves, too. It also must not be assumed that the unaffected siblings to the muscular dystrophy patients are emotionally unhurt. They sometimes face their own emotional issues in response to the disease.

The whole process of living with muscular dystrophy can be tedious for the patient and the parents, from trying to find out what is wrong with the child to accepting the child's condition and their situation, and then trying to find the best help and treatment for the child. Getting a confirmation test done also is a long and difficult process as many tests can only be performed overseas. Most parents want the answers to a lot of things such as they want to know why this has happened to them and what the most current information on this disease is. Some of them go online and find the information is confusing, they don't know either the information they read is a fact or an opinion. Some patients will try the traditional treatments which usually don't work. Some others will try to get into the clinical trials for new drugs which are very difficult to get into as the clinical trials are mostly based abroad. Moreover, Malaysia also lacks adequate support services such as physiotherapy, occupational therapy, early intervention programs, special schools and psychotherapy. In addition, there are not many researches focusing on muscular dystrophy in Malaysia. The few available researches related to muscular dystrophy in Malaysia are mostly revolving around the medical and genetic science aspects of it, not in the psychology and social side of it.

### **3. Muscular Dystrophy and Psychology**

While there is a growing interest in muscular dystrophy research in the west, it is still attracting a very low number of researchers in Malaysia. Even among the limited available researches of muscular dystrophy disorder, most of the researches are focusing on the medical aspect of the disease (Michie & Marteau, 1996). Counseling or other psychological help also usually is not part of the normal medical treatment and assistant for the muscular dystrophy patients and the parents of the muscular dystrophy patients.

At the early stage of disease acknowledgement, it is normally hard for the patients to accept the reality that they are having an incurable illness. The patients can fall into depression and this depression can keep recurring throughout their lives due to the difficulty in coping with the disease. Sometimes, it is possible for the patient to develop an aggression. Sleep problem also is not a foreign issue to muscular dystrophy patients as psychological stress building up. Nevertheless, the role of psychologists is normally left unnoticed where most of the patients are not referred to the experts in the field of psychology and counseling.

Moreover, it is not just the patients who have to face the psychological turmoil as the result of having this disease. Muscular dystrophy is a rare and unique disorder. Therefore, parents of the muscular dystrophy patients sometimes are left feeling lonely in facing all the challenges that come with this disease. Most of the time, their life will be centered by their children and they are rarely having breaks for themselves. For the severe muscular dystrophy cases, the parents have to deal with the loss of their children and have to cope with the grief. In certain cases as well, the parents have to deal with the feeling of guilt, shame and blame. Hence here, parents of the muscular dystrophy patients also need a psychological intervention just like their children.

### 3.1 Psychosocial Adjustment in Muscular Dystrophy Patients

Psychosocial adjustment is a general term referring to emotional, behavioural and social functioning, and is believed to be the central aspect of quality of life. Using boys with Duchenne Muscular Dystrophy as example, psychosocial adjustment occurs within the context of the normal development in addition to the declines of physical functions (Poysky, 2007). Regrettably, the studies examining psychosocial, emotional and behavioural functioning of muscular dystrophy patients have been moderately few.

It has been long known though that some boys with Duchenne Muscular Dystrophy are at increased risk for experiencing depression (Fitzpatrick, Barry, & Garvey, 1986). In general, the boys will have better adjustment as they are growing older, but there is still one exception to this. As they are growing older, their peer relations are becoming difficult, most probably due to the reduced access to social and recreational opportunities as a result of the decreases of physical functioning and health (Hendriksen et al., 2009). The parents need to equip themselves with psychological skill and knowledge so that they can teach their children how to build self esteem as well as how to deal with stressful and emotional issues. For this, a strategy called Emotion Coaching is recommended (Gottman & Declaire, 1997). This strategy involves:

- i. aware of the child's emotion
- ii. recognize emotions as opportunity for intimacy and teaching
- iii. listen empathically and validate the child's emotions
- iv. help the child to verbally label emotions
- v. setting limit while helping the child to solve the problem

In a research involving Duchenne Muscular Dystrophy and Becker Muscular Dystrophy patients (Darke et al., 2006), the affected boys surprisingly have a high level of social and communication problems when compared to the general population and also when compared to the children with other neuromuscular disorders. Based on this research, 18% of boys with Duchenne Muscular Dystrophy and 50% of boys with Becker Muscular Dystrophy have poor social interactions, while 30% of boys with Duchenne Muscular Dystrophy and 43% of boys with Becker Muscular Dystrophy have troubles with communication. This can be said that social interactions and communication are the area of weakness for the boys with Duchenne Muscular Dystrophy and Becker Muscular Dystrophy. Hinton et al. (2006) also reported that many boys with Duchenne Muscular Dystrophy have significant social problems such as being immature and have poor peer relationships if compared to their unaffected siblings and if compared to the children with cerebral palsy. Young et al. (2008) found a high frequency of clinically relevant behavioural and attention problems in boys with Becker Muscular Dystrophy where 67% of the children have clinically significant behavioural problems if compared to the reported Australian frequency which is 14.1%.

### 3.2 Muscular Dystrophy Psychosocial Management

For certain type of muscular dystrophy such as Duchenne Muscular Dystrophy, the mean age at death without intervention is around 19 years, with the leading causes of death being respiratory insufficiency, followed by cardiac complication such as dilated cardiomyopathy (Tay & Lin, 2012).

Management of an illness, especially a unique disease such as muscular dystrophy disease, is not complete if only depending on the medical care without any support for the psychosocial wellbeing. The parents to the sick persons frequently discover the stress due to the psychosocial problems surpass the stress caused by physical struggles of muscular dystrophy.

The National University Hospital of Singapore has a quarterly multidisciplinary neuromuscular clinic since 1995, and in 2010, they Children's Medical Institute at the same National University Hospital adopted interdisciplinary management and care recommendation of Duchenne Muscular Dystrophy from Bushby et al. (2010) and incorporated them into a clinical protocol used for the quarterly multidisciplinary neuromuscular clinic which also includes psychosocial management for the patient's care as part of the holistic approach in the management of Duchenne Muscular Dystrophy. In addition to pain management, emotional support is provided such as addressing issue related to coping, grief, loss and death.

#### 3.2.1 Coping Process

Just like any stressful event, the coping process for the muscular dystrophy patients and their families occurs in five stages; shock and denial, anxiety, anger and guilt, depression and psychological homeostasis (Emery, 2008). Some patients could stay in one of the stages forever. There are cases where they never progress through all the stages. In some cases, there are patients who manage to arrive at a later stage but still end up going back to the

first stage. It is not a shocking thing if a patient never progress beyond the first stage.

During every stage of the coping process, patients and their families are strongly encouraged by the psychologists to talk through their feelings and thoughts. Besides having an open discussion with the family members, help from the mental health professionals such as psychologists or psychiatrists is also needed.

Despite having constructive support, the patients and their families will still face continuous hardships and difficulties (Abramovitz, 2008). They might keep going through stressful decisions making. For example, it is not unusual for Muscular Dystrophy patients to suffer heart, lung or spine problems, and sometimes surgery may be required as part of the treatment. Deciding either to give permission for the surgery or not can be a difficult task for the parents as surgeries normally come with different kinds of risk.

### 3.2.2 Coping Support

As founded in a cancer rehabilitation study by Berglund et al. (1994), giving coping support to the patients in order to help them to adjust to their disease is an important element in the rehabilitation process. There are numbers of additional problems affecting the muscular dystrophy patients such as isolation, loneliness, difficulty in obtaining care, and the lack of knowledge, understanding and empathy on the part of the relatives and the medical staffs (Natterlund, Gunnarsson, & Ahlström, 2000). One of the ways to offer support and to reduce the feeling of uncertainty for the patients with progressive disease is to provide adequate information and education (Carlsson & Strang, 1998). Behavioural treatment, stress management, education and physical training have been identified as important components for effective rehabilitation and intervention for the musculoskeletal disorders (Karjalainen et al., 2004).

Coping is linked very close to the stress issue and was first explained as defence mechanisms in term of a psychoanalytical theory (Haan, 1993). From 1970s, coping has evolved from being viewed as a characteristic style of personality to being viewed as a dynamic process which involves continuous interaction between the individual and the environment (Lazarus, 1993). A study by Ahlström and Wenneberg (2002) regarded coping as the individual's own behavioural and cognitive efforts to handle specific stressful situations. Depending on situational demands and accessible coping resources, coping strategies could vary over time. According to Lazarus (1993), there are two types of coping; problem-focused and emotion-focused. Problem-focused coping is about handling the source of the stress which is to deal directly with situation. Emotion-focused coping is about handling emotions linked to the stressful situations, for example, how to relieve the feeling of the stress without truly need to change the situation itself.

## 4. Psychological Intervention in Muscular Dystrophy

It is important to have proactive interventions in order to avoid emotional issues, social problems and social isolations, which could give bad impacts on the process of a medical care. Bushby et al. (2010) strongly recommended doing a brief emotional status screening on muscular dystrophy patients at every clinic or at least on annual basis. Emotional screening and intervention do not necessarily require comprehensive adjustment and the process could be informal in nature. The screening can be done by social worker, mental health professional or other clinical staff with sufficient training, for instance the attending physicians and the nurses.

According to Bushby et al. (2010), interventions will vary depending on individual. Intervention may include matters on:

#### i. Care and support

It would be crucial to design and assign a knowledgeable care coordinator as a central point of contact for families. The coordinator can help with the information needs, schedule and coordinate appointments, and facilitate communication with the medical staff such as clinicians and therapists. A coordinator should be professional with a sufficient level of training and possesses enough knowledge on muscular dystrophy. Care and support interventions also include transition planning such as encouraging self-advocacy in medical care, facilitating transfer to a new medical care team, and developing education (or vocational) opportunities.

#### ii. Psychotherapy

Psychotherapy intervention techniques can contribute in the areas of parental management (especially for externalising behaviours such as the disruptive behaviour or parent-child conflict) and individual management (for example, low self-esteem, depression, anxiety, obsessive-compulsive behaviour, adjustment and coping difficulties).

#### iii. Social interaction

Social interaction intervention is important for a balance emotional support. Social interaction interventions can

contribute to a better emotional health. Social interaction intervention could include proactive approach in increasing muscular dystrophy awareness and knowledge among school personnel, peer education about muscular dystrophy, and promoting patient independence and self-advocacy.

#### iv. Educational

Education intervention is necessary to promote patient independence and involvement in decision making. It is a good move to have neuropsychological assessment at diagnosis and before entering school. After that, it can be followed by individualised educational programme on entering school. In addition, it is important to make measures to address deficits as they are identified.

### 5. Conclusion

There are some encouraging results in improving quality of life of other chronic disease patients from psychological interventions (Fekete, Antoni, & Schneiderman, 2007). There are also many empirically supported methods to address the change in cognitive and behaviour among other chronic disease population such as behavioural therapy, mindfulness-based cognitive therapy and acceptance-commitment therapy. However, as far as muscular dystrophy is concerned and as far as the author of this study knows, there was only one psychological intervention trial involving the muscle disease patients (Voet et al., 2010).

The lack of psychological interventions probably happens due to poor understanding that psychological factors can relate to quality of life and mood in muscle disease. Therefore, the researchers have limited knowledge on which psychological processes should be targeted by an intervention (Graham et al., 2014).

Clearly Muscular Dystrophy poses psychological challenges both to the patient and parents. There are many aspects that need to be tackled when it comes to the psychological management of muscular dystrophy patients. Due to the lack of a comprehensive psychological program and module for the muscular dystrophy patients in Malaysia, there is a potential for research in finding a proper psychological approach in managing the muscular dystrophy patients in Malaysia.

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