

# Treatment and impact of multiple sclerosis



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Multiple sclerosis is defined as a pharmacological disorder associated with inflammation of the myelin sheaths around axons of brain and spinal cord. The disorder is also called as disseminated sclerosis or encephalomyelitis disseminata and leads to demyelination and scarring 1. Multiple sclerosis is associated with neurological symptoms of fatigue, muscle weakness, paraesthesia, ataxia, dysphagia, diplopia, severe pain, visual impairment, cognitive impairment, Lhermitte, s sign and Uhthoff's phenomenon (Compston and Coles, 2008). In multiple sclerosis, symptoms appear in form of acute episodic attacks termed as relapses and most of these exacerbations are unpredictable (Lublin and Reingold, 1996).

#### Multiple sclerosis and its Impact on self and family

Multiple sclerosis has multiple effects on the individual and surrounding people. The effects range from mild to severe disruptions and last for a life time. Various symptoms of multiple sclerosis like fatigue and difficulty in walking leads to many difficulties interfering with daily activities like unemployment, lack of confidence and disturbance of life style (Halper and Holland, 2002). Many symptoms like visual impairment, dysphagia and diplopia lead to dependence on others for daily activities and increases ambulatory care in family. Memory impairment results in difficulty of reading, writing and basic learning skills and increased forgetfulness which results in hindering daily activities. The presence of these symptoms cause distress, tension, confusion and pain for the individual suffering and family of the individual.

In the course of treatment relating to multiple sclerosis, the doctor, psychologist and health care provider play a pivotal role in reducing stress and difficulty of the patient. Nurse acts as an important mediator in the entire flow and serves as one point of contact for informative and health care related issues (Halper and Holland, 2002).

STRESS: Many studies by Warren, Warren Green hill, Warren (1982), Franklin et al., (1989), Fischer et al., (1994) have cited stress as one of the symptoms in patients suffering from multiple sclerosis by conducting specific scientific tests. Many patients have reported of occupational stress (La Rocca, 1984) and studies have revealed that stress depends on the nature and duration of patients suffering from stress. Stress management seeks essential care and investigators advice to work with stress for reducing rather than completely avoiding stress (La Rocca, 1984). Family members and health care advisors have to take an extra step to reduce the emotional stress in patients suffering from MS as this factor leads to more worsening symptoms.

Case study: Mary, a MS patient was bossy and picky before she developed the disorder and after experiencing emotional stress, behaviour of Mary turned aggressive and rude. These behaviour lead family members of Mary to avoid her and this made Mary to feel lonely and deserted (Amato et al., 1995).

The Psychosocial issues associated with stress relating to some of the real time examples are as follows (Halper and Holland, 2002):

Uncertainty and Unpredictability: This is one of the major psychosocial issues associated with MS- stress and patient cannot predict the severity of the

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disorder and advancement of symptoms. Uncertainty of disease progress leaves the patient confused in taking decisions in family, work and other economical issues (Archibald and Fisk, 2000). In these situations, advice from psychotherapists could be helpful in improving the situation of the patient.

**Denial and Adaptation:** This kind of behaviour is observed when the disease is diagnosed initially. Denial is common behavioural tendency observed in patients due to shock and disbelief caused by the diagnosis of disease progression. While some patients learn to adapt to the changing conditions, some of the patients tend to remain struck with shock. Denial makes patient condition difficult to accept changes in lifestyle and worsens symptoms of emotional and occupational stress (Beatty et al., 1995). In some cases, patients become demotivated, leading to advancement of disease.

Adaptation to the new changes and acceptance of the disease is a means to increase chance of surviving disease. Support of the family and health care provider plays important role in determining these behavioural tendencies.

**Grief and Clinical depression:** Denial behaviour towards the disease leads to grief and depression in patients. There are recorded examples of some people who have stepped down into depression due to denial. These patients have been active throughout their life before outbreak of the disease. In these people where activeness is a predominant factor, lifestyle modifications become difficult (Kalb, 1998). Family members have tough time with these kinds of patients leading to grief over the patient's situation. Patients grief leads to reactions like asking why me only, anger and distress, denial, fear, crying, longing for improvement of health, recollecting past etc.

Grieving is temporary and dependent on time and mood however constant grieving leads to more persistent and permanent disorders like clinical and mental depression. Depression is dangerous and is characterised by lack of appetite, lack of sleep, suicidal and death tendencies, feeling of guilt and worthlessness and inability to focus orientation towards betterment of life (Kalb and Miller, 2000).

Psychotherapy can improve the situation in depression patients (Halper and Holland, 2002). Medications like SSRI anti-depressants and tricyclic antidepressants are used extensively in treating depression.

Mood swings: Mood swings occur regularly in patients suffering from Multiple sclerosis. Patients could either change moods rapidly, or continue to be in the same mood for a long time or depict moods unreflective to the context (Halper and Holland, 2002). These emotions can further be described by:

Emotional Instability: Certain patients suffering from multiple sclerosis suffer from emotional instability which is characterised by hypersensitivity, irritability, anger and mood fragility. Mood gets easily changed over a short period of time and person becomes gloomy and irritable suddenly. This condition is experienced along with the family members in response to patient behaviour. The main cause attributed to this change is distortion of limbic system (Kalb and Miller, 2000).

Increased sensitization: In these conditions, patient suffering from MS reacts extensively to a particular mood for a long period of time. Small issues could provoke extreme reactions in these patients leading to irritability and stress (Kalb and Miller, 2000).

Release of emotions or pseudobulbar effect: Patients suffering from MS, sometimes release emotions of happiness or dullness without self intention (Halper and Holland, 2002). The patients express emotions unknowingly or without intention. In certain cases, emotions could be expressed in opposite situations leading to mental distress for self and family members. Use of drug amitryptiline was found effective in treatment of this (Schiffer et al., 1985).

## **PSYCOSOCIAL ISSUES PERTAINING TO FAMILY**

When a person is diagnosed with multiple sclerosis, suffering begins with the patient and spreads along the family. According to Gonzales, family members have to accept the challenge of incorporating multiple sclerosis in their entire life and learn living along with the disease (Halper and Holland, 2002). There are many challenges faced by the family and some of these issues include (Kalb and Miller, 2000):

Conflicting coping styles: Family members behave and think different from each other and coping with different attitudes may sometimes lead to misunderstandings.

Change in roles: When a person of a family suffers from MS, his role is shared or replaced by other family members. This could result in guilt and emotional stress of the patient.

Sharing grief: Person suffering from MS faces many neurological symptoms over a period of time and the family has to cope with the changing disabilities.

Changes in communication pattern within a family: Communication pattern may change in a family with the advent of the disease and this may cause trouble for the family members.

Parenting Issues: Unlike the previous times, patients with MS, are advised to bear children, but the challenging issue is in relation to managing parenting after children are born.

Case studies:

Susan is a MS patient who likes family members to talk and discuss about her disorder to learn coping with the disorder however Jim, her husband feels it unnecessary. This attitude of family member caused Susan to go through emotional stress and irritability. Consulting a Psychotherapist and extended support of family could be a better approach in this regard (Halper and Holland, 2002).

Richard was a responsible husband and father of two kids before he suffered from MS. After the advent of the disorder, due to his inability to take care of the family, his wife had to bear the responsibility with great difficulty. This role change in his family created guilt and shame causing periodic grieves leading to severe depressive attacks. Spending time with Richard by friends and family members could improve the situation (Halper and Holland, 2002).

CONCLUSION:

Multiple sclerosis is a disease involving high stress levels in patient and family. There are many psychosocial disorders associated with the patient

and family. The health care provider and family members have to extend their support in reducing the pain and grief of the patient.