





The Psychosocial Impact of Multiple Sclerosis

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“Illness is not simply a personal experience: it is transactional, communicative, profoundly social. The study of illness meanings is not only about one particular individual’s experience, it is also very much about social networks, social situations and different forms of social reality.”

Arthur Kleinman, *The Illness Narratives*



“Illness meanings are an integral dimension of lives lived together; deeply embedded in the social world and consequently inseparable from the structures and processes that constitute that world.

An inquiry into the meanings of illness is a journey into relationships.”

Kleinman

Will I ever get another promotion?

Will she stay with me?


What kind of Dad can I be?

I don't want to be a burden to anyone!


What kind of life is this?

That's it! There are just some things I'll never get to do.





“When a severe chronic illness comes crashing into someone’s life, it cannot help but separate the person of the present from the person of the past and affect or even shatter any images of self held for the future.”



“Who I was in the past and hope to be in the future are rendered discontinuous with who I am in the present.

New conceptions of who and what I am – past, present and future – must arise out of what remains.”

Corbin and Strauss



Psychosocial Risk Assessment

- Pre Diagnosis
- Diagnosis
- Exacerbation
- Progression



The Psychosocial Impact of MS: Themes

- Uncertainty
- Loss of Control
- Challenge to Self Image
- Grief/Depression



Uncertainty

- Psychosocial consequence even before confirmed diagnosis
- A partner throughout life with MS
- Risk of:
 - Immobilization



Loss of Control

- Living with an illness that may never be cured
- Exacerbation and progression of the illness
- Risk of:
 - Learned Helplessness,
 - Vulnerability to Quackery
 - Making life decisions prematurely



Challenge to Self Image

- Beliefs, values, personal capabilities, social roles and body image all contribute to self image
- The worth attached to self in each of these domains significantly impacts the definition of self
- Risk of:
 - Sense of worthlessness
 - Definition of self as a burden, not deserving etc.



Grief/Depression

- Life with MS is a life of real and/or anticipated loss
- An understandable psychological reaction to life with an unpredictable, disabling illness



Depression in the MS Patient

- Lifetime prevalence of 25% - 50%
- Prevalence higher than in other chronic conditions
 - Higher in women
 - Higher in 18 – 45 age range



Depression

- Causes of Depression in MS Patients:
 - Psychosocial challenges
 - Maladaptive coping
 - Brain lesions resulting from the MS disease process
 - Immune Dysregulation associated with MS exacerbation
 - An Iatrogenic Effect of Disease Modifying Treatments

Feinstein, 2001



Risk Assessment in the MS Patient - Depression

- Family History of Mood Disorder
- History of Suicide
- Addiction
- Anxiety Disorders



Risk Assessment in the MS Patient - Depression

- Psychotic Disturbance
- Maladaptive Coping in other grief experiences
- Current situational stressors
- Current losses or fear of anticipated losses



The Depressed MS Patient

- Meets the DSM-IV criteria for depression
 - Depressed mood, disinterest in all/most activities
 - Weight loss, decrease or increase in appetite
 - Insomnia or hypersomnia
 - Psychomotor agitation or retardation
 - Fatigue
 - Feelings of worthlessness / excessive or inappropriate guilt
 - Diminished ability to think/concentrate
 - Recurrent thoughts of death



The Depressed MS Patient

- Describes:
 - Social withdrawal
 - Increased irritability
 - Increased frustration
 - Sadness
 - Fear



Assessment of Suicide Risk

- Family history of mental illness and/or suicide
- Previous suicide attempt(s)
- Live alone
- Report significant social stress
- Major depression
- Anxiety disorder
- Substance abuse
- Expressed intent and plan



Depression: Treatments

- Need to consider the biological, psychological and social components of depression
 - Medication
 - Counselling
 - Cognitive Behavioural Therapy
 - Brief Solution Oriented Therapy
 - May involve the individual/the couple/the family

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Psychosocial Adaptation

The process through which persons perceive, assess, cope with, and gradually assimilate various changes in body, self, and person-environment interactions.



Psychosocial Adaptation

- People who achieve a degree of psychosocial adaptation while living with MS:
 - Feel that their neurological symptoms and the emotions that they experience are validated by those around them (partner, family, society and their health care team)
 - Can identify/employ both the internal and external resources available to them when meeting new challenges



Psychosocial Adaptation

- People who achieve a degree of psychosocial adaptation while living with MS:
 - Have learned a process through which they access current accurate information about their chronic illness
 - Access medical and psychological supports as required




Psychosocial Adaptation

- People who achieve a degree of psychosocial adaptation while living with MS:
 - Define their lives and themselves as different than before MS but define this difference as “still good”.



In Conclusion

- The Psychosocial Implications of MS are significant and encompass all areas of life
- As health care professionals we hold a key role in assisting people and families living with MS to negotiate the psychosocial challenges posed by this illness



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