The Psychosocial Impact of Multiple Sclerosis

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The Illness Narratives

“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.”
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 she stay with me?
Will I ever get another promotion?
What kind of Dad can I be?
What kind of life is this?
I don’t want to be a burden to anyone!
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.”

Corbin and Strauss

“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
The Journey of Clinician and Patient

- Psychosocial Risk Assessment
- Psychosocial Tasks towards adaptation

With thanks to Mary and Deb for sharing their journey.

Psychosocial Risk Assessment

- Pre Diagnosis
- Diagnosis
- Exacerbation
- Progression
Pre Diagnosis

Mary

- Overwhelming, stressful, frustrating assessment period
- Potential conflict with medical professionals
- Sense of powerlessness
Pre Diagnosis

- Issues of uncertainty
- Reliance on maladaptive coping mechanisms
- Potential risk to family stability
- Employer’s reaction

Psychosocial Tasks to Facilitate Adjustment at Pre Diagnosis

- Access current accurate information
- Access validation of symptoms
- Access validation of their concerns and feelings
Psychosocial Tasks: Pre Diagnosis

- Begin to develop strategies for dealing with uncertainty
- Access the support of family and friends
- Access support within the workplace

- Quickly access supportive medical services within which a trusting reciprocal relationship can begin to develop
Crisis and grief reactions

Issues of uncertainty

Compromised self image

Emotional reaction of significant others

Diagnosis
Issues of control

Who to tell?

Varying information needs

Access current accurate information

Access validation of the emotional impact of this diagnosis

Develop strategies for dealing with the emotional impact of the diagnosis and the uncertainties
Psychosocial Tasks: Diagnosis

- Maintain Hope
- Access support of family and friends
- Connect with others in similar situations
- Establish a supportive trusting relationship with the health care provider

Exacerbation
Deb
Exacerbation

- Demand for reorganization within family, workplace and societal roles
- Compromised self image
- Emotional chaos

Psychosocial Tasks to Facilitate Adjustment at Exacerbation

- Access medical support to manage symptoms
- Access concrete services within the community as required
- Access validation of the emotional impact of the exacerbation
Psychosocial Tasks: Exacerbation

- Access assistance in adjusting to change – to learn strategies for coping and for realigning roles and relationships
- Maintain hope
- Access support from family and friends

Psychosocial Tasks: Exacerbation

- Access support in the workplace
Progression

Mary

Progression

- Ongoing loss and chronic sorrow
- Compromised self esteem, dignity and sense of self
- Uncertainty
Ongoing demand for change and accommodation within family and societal roles
Themes

- Uncertainty
- Loss of Control
- Grief/Depression
- Redefinition of Self

Psychosocial Adaptation

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

In Conclusion

- Through our understanding of the psychosocial risks associated with life with MS throughout the continuum of the illness, we can assist patients and their families to develop skills and strategies that will help them to mitigate the psychosocial impact of Multiple Sclerosis.


Thank you!