

# Psychosocial Considerations in Multiple Sclerosis

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**IOMSN**

International Organization  
of Multiple Sclerosis Nurses  
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# Emotional Impact of MS: Overview

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- **Psychosocial Impact of MS:** uncertainty, anxiety, loss of spontaneity, depression, grief
- Psychosocial Adaptation
- Family Dynamics
- Hope and Optimism
- Empowerment
- Self-efficacy

# Psychosocial Risk Assessment

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- **Before the Diagnosis** – symptoms cause anxiety, insecurity, and uncertainty
- **The Diagnostic Period** - fear of the unknown, new experiences, invasive testing
- **Relapse** – loss of certainty, security, and control over one's body, new medications, new side effects
- **Disease Modification** – will the treatment work, how can I manage the costs, what about side effects
- **Progression** – there it is. Exactly what I was afraid of.

# The Psychosocial Impact of MS: Themes

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- **Uncertainty**
- **Anxiety**
- **Loss of spontaneity**
- **Depression**
- **Grief**

# Uncertainty

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Psychosocial consequence even before the confirmed diagnosis

- A lifelong uninvited guest; a chronic illness at a young age
- Risk of:
  - Progression
  - Immobility
  - Unexpected relapses
  - Invisible symptoms
  - Stigma

# Loss of Control

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- Living with an illness that may never be cured
- Exacerbations and/or progression of the illness
- Risk of:
  - Learned helplessness
  - Vulnerability to unproven treatment
  - Making life decisions prematurely
  - Free floating anxiety

# Challenge to Self Image

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- 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

# Grief/Depression

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- 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 Multiple Sclerosis

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- **High rates of depression**
  - Prevalence rates of major depressive disorder: 36% - 54%<sup>1,2,3</sup>
- **Depression may lead to altered quality of life and loss of self-esteem<sup>4</sup>**
- **Increased incidence of suicide**
  - 7.5 times higher in MS than general population<sup>5</sup>
- **Assessment of depression in critical cases**

1. Minden et al. NMSS, 2014.

<http://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Clinical-Bulletin-Emotional-Disorders-5-5-14.pdf>.

2. Sadovnick AD, et al. *Neurology*. 1996;46(3):628-632.

3. Feinstein A. *Can J Psychiatry*. 2004;49(3):157-163.

4. Bashir K, Whitaker JN. *Handbook of Multiple Sclerosis*. 2002.

5. Sadovnick AD, et al. *Neurology*. 1991;41(8):1193-1196.

# Depression

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- **Possible causes of Depression in MS Patients:**
  - Psychosocial challenges
  - Maladaptive coping
  - Brain lesions resulting from the MS disease process
  - Immune Dysregulation associated with MS exacerbations
  - An iatrogenic effect of disease modifying treatments?

Feinstein et al. *J Affect Disord.* 2001 Oct;66(2-3):193-8.

# Depression

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- **Depression can:**
  - Decrease Quality of Life
  - Increase risk of suicide
  - Increase severity of some MS symptoms ( fatigue, cognitive impairment)
  - Decrease adherence to medication routines
  - And may aggravate pathogenic inflammatory process?

Mohr et al. *Multiple Sclerosis*. 2007;13:215-219.

# Risk Assessment in the MS Patient

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- **Depression:**
  - Family History of Mood Disorder
  - History of Suicide
  - Addiction
  - Anxiety Disorders

# The Depressed MS Patient

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- **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

# Assessment of Suicide Risk

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- 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

# Comprehensive Management

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- Provide a supportive, therapeutic environment
- Identify risk factors (screening, self-report, environmental factors, family history)
- Use psychotherapy plus antidepressants
- Be alert for suicidal ideation/plan
- Assess and reassess continually
- Adjust medications appropriately

Fragoso YD et al. *Pract Neurol*. 2014 Feb 5.

Minden SL et al. *Neurology*. 2014. Jan 14;82(2):174-81.

Bashir K, et al. *Handbook of Multiple Sclerosis*. 2002.

# Depression: Treatments

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

Fragoso YD et al. *Pract Neurol*. 2014 Feb 5.

Minden SL et al. *Neurology*. 2014. Jan 14;82(2):174-81.



# Emotional Impact of Multiple Sclerosis

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- The significance ... of the progressive nature of the disease process includes the need for ongoing treatment to deal with changes over time.
- The implication of an ... inexorable course must have enormous impact on the ability to deal with the consequences of the disease.

# The Element of Chronicity

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- Implies the need for adaptation over time so that management becomes the goal, rather than the cure
- Aims are to maintain functional ability in accordance with life goals in the presence of progressive disease
- Requires maintenance of emotional stability and positive interpersonal relationships

# Psychosocial Adaptation

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- **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

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- **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
  - Define their lives and themselves as different than before MS but define this difference as “still good”

# Psychosocial Issues

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- **These issues have far-reaching impact**
  - Impact of grief/uncertainty
  - The need to have hope/maintain control
  - Ability to adjust lifestyle/career
- **Goals:**
  - Improve mood/bolster self-esteem
  - Preserve lifestyle
  - Promote self-care/self-sufficiency
  - Facilitate relationships

# How Do Family Members Feel About MS?

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- **Grief**
  - Natural response to change and loss
  - Individual grief
  - Shared grief
- **Anxiety and resentment resulting from**
  - Unpredictability
  - Loss of control
- **Guilt related to**
  - Not being able to fulfill roles and responsibilities
  - NOT being disabled
  - Uncomfortable feelings

# Things That Interfere With Family Communication

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- **Protectiveness**
- **Conflicting coping styles**
- **Embarrassment**

# Preserving the Family Identity

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- When faced with MS and change, explore the family history (ways of coping, normal rhythms, family patterns)
- Be aware that MS causes family disruption
- Seek ways to preserve the family identity while adapting to incorporate the disruption of multiple sclerosis



# Impact on Marital Partnership

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- Assess status of sexuality and intimacy
- Evaluate role changes
- Explore family planning and child rearing
- Talk about the family's hopes and dreams

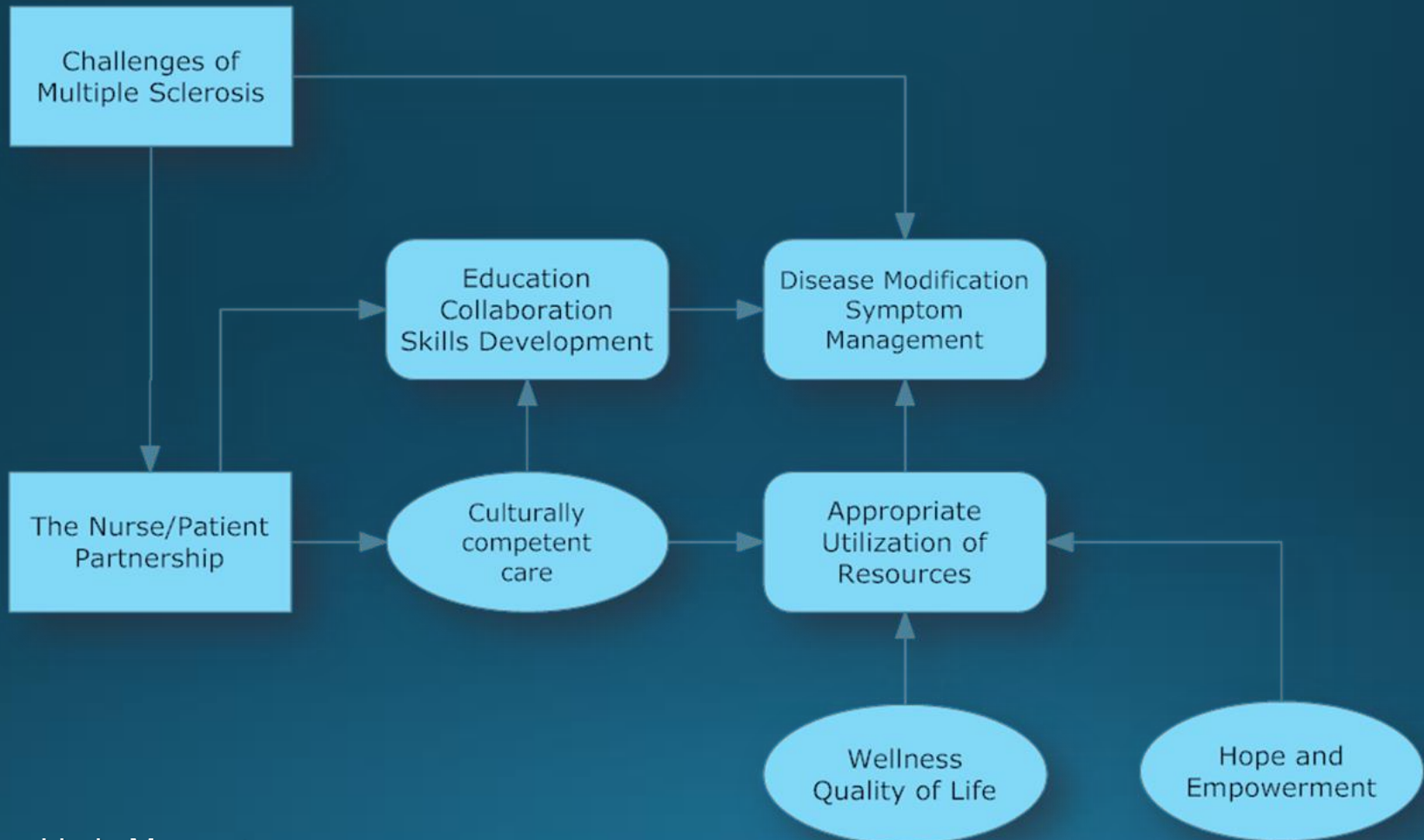
# Hope Defined

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*Hope is an essential element of life—it embodies our vision of the future, our opinion of ourselves and others, and our sense of control over the events and direction of our lives. The presence of hope for someone experiencing an illness can provide the energy necessary to promote health and enhance well-being.*

Linda Morgante

# Conceptual Framework of Hope



Linda Morgante

# Promoting Optimism & Hope

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- Active reflection and self awareness
- Affirmation of worth
- A creative partnership
- Total patient care
- Realistic goals
- Emphasis on outcomes
- Accentuate the positive
- Acknowledge grief and loss
- Find and define “MS-free zones in life”
- Support spirituality

# Defining Empowerment

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- Empowerment and hope are related concepts
- Empowerment enables recognition and mobilization of strengths and resources
- Empowerment involves knowledge, skills development, coping, mastery over the environment, and flexibility
- Empowerment=self-direction=hope

# Empowerment in MS

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- Establish realistic and meaningful goals
- Seek experiences with other disabled people
- Try to feel a sense of personal affirmation
- Maximize physical and psychological functioning

# Empowerment in MS

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- Be motivated
- Find meaning in life experiences
- Communicate with others
- Listen well and hear others' messages
- Have a belief in yourself
- Develop effective coping strategies
- Find humor in your life

# Empowerment by MS Nurses

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- Facilitate goal setting
- Provide experiences with peers
- Provide affirmation
- Maximize wellness
- Encourage motivation and persistence
- Affirmation of personal value and strength



# Summary: Nursing Implications

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- Consider the psychosocial implications of MS are significant and encompass all areas of life
  - Uncertainty
  - Anxiety
  - Loss of spontaneity
  - Depression
  - Grief
- **Provide care:** 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
- Emphasize **HOPE** and **EMPOWERMENT**
- Educate and Communicate

# QUESTION AND ANSWER SESSION

# Thank you for your participation!

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