

Using a Palliative Care Approach in Caring for Patients with Advanced Multiple Sclerosis (MS)

An IOMSN continuing education program for nurses



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Target Audience

The target audience is nurses (including advanced practice nurses) who care for patients with MS in their practices. This encompasses nurses in long-term care settings where patients with advanced MS may be encountered, and nurses in specialized palliative care areas.

Need Assessment & Gap Analysis

The estimated world-wide prevalence is 2.3 million (NMSS.com), with advanced MS seen in two of the four major classifications of MS disease course: primary progressive MS and secondary progressive MS. These have been recently collapsed into the “progressive disease” phenotype (Lublin et al, 2014). The special needs of people with progressive disease (leading to advanced MS) have been inconsistently addressed. When faced with persons with progressive disease, clinicians can often struggle to find the best approach to care as well as the right interventions to alleviate their suffering. Interventions for those with progressive disease usually occur around specific symptoms and the person’s ability to manage their disability in the context of their life is often overlooked or addressed too late. Through learning about and integrating the palliative care model within the MS approach to care clinicians can gain the needed tools to move forward to address the symptoms that can frequently occur with advanced disease while also enhancing the quality of life for those living with MS and their families.



Learning Objectives

1. Describe the model of palliative care and identify indicators for applying the palliative care model in nursing practice when caring for patients who have advanced multiple sclerosis.
2. Describe frequent and distressing symptoms as well as possible interventions in those with advanced MS.
3. Identify how resources, culture and spiritual practices may influence palliative care.

Palliative Care Overview

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Part I

What is Palliative Care?

Palliative care is primarily a philosophy, with emphasis on comfort and compassion. *Center to Advance Palliative Care*

Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice. *Medical National Quality Forum, Centers for Medicare & Medicaid Services*

Concepts may be initiated at the time of diagnosis of a serious, potentially life-threatening disease. *National Hospice and Palliative Care Organization*



The Focus of Palliative Care

- Is on symptom alleviation and psychosocial/spiritual care. Although more prominent in advanced disease, it can be a component of care “...regardless of the stage of the disease or need for other therapies”. *American Academy of Hospice and Palliative Medicine*
- Heightens with advanced disease and increasing debilitation.

Goals of Palliative Care

- Prevent and ease suffering, e.g. by relieving distressing symptoms such as pain and breathing difficulties.
- Support maximal patient and family quality of life, in accordance with their values, preferences and beliefs.
- Facilitate communication, decision making and advance planning.
- Support potential for personal growth.

National Institute of Nursing Research

Public Health: Advancement of Palliative Care

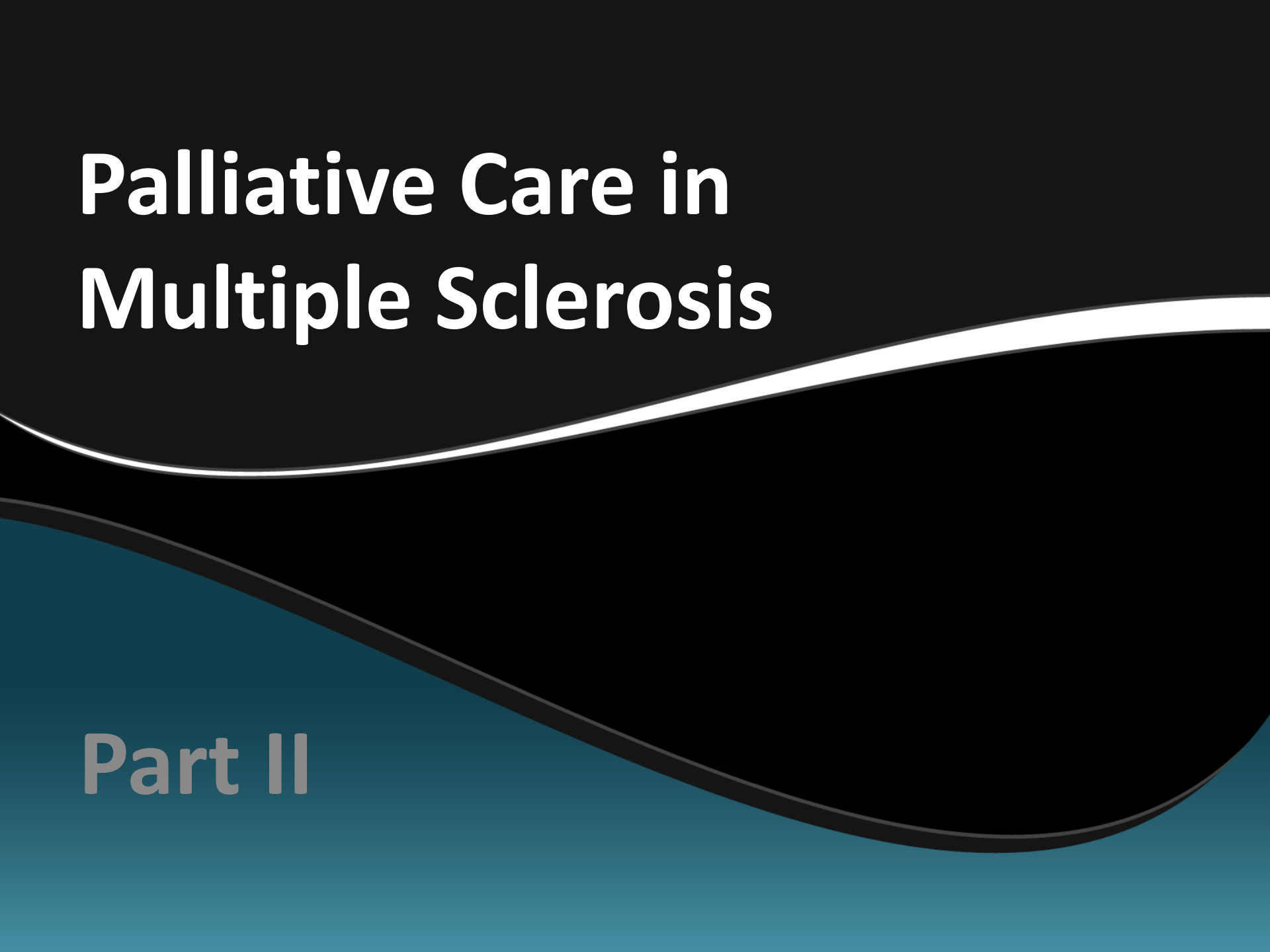
Summary of palliative care philosophy in the US:

It is *less about doing more* life-sustaining treatments and *more about doing less* harm and ensuring that our patients enjoy the quality of life they desire when time becomes limited.

Hospice

- **“... just one end of the palliative care continuum”**
American Academy of Hospice and Palliative Medicine
- Incorporates palliative care concepts
- Usually provided at the end of life; terminal care
- For patients with a prognosis of six months or less
National Consensus Project for Quality Palliative Care
- Can take place in many settings including the home, a long-term care site, a dedicated hospice and palliative unit/facility
- Includes family bereavement counseling

Palliative Care in Multiple Sclerosis

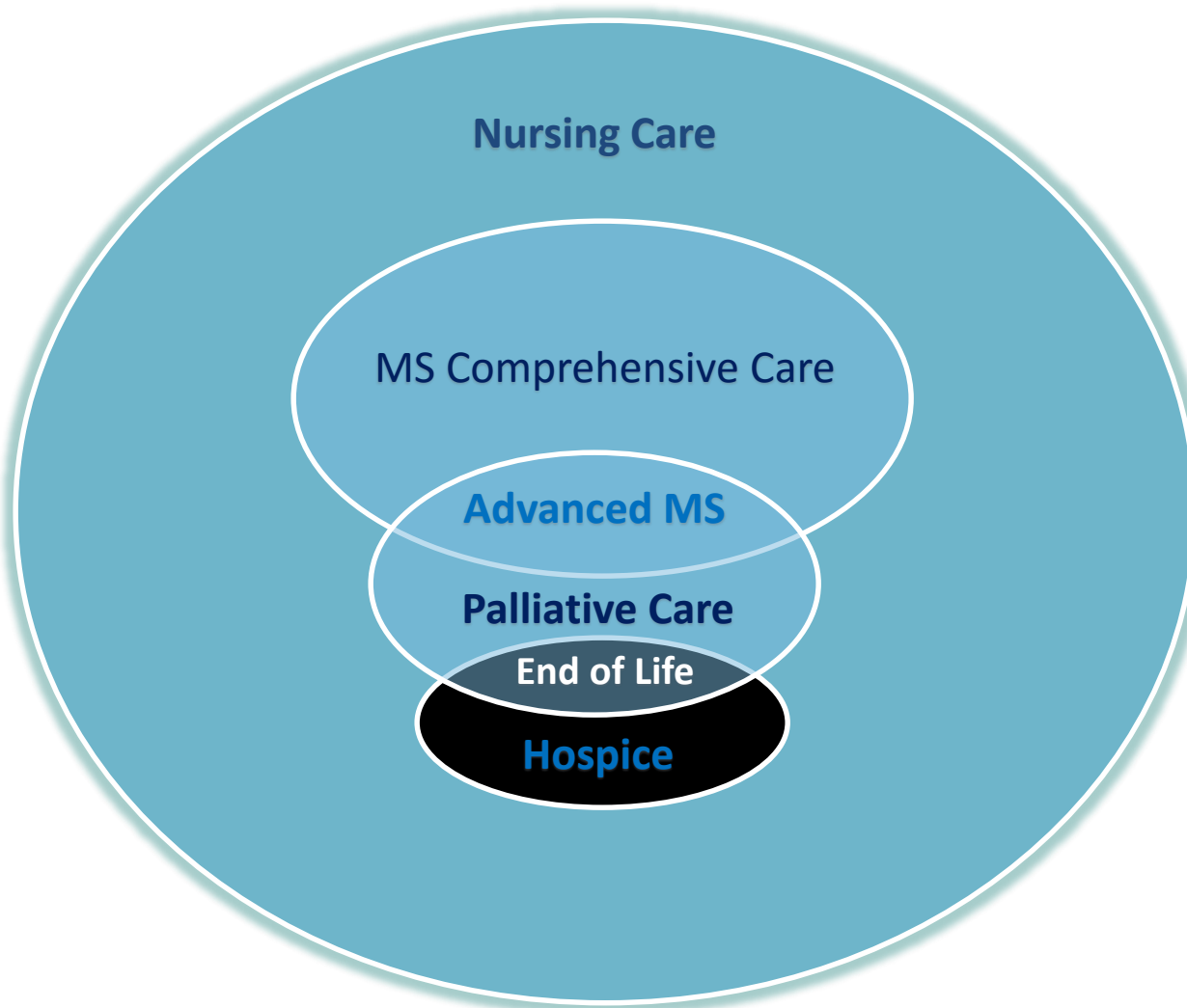


Part II

Palliative Care in Multiple Sclerosis

- Component of traditional, comprehensive, multi-disciplinary MS care
- Can be carried out in any patient care setting including clinic, home, hospital, hospice and long-term care facility
- Indicated for those experiencing **advanced MS**:
 - No clinical definition of advanced MS, but commonly refers to persons that have difficulty functioning in day to day life and require assistance with most activities of daily living (ADL)
 - Associated with an accumulation of disability with generalized debilitation
 - A complex range of symptoms, many of which can cause life threatening complications
- Indicated for those experiencing unrelieved psychological or spiritual distress
 - Concepts may be introduced early in the disease process if suffering is present

Palliative Care



Using a Patient and Family Approach to Assess and Plan

- As in any chronic disease, progression impacts the core family of the person with MS
- The burden of this disease on the family and the person with MS is real – not just a fear
- Early and ongoing discussion, as well as concrete planning to bolster support systems for the individual and family (as defined by the person with MS) are important
 - Core family members need assistance to identify what they can realistically provide, whether it is financial, physical, emotional or spiritual that is consistent with their own strengths and needs
 - Identifying both unique strengths and needs as a family unit may avoid unrealistic expectations and the creation of plans that can be unsustainable
- Most individuals with MS will suffer impaired cognition in advanced stages of the disease, particularly in the areas of executive function (critical thinking, organizing, planning, making decisions), making it important to have this type of conversation early and often throughout the disease process

Traditional medical care, focuses on a patient's disease or illness by asking the question "What's the matter?".

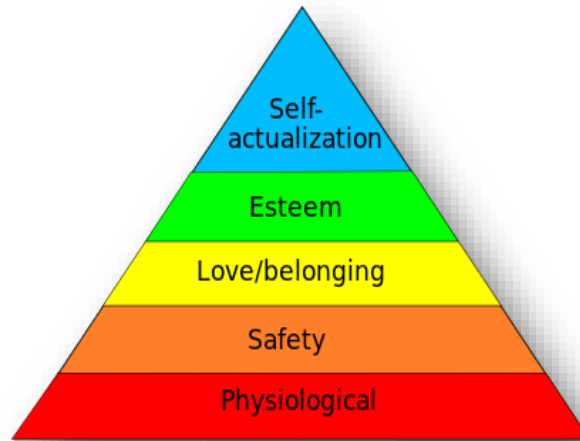
**Instead providers should focus on the person and family's needs which leads with the much more intimate question:
"What Matters To You?".**

Institute for Health Care Improvement



Techniques for Introducing the Concept of Palliative Care

As the burden of the disease increases, the multiple needs of the individual can be overwhelming. It is difficult, if not impossible, to address them all at once. Maslow's Hierarchy of Needs can be a useful tool to organize and prioritize a plan.



As nurses, we tend to focus on the most obvious needs such as pain, bowel and bladder support, spasticity management, fatigue. Maslow places these needs at the foundation of the pyramid – absolutely necessary to address but only as the basis of what allows an individual to gain self actualization, which is an important aspect of palliative care. How can we assist them to decrease anxiety and increase their sense of security? What can we do to decrease isolation and increase both a sense of belonging and purpose?

Techniques for Introducing the Concept of Palliative Care (... continued)

While Maslow's hierarchy is one way to organize and prioritize a palliative plan of care, how the individual views the impact of their needs on quality of life is also a way to prioritize and design an approach to their care.

Some possible questions to ask include:

- "What does a good day look like to you?"
- "Can you tell me what is most important to you now?"
- "How do you feel about what's been happening to you?"
- "Can I ask you about what you would like to see happen?"
- "What is the worst thing about all of this is for you?"

Caregivers:

Asking these questions can also be an effective way to have a conversation with the primary family caregivers in the family who are impacted by the advancing disease process of their loved one. It also provides a way to introduce some self care strategies. for them as well.

Remember: this is not a one time conversation. MS may progress over decades and the family constellation, strengths and needs change over time as well.

Adams, Campbell 2013



MS Symptoms Suggesting Need for Palliative Care Focus

- Dysphagia is present and the person is having difficulty mobilizing liquids or solids
- Respiratory weakness/dyspnea
- Inability to perform ADLs (activities of daily living) due to severely impaired upper and/or lower extremity function
- Repeated infections requiring hospitalization such as urosepsis, aspiration pneumonia, infected decubiti (pressure ulcers)
- Decubitus ulcers
- Bowel incontinence
- Serious cognitive deficiency which impairs self-management decisions

While additional symptoms such as chronic pain and urinary incontinence, may also suggest the need for palliative care and are important to address, they will not be covered in this program.

Quality of Life and the BIG FOUR

The palliative care discussion should occur throughout the course of the disease to prepare for the time when 24 hour care may be needed and to develop a back up plan for family caregivers as the burden and stress increases.

Of the previous symptoms these four areas are most often associated with a need for 24 hour care due to increased burden and stress on family caregivers:

1. **Impaired ability to communicate** – negatively impacts relationships
2. **Impaired ability to swallow** – increase fear of choking, diminished pleasure in the dining experience
3. **Cognitive decline** – negatively impacts relationships and safety
4. **Incontinence or inability to move bowels unassisted** – difficult to manage, socially stigmatizing

A Case Study: MARIA

Maria was first seen in clinic, accompanied by her mother, when she was 33 years old. She had been diagnosed since 1993 and came to see us after her prior neurologist relocated to Fargo, ND. Divorced with three children, Maria had twin boys who were 15, and a 12 year old daughter. Her mother lived nearby and visited daily.

For the past several years she used a wheelchair. She also had spasticity and upper extremity tremors. Her mom was the primary caregiver, and clearly experiencing extreme stress. Maria required assistance with all ADLs (activities of daily living) and IADLs (instrumental ADLs).

Due to her cognitive impairment, it could be difficult to extract what was going on. However, the RN knew her well and was able to perform a review of systems and clinical exam which revealed the following:

- Upper extremity weakness and tremors interfered with eating and overall self-care. Maria's mom and children helped, but Maria was eating erratically and spending most of the day isolated in her wheelchair



A Case Study: MARIA (... continued)

- Choking was experienced when she drank water, took her medication and ate anything thin in texture, like lettuce
- Urinary incontinence was poorly managed with a Foley catheter and padding for leakage, and frequent urinary tract infections often required hospitalization
- Redness was observed in the coccygeal area
- Cognitive impairment was clearly present. Depression was long standing, with a suicide attempt several years earlier

When the nurse asked Maria what mattered to her, she responded quickly. “*My children. I want to be with them as much as I can.*”

When the nurse asked Maria’s mom what care she felt she could successfully provide to Maria with, she replied “*She is my daughter, I want to help her but now I do everything for Maria. It has become too hard for me. My own health is suffering.*” Maria’s mother felt that if she had someone assist her during the day, she would be able to stay with Maria at night.

Interventions for Common Symptoms and Complications in Advanced MS: Dysphagia

Common Presentations: Choking/gagging while drinking or eating, the sensation of food getting stuck in the throat or chest, drooling, pain while swallowing, weight loss

Risks: Malnutrition and aspiration pneumonia

Impact on Quality of Life: Less pleasure in dining with others, less access to comfort foods, discomfort and embarrassment from constant drooling

Interventions:

- Swallowing evaluation
- Swallowing exercises or positioning techniques to help compensate
- Thickened fluids and/or pureed foods
- Botox injections to the lower portion of the esophagus
- May require cessation of oral intake and feeding through a percutaneous endoscopic gastrostomy (PEG) if symptoms persist



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Dysphagia: Considerations for a Percutaneous Endoscopic Gastrostomy (PEG)/Enteral Feeding Tube

Inability to swallow thin liquids is usually the initial swallowing impairment.

- The **Frazier Free Water Protocol** allows people with dysphagia free access to water with almost no incidence of aspiration pneumonia, due to water's neutral pH
Mosheim, 2006
- Thickened liquids are options for maintaining hydration without an enteral tube. They are more palatable if served very cold and introduced as textures that are familiar such as a milk shake for thickened milk, or a slushy for thickened juices
- Reduced intake of fluids exacerbates fatigue which decreases swallow reflex and ability to concentrate on the safe eating techniques that allow the individual to eat solid foods safely



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Dysphagia: Considerations for a Percutaneous Endoscopic Gastrostomy (PEG)/Enteral Feeding Tube

PEG tubes for maintaining hydration can be an effective palliative measure.

- Can be less burdensome for caregivers
- Many times an individual with dysphagia can continue to safely eat solids if well hydrated through the PEG tube
- Most medications can be given through a PEG tube
- Enteral formulas can be added as needed to support nutrition

A decision to place an PEG tube should always be accompanied by a discussion and documentation of the wishes of the individual as to the circumstances in which they would want all artificial nutrition stopped.

A Case Study: MARIA (... continued)

Maria reluctantly agreed to see a speech therapist who recommended a pureed diet and adding thickeners to her beverages. This would address the swallowing and choking difficulties, and reduce her risk of aspiration pneumonia. Maria's mother liked to cook and a nutritionist worked with both of them to come up with flavorful foods that could be served to the children but also pureed for Maria.

Interventions for Common Symptoms and Complications in Advanced MS:

Respiratory Weakness/Dyspnea

Common Presentations: Shortness of breath, difficulty breathing deeply, ineffective cough, frequent sighing, hiccups, difficulty carrying a conversation or speak loudly enough to be heard, sleep apnea

Risks: Respiratory failure, respiratory infections

Impact on Quality of Life: Less pleasure and tolerance for activities

Interventions:

- Assess for medications that may depress breathing
- Prophylaxis with influenza and pneumonia vaccines
- Pulmonary function tests
- Pulmonary rehabilitation to strengthen ventilator muscles and enhance respiration
- The cough assist machine: applies a positive pressure to the airway followed by a rapid shift to negative pressure to simulate a cough to void secretions
- Ventilator support (invasive or non-invasive):

Considerations for Mechanical Ventilation

- Rarely needed in advanced MS as a chronic support but may be required during acute episodes of pneumonia or sepsis. Weaning from ventilation during a hospital stay may be prolonged due to the fatigue factor that is exacerbated in persons with MS when stressed by illness. Most are successfully weaned.
- Medication and supplemental oxygen can address both the fear of being short of breath and dyspnea itself.
- Ensure that the person and/or surrogate understand the benefits and risks of ventilation and that the hospital care team confers with the MS team.
- A competent person has the right to decide if they want to be ventilated but in an acute episode they may not be able to communicate their needs or wishes.
- When a person becomes unable to communicate their needs, the decision rests with the surrogate. If the person has not expressed wishes in this area, the surrogate must try to decide what the person would have wanted.

Dunn, 2009

Interventions for Common Symptoms and Complications in Advanced MS:

Significant Mobility Impairment

Common Presentations: Frequent falls, spasticity, ataxia, sensory and/or movement disorders, usually occurs in combination with weakness predominant. Difficulty transferring in and out of bed or from a seated position

Risks: Social isolation, falls, fractures, pressure ulcers, contractures

Impact on Quality of Life: Increased dependence on others, difficulty participating in favorite activities

Interventions for Common Symptoms and Complications in Advanced MS:

Significant Mobility Impairment (continued...)

Interventions:

- Assistive devices such as a cane or a walker can allow the person to stay mobile and prevent accidents such as falls
- Refer to a wheelchair seating clinic or rehabilitation team for an equipment evaluation. Customized motorized wheelchairs can allow people with significant mobility limitations to be independent in their chairs
- Devices such as “Hoyer lift” can assist in transferring patient from bed to chair or commode
- Manage mild to moderate spasticity with exercises and medication (primarily baclofen, tizanadine). Severe spasticity may respond to muscle injections (e.g. botulinum) or intrathecal baclofen, which have less sedating properties than increasing doses of oral medications. Surgical intervention such as tendon release may be necessary in extreme cases
- Personal assistance/home care aide should be discussed to assist with ADLs and IADLs

A Case Study: MARIA (... continued)

- The MS team was able to get Maria assistance at home. The home health aide assisted Maria with her daily care activities by providing support with her ADLs/IADLs
- Assistive devices such as a commode and a shower-chair made it possible for allowed her to continue to shower, which she loved, and eased in care delivery
- A referral to a local wheelchair and seating clinic, where a motorized wheelchair and cushion were selected to fit Maria's individual physical needs, resulted in her being independent once she was in her chair. The seating system, which included lateral trunk supports, reduced her pain and her risk of a decubitus ulcer
- Gentle lower extremity stretching and slowly titrated oral baclofen and tizanidine relieved her leg spasticity

Interventions for Common Symptoms and Complications in Advanced MS:

Decubitus Ulcers

Common Presentations: Change in skin color or opening of the skin usually over a bony prominence. Usually occurs in persons who are unable to change positions or transfer independently; increased risk with incontinence, decreased sensation, and malnutrition. Frequently seen during a current or recent hospitalization

Risks: Tissue death, anemia, infection/osteomyelitis, sepsis, fistula and gangrene

Impact on Quality of Life: Pain and discomfort, increased burden on caregivers, wounds can often become chronic non healing ulcers, reduces time out of bed depending upon area impacted

Interventions for Common Symptoms and Complications in Advanced MS:

Decubitus Ulcers (continued...)

Interventions:

- Assess skin frequently for redness. May appear darker for those with darker pigmentation
- Keep skin clean and dry
- Apply a protectant skin barrier if incontinent
- Well balanced diet- nutritional evaluation if needed
- Physical therapy for evaluation on transferring and support services
- Redistribute pressure by regularly changing positions and ensuring that there are preventative support surfaces in place (wheelchair cushion and mattress)
- Wound care evaluation if needed

Interventions for Common Symptoms and Complications in Advanced MS: Urosepsis

Common Presentations: Fever, confusion, generalized weakness, fatigue, tachycardia, dehydration, hypotension and increase in spasticity. May also have symptoms of a UTI: pain with urination, difficulty urinating, frequent urination, increased incontinence, odor to urine, pain in the side or back

Risks: Kidney failure, septic shock

Impact on Quality of Life: Recurrent admissions, pain and discomfort, decrease participation in activities

Interventions for Common Symptoms and Complications in Advanced MS: Urosepsis

(continued...)

Interventions:

- Urologic evaluation to determine cause of frequent UTIs
- Increase fluids and decrease bladder irritants such as caffeine
- Early identification and intervention with antibiotics for cystitis, or nephritis when appropriate and desired by patient or surrogate
- Catheterization - suprapubic cystostomy may be needed
- Reduction of urinary leakage around catheter with anticholinergic type medication
- Uroscopic removal of bladder and renal calculi

Considerations When Treating Sepsis in Those With Advanced Multiple Sclerosis

- Sepsis can occur rapidly without much warning in persons with MS, making it hard to treat outside the hospital setting
- Early warning signs such as increased fatigue and decreased mental acuity are present BUT often in the absence of specific complaints or symptoms to treat
- Initiating antibiotics prior to confirming presence of infection and specific organism and sensitivity is counter to standard medical practice however, waiting to initiate antibiotics and IV fluids generally results in acute onset of sepsis
- For most individuals in advanced stages of MS, sepsis is treatable and they regain their baseline functional status within a few weeks. If their baseline QOL is satisfactory to them, then aggressive treatment makes sense even as part of palliative care
- May be challenging for hospital based palliative care teams to agree to aggressively treat when they see someone in advanced stages of MS in an ICU. It is imperative that the person's wishes are communicated to the inpatient team and that there is effective and frequent communication by both the nurse in the ICU and the nurse in the community setting during these hospitalizations



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A Case Study: MARIA (... continued)

Maria's urinary incontinence was controlled by use of a smaller Foley catheter and addition of an anticholinergic medication. This increased her comfort and reduced the risk of decubiti. Improved catheter care techniques by her aide helped to decrease potential urosepsis.

Interventions for Common Symptoms and Complications in Advanced MS:

Bowel Evacuation Impairments

Common Presentations: Chronic constipation, dependency on medication for a bowel movement; may also present with incontinence

Risks: Perforated bowel, decubitus ulcers, ileus

Impact on Quality of Life: Discomfort, increased focus on bowels and less participation in social activities, increased burden on caregivers, increased risk of pressure areas due to sitting on commode or bedpan for extended periods

Interventions for Common Symptoms and Complications in Advanced MS:

Bowel Evacuation Impairments (continued...)

Interventions:

- Prevent and reduce constipation (and impaction) with dietary bulk, adequate fluids and exercise or movement as tolerated
- Manage fecal impaction and loss of bowel tone and motility with manual extraction and enemas on a regular schedule
- Bowel incontinence usually managed by incontinence products; medications such as anticholinergics may also be helpful
- Surgical diversions such as colostomy are an option but rarely performed
- Bowel obstruction may require emergency surgical intervention



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Interventions for Common Symptoms and Complications in Advanced MS:

Impaired Cognition

Common Presentations: May present with missed medications and appointments; impaired judgment may lead to accidents and poor relationship decisions

Risks: Over/under medication, social isolation, care provided is not aligned with person's wishes

Impact on Quality of Life: Decreased self esteem, increased anxiety, increased depression, role reversal within the family, poor financial decisions, increasing stress on family

Interventions for Common Symptoms and Complications in Advanced MS:

Impaired Cognition (continued...)

Interventions:

- Neuro-psychological evaluation to determine limitations and remaining abilities, e.g. what the person can and cannot understand
- Cognitive assists can be designed to meet the specific cognitive challenges. An occupational or speech therapist trained in cognitive rehab can be very helpful in addressing these challenges
- Person must be included in decision making process, with clear explanations, repetition as necessary, and recognition of limitations
- Diminished or lost ability to direct personal care and make decisions about end of life choices means that end of life determinations must be communicated earlier in the disease trajectory, but reviewed and revised periodically since the “line in the sand” often shifts over time
- Health Care Surrogate or proxy should be identified early in the disease course
- If surrogate or proxy has been identified, guardianship may be need to be pursued



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Maria: Considerations and Interventions

- Maria was alert and oriented, without readily apparent indications of her cognitive decline, a frequent occurrence in MS cognitive impairment. However, poor short-term memory and inability to compare potential options, demonstrated that impairment was present
- Despite these limitations, the team determined that Maria still had the capacity to appoint a health care surrogate. A family discussion with the nurse formally identified Maria's mom as Health Care Surrogate, who could then assist with, or direct if necessary, future care decisions
- A social worker was consulted to work with the family, particularly Maria's children, and Maria regarding her depression. A trial of antidepressant medication was an outcome
- The occupational therapist demonstrated ways for the family to assist Maria to compensate for some of her cognitive issues such as keeping to a routine, writing down reminders, organizing ADL items such as oral care and hair care in separate containers

Mortality in MS Patients

- Overall, mortality is only slightly higher in MS patients when compared with that in the general population
 - The rate is higher particularly for older patients and those with longer disease duration
 - People with MS and comorbidities were more likely to die younger, compared to people with MS alone. *Marrie et al, 2015*
- Severe disability can lead to premature death from secondary complications such as decubitus ulcers, aspiration pneumonia, and urosepsis
- Frequency of death by suicide was found to be 7.5 times higher among patients with MS compared to the general population. It was found that in suicidal patients, suicide rate did not correlate with disability

Discussing Mortality With Those Who Have MS

One of the most useful roles of the health professional involved in the care of someone with MS is to seek out what is important to the person.

Advance care planning can include a discussion about what is a good death – or what that means to the individual with MS.

Pros

- Tools such as the 5 wishes can be used as a health care proxy and also address QOL issues (<https://agingwithdignity.org/five-wishes>)
- Fears about the dying process can be discussed and often addressed when making decisions about palliative care

Cons

- May raise fear that palliative care is hastening their death rather than improving QOL



Making Goals for End-of-Life Care

- More than 90% of the people think it's important to talk about their loved ones' and their own wishes for end-of-life care
- Fewer than 30% of people have discussed what they or their family wants when it comes to end-of-life care
- 80% of people say that if seriously ill, they would want to talk to their doctor about end-of-life care
- 7% report having had an end-of-life conversation with their doctor
- 82% of people say it's important to put their wishes in writing
- 23% have actually done it

The Conversation Project, 2013

Creating Long-Term Goals:

The Benefit of Advance Care Planning

- Process of developing a valid expression of wishes rather than signing a document
 - Approach similar to informed consent; an informative decision-making process
- Could be considered a component of preventative medicine
 - Best approach is when it is started early on and when the patient is not in crisis
- Components of Advance Care Planning can take place over several encounters with the person:
 1. Introduce the topic
 2. Facilitate the discussion
 3. Complete directives
 4. Review and update
 5. Apply to actual circumstance



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What does a good day look like to you?

A Case Study

- The conversation project

<https://www.youtube.com/watch?v=Dnnu43Zt-oA>

*Are you ready to have the conversation with
your patients?*



Hospice

- Is intended for patients with a life expectancy of six months or less
- A terminal status can be difficult to determine in people with MS
- Hospice services often include nursing care, physician services, physical/occupational/speech therapy, services of a home health aide, counseling and medical social services under the direction of a physician
- Introduction can be done by asking what the patient and family's goals are about the future and then if appropriate, determining what the patient or family knows about hospice
- Discuss hospice care as a means of fulfilling the patient's wishes
- If member is referred to hospice, there is a risk of duplication of services since both MS centers and hospice provide comprehensive care
 - Frequent communication between the teams is crucial
 - A shared care plan with established communication mechanisms and timeframes can improve the experience for the patient and the providers

The Impact of Culture in Palliative Care

- Cultural Competence is the process of becoming, not a state of being
- Culture is not only determined by ethnicity or race; it can be determined or influenced by spirituality/religion, socio-economic status, level of education, level of acculturation, gender, age, sexual orientation, country of origin and immigration status
- Culture is an important concept to consider as we care for those with advanced MS, as an individual's culture this will influence how they make sense of their illness, as well as how they make end of life decisions

The Impact of Culture in Palliative Care (continued...)

For example:

- In traditional *Hispanic* families, the bulk of care provided for a terminally ill family member is performed provided by female relatives who are unlikely to ask for outside help to cope with the stress of looking after someone who is close to death
- In the *Chinese* culture, it may be considered bad luck to talk about illness or death, as verbalizing may cause illness and death to happen
- *African Americans* have a mistrust of the health care system based on past history of segregation and discrimination. Several studies suggest that African Americans are less likely to complete advanced directives such as DNR orders or living wills.
- Older adults may feel it they decided to sign a “do not resuscitate” clinicians may provide sub-standard care or ‘give up’ on them too soon

Providing Culturally Competent Care: Transcultural Assessment Model

Principles imbedded in this model include that MS nurses:

1. Recognize every individual as unique
2. Identify literacy level and those “at risk”
3. Identify cultural health practices and beliefs
4. Plan culturally based learning experiences
5. Use materials using different languages when appropriate
6. Use visual aides
7. Use concrete rather than abstract words
8. Invite questions
9. Avoid use of complex medical terminology when possible

Spirituality

- Studies suggest that patients wish to have their spiritual concerns addressed
- Most patients faced with life threatening illness have spiritual needs that are not adequately addressed by their health care providers
 - For many with serious or life threatening illness, this is when spiritual needs are the greatest
- Spiritual assessment does not have to be a complicated process but may be as simple as asking open ended questions: “Is spirituality or religion something that is important to you?”
- Exploration of spiritual beliefs can be a less formal process that can occur as a part of any patient encounter
- Clinicians may ask how individual’s have coped with challenging times in the past, and whether spirituality or religious beliefs were a part of what helped them to cope

Richardson 2014, Steinhauser 2000

Ethical Issues

- Challenging situations may occur for a nurse when providing care at the end of life
 - A person's or their family's choice may not align with our personal values or choices. Self-awareness and the belief in patient-centered-care can assist a nurse to address this challenge
 - Ethical dilemmas may include inadequate communication, patient autonomy usurped/threatened, issues with symptom management and the use of opioids, issues related to decision making, and issues related to discontinuing life-prolonging therapies
 - These issues may be addressed by requesting a formal ethics consultation, involvement of the palliative/hospice team, consulting with other professionals, and use of educational resources

A Case Study: MARIA (... continued)

- Over the next few years Maria's MS continued to progress. She became quadriplegic, more cognitively impaired, and was hospitalized several times for urosepsis. A cystostomy was recommended, but Maria, unable to comprehend what this entailed, refused
- Her mom as Health Care Surrogate, after discussion with her family and the care team, decided not to have the procedure performed

Additional Factors that Impact Palliative Care in Patients with Multiple Sclerosis



Part III

Geography and Social Systems

- Palliative care practices across countries and models of healthcare are complex and highly variable
- Geographical variability is based on financial, logistical and personal factors
- Obstacles present to the growth of palliative care may include:
 - Population density
 - Poverty
 - Geographic diversity
 - Restrictive policies regarding narcotic prescriptions
 - Workforce development at base level
 - Limited palliative care policy
 - Lack of institutional interest in palliative care

Geography and Social Systems

(continued...)

- In rural communities, palliative care may be provided by a generalist practice
 - To meet the local needs of the community, rural communities can join together by developing a palliative care programs model
 - An approach to development:
 - Antecedent community conditions – develop a vision for change, need sufficient health services infrastructure in place
 - Catalyst – a stimulus to change, motivation
 - Creating the team – dedicated providers join together
 - Growing the program – includes educating providers, patients, families and community members, building community relationships, building external linkages
- Despite the challenges of these variables practice guidelines and current literature both reinforce the person with MS as the center of the model of care
- Care of the person should be provided in their choice of environment whenever possible



India: An example of how a palliative care program can be incorporated into practice

Antecedent community conditions

- Population of India was aging and had a high prevalence of advanced cancer

Catalyst: a change is noted in the mindset of healthcare providers

- Patients were presenting with Stage III and IV cancers. Governmental restrictions on opioids made access to morphine extremely difficult. People were dying in agonizing pain

Creating the team: policy makers began to understand the need for palliative care

1. In 1984, the National Care Program was modified to make pain relief one of the basic services to be delivered at the primary health care level. Eventually, this blossomed into the Indian Association of Palliative Care (IAPC)
2. With the help of the World Health Association (WHO), pain clinics were established throughout the country

India: An example of how a palliative care program can be incorporated into practice (continued...)

3. From the 1990s onwards, there was a significant increase in the momentum of the development of the hospice and palliative care provision
4. In 1995, IAPC set up a Palliative Care Drugs Committee and Educational Task Force. With the help of the WHO, Indian palliative care activists worked to get the Indian government to lift strict opioid restrictions and in doing so made access to morphine and other opioids easier
5. CanSupport was founded in 1997 in Delhi which provided the first free palliative care home care support service in North India

India: An example of how a palliative care program can be incorporated into practice (continued...)

Growing the Program:

- Systematic and continuous education for medical staff on palliative care is now mandatory
 - The WHO offered education and training as one of the foundations measures of palliative care. The other two included government policy and drug availability
- Universities have an increasing number of palliative care courses and faculties
 - The WHO recommended an introduction of Palliative care into the curricula of the undergraduate education of all doctors and nurses. They held it as an efficient way to broaden the base of palliative care coverage at the national level

A Case Study: MARIA (... continued)

- After a recent admission with pneumonia, Maria requested a meeting with the chaplain. Maria's family report that they attended church regularly when Maria was still walking, but had stopped when it became difficult to get to church. The hospital chaplain arranged to visit Maria at home.
- At Maria's next follow up visit, the MS team revisited goals of care with Maria and her family. Her ability to breathe was now compromised. Maria again repeated, that being with her family was what mattered to her. She also wanted to be comfortable but did not want any more treatment or procedures. Her family supported her decision.
- Maria was referred to home-based hospice program for the next several months until her death.
- Her family subsequently reached out to the MS team to report that although they were sad, they felt good about being able to honour Maria's wishes. She was in her home, with her children, until the end. Her mother added that her passing was peaceful, and to express their gratitude for the care that Maria had received.

Considerations to Practice: Applications to Patients Throughout the Disease Process

- Palliative care can be introduced at any time during the disease course if distressing symptoms are present
 - The goal is to prevent suffering and maximize QOL
- Critical elements of palliative care that can begin immediately post diagnosis:
 - Facilitating communication: encourage the person and their family to verbalize their fears, understanding of MS and learning style
 - Decision-making: related to choosing a MS clinician and whether to start a disease modifying medication
 - Advance care planning: to ensure patients wishes are followed and prevent suffering
 - Intensive disease treatment to prevent disability
 - Timely symptom management to promote wellness and improve quality of life
 - Management of psychosocial needs: To diminish stress and promote psychological wellness
 - Interdisciplinary rehabilitation interventions to promote flexibility, diminish pain and increase strength

Summary, Resources, References



Part IV

Summary

- Palliative care emphasizes comfort and compassion
- Palliative care for people with multiple sclerosis focuses on patients with advanced disease and disability which can severely impairing quality of life
- Concepts may be introduced early in the disease as opportunities arise, such as discussion of advance planning directives, which are now routine in many healthcare settings. These discussions are needed periodically since feelings about future decisions change over time
- The burden of MS on the family can be enormous. Identifying family strengths and bolstering support systems are important, as is recognition that most people with advanced disease will have some impairment of cognition

Summary (continued...)

- Culture, socioeconomic status and healthcare systems impact the provision of palliative care, and must be considered in all aspects of planning
- Religious beliefs and customs are core to many people's experience and spiritual support is often critical to the patient and family
- Hospice is the end of the palliative care continuum, generally intended for patients with a life expectancy of six months or less
- Hospice care can be provided in many settings including home, long-term care facility, and dedicated hospice or palliative care unit or facility
- Nursing care is central to the palliative care process - from planning, through coordination and implementation, family support and direct provision of comfort care - to end of life/hospice care

Multiple Sclerosis, Palliative Care, and End of Life Organizations and Resources

- American Academy of Hospice and Palliative Medicine: www.aahpm.org
- Brandis M, Stacom R. Long-term care in the home for people with multiple sclerosis. Care Manag J10: 128-137, 2009.
- Center to Advance Palliative Care: www.capc.org
- Get Palliative Care: www.getpalliativecare.org
- Hospice and Palliative Nurses Association: www.hpna.org
- Multiple Sclerosis Association of America: www.msaa.org
- National Hospice and Palliative Care Organization: www.aahpm.org
- National Institute of Nursing Research, NIH: www.ninr.nih.gov
- National Multiple Sclerosis Society: www.nationalmssociety.org
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- Share the Care: www.sharethecare.org
- The National Hospice and Palliative Care Organization: www.nhpco.org



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