

# Shared Decision Making in MS Care and Treatment

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**IOMSN**

International Organization  
of Multiple Sclerosis Nurses

# Outline

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1. What is Shared Decision Making?
2. Why use Shared Decision Making?
3. Barriers and consideration when using Shared Decision Making
4. DMT Decision Making
5. Shared Decision Making and symptom management
6. Pregnancy, MS, and Shared Decision Making
7. Other considerations
8. Summary

# What is Shared Decision Making?

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**“Shared Decision Making (SDM) is a collaborative process that allows patients and their providers to make health care decisions together. It should take into account the best scientific evidence available, as well as the patient’s values and preferences.”**

# What is Shared Decision Making?

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**“SDM honors both the provider’s expert knowledge and the patient’s right to be fully informed of all care options and the potential harms and benefits. This process provides patients with the support they need to make the best individualized care decisions, while allowing providers to feel confident in the care they prescribe.”**

# When is SDM Applicable?

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- SDM allows for both the provider's expertise and the patient's right to be fully informed of their care options to be weighed with potential harms and benefits.
- "This process provides patients with the support they need to make the best individualized care decisions, while allowing providers to feel confident in the care they prescribe."

# Rationale for SDM?

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**“Experience has shown that when patients know they have options for the best treatment, screening test, or diagnostic procedure, most of them will want to participate with their clinicians in making the choice.”**

**This puts patients at the center of their care and gives them sense of control over their medical care.**

Barry MJ, Edgman-Levitan S. Shared Decision Making - pinnacle of patient-centered care. *N Engl J Med.* 2012; 366:780-1.

# When To Use SDM?

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- Situations where healthcare providers should be utilizing Shared Decision Making with our MS patients:
  - Newly diagnosed
  - DMT decision making
  - Symptom management
  - Pregnancy and lactation with MS

# BARRIERS TO SHARED DECISION MAKING

# Barriers to Shared Decision Making

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- **Cultural differences**

- Language barriers, opposite gender providing care, patient may not feel comfortable asking questions seen as confrontational

- **Family dynamics**

- Spousal relationship, privacy often needed to discuss sensitive issues

- **Support system**

- Who comes with them to appointments
- Never assume the relationship definition of who comes with patient

# Barriers to Shared Decision Making (cont.)

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- **Education level of patient**
  - Using medical terminology that patient may not understand
- **Generational differences**
  - Elders receiving care from those <40 y.o.
- **Quality of life issues**
  - What is important to the patient, do benefits outweigh potential risks, is the issue at hand not a big deal to the patient?
- **Access to healthcare and resources**
  - Rural vs urban environment

# Barriers to Shared Decision Making (cont.)

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- **Transportation issues**
  - Gas money, ability to drive, reliance of others or public transportation to attend appointments
- **Cognition**
  - Memory issues. Is patient able to verbalize back what you discussed or taught them?
- **Denial or depression**
  - Ability to even have these conversations or are they so debilitated from this that timing is everything?
- **Sources of information**
  - Blogs, internet sources, social media – not always reliable or truthful

# CASE #1: ADDRESSING BARRIERS

# Case Study #1: Ethel

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- Ethel is a 75 y. o. African American woman diagnosed with MS 40 years ago; recently relocated to be closer to family; previously lived in a big city and relied on public transportation; never learned to drive
- She has never been on DMT and her EDSS is 4.5
- Despite having family nearby, she voices frustration and isolation after leaving her friends behind
- Her main goal of today's appointment is to establish care. She also reports ongoing fatigue and bladder issues resulting in 5-6 episodes of nocturia nightly. Ethel attributes this to being "an old lady"

# Case Study #1: Ethel

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- **Shared Decision Making considerations with Ethel**
  - Age difference between patient and provider
  - Her expectations of care at new clinic
  - Transportation to appointments or social events
  - While closer physically to family, are they involved in care?
  - Isolation can lead to depression. Can this be decreased?
  - Bladder issues attributed to her age. Discussing QOL issues with managing this better would improve sleep, decrease fatigue, and possibly having less of a fall risk at night going to bathroom. Would she consider this?

# DMT DECISION MAKING

# DMT Decision Making

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- **Patient on therapy?**

- Stable or not?
- If stable, are they satisfied with current treatment?
- If not satisfied, then need to discuss DMT options
- Efficacy - relapse rate, disability progression, MRI evidence
- Safety - lab monitoring or other required monitoring, co-morbidity issues, JCV status, other risks factors
- Tolerability - side effects, how is it administered, injection site reactions
- Convenience - transportation to receive med, self administered, days of side effects, how often do labs or MRI need to be done for monitoring?
- Cost/Co-pay
- Expectations of medication

# DMT Decision Making

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- **Treatment naïve patient**
  - Newly diagnosed
  - Stopped DMT and wish to resume
  - Diagnosed but never pursued DMT
    - Efficacy
    - Safety
    - Tolerability
    - Convenience
    - Cost/co pay
    - Fear of the unknown
    - Other options
    - Holistic or alternative therapy

## CASE #2: DMT DECISION MAKING

# Case Study #2: Daniel

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- Daniel is a 32 y.o Hispanic male originally from Ecuador. He lives about 2 hours from your clinic; however, he does not have insurance and goes to your clinic for free and/or discount services.
- He is not married and it is unclear if he is in the US legally. His church helps take care of him and provides transportation.
- His EDSS is 6.0. He is JCV antibody negative.
- English is his second language but he communicates fairly well but with obvious cognitive issues. Daniel is very pleasant and jovial; he is appreciative of resources provided to him.

# Case Study #2: Daniel

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- **Shared Decision Making considerations with Daniel**
  - Cultural, language, cognitive, financial, and transportation issues to consider
  - Who helps Daniel with medical decision making?
  - Does he comprehend what his diagnosis means and how medications may or not help?
  - What to consider with DMT decision making given Daniel's social situation? What about the severity of disease in a young, Hispanic male?
  - Having a translator present is imperative especially when discussing DMT risks and benefits
  - Also consider gender and age of translator when discussing sensitive issues such as bowel, bladder, and intimacy issues
  - Certain patients can be lost to follow up especially if rapport is not established with them - "no one really cares about me and my situation"

# SDM AND SYMPTOM MANAGEMENT

# SDM and Symptom Management

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- Initial assessment is the key to SDM success
- Asking the right questions in the right way is imperative
  - What symptoms are they experiencing?
  - Are these new symptoms that may signal a relapse?
  - If chronic symptoms, is it related directly or indirectly to their MS?
    - Indirect symptom: Complaining about hip pain which is due to leg spasticity and weakness.
    - Direct symptom: Loss of vision from optic neuritis.

# SDM and Symptom Management

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- Is the symptom bothersome to the patient?
- What have they tried previously? Did it work?
- What conservative measures are available?
- What medications and/or procedures are available for this issue?
- What can be done if first line measures fail?
- What is the cost or burden of treating?
- What is the benefit directly and indirectly?

## CASE #3: SDM AND SYMPTOM MANAGEMENT

# Case Study #3: Kelley

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- Kelley is a 51 y.o. Caucasian woman with PRMS diagnosed in 2007.
- She has been doing well on an oral DMT for the past 2.5 years; her EDSS is 3.0 (mainly pyramidal).
- She works part time in her husband's law firm and has 2 sons in college; enjoys exercising, travelling, and being with friends and family.
- Kelley and her husband were invited to go to NYC with friends to see some Broadway shows and enjoy the city
- She declined due to mobility issues. She would have loved to go but didn't want to hold up the group.

# Case Study #3: Kelley

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- **Shared Decision Making considerations with Kelley**
  - Age and gender may be consideration depending on healthcare provider involved
  - Symptom of weakness and fatigue resulted in patient not doing activities limiting her quality of life
  - Declining this trip was significant to Kelley; it meant MS was “winning”
  - Discussion involved her willingness to use an ambulatory device to assist with walking and walking fatigue. She was open to this
  - Referral placed to PT to try an AFO
  - Also discussed possible trial of Ampyra which she is not ready for yet
  - Lastly, discussed rental of a scooter on trips to conserve energy and to keep up with her traveling companions; Kelley was open to this idea; since then, she has gone on many trips using a scooter which has greatly improved her sense of self and independence

# PREGNANCY, MS, AND SDM

# Pregnancy, MS, and SDM

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- This is a sensitive and arduous topic to discuss with our young female patients.
- It is imperative to know your patient's family plans to help with DMT and symptom management choices.
- Explaining risks and benefits of medications during pregnancy needs to be based on patient's educational and/or cognitive needs.
  - For example: "You cannot get pregnant on this medication" can be interpreted as the DMT is a form of birth control. It is more direct to say "It is not recommended to get pregnant while taking this medication."

# Pregnancy, MS, and SDM

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- Education with MS pregnancy related concerns is necessary.
- Planned pregnancy is always best.
- Knowing that most DMTs take 6-9 months to be fully effective should be taken into account when planning pregnancy and post partum.
- Patient should be evaluated by gynecologist prior to attempting to achieve pregnancy to identify any issues that may impede pregnancy (PCOS or fibroids).
- Stopping DMT needs to be clearly outlined before attempting to achieve pregnancy.

# Pregnancy, MS, and SDM

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- Does patient plan to breastfeed and if so, how long?
- What is their risk tolerance for being on DMT while nursing?
- What are the concerns of their family or significant other with pregnancy, potential for post partum relapse, or nursing?
- This is somewhat uncharted territory in the world of MS but we need to support our female patients to have healthy pregnancies while minimizing post partum relapses and supporting if mother chooses breastfeeding.

## CASE #4: PREGNANCY, MS, AND SDM

# Case Study # 4: Amanda

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- Amanda is 30 year old woman who has been married for 3 years but with her husband for 8 years. He was present when she was diagnosed but rarely comes to appointments with her.
- When she was diagnosed, they were incorrectly told she could not or should not have children.
- Amanda works full time as a radiology tech.
- She presents today to discuss changing DMT after having a relapse on an oral agent. She has previously had breakthrough disease on the injectables. Her husband is with her today.

# Case Study # 4: Amanda

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- **Shared Decision Making considerations with Amanda**
  - What are their family plans and how soon?
  - What concerns does her husband have about her recent relapse and possible new DMT?
  - What is she on for birth control?
  - If no children now, do they ever want to have children?
  - Education about MS and pregnancy and lactation since they were given incorrect information previously.

# Nursing Implications

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- **Some patients do want to be “told” what to do. It is overwhelming for them to make choices. It is important to assess if SDM is appropriate for each patient.**
- **Explaining ALL options or ALL consequences of related risks and benefits is next to impossible.**
- **Too much information can be confusing to patients.**
- **It can take time to finesse SDM techniques as healthcare providers. It can also lead to a longer clinic visit. However, the end result is worth it.**
- **There are various tools and methods for SDM visits.**

Col N. Chapter 17: Shared Decision Making. In: Communicating Risks and Benefits: An Evidence-Based User's Guide; Fischhoff B, Brewer NT, Downs JS (eds). Maryland: Food and Drug Administration (FDA), US Department of Health and Human Services; August 2011: 173-184.

# Summary: Shared Decision Making in MS

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- Shared Decision Making can be a valuable tool to give holistic care to patients with MS.
- SDM can empower patients to feel more involved in their healthcare which in turn increases their confidence in your care delivered and therefore compliance.
- Helping our patients make the best individualized decisions for themselves helps us reconnect with patients on a more personal level.

# References

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# QUESTION & ANSWER SESSION

# Thank you for your participation!

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