

How to Talk With Your Health Care Team About What is Best for You

Shared Decision Making for Patients and Caregivers



Co-Presenters



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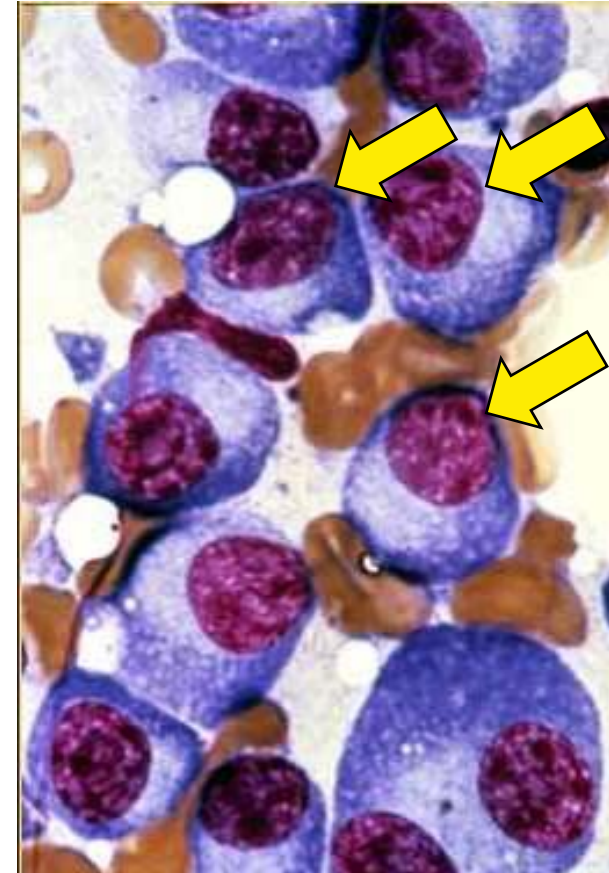
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Myeloma Review: Cancer of Plasma Cells

- ▶ Cancer of antibody-producing cells
- ▶ Myeloma cells crowd out normal bone marrow cells and produce ineffective antibodies, or parts of antibodies
- ▶ Myeloma Diagnosis:
 - Clonal bone marrow $\geq 10\%$ or bony/extramedullary plasmacytoma **AND** any one or more **Myeloma Defining Events (MDE)**
 - ***SLiM-CRAB criteria***
 - Sixty percent clonal plasma cells
 - serum free Light chain ratio >100
 - Magnetic resonance imaging (MRI) \Rightarrow 1 focal lesion

Bone Marrow of MM Patient



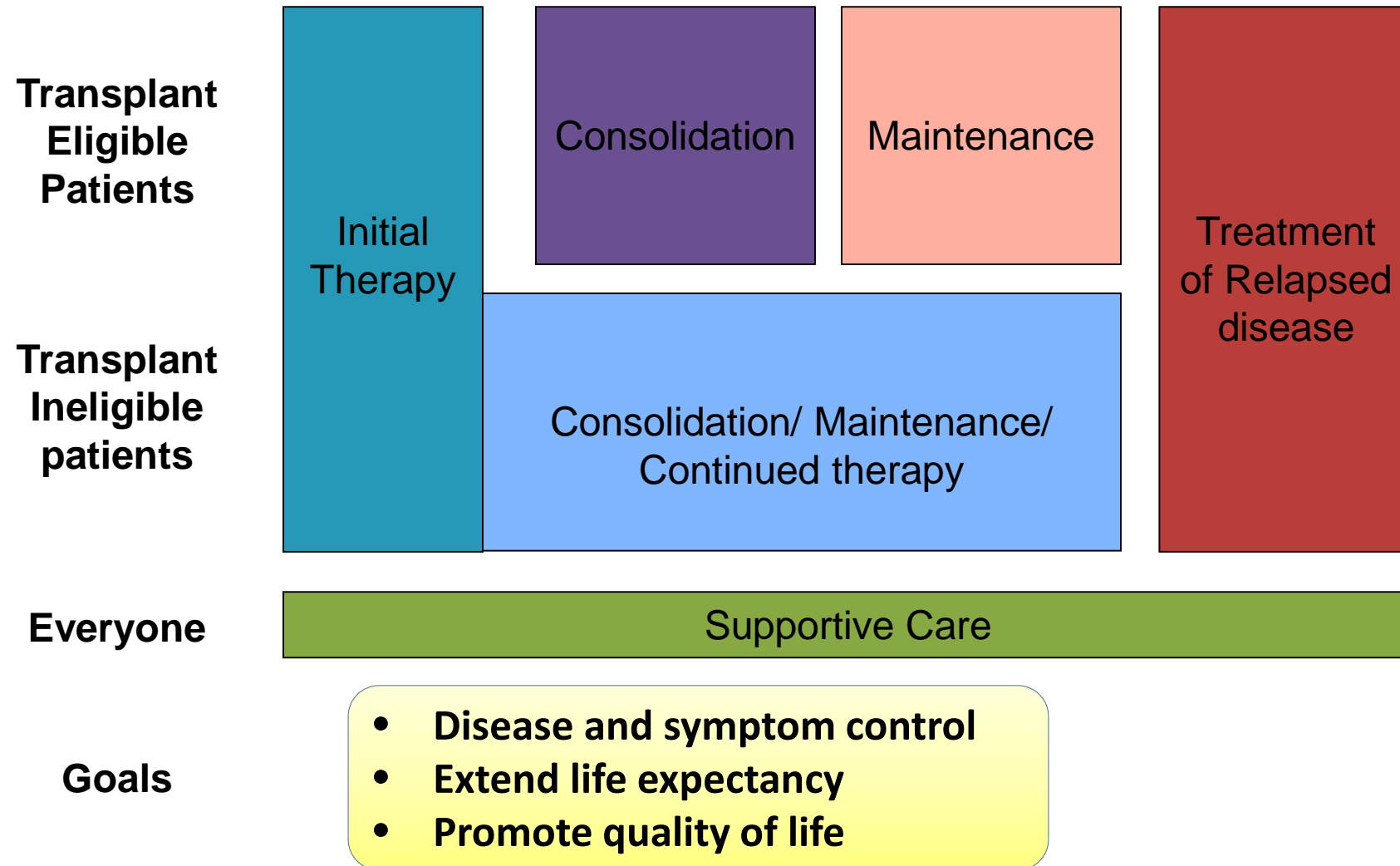
Myeloma cells often have large eccentric nuclei

Making a correct diagnosis is essential. Monitoring and whether or not to treat is an important question



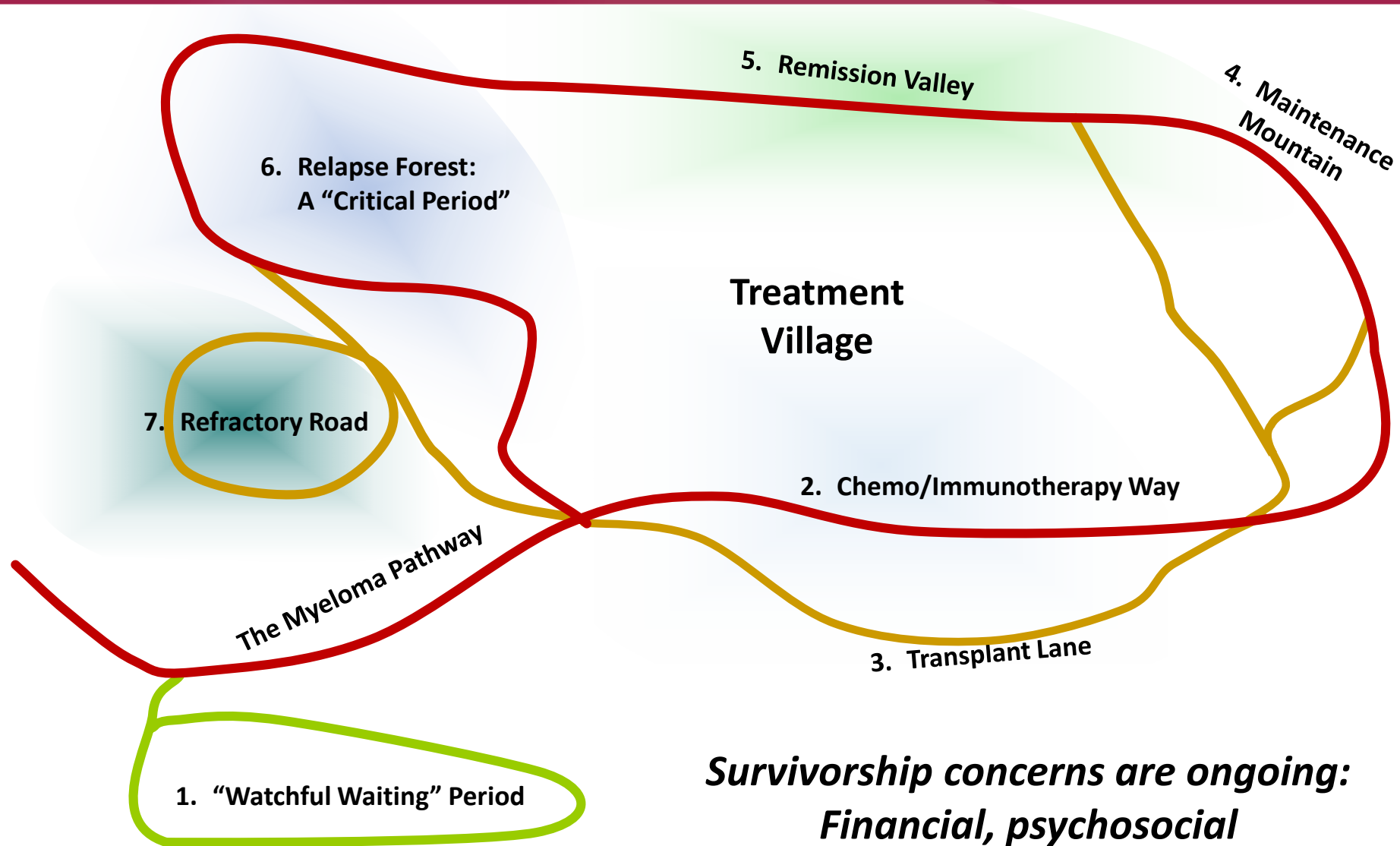


Managing Myeloma: Balancing Many Components





Long and Winding Road of Myeloma Diagnosis, Treatment



***Survivorship concerns are ongoing:
Financial, psychosocial***

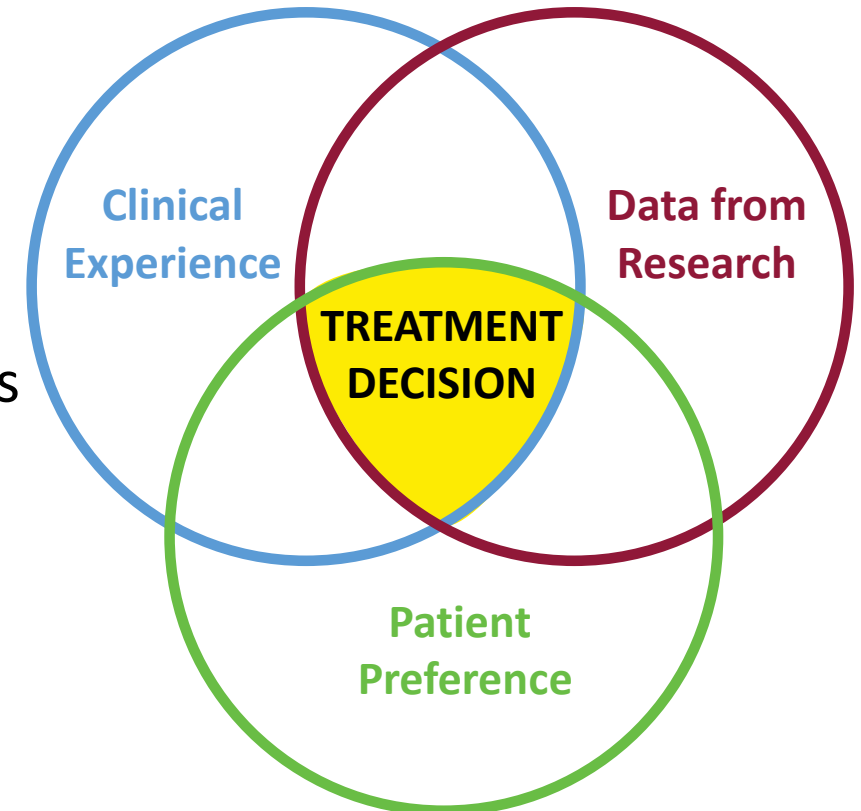


There will be “critical periods” where decisions need to be made



Examples of Critical Periods:

- 1) Starting/stopping myeloma treatment
- 2) “Supportive treatment”
 - Radiation, blood transfusions, bone-building medications (bisphosphonates), antibiotics, vaccines
- 3) Transplant or not
- 4) Am I in remission or relapsing?
- 5) Starting/stopping maintenance
- 6) Radiation for plasma cell tumors, pain
- 7) Elective or necessary surgery (kyphoplasty, rod placement)



Philippe Moreau, ASH 2015



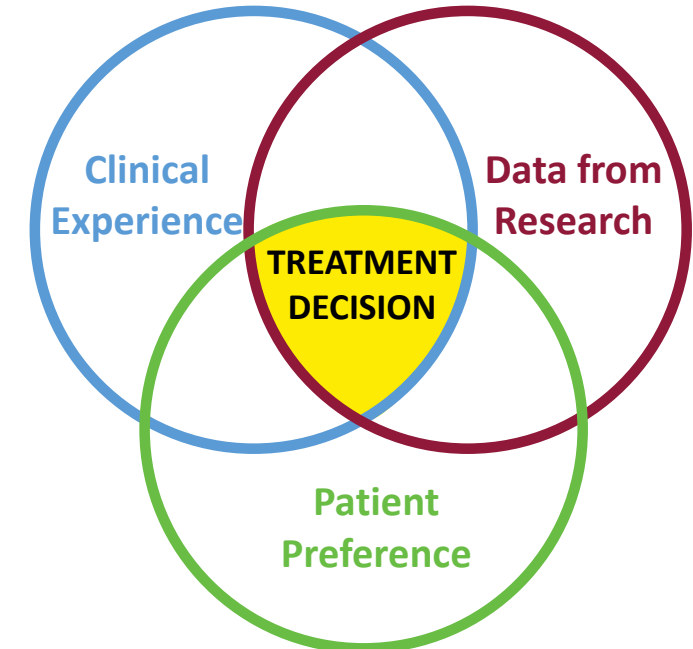
To treat or not to treat.... That is the question. And with what?



Considerations

- ▶ Options explored with health care provider
- ▶ Current results of clinical trials
- ▶ Lifestyle and Quality of Life (IV/oral)
- ▶ Previous treatment
 - Response and Duration? Retry?
 - Tolerability - Side Effects?
- ▶ Maximizing benefits of each drug (avoid rapid switching unless medically necessary)
- ▶ Clinical trial participation, if eligible
- ▶ Second opinion or consultation with a myeloma specialist

Tip: Write down what is important to you and discuss with your healthcare team



Philippe Moreau, ASH 2015

**Treatment decisions are individualized.
With many good treatment options patient preferences play a larger role**



Evolution in Health Care: From “Father-knows-best” to “Shared Decision Making”



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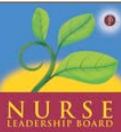


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- In the past, paternalistic or provider-driven decision-making model was dominant
- Now an emphasis on patient-centered care and involving the patient in the health care decisions¹⁻⁴



1. <http://www.ahrq.gov>. 2. Institute of Medicine Committee on Quality of Health Care in America. 3. Patient Protection and Affordable Care Act. 4. AACN Competencies for Baccalaureate and Graduate Nurses. 5. Tariman J, et al. *Clin J Oncol Nurs*. 2015;19:548-556. 6. Tariman J, et al. *Ca Treat Comm*. 2014;2:34-377.





Why Shared Decision Making in Multiple Myeloma?



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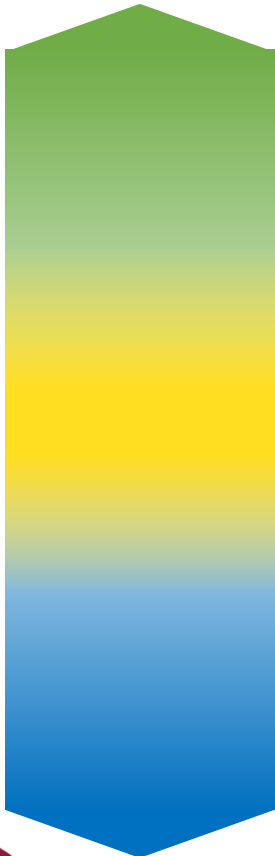
- Multiple treatment options; patient and caregiver's goals, preferences and values may influence treatment decision
- Relapsing nature of multiple myeloma; multiple decision points
- Myeloma patients are living longer; goals, preferences and values may change over time
- Note: shared-decision making has been studied in multiple cancer types although relatively little research in multiple myeloma patients to date





Patterns of Decision Making: Myeloma Patients' Preferences

Patient
Controlled



Provider
controlled

Degner and Beaton's Pattern of Decision Making¹

"I prefer to make the final treatment decision"

"I prefer to make the final treatment decision after seriously considering my provider's opinion"

"I prefer that my provider and I share responsibility for deciding which treatment is best"

"I prefer my provider to make the final treatment decision, but only after my provider has seriously considered my opinion"

"I prefer to leave all treatment decisions to my provider"

Among Myeloma Patients²

N = 20

40%

55%

5%

1. Beaton JI, et al. *Can Nurse*. 1990;86:18-22. 2. Tariman JD, et al. *Oncol Nurs Forum*. 2014;41:411-419.



What is Shared Decision Making?

Shared decision making is a model of treatment decision making

4 essential elements:

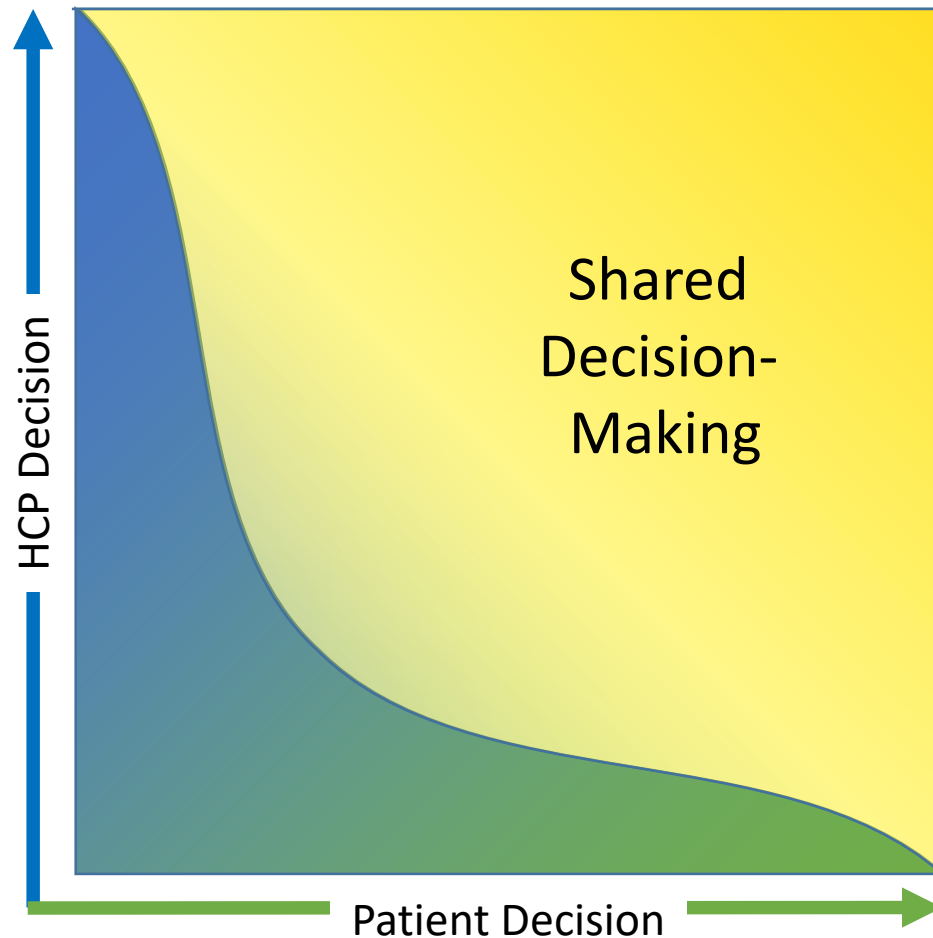
1. 2 parties: healthcare providers (MD/APP/RNs) and patient/caregiver
2. Both parties share information
3. Both parties take steps to build consensus about preferred treatment
4. Mutual agreement is reached between patient and healthcare member on treatment approach



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Shared Decision-Making Implementation in Oncology



- Present treatment options; discuss pros and cons; ensure patients and caregivers are understanding the information
- Discuss personal preferences, values, issues and concerns related to treatment options
- Allow time to think about the options (assuming not a medical emergency); facilitate follow up visit to discuss further questions/concerns
- Arrive at an agreement on treatment approach

Tip: Research shows that providers want to hear from patients, and that their opinion helps treatment outcomes. Use your voice.



The New Era of Shared Decision Making Benefits Both Patients and Health Care Providers



Shared Decision Making Benefits & Outcomes

Short-Term Benefits

- Increased confidence with treatment decisions
- Higher satisfaction with treatment decisions
- Enhanced trust in healthcare team
- Improved self-efficacy
- Avoidance of decisional regrets
- Decreased patient/caregiver stress and anxiety related to cancer treatment decisions

Long-Term Outcomes

- Treatment adherence
- Better quality of life
- Improved treatment outcomes: disease remission



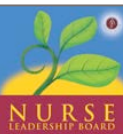
Reasons Why Shared Decision Making Is Not Always Used



Practice Barrier	<ul style="list-style-type: none">▪ Limited time during patient encounter “too busy”▪ Commitment by all multidisciplinary team members▪ Nurses/Doctors might not think they make a difference.
Patient Barrier	<ul style="list-style-type: none">▪ Patient is hesitant to “speak up”▪ Difference in goals between patient and caregiver▪ Not sure what is important to them – “trust provider’s judgment”
Institutional Barrier	<ul style="list-style-type: none">▪ Lack of policy or time commitment
Scope of Practice Barrier	<ul style="list-style-type: none">▪ Laws and guidelines prohibiting autonomous practice
Administration Barrier	<ul style="list-style-type: none">▪ Inadequate support by hospital administration (types of treatments restricted)

Tip: Patients can help overcome many of the barriers to share decision making by being organized and proactive. Make a list of your questions and priorities in advance of an office visit. Be proactive in learning about myeloma from reputable sources like the IMF.

McCarter SP, et al. Barriers and promoters for nurses' participation in cancer treatment decision making process and patient satisfaction with treatment decision. Sigma Theta Tau International's 26th International Nursing Research Congress. 2015. On-line: <https://stti.confex.com/stti/congrs15/webprogram/Paper71335.html>





Patient and Caregiver's Roles in Shared Decision Making

Ask questions (write them down in advance of visit)

- What are my treatment options?
- What are the pros and cons of each option?
Efficacy? Side effects?
Administration?
Insurance nuances?
- Are there treatments that wouldn't be a good option for me? Why?

Express your desire to participate in the treatment decisions

- I want to make sure the treatment we chose is the best option for me
- I want to be sure we are choosing the best therapy for my husband/wife

Ask for time (if needed/ appropriate)

- There is a lot to think about. Can I/we have some time to consider the options?
- Ask for information you can consider at home
- Note: if medical emergency/high risk, may not be appropriate





Patient and Caregiver's Roles in Shared Decision Making

Understand options; consider priorities

- Use reliable sources of information
- Use caution considering stories of personal experiences
- Consider your goals/values/preferences

Express your goals/values/preferences; create a dialog

- My top priority is [goal/value]; additional [preferences] are also important.
- I think [treatment] may be a good choice given my priorities... What do you think?
- What treatment would you recommend given my goals and priorities?

Arrive at a treatment decision together



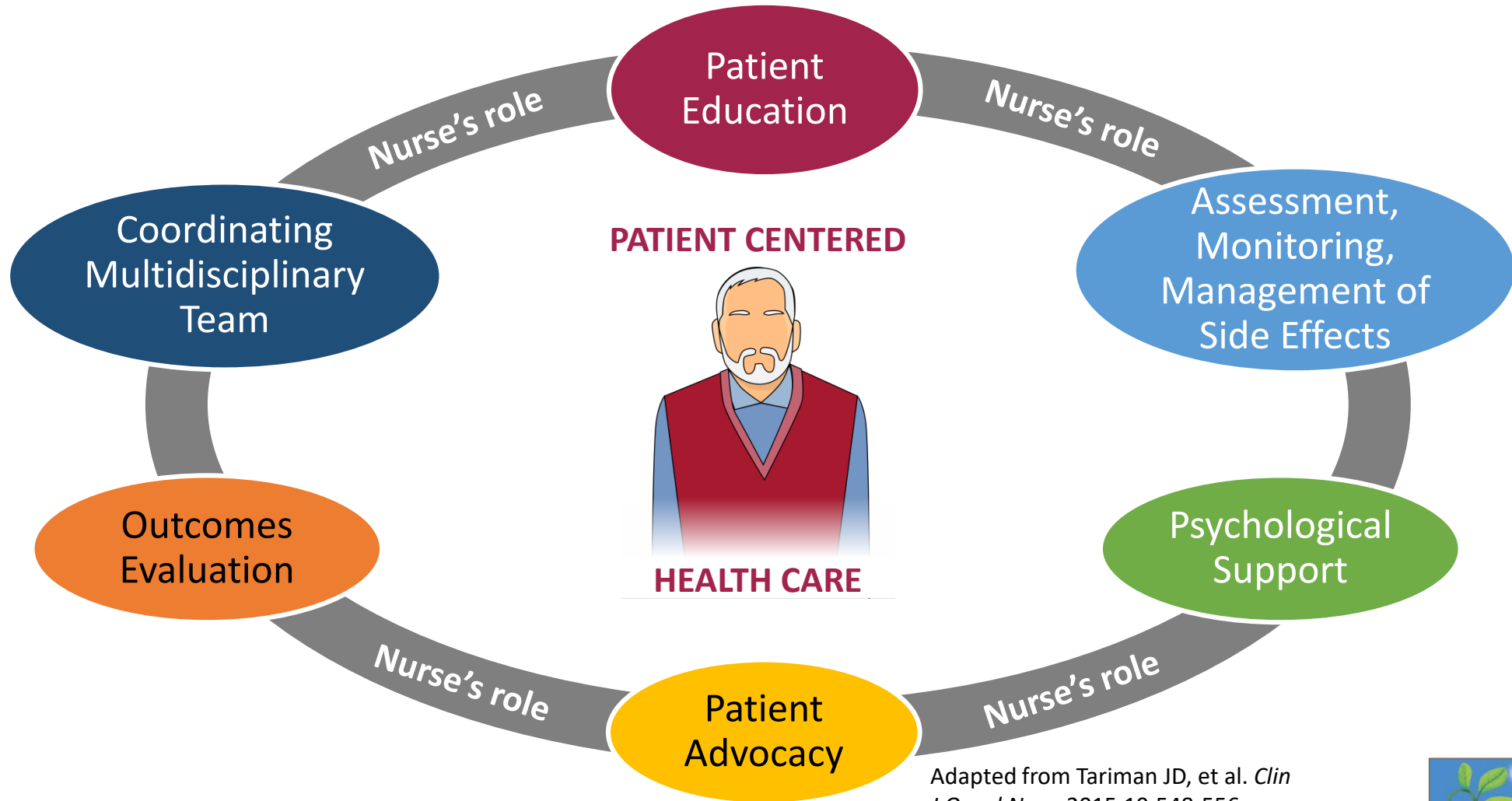
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Nurse's Can be a Helpful Resource for Shared Decision Making

- Oncology nurses are involved in shared decision-making¹
- Nurses are a trusted source of patient information²



Adapted from Tariman JD, et al. *Clin J Oncol Nurs*. 2015;19:548-556.

1. Tariman J, et al. *Clin J Oncol Nurs*. 2015;19:548-556. 2. Tariman J, et al. *Ca Treat Comm*. 2014;2:34-377.



SHARE Approach

- The SHARE Approach Essential Steps of Shared Decision making has been suggested by the Agency for Healthcare Research and Quality (AHRQ) and other organizations.
- The 5 steps to SHARE are:
 - Step 1: **S**eek your patient's participation
 - Step 2: **H**elp your patient explore and compare treatment options
 - Step 3: **A**ssess your patient's values and preferences
 - Step 4: **R**each a decision with your patient
 - Step 5: **E**valuate your patient's decision



Here is an Example...



- Margaret is a 46 YO single mother, diagnosed with MM in 2008.
- She enrolled in a clinical trial with a proteasome inhibitor and an IMiD drug.
- Achieved a complete response.
- On maintenance since 2009.
- She never had a transplant.
- 2 children: both are now in middle school.
- Her MM is becoming active “biochemical disease progression”
 - How does the discussion go?
 - What should she keep in mind when meeting with the healthcare team?

Tip: A new diagnosis of MM and/or new treatment options can be overwhelming. Follow 10 steps to better care (<https://www.myeloma.org/understanding/10-steps>) for suggestions.



Here is another Example...



- William is a 77 YO married retired store owner, diagnosed with MM in 2015.
- Married 52 years; wife in generally good health.
- Treated an IMId drug and dexamethasone continuous therapy. Transplant ineligible due to pulmonary hypertension.
- Achieved a complete response.
- Wife now showing early signs of dementia.
- Priorities are changing.
 - How does the discussion go?
 - What should he keep in mind when meeting with the healthcare team?

Tip: Bring up changing circumstances and priorities proactively.



Special circumstances



- What if a patient does not have a caregiver
 - Resources
 - Strategies for identifying someone to provide input and help with decision-making process, transportation and logistics

Tip: Sometimes there is not a care giver to help with your care. Someone or a group can be appointed to help you with your decisions (place of worship, community, or through the hospital).

- What if patient/family do not agree on treatment
 - Example: Transplant vs no transplant
 - Intravenous versus oral treatment

Solution:

Determine what is most important...

Consider if Quality of life, office visits, quantity of life or where one receives treatment (office versus home) is most important

Tip: Sometimes patients, providers do not mutually agree on recommendations. That is natural. Discussing concerns, pros- and cons- can help arrive at a decision.



Important Decision for Patients With Multiple Myeloma

- When to start treatment? Not everyone with M protein has multiple myeloma. MGUS vs. smoldering MM vs. Active MM
- When to change treatment? Measuring response
- Duration of bisphosphonates?
- How often to obtain lab tests? Office visits?
 - eg, if someone travels a far distance do they really need to come monthly to the clinic, or see if other solutions are available such as less frequent monitoring after a few months, or virtual “telemedicine” visits, or establish with a provider closer to home
- Adding, removing or adjusting medications (eg, antibiotics, diuretics, blood thinners, blood pressure meds, insulin)? Some myeloma medications can affect other medications



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Additional Strategies, Suggestions for Communicating with Team



- Continue to communicate about changing life events, priorities
 - What is the latest data? New therapies with good results for patients?
 - Importance of attending a graduation, reunion or other events; ask about treatment timing
 - “Attending my grandson’s high school graduation May 25th is very important to me. What can we do to make sure I feel well that day and am able to attend and participate?”
- Mention challenges (eg, transportation, affording medication)
 - There may be options but your health care team does not know to offer unless you ask
- Do not be afraid to ask questions/seek second opinions
 - Health care is fragmented; no provider knows all the tricks/programs
 - Can be worth it to have other health care providers weigh in; they may know additional programs or services that may be helpful for you



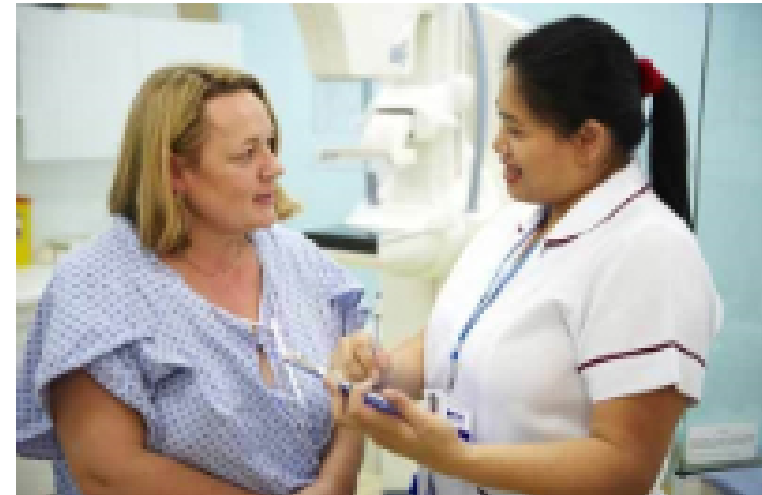
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Conclusion

- With all of the available treatment options for multiple myeloma, it is now more important than ever to have open discussions with your healthcare team
- It is OK to ask your healthcare team to discuss options from treatment to supportive care strategies (bone strengtheners)
- Consider the shared decision making approach to find what works for you and your family, caregivers
- Remember: You are your own best advocate



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Questions Encouraged



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Shared Decision Making



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