

MPN – How to talk to patients about MPN?

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Conflict of Interest

Research funding- Incyte, ASH-AMFDP, MGH PSDA

Advisory boards- BMS, Novartis, Pfizer, MorphSys, Abbvie, Pharmaxis, Pharmaessentia

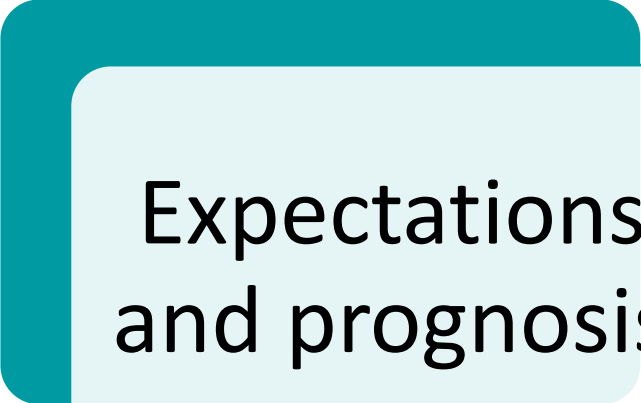
Regeneron- spouse employment



Objectives



Diagnosis



Expectations
and prognosis



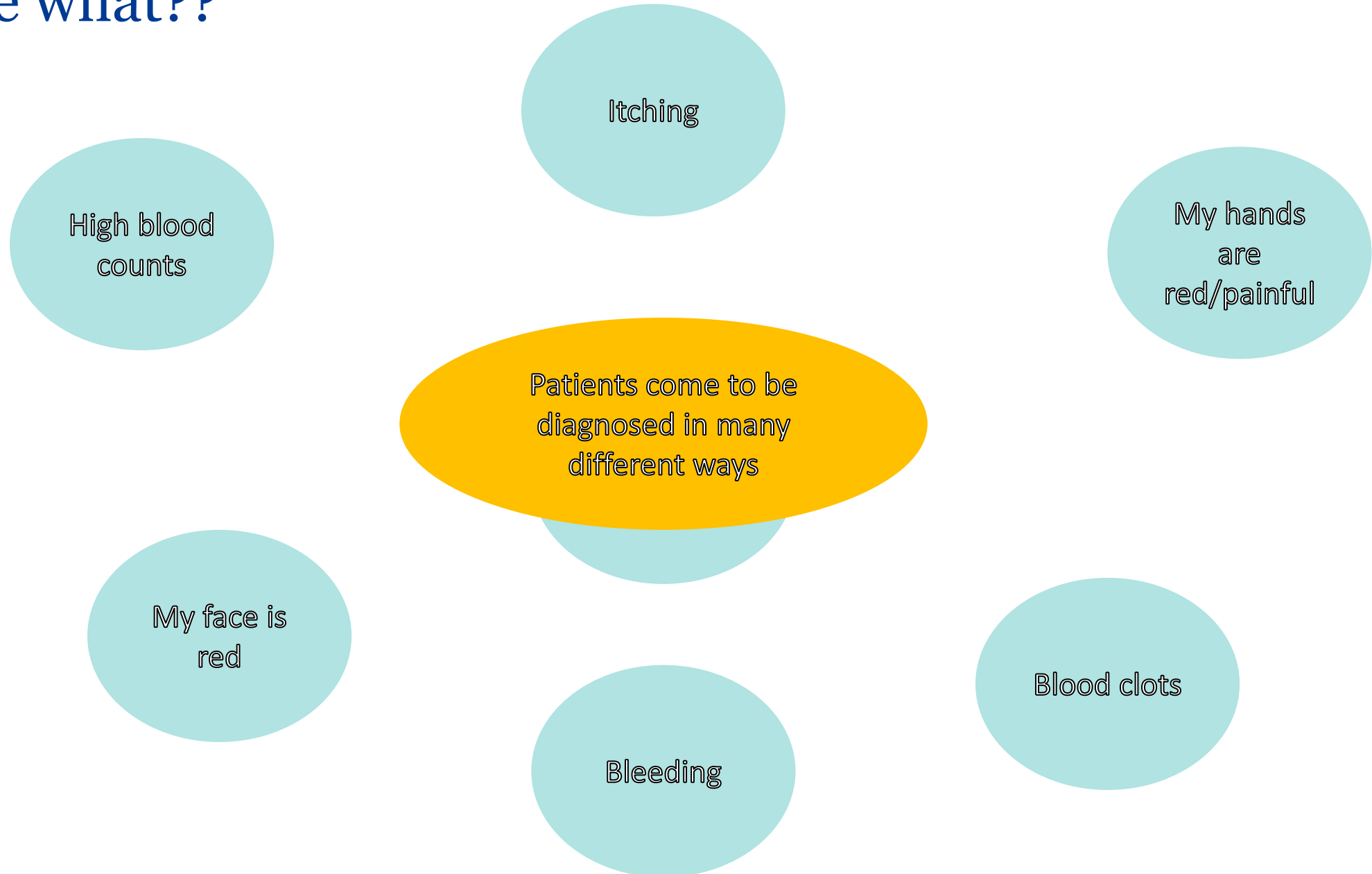
Management



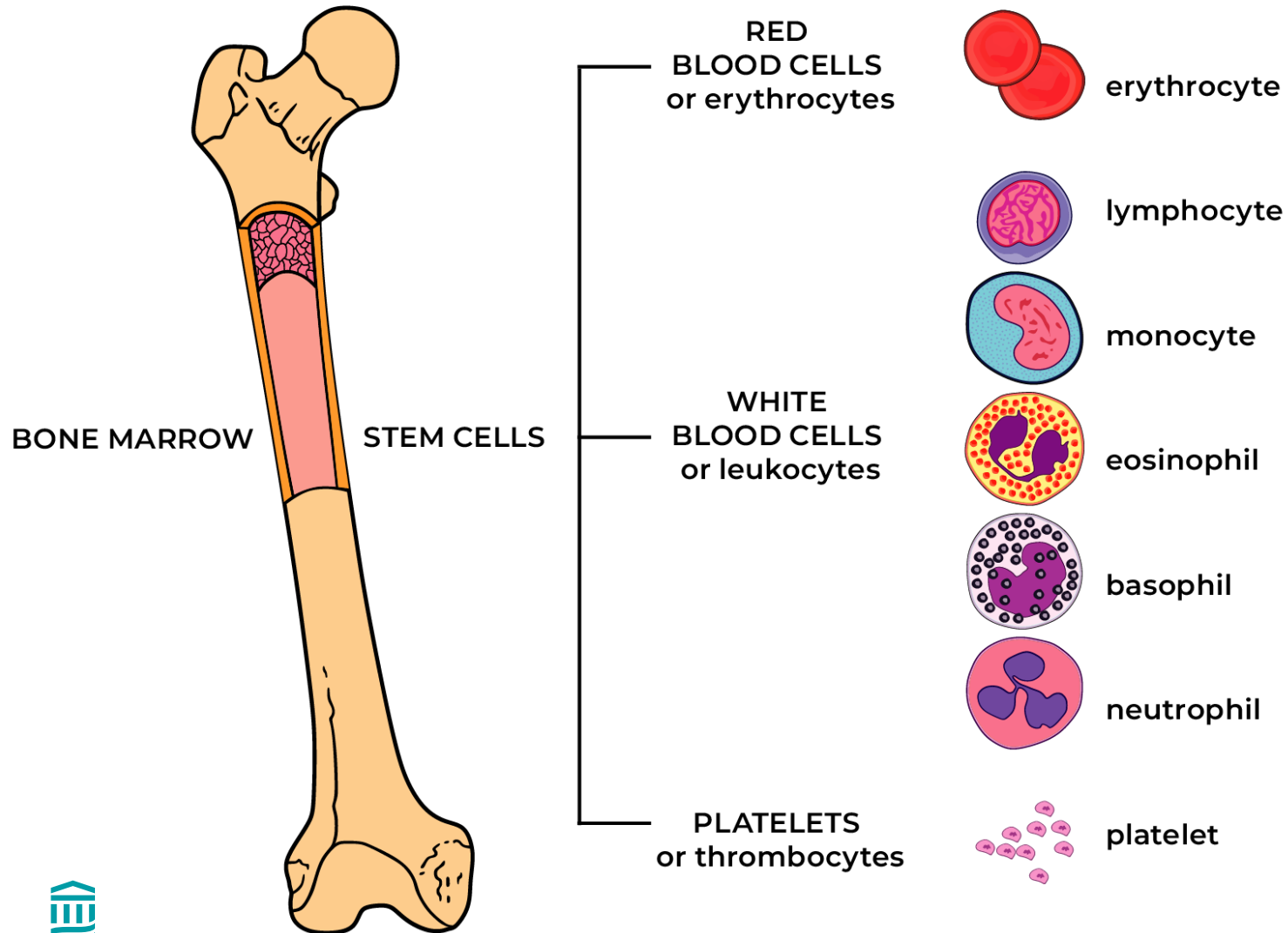
Diagnosing MPNs



I have what??



Talking to patients about a diagnosis



**We have to go to the source!
Bone marrow biopsy
Genetic mutations**



So, I have cancer?



What happens after diagnosis?



It can take many visits to the doctor for the patient to fully process the diagnosis



Offering frequent visits and communication is helpful during this period (and in general)



Tension between accepting diagnosis vs starting medical treatment

Starting treatment



Starting treatment

- Discussing treatment initiation can be challenging
 - Fear of side effects
 - Will I be on this forever?
 - What if it doesn't work
 - Is this chemo?
- Patients will do better with treatment if they:
 - Understand their diagnosis
 - Understand why they need treatment
 - Understand what treatment they will take, how to take it, side effects



Expectations from treatment- Big picture



- For PV and ET:
 - Goals: Prevent blood clots/bleeding, improve quality of life, ?prevent progression
- For MF:
 - Goals: Improve symptoms/spleen/QoL, ?improve survival
 - Bone marrow transplant: Cure



Expectations from treatment- Day to day



New pills



Frequent lab draws



Frequent clinic visits

Feeling scared

Anxiety



Side effects
From treatment



For some.... Watch and wait

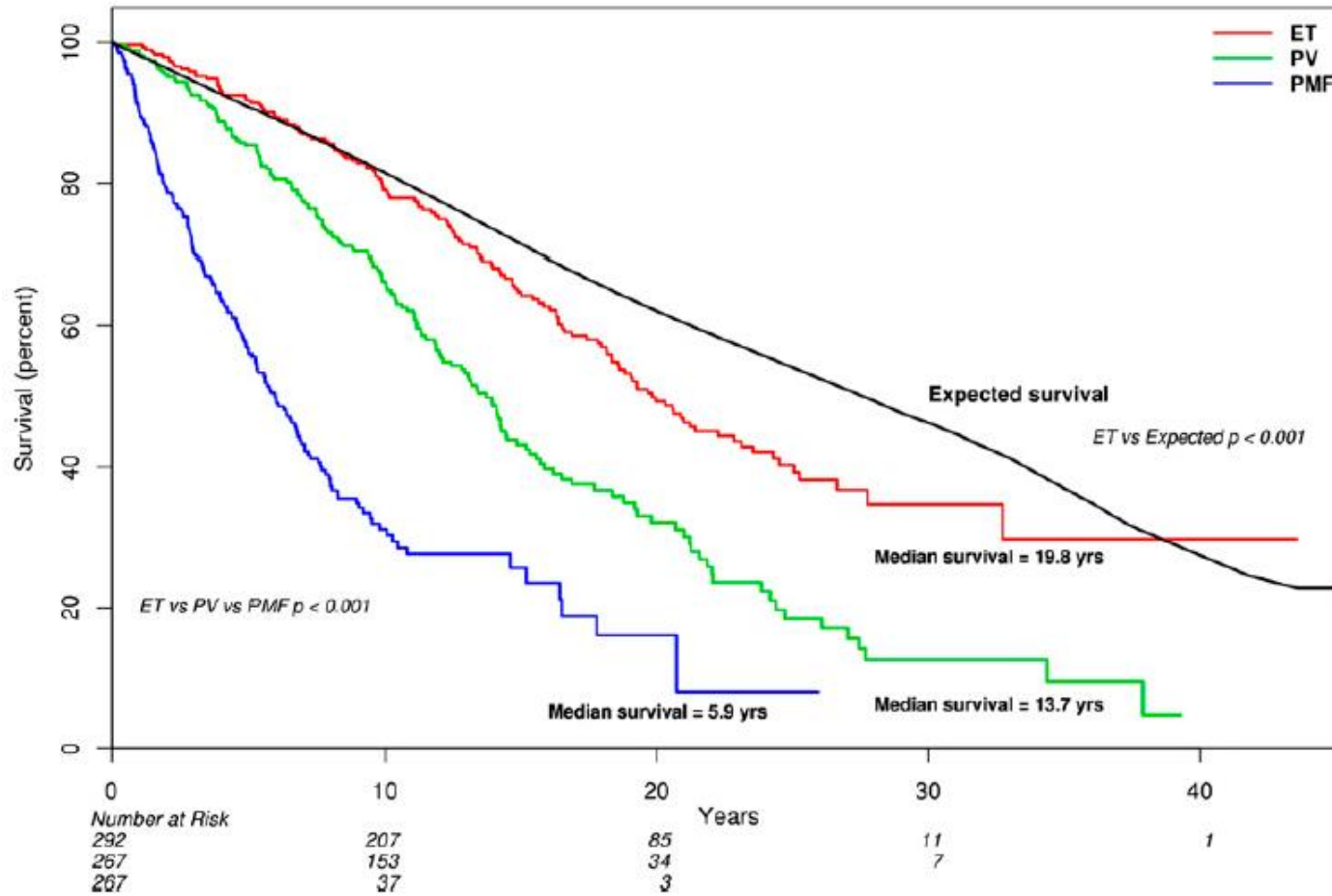
- Difficult to reconcile having a disease without treating it
- Watch and wait doesn't mean doing nothing
- Good opportunity to empower patients and emphasize the importance of:
 - Lifestyle modification
 - Managing cardiovascular risk factors
 - Staying up to date with healthcare management



Discussing prognosis



Survival in MPN

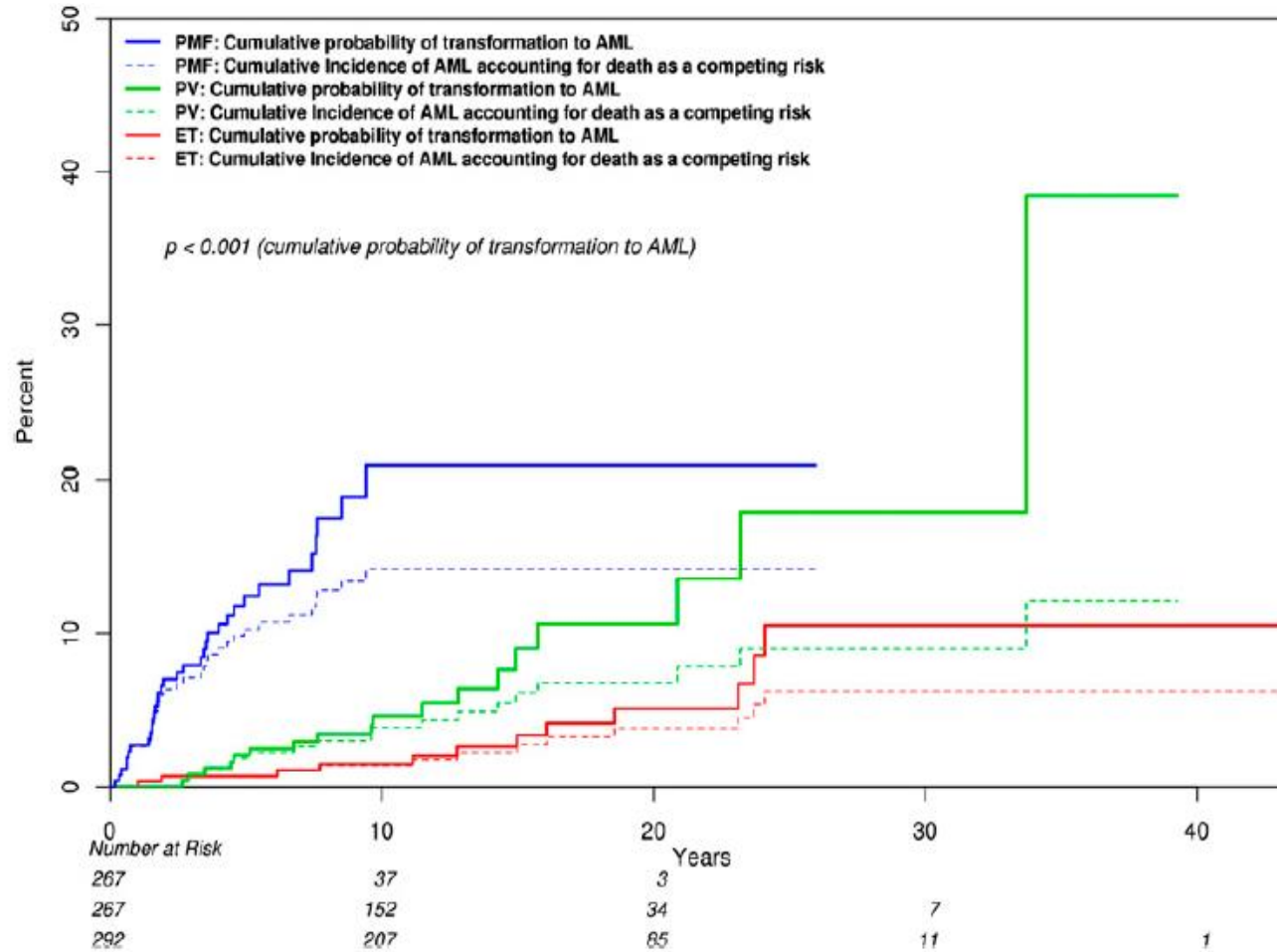


Overall Survival:

- ET: 19.8 yrs
- PV: 13.5 yrs
- PMF: 5.9 yrs



Fibrosis and Blast transformation in MPN



Blast transformation:
 ET: 3.8%
 PV: 6.8%
 PMF: 14.2%

Fibrotic transformation:
 ET: ~10%
 PV: 12-21%



Thrombosis risk in ET and PV

Essential Thrombocythemia

Risk Category	Risk factors
Very Low Risk	None
Low Risk	JAK2 V617F mutation only
Intermediate Risk	Age >60
High Risk	Prior thrombosis or age >60 AND JAK2 mutation

Variables: Age>60, prior thrombosis, JAK2 mutation

Polycythemia Vera

Risk Category	Risk factors
Low Risk	Age <60 AND no history of thrombosis
High Risk	Prior thrombosis or age >60



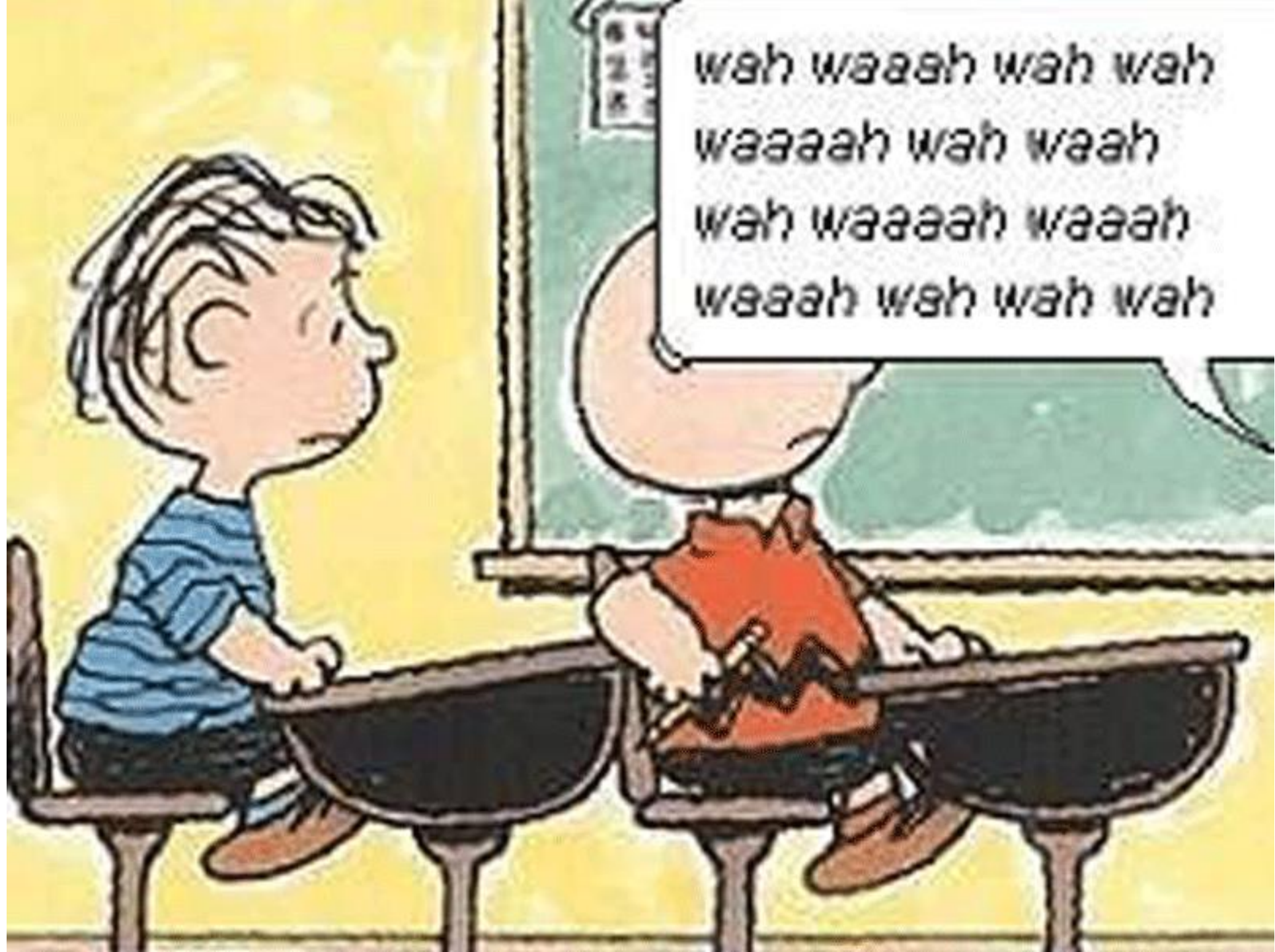
Prognostic Scores and Risk Stratification

	Lille	IPSS	DIPSS	DIPSSplus	MIPSS70	GIPSS	MYSEC-PM
Age		X	X	X	X		
Leukocytosis	X ^a	X	X	X	X		
Anemia	X	X	X	X	X		X
Symptoms		X	X	X	X		X
Circulating blasts		X	X	X	X		X
Thrombocytopenia				X	X		X
RBC transfusion dependent				X			
Adverse Karyotype ^b				X	X	X	
BMF					X		
Non-CALR type 1					X	X	X
HMR = 1					X ^c	X ^d	
HMR > 1					X ^c		

BMF, bone marrow fibrosis; DIPSS, Dynamic International Prognostic Scoring System; HMR, high molecular risk; IPSS, International Prognostic Scoring System; MIPSS; Mutation-Enhanced International Prognostic Scoring System 70; GIPSS, Genetically Inspired Prognostic Scoring System; MYSEC-PM, Myelofibrosis Secondary to PV and ET-Prognostic Model; RBC, red blood cell.

Mascarenhas J, et al. Leukemia, 2023. 37; 255–264





Tension between patient and doctor goals

Preventing thrombosis
Controlling blood counts
Improving symptoms
Can't cure outside of transplant

How long will I live?
Will I feel okay?
Can I still work? Have kids?
Can I afford the medications?
How will I feel with medications?



Summary- Learning to speak the same language

- Diagnosis-
 - Ensuring the patient understands their diagnosis
- Treatment-
 - Ensuring the patient knows WHY they are taking medications
 - Ensuring the patient knows WHAT to expect from treatment
- Prognosis-
 - Ensuring thrombotic risk and survival prognosis are separated and explained
 - Offering additional support when needed from social work, psychology and psychiatry



Thank you

