



# Patient Power

## Prognosis, Progression and Survival: Advice on Interpreting MPN Statistics

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### Andrew Schorr:

Dr. McMahon, so I wanna talk to you a little bit about statistics. So, you and your colleague there involved in research, and hopefully changing the numbers, if you will. Okay? And we talked about how individualized it can be among these three illnesses we're talking about. So, somebody says to you—and a family member, I can imagine somebody and Nelson you might have said to him on day one, “Doc, how long do I have?” You know, so how do we interpret statistics, or do we just forget about ‘em?”

### Dr. McMahon:

I think it's a very difficult thing. You want to be upfront with people. We wanna be very upfront with people so they know exactly what they're dealing with, but at the same time you have to understand that these are averages and with very specific populations of people, and it may not necessarily be applicable to you, even though it would be seemingly very objective, and may not necessarily apply to your particular—your specific case, and that's why I think it's important to—it's fine to go on the Internet, it's fine to go get information, but definitely ask the questions when you read those kinds of things.

Like, “I hear that the median survival is two years.” And you say, “Well, that's true. However, you have to understand that there's stipulations with that number.” So, it's hard as a patient or a family member of a patient, not to get hung up on the number, or numbers. But at the same time, there's a whole other context for each individual person. And it's definitely a dialogue with the providers, because it may not necessarily be applicable to you.

**Andrew Schorr:**

Dr. Daver, you alluded to something when you were talking about studies with Jakafi, or ruxolitinib, where you said, “Well, there was an indication that you’re learning more about whether it increases survival,” which were not the original end points of this study. So, the statistics from before may be changing now.

**Dr. Daver:**

So, I think—there are two points here, so one, when we talk about PV and ET, there’s actually very nice data from European Italian groups as well as from the Mayo clinic here, showing that these patients actually have very close to normal survival for age matched patients.

So, the goal is treatment in ET and PV is, one, preventing thrombosis complications, improving symptoms, and improving quality of life. Everything we’ve discussed. So, those patients there is a small risk of progression, but really the focus should be, “How I can maximize my quality of life?” Time with family, do the things you like. Now, myelofibrosis is a moving field, so you’re right, ten years ago the median survival, if I had to take all myelofibrosis patients without doing any stratification scoring, was about three to four years.

Today, we have an average of eight to ten years. But that also is based on data that is already outdated. So, you know when you go to big cancer centers, Colorado, MD Anderson, these statistics have already moved on, because this was published by Sear in 2012. And today, there are four new drugs with new ones coming, and so the whole field has changed. So, I think with myelofibrosis, especially, you just have to make contact with a big center, know what’s out there, and get the best treatment. And there’s really no number that you can plan for.

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