**Evan** (Physician) and **Everett** (BMT recipient)

**Articles**

* Informed consent – is that an understood consent
* Info needs of patients over 50
* Understanding of disease status and treatment plans at initial HCT consult

**Key learnings**

* Patients were not aware of diagnosis, relied on physicians for information about disease and treatment, patients tended to focus on prolonging their lives and less focus on QOL
* Age may play a significant role in decision making
* Patients wanted to be better informed of treatment options
* Most patients over estimated benefit of HCT when making treatment decisions
* Patients would have liked to be better informed of post-transplant outcomes (GVHD etc.)
* Studies were small in size, homogenous – so difficult to know if findings would be same with more diverse populations

**Research questions**

* Need larger number and more diverse participants
* Need longer studies following people over 5-10-15 years
* Written document that informs patients on diagnosis, prognosis, treatment options for pts/caregivers
* Stress what educational information is reliable/accurate and what might not be reliable/accurate
* Multidisciplinary teams should be involved in planning education, including specialists
* Patient treatment & education plans should also include interventions for caregivers
* Information on potential socio-economic impact of treatment should be provided

**Personal / Clinical Experience**

* Had full body radiation – and it’s pretty common knowledge about cataracts etc. – but I serious complications. Needed education about some of these post-transplant effects, in more detail. Consider bringing in other areas/specialties for brief education pre-HCT.

**Discussion**

* Margaret – appreciate the personal stories because opens mind to what people experience. But curious – the issue of pacing education. Transplant is complicated. And there’s a lot of toxicities. Early effects, late effects, chronic effects. We present a big binder with everything at the beginning. But wonder if we should try to understand the pacing of education. Heard the message that knowing something earlier allows you to affect its trajectory. But what is the balance between too much and not enough.
* Everett – Pacing is one thing, but a lot of times people don’t have the time. AML – diagnosis – moved fast through diagnosis and starting chemo.
* Kim – very good question. When/what is too much? Lend itself to a comparative effectiveness question.
* Susan – it might be just so personal. In my daughter’s case – diagnosis/treatment was very fast, and her focus was on 2 daughters. Support group was too stressful. She didn’t want to hear all the possibilities at that time.
* Barry – I very much agree with both sides in this – 2 parts of assessment: 1) how do we stage it out for different types of patients; 2) techniques for doing that – and tailored to each person. May vary by how much time is between diagnosis and HCT. At Loyola we offer patients a big book and a class. We describe the book as a reference. But everyone does it differently. How do we assess from both a timing and technique perspective, how best to give this particular patient information?
* Kim – yes, everyone has a different learning style and different needs. How do you assess quickly what is best for each individual patient?
* Susan – From the clinician perspective, are there things for patients to know in advance, that can help them prepare/avoid some GVHD? Or are these things you just have to deal with as they come?
* Margaret – I don’t think there is any expectation that patients can prevent GVHD. We talk about compliance, adherence, and taking medication as prescribed. Those behaviors might change the severity of a complication.
* Kim – To add on to that, it’s hard for health professionals to know how much to give. Give too much and not everything will happen. Give too little and it’s not enough. Personal story of BMT professional who had a family member go through BMT and had rare complications. She said of all the people who should know what to expect, she felt unprepared even with everything she knew about BMT.