**Helene** (Transplant physician in Belgium) & **Susan** (Caregiver for daughter, transplant 11 years ago)

**Key learnings**

* Importance of including electronic tools
  + Article #6 – Epic developing an app for pediatric setting (parents, patients). Not put into practice yet. So just a description of tool. Used patient and caregiver feedback to develop the tool.
  + E-tools allow personalized information, not a standard brochure
  + If we invest into e-tools, need enough patients to make it cost effective
* Article #21 – About liver/kidney transplant recipients. Quality article, saw it was positive to give information throughout hospitalization period, and not just after discharge. Gave learning goals every day to patient and caregiver. Months after transplant, patients were more satisfied.
* Statistics about survival, infection etc. need to be adapted to the age of the patient. Always think about giving pediatric information, but we don’t always think about 65+
* Health belief model – if you want to change the behavior of someone must take into account patient’s perception of risk, etc.
* 3 learning style – majority of people are visual, but some auditory and kinesthetic
* Article #77 – videos, how videos address all 3 learning styles and addresses health literacy issues
* Article about patients with breast cancer; free group education sessions – not effective.

**Research questions**

* Compare conventional educational materials with e-tools?
* Article about lung transplant patients – compared regular education to e-tool
* Compare education needs of different age groups?
* Test for learning style and give adapted patient education and measure outcome?

**Personal or clinical experience**

* Interesting to think about other ways of getting information to people. Shocked in clinical practice by low level of understanding by patients in front of me.
* Very good ideas to take your time, and repeat information. Sensitive to that because we don’t do much of that – discuss and do problem solving, instead of talk and talk (monologue)
* Need to include patients and partners in development
* Large groups are difficult for patients and caregivers because so many variables and time is of the essence.
* Videos are so nice because can go back to them as needed
* Repeating information is so important. One reason people have low level of understanding or retention is because patients/caregivers are so stressed.
* Did not resonate – solid organ transplant is very different in educational needs. Recovery is very different and slower. Transplant is surgery. Don’t just take things from solid organ and apply to BMT.
* Old review (2007) – It’s not that old, but we need to make sure that whatever educational material we use we need to update it to the state of science. It will make our research questions a challenge because whatever material we use it must be up to date.
* Is any research being done on the benefit of mental health services for BMT patients and their caregivers? It’s something that could improve people’s ability to heal, cope with treatment, and deal with extreme stress. Someone who specializes in this treatment.
  + Margaret – agree. Sufficient evidence to suggest that patients and caregivers have significant challenges re: emotional health. Should be doing this as part of regular practice.
* When Susan’s daughter was getting transplant, group was available, but didn’t want to go to a group. All that mattered was her experience. A lot was happening at that time. Caregiver needs support and info too.
* Support group in Maryland – caregivers laying out their issues and frustrations. Asked other caregivers how they get by. Caregivers need support. How to help them take the support?