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| **Emotional, social, and cognitive health meeting minutes** |
| **Date: September 23, 2016 Start Time: 10:30am CST End Time: 11:30am CST** |
| **Attendees:** Beattice Abetti, LCSW, Co-chair; Areej Al-Jawahiri, MD, Co-chair; Cynthia Bell, RN; Anna Barata, Psychologist; Jennifer Blosser, LCSW; Heather Jim, PhD; Jill Randall, LICSW (lead staff), Gerardo Camarillo, Caregiver; Wendy Gorrell, Patient; Kate Houg (admin staff)**Not in attendance:** Lizette Salazar, Caregiver, Betsy Lucas, Patient; Rob Minton, Patient; Eneida Nemecek, MD; Tim Walsh, Patient; |
| **Topic** | **Discussion Leader** | **Time** | **Discussion Summary** | **Action Items** |
| Welcome/Roll call | Jill | 5 min | Roll call with attendance noted above  |  |
| Reports from subgroups: common themes | Subgroup leaders | 35 min | * **Pediatric Social and Emotional Subgroup:** in terms of Health related QOL: younger children have higher QOL than older children and adolescents. Peds tend to experience more pain and lower self-esteem than older patients. Families tend to struggle emotionally and socially when a child is going through transplant. Children with ALL tend to have poor QOL health related outcomes. Overall stress decreases as time goes on. Open communication is essential for supporting kids through the BMT process. Very little account for racial/cultural differences in coping.

**Recommendations:** -Use multi-method approach**-**Using qualitative and quantitative methods**-**Assessing developmental impact on social health**-**looking long term, interventions**-**Design studies to account for changes in clinical status and personal factors**-**Clinical and sub clinical manifestations of symptoms**-**Peer support for parents**-**Impact of parents being decision makers, and differences in prognosis of children**-**Longitudinal studies are important**-**how couples cope together with a child’s transplant* **Emotional, Psychosocial Adult Subgroup:** Similar factors in what was found with the other literature. Methodology was seen as an issue—small sample sizes, bias, etc. There is a lack of cultural linguistic and ethnical diversity in the studies. Not as many studies with caregivers. There are time constraints for doing an interventional study. BMT programs vary in their long term follow up

**Recommendations:**-Better methodology/diversity of patient populations-Separate auto and allo patients-Control for different types of prep-Include more diversity-Consider use of technology for study and intervention-Capture patients with less ideal course of recovery-Focus on 1-5 year survival period-Look at Social Wellbeing and Social Support-Study the population from QOL and situational attributions* **Cognitive subgroup:** Would be helpful to get patients before their induction regimen. Would be helpful to study peds and adult populations separately. Adult auto and allo should be studied separately. Functional MRI, ERP, cognitive tests would be helpful. Identify and test interventions to help people recovery cognitively after transplant. Research needs to be presented in a meaningful way for patients, not just data driven. Insurance reimbursement is a concern.
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| How do we prioritize our recommendations? | Areej & Beatrice | 15 | * It’s difficult to figure out what a good approach would be as there are so many different circumstances from patient to patient
* We will organize all the summaries into one document and share with the group
* Think about the areas that are highest yield: burning topics that we need to cover and set as a priority research area, and how it could relate to comparative effectiveness research
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| Next steps | Areej and Beatrice | 5 min | * Summary will be sent to the group
* WG members look at two areas of highest yield: Topics we need to cover and set as a priority for research, and Comparative effectiveness research topics
* Next meeting will be a working meeting after everyone took a look at the summaries
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