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| **Emotional, social, and cognitive health meeting minutes** |
| **Date: June 29, 2016 Start Time: 10:30am CST End Time: 11:30am CST** |
| **Attendees:** Beattice Abetti, LCSW, Co-chair; Areej Al-Jawahiri, MD, Co-chair; Heather Jim, PhD; Cynthia Bell, RN; Anna Barata, PhD; Wendy Gorrell, Patient; Jennifer Blosser, LCSW; Eneida Nemecek, MD; Tim Walsh, Patient; Jill Randall, LICSW (lead staff)**Not in attendance:** Lizette Salazar, Caregiver, Betsy Lucas, Patient; Rob Minton, Patient; Gerardo Camarillo, Caregiver; Kate Houg (admin staff) |
| **Topic** | **Discussion Leader** | **Time** | **Discussion Summary** | **Action Items** |
| Welcome/Roll call | Jill | 7 min | Roll call with attendance noted above  |  |
| Literature review: questions, concerns, problems? | Areej and Beatrice | 5 min | We have reviewed a large number of articles using a divide and conquer approach.  |  |
| Reports from subgroups: common themes | All | 25 min | * Scarcity of pediatric studies
* 2 groups emerge: outcomes in the acute stage and outcomes in the chronic stage
* Issue of combining auto and allo patients in 1 sample
* Lots of methodological problems identified
* Mainly descriptive research
* Lack of research on interventions
* Question how changes in transplant medicine impact the results of the older research
* Great variety in measurement instruments used
* In peds psychosocial literature, there is a focus on family factors and resilience
* In peds, the sample population can be the pt, mother, father, donor siblings, and non-donor siblings
* Attrition rate impacts longitudinal studies
* Who is willing to participate in studies? Question if we’re capturing those pts/fams who need interventions the most.
* Per our patient members, the acute stage is when people are in survival mode. Psychosocial issues for patients and caregivers can surface months to years after transplant. Pts/cgs question why they’re struggling so far out of transplant. There are more resources available through the transplant center during the acute stage but few resources the farther out someone is. It’s an isolating experience to be dealing with post-transplant challenges when you rarely see the transplant team and live far from the center. Peer support through programs like *Peer Connect* are vital for patients to connect with one another. Recommend education at the outset that emotional issues can hit down the line. Also, in longer-term follow-ups, part of the visit should include a psychosocial/cognitive check-in: This is how your numbers and organs are doing; now, how are *you* doing.
* In the chronic phase, interventions may need to involve technology: skype, phone, email.
* It’s an exciting time to see medicine becoming interested in quality of life. Social, emotional, cognitive outcomes are seen as important.
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| Next steps: subgroups and input from patients, caregivers, and parents | Areej and Beatrice | 15 min | * 4 meetings left to prepare for ASH symposium: August, Sept, Oct, and Nov.
* The next large group meeting will be used for the subgroups to meet on their own to prepare one summary (1-2 pages outlining current knowledge and gaps) in their topic area for the co-chairs.
* Discuss these summaries and our large group’s recommendations in light of input from our patient, caregiver, and parent members’ expertise.
 | * Kate will assist with scheduling a call for each subgroup on Friday, August 26, 10:30-11:30 a.m. CT
* Finalize your individual summaries and circulate them to your subgroup by August 12.
* Final subgroup summary is due to Beatrice and Areej on September 9.
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