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| **Patient, caregiver and family education and support WG** |
| **Date: 9/23/16 Start Time: 9:00am CST End Time: 10:00am CST** |
| **Attendees:** Kim Schmit-Pokorny, RN, MSN, OCN, BMTCN (co-chair); Hélène Schoemans, MD; Margaret Bevans, RN, PhD, AOCN, FAAN; Everett Lee; Barry Schatz; Susan Kullberg; Kristin Scheeler, LSW; Kate Houg (NMDP admin staff); Jackie Foster, MPH, RN (lead NMDP staff), Alva Roche-Green, MD (co-chair); Elizabeth Murphy (NMDP staff)**Not in attendance:** Jack Aiello; Bronwen Shaw, MD; Laura Finn, MD; Cindy Sargeant; Evan Shereck, MD; |
| **TOPIC** | **DISCUSSION****LEADER** | **Time** | **DISCUSSION SUMMARY** |
| Welcome / Introductions | Jackie Foster | 5 min | Jackie conducted roll call |
| Review agenda and working group goal | Kim/Alva | 5 min | * Goal for this meeting is for the remaining teams to run through their article discussions
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| Share Findings | Kim & Alva | 10 min | * Kim reviewed mostly literature reviews
* One article talked about developing a clinically informed and patient centered measure of knowledge to help measure patient’s knowledge. The goal with developing tool was to help facilitate discussion and measure the patients understanding of treatments options
* Quantitative review of interventions-QOL, pain intensity and pain interferences, and determined if patient education affected the QOL, pain intensity, how much pain patients reported. Looked at a variety of studies in relation to these topics
* One article talked about including patients name on education materials may make a difference in how well the patient absorbed information
* **Themes:**

-Variability and lack of standardization in educational processes -Education does need to be standardized and consistent-Smaller amounts of education at any given time may be better-Different learning formats are important-Education needs to be consistent between different settings and health care providers-Education understanding for low literacy-Cultural differences* **Gaps and questions:**

-Lack of information aggravate distress felt by patients? -Can development and usage of knowledge scale identify gaps and strengths in knowledge, and measure -Understanding of treatment options? -Does higher quality education improve access to transplant? -Does patient education enhance knowledge acquisition and sharing? -Does individually tailored education enhance learning? -How many educational sessions, and at what point in the treatment process should they be given? -By educating the family member, can you help to educate the patient?* Alva also completed a review of the articles
* Accessibility of mobile devices for health information-translatable to our population
* Importance of culturally sensitive education
* **Themes:**

-Multiple modalities-Using individualized modalities-Standard needs assessment tool* **Gaps identified:**

-Pre-BMT needs assessment tool-How often educational conversations need to occur |
| Share Findings | Evan & Everett | 10 min | * Everett reviewed 3 articles with the assistance of his caregiver.
* Focused on informed consent, information needs of patients, and understanding of disease status and plans at the initial consultation
* Patients were not aware of their prognosis, and trusted their physicians to make the decision making process, and primarily relied on getting information from their physicians
* Patients focused more on prolonging their lives, and less on QOL
* Age may play a role
* Patients would have liked to have been better informed on treatment options, and overestimated the benefits of the transplant when making treatment decisions
* Patients would have liked to have been better informed on post-transplant outcomes
* **Recommendations:**

-Post-transplant studies that would follow patients over long periods of time are needed-Written document that informs patients and caregivers on prognosis, treatment options, and potential complications-When referring individuals to online resources, it should be stressed that the sources are reliable and general information on the internet may not be-Multidisciplinary teams should be involved in sharing certain types of information-Involve specialists in other areas who may be needed before beginning treatments-Patient treatment plans should include interventions for caregivers-Education about post-transplant side effects-Need to look at how much information to give patients and when to give it-How do you assess how people learn? |
| Next steps | Alva/Kim | 5 min | * Next group meeting is October 13, 2016
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| Summary of tasks and next steps | Kate Houg | 5 min | Website for our working group: <https://network.bethematchclinical.org/research/research-protocols/patient-centered-research-agenda/patient--caregiver-and-family-education-and-support/> |