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| **Patient, caregiver and family education and support WG** |
| **Date: 9/1/16 Start Time: 9:30am CST End Time: 10:30am CST** |
| **Attendees:** Kim Schmit-Pokorny, RN, MSN, OCN, BMTCN (co-chair); Hélène Schoemans, MD; Margaret Bevans, RN, PhD, AOCN, FAAN; Cindy Sargeant; Everett Lee; Barry Schatz; Susan Kullberg; Evan Shereck, MD; Kristin Scheeler, LSW; Kate Houg (NMDP admin staff); Laura Finn, MD; Jackie Foster, MPH, RN (lead NMDP staff), **Not in attendance:** Jack Aiello; Bronwen Shaw, MD; Alva Roche-Green, MD (co-chair); Elizabeth Murphy (NMDP staff) |
| **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 | * In the summary spreadsheet, the group filled in the gaps identified in research, research questions, and what they learned from the articles or what they found interesting
* Asking patients & caregivers to let us know if the questions/ gaps are important to them
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| Share Findings | Hélène & Susan | 15 min | * Electronic tools (article #6) - app for pediatric setting, but hasn’t been put into practice yet
* Article #21- liver/kidney transplant recipients—gave learning goals every day to the patient/caregiver
* Give personalized information
* 65+ populations—statistics need to be adapted to the age of the patient you are working with
* Health belief model
* 3 learning styles—visual, auditory, and kinesthetic all need to be addressed, and find out what kind of learners your patients and caregivers are
* Videos to address the 3 learning styles— able to re-watch videos
* Warning against organizing large group education sessions—so many variables with BMT patients, you don’t want to spend time addressing needs that don’t apply to you
* Issue with cost of hardware and development of tools
* **Research** **questions:**

-Compare conventional education material with patient specific education-Compare educational needs by age groups (article #78)-Assess patients/caregivers for learning style; give adapted education material & compare outcomes* **What Resonated?** Interesting to think about other ways to get information to people—not everyone is equal in amount of information they already know. Good idea to take your time, repeat information and do problem solving activities. We need to look at different needs related to different ages and lifestyles.
* Solid organ transplant is very different. Educational needs are very different for BMT
* Is there research on the benefits of mental health services for BMT patients and their caregivers? Could improve people’s ability to heal and cope with treatment. Margaret stated there is research and work in this area, and we have enough evidence to suggest this should be standard practice.
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| Share Findings | Margaret & Cindy | 15 min | * The articles were more on the early side of research
* Many resources available were pamphlet type resources with online resources available
* Need information available not only by hard copy, but online as well
* Communicating/documenting/tracking the education experience (not always a healthcare provider providing information)
* Coping styles/literacy is important to understand—need a way to assess patients and caregivers as we start the education process (individual needs, etc) to learn if it’s a literacy issue, or a timing issue
* BMT is so different than other transplants. It’s two steps forward, and one step backwards. This needs to be validated at every single appointment
* Discharge planning should be done by all people involved in your care and treatment—need to do ongoing assessments every time there is a visit, and should be required
* Not enough information on survivorship studies (issues of non-compliance, person gets sick)
* Need studies evaluating age specific educational strategies
* Inspire model: developed specific survivorship content and then pilot tested at multiple sites. There are more recent papers about this model that Margaret will find.
* **Questions:**

-Compare how to provide info to different age groups-How to educate on emotional support-How is the patient/caregiver absorbing the information?-Are there readiness assessment tools?-How to collect patient/caregiver experience and questions and integrating into EMR?-Need to provide mental health support for the caregivers |
| Next steps | Alva/Kim | 5 min | Will schedule another call mid-September.  |
| 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/> |