Palliative Cancer Care: Music Video for AYA-Parent Communication and Resilience

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Dates of Support: 08/18/2011– 06/31/2016 Total Award Amount: $2,426,507

Funding Agency: National Institutes of Health National Institute of Nursing Research (5R01CA162181-08)

Abstract:

Adolescents/young adults (AYA) undergoing treatment for high risk cancer, and parents, experience high distress, including symptom distress and uncertainty about the cancer, treatments, and future. Parents' distress can exacerbate AYA distress and render the parent emotionally unavailable. Parent and AYA distress also hinders AYA-parent communication about cancer-related concerns, including palliative care goals, treatment decisions, and the possibility of death. The proposed study addresses palliative care research priorities of the NIH, Institute of Medicine, and National Palliative Care Research Center related to emotional, spiritual, and practical needs of AYA and their parents. The study builds on significant findings from our current trial (NIH 5R01NR008583) which established efficacy of a Therapeutic Music Video (TMV) intervention to improve positive health outcomes for AYA undergoing stem cell transplant; qualitative findings indicated parents derive indirect benefit from the TMV by gaining insight into their AYA’s perspectives, but parents require support to manage their distress and initiate important conversations with their AYA. By adding a parent intervention component to our already efficacious TMV intervention, we propose parents will have less distress, and parents and AYA will perceive better family environment, which in turn will result in additional significant AYA outcomes during treatment not observed in the current R01. Specific Aims are to compare the efficacy of a TMV with a TMV plus parent component (TMV+P) on outcomes for both AYA and their parents; and determine relationships of parent distress and parent perceived family environment with AYA outcomes using a mixed methods approach. AYA (n = 129) and a parent will be randomized to the TMV or TMV+P condition. All AYA participants will receive the TMV intervention; parents randomized to the TMV+P will receive the parent intervention component. Findings from the study will directly impact care for thousands of parents and AYA with high risk cancer by increasing our understanding of parent/AYA needs and knowledge about relationships of parent distress and positive health factors to AYA outcomes, while directly addressing the interrelated needs of parents and AYA during treatment.