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Exploring attitudes, perceptions and coping from the perspective of families at risk of extremely preterm delivery

Karen Kavanaugh[1], **Brownsyne Tucker Edmonds**[2], **Shelley M Hoffman**[2], **Erin L Jeffries**[2] and **Tatiana Laitano**[2]
[1]Children's Hospital of Wisconsin, USA
[2]Indiana University, USA

The majority of periviable neonates (i.e., born between 22 and 24 weeks gestation) die or suffer moderate to severe disability. Parents and physicians are faced with the unique and unfortunate challenge to make 'end-of-life decisions' (EOL) at the very beginning of life. Unfortunately, little is currently known about parent's goals of care-particularly their attitudes, perceptions and coping mechanisms related to the death or long-term disability that may result from periviable birth. Our study aims to: utilize qualitative methodologies to prospectively assess attitudes, perceptions and coping mechanisms related to death and disability from the perspective of pregnant women, fathers, or important others when making decisions concerning periviable delivery; obtain preliminary quantitative data to assess the relationships between coping responses utilized by pregnant women and their partners or support persons, decision conflict, decision satisfaction and mental health status following periviable birth; and compare the attitudes, perceptions and coping mechanisms related to death and disability across racially and ethnically diverse populations. We are recruiting 30 women admitted with a pregnancy complication that poses the threat of or need for periviable delivery, along with the woman's partner and/or other important support person. Interviews are being conducted with participants at two time points over a three-month period. Using validated scales, we are quantitatively assessing coping responses, decision quality and post-decisional mental health outcomes. To date we have recruited 25 women and 12 partners and conducted 56 interviews. Data collection will be completed and analysis begun by May 2018.

Biography

Karen Kavanaugh is currently the Senior Nurse Scientist at Children's Hospital of Wisconsin and Professor Emerita at University of Illinois at Chicago. She has more than 30 years of research experience with parents facing serious conditions with their newborn. Her contributions to improving perinatal palliative and end-of-life care have had a broad impact nationally through her scholarship, leadership in national and regional initiatives and mentoring of clinicians and researchers. She has conducted nine NIH funded studies, authored more than 85 publications, and served as Guest Editor for several journal issues dedicated to perinatal palliative and end-of-life care.

karenlkavanaugh@gmail.com

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