Duke Center for REsearch to AdvanCe Healthcare Equity (REACH Equity)

Research Project 3

Improving racial disparities in unmet palliative care needs among intensive care unit family members with a needs-targeted app intervention

The quality of palliative care is highly variable for the nearly 5 million annual intensive care unit (ICU) admissions. These markers of poor quality are even more common among Black patients and families than among Whites. Yet improving ICU-based palliative care quality on a broad scale is challenging because of a limited palliative care workforce and ICU clinicians' difficulties in proactively identifying and addressing unmet needs among diverse patients and family members. To address these challenges, we developed PCneeds, a mobile app that allows families to self-report needs, receive information about palliative care, and get 'question coaching' to improve understanding. Clinicians can visualize patient/family needs and get decisional support on how to address them. In a series of pilot studies, we found that PCneeds was acceptable, feasible, and can reduce unmet palliative care needs and improve the quality of communication in racially/ethnically diverse populations.

While our pilot data are promising, we need to test the PCneeds intervention's effect on racial disparities in ICU care. We propose to enroll 335 family members (167 White and 168 Black) of ICU patients and 55 ICU physicians from academic and community settings in a 5-year project with four specific aims: (1) Optimize the app platform's usability, (2) Using a cluster randomized clinical trial, determine the effect of PCneeds vs usual care on unmet needs and patient-centered care in both Black and White patients, (3) Determine the impact of PCneeds on racial disparities in unmet needs and patient-centered care, and (4) Explore family member and clinician experiences with PCneeds using mixed methods to understand mechanisms within unique case contexts. We hypothesize that compared to usual care, PCneeds will reduce family members' unmet needs, increase the patient-centeredness care, and reduce hospital length of stay overall—though the magnitude of effect will be greater in Blacks compared with Whites.

PCneeds could be a transformative, paradigm-changing approach to personalized 'primary' palliative care delivered by non-specialists, and reduce racial disparities in ICU care by improving clinicians' ability to delivery patient/family centered care—the overarching goal of REACH Equity. It will do this by operationalizing a replicable care model, providing scalable digital tools and infrastructure usable by any health system, optimized for use by race/ethnically diverse populations, and automating the measurement of patient-/family-centered outcomes and quality indicators—all areas of care that are currently lacking. This theoretically grounded project’s numerous technological and conceptual innovations address research priorities described by the National Institute of Minority Health and Health Disparities, the National Academy of Medicine, and the NIH-NPCRC (Palliative Care Priorities Workgroup). We can successfully perform this research because of our multidisciplinary team’s expertise as well as the enthusiastic support of our institution and its clinicians.