Abstracts - e-Poster Presentations (Mini-Free Communications)

Friday, May 3rd, 2024 from 16:30-18:00 EDT
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P-150

ANEMIA AND CKD: UNDERSTANDING THE PATIENT EXPERIENCE AND LEVERAGING PATIENT PERSPECTIVES TO INFORM THE DEVELOPMENT OF A NEW EDUCATIONAL TOOLKIT

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Background: Anemia is a common comorbidity among people living with chronic kidney disease (CKD), and yet there is a lack of qualitative studies regarding anemia-related experiences and patients' gaps in knowledge, and a lack of educational tools for patients with CKD and anemia.

Objectives: To explore the multidimensional effects of anemia on people living with CKD and their caregivers, with a focus on the day-to-day challenges, experiences navigating the healthcare system, and gaps in knowledge regarding anemia and CKD.
Our second objective is to use this data to inform and develop an educational toolkit to support patients and caregivers of people living with CKD and anemia

Methods: We conducted three focus groups sessions with a total of 17 CKD patients and caregivers. The sessions were led by patient partners who were co-leads on this project. Transcripts were coded, and themes and subthemes were identified using inductive thematic analysis. The data that pertains to gaps in knowledge was used to inform the content for an educational webpage and flier on anemia and CKD.

Results: Themes relate to three large categories: A) impact of anemia on individual, B) patient experience within healthcare system and C) Gaps in knowledge and information needed.
Within these categories, the themes identified by patients and caregivers were 1) Physical and Emotional Toll of Anemia, 2) Challenges with Management of Anemia, 3) Impact on Quality of Life, 4) Disconnect Between Patients and their Healthcare Provider, 5) Experiences Interacting with Healthcare Teams, 6) Information needed, and 7) Consequences of lacking information.

Conclusions: In this study, participants described important challenges that accompany a diagnosis of anemia and CKD, including confusion about anemia, unanticipated severe symptoms, challenges with management and disconnects between patients and providers. Our educational toolkit was developed to address gaps in knowledge and empower patients to engage in their care.