Children's Hospital of Philadelphia PolicyLab

Community health worker support to adolescents and young adults with sickle cell disease: A multi-method analysis on transition-related support

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Background
Transitioning to adult care is challenging for adolescent and young adults (AYA) with sickle cell disease (SCD), often leading to increased morbidity and mortality. Community health workers (CHWs) may offer patient-centered support during this vulnerable transition.

Methods
We conducted a multi-method descriptive analysis of CHW encounter documentation from the CHW arm of the COMETS randomized clinical trial, which compared CHW support, mobile health, and enhanced usual care in improving health-related quality of life among transitioning AYA with SCD. Quantitative analyses characterized participant engagement and progression of participant-identified, transition-related goals during a 6-month intervention period. Qualitative analyses examined CHW documentation to contextualize how CHWs supported development of self-management and self-advocacy skills among AYA with SCD.

Results
Among the 120 participants (median age 18.7 years; 52% female; 92% Black or African American), 95% were successfully contacted within a median of 5 days. Participants set an average of 2.5 goals during the six-month intervention period, with 70% achieved by the end of the program. Qualitative analysis of CHW documentation revealed primary themes of transition readiness (48%), lifestyle improvements (21%), and hospitalizations or medical emergencies (19%).

Conclusion
This multi-method descriptive analysis demonstrates that CHWs can provide effective, scalable support for AYA with SCD during the transition to adult care. Future studies should explore the value and applicability of this model to other chronic pediatric conditions.

Journal:

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