Children's Hospital of Philadelphia PolicyLab

Community Health Workers Supporting Emerging Adults with Sickle Cell Disease

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Background: Community health workers (CHWs) are vital links between communities and health systems, with CHW models facilitating positive health and life outcomes. However, little is known about CHWs' experiences serving in these roles or their potential to support the transition to adulthood for adolescents and young adults (AYA).

Methods: Semi-structured interviews were conducted with CHWs and their supervisors from five recruitment sites affiliated with Community Health Worker and Mobile Health for Emerging Adults Transitioning Sickle Cell Disease Care (COMETS) Trial. COMETS compared the effectiveness of a CHW intervention, mobile health application, or enhanced usual care on the health-related quality of life of AYA with SCD transitioning from pediatric to adult care. To understand CHW and CHW supervisor experiences during the COMETS trial, interviews were analyzed using an integrated inductive and deductive thematic analytic approach.

Results: Three key themes emerged as interviewees described the unique aspects of the CHW role: (1) the supports for transition to adulthood that CHWs provided to patients, (2) the experiences of establishing trusting relationships with patients, and (3) the impact of the role on CHWs themselves. All interviewees reported unique contributions made by CHWs in supporting patients' transition readiness, and CHWs expressed that participating in COMETS impacted them personally and professionally.

Conclusion: This study highlights that the CHW role is unique both in how CHWs connect with AYA and how it impacts CHWs. Health systems should explore paths for sustainable funding and workforce development for CHWs and invest in infrastructure for CHW transition programs.

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