Training Young Adults as Community Health Workers Specializing in Pediatric to Adult Health Care Transition to Support Emerging Adults with Sickle Cell Disease

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Transition to adulthood is a vulnerable time for emerging adults (16–25 years of age) with sickle cell disease (SCD), as there is a seven-fold increase in mortality rates during the transition period. Emerging adults with SCD also have the highest rates of hospitalizations, emergency room visits, and hospital readmissions compared to other age groups. Community health worker (CHW) programs have been developed to address outcomes such as patient activation which includes an individual's knowledge, skill, and confidence for managing one's health and healthcare, quality of life, and healthcare utilization for patients with chronic illnesses. However, few programs specifically target transition-age patients with SCD. The aims of this study were to (1) create and adapt the existing Penn Center for Community Health Workers IMPaCT model trainings and materials to specifically support CHWs working with transition-age patients with SCD and (2) evaluate the feasibility of this adapted model to improve job readiness of the CHWs and perceived value of the CHWs by patients with SCD. A multidisciplinary workgroup defined specific goal-setting categories and developed a targeted CHW training curriculum. Additionally, the workgroup wrote a job manual including step-by-step guidelines with example talking points and defined an ongoing supervision of CHWs. Measures of implementation and impact on CHW job readiness included CHW training completion, job retention, knowledge evaluation, and patient reported CHW engagement. 15 individuals completed CHW training with an average employment length of 1 year and 4 months. 7 (47%) CHWs had research experience, 8 (53%) had clinical experience, and 11 (73%) reported SCD experience. On post-training knowledge evaluations, CHWs successfully identified key aspects of SCD, role scope, and research ethics. Patients frequently reported that they reached their goals while working with trained CHWs. This CHW training program provides a novel adaptation to the evidence-based IMPaCT CHW model to support the needs of youth with SCD during the vulnerable time of transition from pediatric-focused to adulthood-focused healthcare.

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