Community Health Worker and Mobile Health Interventions for Quality of Life Among Young Adults With Sickle Cell Disease

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Importance

Young adults with sickle cell disease (SCD) experience challenges transitioning from pediatric to adult care, leading to increased morbidity and mortality.

Objective

To evaluate the effectiveness of community health worker (CHW) support or a mobile health application (mHealth) compared with enhanced usual care (EUC) in improving health-related quality of life (HRQOL) for young adults with SCD transitioning to adult care.

Design, Setting, and Participants

The Community Health Workers and Mobile Health for Emerging Adults Transitioning Sickle Cell Disease Care study was an observer-blinded, multicenter, randomized clinical trial performed at 5 US children's hospitals with a recruitment period from January 15, 2019, to December 31, 2022, and data analysis performed from September 30, 2024, to June 30, 2025. Participants were 17 years or older with SCD.

Interventions

Participants were randomized 1:1:1 to 6 months of EUC, CHW plus EUC, or mHealth plus EUC. Both interventions included goal setting, self-management, skill development, symptom tracking, and transition support. The CHW plus EUC intervention provided weekly synchronous support primarily via phone calls, while mHealth plus EUC offered virtual peer support via interaction with discussion boards. The EUC group received standard care consisting of a transition checklist for consistency across sites.

Main Outcomes and Measures

The main outcome was HRQOL, assessed using the Pediatric Quality of Life Inventory (PedsQL) for SCD module. Clinically meaningful improvement was prespecified as a 10-point change. Secondary outcomes included SCD knowledge, transition readiness, and social support. All outcomes were collected at baseline and follow-ups at 6, 12, and 18 months.

Results

Of the 700 eligible patients across the 5 sites, 405 were enrolled, and 375 participants with SCD were randomized, 191 (51.5%) of whom were women. The mean (SD) age was 18.9 (1.9) years; the median age was 18.0 (IQR, 17-20) years. Baseline demographic data, clinical characteristics, and markers of disease severity were comparable across the study groups. At 6 months, the CHW plus EUC group showed modest improvements in HRQOL compared with the EUC group at 2.67 (95% CI, 0.25-5.09) at 6 months; there was no change for the mHealth plus EUC group at 0.73 (95% CI, ?1.48 to 2.93) at 6 months; and the EUC group had a

decline of 2.58 (95% CI, ?4.67 to ?0.49). CHW support demonstrated the greatest improvement in PedsQL scores compared with EUC at 6 (5.25 [95% CI, 2.05-8.45] points), 12 (5.56 [95% CI, 1.52-9.61] points), and 18 (6.14 [95% CI, 1.75-10.54] points) months. The mHealth plus EUC intervention demonstrated improvement in PedsQL scores at 6 months only (3.31 [95% CI, 0.27-6.35] points). Throughout the study, the HRQOL for the EUC group declined. No significant differences were found in secondary outcomes.

Conclusions and Relevance

Although neither intervention met the prespecified 10-point threshold for a large clinical effect, the CHW intervention produced a significant and durable improvement in HRQOL that halted the decline observed in EUC. This sustained effect during the 18 months of follow-up suggests that CHW support provides a clinically relevant benefit for young adults with SCD during their transition to adult care. Integrating such programs into routine care could improve outcomes for this vulnerable population.

Journal:

JAMA Network Open
Authors: Jan S, Steinway C, Belton T, et al.

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