

Improving the transition process from pediatric to adult HIV care in North Carolina: A patient- and family-centered perspective system dynamics model

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Abstract: Improving the Transition Process from Pediatric to Adult HIV Care in North Carolina: A Patient and Family-Centered Perspective System Dynamics Model (Under the direction of Andrea K. Biddle) When the adolescent's journey to adulthood is compounded by a complex chronic disease such as HIV the young person and their caregivers are oftentimes overwhelmed by the multifaceted array of issues. HIV-infected youth must learn to navigate a complex health regime and the social stigma that is associated with HIV. Studies show that youth may lack skills and confidence to adapt to the impersonal nature of many adult care institutions, and adherence to care regimes and medications is frequently a challenge. The parenting of HIV-infected youth is also a challenge and caregivers often lack the support they need. Youth need transitional care that is supportive and empowers self-efficacy.

This study focuses on transition of care from the perspective of HIV-infected young adults and the parents/caregivers of HIV-infected adolescents with a goal of formulating a patient-family-centered set of recommendations. The study assesses the common barriers and predictors of successful transition of care from the perspective of those most affected. The three-phase qualitative research design assessed effective transition strategies. Phase 1 consisted of key informant interviews (KII) with HIV-infected young adults and family members. Phase 2 prioritized key themes from the KIIs and correlated existing recommendations from the American Academy of Pediatrics (AAP) Committee on Pediatric AIDS (COPA) and the literature review findings to formulate a system dynamics causal loop diagram. Phase 3 involved a Stakeholder Action Planning (SAP) Session composed of: HIV-infected young adults 18-25 years of age, caregivers of HIV-infected adolescents, and healthcare providers to address "sticking points" identified in the transition process. Findings were then triangulated to propose key recommendations from the individual- and family-centered perspective. Summary of key findings revealed the top ten issues identified by the key informants: adequate medical insurance, family/caregiver support, individualized physical/mental healthcare plans, ongoing provider support throughout the transition, strong self-efficacy, patient centered medical homes with wrap-around services, electronic health records and technology support, age appropriate educational support, stigma issues, and career guidance and planning.

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