

Helping High-Risk Youth Move through High-Risk Periods: Personally Controlled Health Records for Improving Social and Health Care Transitions

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Abstract

Background:

New patient-centered information technologies are needed to address risks associated with health care transitions for adolescents and young adults with diabetes, including systems that support individual and structural impediments to self- and clinical-care.

Methods:

We describe the personally controlled health record (PCHR) system platform and its key structural capabilities and assess its alignment with tenets of the chronic care model (CCM) and the social-behavioral and health care ecologies within which adolescents and young adults with diabetes mature.

Results:

Configured as Web-based platforms, PCHRs can support a new class of patient-facing applications that serve as monitoring and support systems for adolescents navigating complex social, developmental, and health care transitions. The approach can enable supportive interventions tailored to individual patient needs to boost adherence, self-management, and monitoring.

Conclusions:

The PCHR platform is a paradigm shift for the organization of health information systems and is consistent with the CCM and conceptualizations of patient- and family-centered care for diabetes. Advancing the approach augers well for improvement around health care transitions for youth and also requires that we address (i) structural barriers impacting diabetes care for maturing youth; (ii) challenges around health and technology literacy; (iii) privacy and confidentiality issues, including sharing of health information within family and institutional systems; and (iv) needs for evaluation around uptake, impacts, and outcomes.

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Abbreviations: (CCR) chronic care model, (HIT) health information technology, (HITECH) Health Information Technology for Economic and Clinical Health, (PCHR) personally controlled health record, (PHR) personal health record, (T1DM) type 1 diabetes mellitus

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