Healthcare 4 (2016) 57–68

Contents lists available at ScienceDirect

Healthcare

journal homepage: www.elsevier.com/locate/hjdsi

Into Practice

Better health, less spending: Redesigning the transition from pediatric to adult healthcare for youth with chronic illness

Yana Vaks [a,b,*,1], Rachel Bensen [a,c,1], Dana Steidtmann [a,d,1], Thomas D. Wang [a], Terry S. Platchek [a,c], Donna M. Zulman [a,e,f], Elizabeth Malcolm [a], Arnold Milstein [a]

[a] Clinical Excellence Research Center, Stanford University School of Medicine, United States
[b] Department of Pediatrics, Loma Linda University Children's Hospital, United States
[c] Department of Pediatrics, Stanford University School of Medicine, United States
[d] Department of Family Medicine, University of Colorado School of Medicine, United States
[e] Division of General Medical Disciplines, Stanford University School of Medicine, United States
[f] Center for Innovation to Implementation, VA Palo Alto Health Care System, United States

ARTICLE INFO

Article history:
Received 2 April 2015
Received in revised form
1 September 2015
Accepted 1 September 2015
Available online 21 October 2015

Keywords:
Care transition
Health care delivery
Chronic illness
Adolescent medicine
Affordability

ABSTRACT

Adolescents and young adults (AYA) with serious chronic illnesses face costly and dangerous gaps in care as they transition from pediatric to adult health systems. New, financially sustainable approaches to transition are needed to close these gaps.

We designed a new transition model for adolescents and young adults with a variety of serious chronic conditions. Our explicit goal was to build a model that would improve the value of care for youth 15–25 years of age undergoing this transition. The design process incorporated a review, analysis, and synthesis of relevant clinical and health services research; stakeholder interviews; and observations of high-performing healthcare systems. We identified three major categories of solutions for a safer and lower cost transition to adult care: (1) building and supporting self-management during the critical transition; (2) engaging receiving care; and (3) providing checklist-driven guide services during the transition. We propose that implementation of a program with these interventions would have a positive impact on all three domains of the triple aim – improving health, improving the experience of care, and reducing per capita healthcare cost. The transition model provides a general framework as well as suggestions for specific interventions. Pilot tests to assess the model's ease of implementation, clinical effects, and financial impact are currently underway.

1. Background

Life expectancy has increased dramatically for a wide range of childhood-onset medical conditions, enabling many affected children to survive into adulthood. Increased survival of extremely premature infants,[1] expanded surgical options for patients with congenital heart defects,[2,3] and improved treatment of genetic disorders such as cystic fibrosis[4] and sickle cell disease[5] are salient examples of advances that contribute to this trend. Although these breakthroughs represent a triumph of modern medicine, they introduce a new and growing challenge as an increasing number of adolescents and young adults (AYA) with childhood-onset chronic illness transition from pediatric to adult-oriented healthcare.

2. Organizational context

A healthcare delivery innovation lab was established in 2010 at a major academic center with the mission of developing more affordable ways to deliver better healthcare for conditions consuming a significant portion of U.S. healthcare spending.[6] Guided by national experts, the lab leadership recognized healthcare transition in AYA with chronic illness as an emerging clinical and economic challenge. A design team was assembled to create a new transition care model that would provide high quality, evidence-based care and lower per capita health spending for this population. The team included two physicians, a clinical psychologist, and an economist, each contributing expertise from their field to reach

* Corresponding author at: Clinical Excellence Research Center, Stanford University School of Medicine, 75 Alta Road, Palo Alto, CA 94305–6015, United States. Fax: +1 650 723 8611.
E-mail address: yavaks@gmail.com (Y. Vaks).
[1] Denotes equal contribution.

http://dx.doi.org/10.1016/j.hjdsi.2015.09.001
2213-0764/

unique solutions to the complex problem of transition. The new delivery model was presented to health systems leaders to discuss opportunities for implementation, evaluation, and refinement.

3. Problem

During the transition to adult care, AYA with chronic illness experience lapses in care as well as increased rates of emergency room visits and costly, avoidable hospitalizations.[7,8] Studies have documented poor health outcomes associated with transitions in care, including elevated glycosylated hemoglobin in patients with type 1 diabetes,[9] increased frequency of sickle cell crises,[10] loss of transplanted organs,[11] and, in extreme cases, death.[12] Treatable mental health conditions, particularly anxiety and depression, are common comorbidities of chronic illness in AYA[13] and are associated with poor health status[14] and greater cost compared to chronic illness without comorbid mental health conditions.[15]

This transition from pediatric to adult-oriented care is especially difficult because it occurs at a time when young people face numerous life changes, including education, employment, relationships, and living arrangements. Young adults historically have higher rates of uninsurance, decreased access to regular sources of care, and worse overall health status compared to either children or adults in their 30s and 40s.[16–18] Yet despite the need, it remains challenging to provide high quality transition care due to lack of financial incentives for services such as care coordination and limited accountability for health outcomes when AYA change providers or transition to new insurance plans.

Consensus statements outlining the importance and key components of optimal transition care were released by several professional organizations[2] in 2002 and 2011.[19] Despite the calls for action, a recent survey indicated that 60% of youth with special healthcare needs do not receive core elements of care recommended during this vulnerable time.[20] Additionally, few transition interventions described in published literature include cost and outcomes data.[20–22]

Many existing transition programs have been designed within a single clinic or disease process.[23] Such an approach may leave young people with especially rare conditions (e.g. genetic and metabolic disorders) without transition services. Because of the heterogeneity and low prevalence of many childhood-onset illnesses,[23] we aimed to create a model for a wide variety of chronic conditions with an explicit focus on addressing all three elements of the Institute for Health Care Improvement's "triple aim" of improving health, enhancing experience of care, and reducing total costs of care.[24] While guidelines call for initiation of transition preparation by early adolescence,[19] there is a lack of consensus about the optimal time to transition care[25] and a great deal of variability exists in clinical practice. We focus on youth aged 15–25 years, with the goal of encompassing the years surrounding transition to adulthood and transfer of care for the majority of youth in the U.S., while maintaining flexibility about the timing of transfer.

4. Solution

4.1. Model design

4.1.1. Overview

We based the model design on a review and synthesis of clinical and health services research as well as observations of successful transition programs and high-performing healthcare systems[6] (see Appendix 1). We first identified patients' and providers' unmet needs related to transition and then generated a model focused on addressing these needs utilizing high value care strategies. This project was determined to be exempt from review by the local Institutional Review Board.

4.1.2. Literature review

Our initial literature review focused on identification of cost-driving factors for AYA with chronic illness. A subsequent review examined evidence-based transition programs with impact on reducing utilization and/or costs. Where evidence from interventions with AYA populations was not available, we searched for interventions that reduce cost in adult chronic disease populations and/or during other types of transition (e.g. hospital to home).

4.1.3. Observation and interviews

Experts in the fields of transition and care coordination for complex patients nominated exemplar sites for observation and interview. We directly observed care at four clinical sites and conducted semi-structured interviews of patients, parents, staff, and providers. Two of these sites were state-of-the-art pediatric transition clinics: one staffed by medicine-pediatrics providers specializing in care of AYA with complex chronic illness in an academic setting and one with a multidisciplinary transition program within a pediatric transplant clinic. In addition, we observed pediatric primary and specialty care at one integrated health system known for providing exemplary high value care to children but which lacked a structured transition program. The fourth observation was at an "adjacent possible" site – a health plan delivering high value integrated care to high-risk seniors with chronic illness. We also conducted semi-structured interviews with providers in three additional types of transition delivery models: a consult service, in which the patient and family attend a clinic devoted to issues of transition while still receiving medical care from their usual primary and specialty care providers; a transition program embedded within a patient's pediatric medical care; and a transition clinic to which patients transfer during adolescence to receive primary care until the age of 24. We interviewed clinicians providing care to adults in four different health systems in order to understand issues that receiving providers face after transfer. Finally, we spoke with a convenience sample of additional patients, parents, and advocacy groups with personal experiences in transition.

4.1.4. Synthesis of identified needs

We compiled a list of over 100 unmet needs and transition challenges from the literature review, site observations, and interviews. Three members of our team coded these needs into 10 themes (Fig. 1, Appendix 2). Discrepancies were discussed among team members and resolved by consensus. The same team members then independently rated each theme in three equally weighted categories: the degree to which, based on existing evidence, addressing the need could influence: (1) clinical outcomes, (2) care experiences, and (3) cost of care. Twenty-five external stakeholders identified during literature review, observations and interviews used a 10-point Likert scale to rate each of the 10 major themes by degree to which addressing the area is important for high quality transition care and rank ordered the top 3 most important themes. Needs that emerged as highest priority are listed in Fig. 1.

4.1.5. Model prototyping

We generated potential solutions for addressing high-priority needs with a focus on incorporating evidence-based interventions and high value care strategies to maximize health outcomes per dollar spent.[26] Proposed solutions were refined iteratively based

[2] The American Academy of Family Physicians, the American College of Physicians, and the American Academy of Pediatrics.