Development of a Transition Program for Emerging Adults with Type 1 Diabetes - A Feasibility Study

Elizabeth A. Minchau, DNP, APRN-BC, FNP-BC
West Virginia University School of Nursing, Morgantown, WV

Problem

Emerging adults with chronic diseases, like T1D, are often under-prepared to independently navigate the required self-care responsibilities that are common with progression into young adulthood. [1]

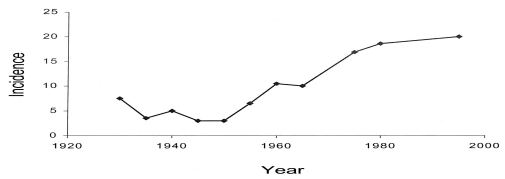
The developmental challenges that occur during the transition time period for those with T1D can lead to:

- gaps in diabetes care
- noncompliance with daily medication administration
- suboptimal health care utilization
- deteriorating glycemic control
- increased occurrence of acute complications
- emergence of chronic complications of diabetes that may go undetected or untreated
- psychosocial, behavioral, and emotional challenges [2]

Significance of the Problem

- 30% of young adults with type 1 diabetes disengage from care during transition and 46% report difficulties with the transition process [3,4,5]
- Clinic attendance declines in this age group; among those lost to follow-up, glycosylated hemoglobin (HgbA1c) is noted to be 1.5% higher than among those who remain in medical care [6]
- Youth who abruptly transfer from pediatric to adult services are 2.5 times more likely to have poor glycemic control than those who stay with their pediatric provider [7]
- Given the increasing incidence of diabetes in childhood over the last century, it is expected that tens of thousands of young adults with T1D will be transitioning from pediatric to adult care each year [8]

Incidence of T1D Over Last Century



Program Development

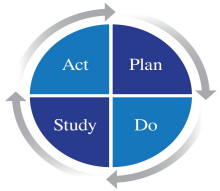
- *Healthcare transition (HCT)* is, "the purposeful, planned movement of adolescents and young adults with chronic conditions from pediatric to adult care within healthcare systems." [9]
- For children with chronic disease, the evidence shows that organizing the transition process is imperative to enhance continuity of care, improve treatment adherence, reduce morbidity, increase patient and family satisfaction and self-confidence, and prevent emergency room and hospital visits.[10]
- A formal transition of care program titled, ***Preparing Emerging Adults with Knowledge and Skills*** **(PEAKS),** was designed for adolescents with T1D between the ages of 16-18 with the following two aims:
- **Aim 1**: Adapt the federal "Got Transition" *Six Core Elements of HCT* [11] framework to the specific needs of the pediatric endocrinology clinic via integration with the ADA's 14 (diabetes-specific) recommendations for transition
- **Aim 2:** Examine the feasibility of implementing the PEAKS transition of care program in a rural pediatric endocrinology practice in West Virginia

Core Element	ADA Practice Guideline	PEAKS Program Structure
Transition Policy	Sharing purpose, goals and objectives; orienting patients to adult care; intervening with respect to developmental age	Policy development and distribution
Tracking/monitoring	Closing gaps in care with ongoing visits every 3 months; screening for eating and affective disorders; monitoring for complications	EHR recognition of age to enroll; in-clinic transition specific education topics with additional online resources; PEAKS flowsheet to track program components
Transition Readiness	Self-management; transition topic education and skill development; individualized care	Transition readiness assessment using READDY tool and individualized self-management education
Transition Planning	Health care transition plan that starts one year prior to transfer of care	Start program at age 16; offer list of regional adult providers; continue focus on self-care and independent medical decision-making; focus on personalized goal-setting
Transfer of Care	Aligning adult endocrinology care and primary care; providing a written clinical summary	Complete *Passport to Adult Care* and *Clinical Summary*; make first adult appointment for patient
Transfer Completion	Communicating with receiving providers; collecting data on satisfaction with transition processes	Follow-up call from clinical nurse coordinator at 6 months post-discharge; offer transition program satisfaction surveys

Methods

- The Model for Improvement's Plan-Do-Study-Act [12] was used to **guide and evaluate program design and implementation** using a 4-phase process that continually elicited stakeholder feedback.

Phase 1: Early program design
Phase 2: Integration of program into the electronic health record
Phase 3: Education of staff on program package
Phase 4: Program roll-out; semi-structured interviews focused on the acceptability and practicality of program design



Feasibility Analysis

Codes:	Categories:	Subcategories:	Exemplars:
Acceptability	*Satisfaction*	ease of use beneficial good fit	"As a CDE, I love it because it gives me a template for topics to dive into - some of which we may not have even considered discussing with a patient."
	Intent to continue use	sustainable meets standard of care time concerns	"This program really took into account our small size and was designed in a way that did not increase personnel requirements." "It does add additional time to visits, especially when we run the catch-up visits for the older adolescents."
	Perceived appropriateness	improved quality of care improved transfer of care	"All diabetes clinics should be doing this." "It allows us to sever ties gracefully."
Codes:	**Categories:**	**Subcategories:**	**Exemplars:**
Practicality	*Factors affecting ease or difficulty of use*	adds time requirements organized framework within Epic	"Time remains the issue. The readiness tool can be difficult time-wise for some patients based on technology issues or cognitive abilities such as mother having to read and explain each question." "Linking everything through Epic has made things much easier than they otherwise would have been."
	Efficiency, speed, and quality of implementation	some components add time some components save time	"Catch up visits are difficult and add time to the overall appointment." "My experience using the EHR as the framework for the program is excellent - pretty much automatic. Good resources available with just a couple of key-strokes."
	Positive and negative effects on target population	helps identify deficits closes gaps in care	"We are now having longer discussions based on identified deficits, but it's valuable time spent." "Creates a gracious and organized transition process as they move on to their new provider."
	Ability of participants to carry out activities	offers guidance	"It's forcing us to follow an algorithm and ultimately engage in an organized transition process."

Conclusions/Clinical Implications

- The PEAKS program was deemed acceptable and practical by stakeholders in this busy, rural pediatric endocrinology clinic. The transition-focused education, documentation, and transfer of care processes helped the clinic reach the best-practice standard of care, but added time to clinic visits. Continued program evaluation that is focused on patient outcomes is a vital next step.

References

Available on separate sheet