

Transition from pediatric to adult care in patients with Type 1 Diabetes Mellitus

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Introduction

Description of the problem

Transition to adult care for adolescents with Type 1 diabetes mellitus (T1DM) is challenging for patients who are gaining independence. Care is typically managed by the parents, and teens do not always understand the importance of optimal blood sugar control (Borus & Laffel, 2010). There is little understanding of the consequences of poor blood sugar control or the impact of lifestyle choices in the late adolescent years and early adulthood years. Many adolescent patients have poor HbA1c levels and the risk of long-term complications is very high (American Diabetes Association (ADA), 2015). A disjointed transition to adult care can lead to poor outcomes when adolescents do not learn to manage their disease properly (Cohen et al, 2015). These adolescents are often moving on to college or out of their parents' household.

Epidemiology

Diabetes is a metabolic disease that is characterized by hyperglycemia due to an interruption in insulin secretion, impairment in insulin action, or both. There are two classifications of diabetes, type 1 diabetes (T1DM) and type 2 diabetes (T2DM). Autoimmune destruction of the β - cells in the pancreas and therefore interruption in insulin secretion causes T1DM (ADA, 2014). In the United States, 1.2 million people are living with T1DM and 40,000 people are newly diagnosed each year (ADA, 2014). While T1DM typically occurs in childhood and adolescence, onset of the disease can occur at any age (ADA, 2014). T1DM accounts for only 5-10% of those with diabetes however, it is the second most common chronic illness in teenagers following asthma (ADA, 2014, Borus & Laffel, 2010). Youth (aged less than 20 years-old) account for 200,000 of these people living with T1DM with a notable increase of

21% in prevalence between 2001 and 2009 (Juvenile Diabetes Research Foundation (JDRF), 2014). At least 40,000 people are diagnosed with diabetes every year and the number diagnosed each year is on the rise (JDRF, 2014).

Risk for development of T1DM often bears a genetic component, although it is possible to develop T1DM without a known family history of the disease. Risk for development of T1DM for the overall population is approximately 0.3%, while a person with a first degree relative with T1DM has a risk of 5% (Chiang, Kirkman, Laffel, & Peters, 2014). Evaluation and screening for people with a first-degree family history of T1DM is not recommended due to inability to address prevention prior to onset of disease (Chiang et al., 2014). There is a significant increase in risk for people with family members diagnosed with T1DM however, the utility of screening asymptomatic relatives of people with T1DM is low. Screening patients with a family history of T1DM is discouraged (ADA, 2015).

Maintaining optimal glycemic control promotes overall health and reduces the risk of long-term complications (Kelo, Martikainen, & Eriksson, 2011). Nearly 2/3 of diabetic adolescents do not meet treatment targets (Hilliard, Wu, Rausch, Dolan, & Hood, 2013). Glycated hemoglobin (HbA1c) is the gold standard in evaluating control of blood glucose in diabetic patients (ADA, 2014). The HbA1c measures the average blood sugar level over the previous three-month period. The guidelines for diabetes control in children were revised by the American Diabetes Association (ADA) in 2015. In previous guidelines, age groups were established with a goal HbA1c for each age group. Guidelines currently state that for all age groups, a goal HbA1c is no greater than 7.5% (ADA, 2015). HbA1c levels above these guidelines can lead to long-term risks associated with diabetes.

Children face similar risks associated with diabetes as the adult population. There are fewer risks for pre-pubertal children who have had a T1DM diagnosis for less than 2 years (Chiang et al., 2014). Post-pubertal children or 5-10 years after diagnosis however, are subject to risks associated with microvascular changes such as retinopathy, nephropathy, and neuropathy (Chaing et al., 2014). This elevated risk for complications indicates a need for screening for cardiovascular and microvascular changes in the post-pubertal pediatric population or in children who have had the diagnosis for 5-10 years. Screening includes ophthalmologic exams, blood pressure screening, and lipid screening. Pediatric patients who are post-pubertal or with T1DM diagnosis for greater than 5 years, should adhere to adult cardiovascular screening guidelines. Screening would lead to earlier detection of cardiovascular changes associated with diabetes (Chaing et al., 2014).

Purpose of the project

The purpose of this project is to evaluate a current transition program for adolescents with T1DM who are transitioning from pediatric to adult management that aims to address the issue of gaps in care relating to follow-up with an adult provider in patients with T1DM transitioning from pediatric care.

Review of Literature

Transition to adult care from pediatric care is a necessary step when caring for a patient with a chronic disease such as T1DM. There are approximately 500,000 youth with chronic medical conditions that will transition from pediatric to adult care each year (Raymond et al., 2013). The majority of youth and their parents have not discussed the idea of or planned for

transition from pediatric to adult diabetes care (Raymond et al., 2013). Approximately 46% of adolescents transitioning care state that there were problems with the transition process (Raymond et al., 2013). An example of a problem with the transition process are gaps in care. Gaps in follow-up occur directly after transition to adult care and can lead to poor glycemic control and higher rates of hospitalization (Peter & Laffel, 2011). A joint position statement by the American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, and American Society of Internal Medicine was released that stated that adolescents with special healthcare needs should have a transition plan by the age of 14 (Ladores, 2015). The American Diabetes Association (ADA) states that, at a minimum, transition should be discussed and prepared for a year before the anticipated transition date (Polfuss, Babler, Bush, & Sawin, 2015). Although transition has been stated as a priority for many years, there still remains a lack of evaluation of transition and universal expectations for care (Ladores, 2015). The hope with focused transition programs for patients with chronic diseases is that patients will be more adequately prepared for independent management of their disease and adequately prepared to adjust to the differences between pediatric and adult care.

OVID Medline, PubMed, and Cumulative Index of Nursing and Allied Health Literature (CINAHL) were used to search key terms. Terms used were 'diabetes mellitus', 'transition', 'pediatric', 'type 1 diabetes mellitus', and 'education'. Keywords also used were 'transition' and 'education'. Articles were limited to publish dates 2010 or later. This search resulted in 113 articles. Review of articles in order to eliminate duplicates and articles not addressing the topic decreased the number of articles to 25. The American Diabetes Association was used as a resource outside of the search adding 2 articles. The Journal of Pediatric Nursing was also used after an edition dedicated to transition adding 6 articles. The articles from the Journal of

Pediatric Nursing did not appear in the initial search due to the search occurring prior to the publication of the issue.

Gaps in the Literature

Current gaps in the literature include the best way to provide support during the transition period and the lack of criteria to gauge readiness for the transition from pediatric to adult care. There are many tools used to assess transition readiness and various programs currently in use, however, there is still a lack of well-defined criteria for transition (Peter & Laffel, 2011). There are no current guidelines for transition from pediatric to adult care. Peter & Laffel (2011) and the ADA (2015) recommend that preparation for transition begin at least one year prior to transfer of care to an adult provider.

Project Solution and Goals

This quality improvement project evaluated an existing transition program. Success of the transition program was defined as timely (within 6 months) follow-up with an adult provider for young adult patients and the delivery of patient education. The evaluation of the program involved measuring time to follow-up after release from the pediatric clinic and the delivery of education perceived by the patient within the program. The evaluation sought to identify any gaps in the current program allowing for recommendations to be made for next steps for the future.

Approach to the Conduct of the Project

Project Setting

The quality improvement project occurred in the Legacy Emanuel Children's Diabetes and Endocrine Clinic in Portland, Oregon. The clinic serves patients with endocrine disorders in the pediatric population from age 0 - 18. The endocrine condition of interest for this quality improvement project is T1DM. The clinic serves pediatric patients with T1DM and works with an interdisciplinary team to monitor T1DM control as well as make changes as needed to treatment regimens such as insulin dosing. Transition to adulthood for patients includes changing providers from a pediatric specialist to an adult specialist as well as independent monitoring and management of T1DM. Patients attend clinic appointments on a monthly to biannual basis depending on level of control and self-management.

The clinic implemented a structured transition program approximately 1 year ago. The staff involved in the implementation consisted of endocrinologists and diabetes educators. The program is geared toward assisting teens with T1DM transition to independent self-care with adequate blood sugar control and a seamless move to an adult provider. Transition specific classes were developed and provided for each transitioning teen. Classes were provided in either a group or one-on-one format. Each transitioning adolescent started review of care with the endocrinologist up to a year before expected transition period. Review of care consisted of independent management, review of adult diabetes surveillance, and time for questions specifically related to establishing care with a new provider. A transition appointment with a diabetes educator was also provided on the day of or before the last appointment with the pediatric endocrinologist. The clinic is enthusiastic about the transition process and is eager to evaluate the current transition program in order to improve and ease transition for future patients.

Barriers, facilitators, and challenges

There are challenges with evaluating this transition program. The greatest challenge was making contact with potential participants for involvement in the survey. We relied on the accuracy of phone numbers and receptiveness to a conversation over the phone. There are facilitators that assisted in evaluation of the current transition program. Legacy Diabetes and Endocrine has up-to-date information on each patient since transition occurred within the last year. Once contact was made and agreement to complete the survey had been expressed, the ease of completion of the survey was a likely facilitator. There are barriers that could affect evaluation of the program. The largest barrier is the response rate to an online survey. Although the process is simple, it is often difficult to predict response rates. Our hope was that response rates would be high (up to 60%) due to ease of the survey and that participants would be motivated by their close relationship with the clinic. There was not a baseline follow-up rate measured for the clinic so we were unable to compare to previous results for this clinic. There is also a lack of evaluation for transition programs making it difficult to compare these results to other programs.

Participants and Population

Inclusion and Exclusion Criteria

The target population was young adults aged > 18 years who transitioned in the past year out of the pediatric clinic to an adult endocrinology practice. Patients were included if they had been patients receiving care for T1DM in the Children's Diabetes and Endocrine practice and were English-speaking. Exclusion criteria were patients who were < 18 years of age and were not patients in the Children's Diabetes and Endocrine practice for their T1DM care.

Size and rationale

The initial sample size was 50 - 100 patients. Approximately 100 patients have transitioned out of the Children's Diabetes and Endocrine Clinic in the past year. Due to the limits of patients who have transitioned, the maximum number of participants will be 100. We expected to have a 60% response rate so this would be appropriate for a goal of 50-100 participants.

Recruitment

Recruitment occurred in the clinic and by telephone. Patients who have transitioned were called, the study was described, and informed consent was obtained. Once consent was obtained an email with a link to the survey was sent to them. Patients who were attending clinic for the final transition visit were to be informed of the survey with a request for participation.

Protection of participants

Participants were emailed an information sheet describing the survey. Participants were able to discontinue participation anytime before submitting the survey. Patient charts were accessed on a password-protected computer through an encrypted server. Any patient information will remain in the clinic and will be destroyed by shredding in a timely manner. The online surveying tool (Survey Monkey) did not identify which participants had responded to the survey nor their individual responses to survey questions.

Outcome Evaluation

Data collection and use of information systems and technology

Recruitment and data collection began when Institutional Review Board approval was achieved. A retrospective chart review using the EPIC charting system was conducted and potential participants were selected if they met the inclusion criteria. Participants were initially

contacted by phone to discuss the survey and retrieve accurate email addresses. This was necessary due to the fact that many email addresses belong to the parents of the patient while being seen in the pediatric clinic and the patients' email was needed for participation.

Survey monkey, an online survey software program was used for data collection with an email being sent to each participant with an individualized link to the survey. Each participant was only able to submit the survey one time. All answers to survey questions were anonymous and participants were identified with their individual survey responses. Reminder emails were distributed to unanswered surveys by way of a blind email list provided by Survey Monkey. Data collectors were able to see numbers and percentages of participants who have responded but unable to see which participants had responded. At the termination of the survey period, data was compiled into bar and/or pie graphs to display the data.

Implementation of the Project and Results

The program evaluation project was completed at the Legacy Emanuel Children's Diabetes and Endocrine Clinic in Portland, Oregon over a six-month period. Institutional Review Board (IRB) approval was obtained initially followed by survey distribution and electronic chart review.

A retrospective chart review using the EPIC charting system was conducted and potential participants were selected if they meet the inclusion criteria. Participants met the inclusion criteria if they were 18 years old or greater, they had a diagnosis of Type 1 Diabetes Mellitus, and they had transitioned from the clinic since the program was implemented

EPIC chart review was used to record accurate follow-up appointments for patients who have been referred to adult endocrinology for transition of care. The estimated sample size was

lower than expected after eliminating duplicate records and patients who transitioned out of the clinic but did not meet the inclusion criteria, with a total of 57 patients.

Participants were contacted by phone to discuss the survey and retrieve accurate email addresses. An email was sent to each participant with an individualized link to the survey. The distributed survey was a transition evaluation by Garvey, et al. (2012) titled “Assessing Specific Transition Preparation” published by the American Diabetes Association (ADA) and included seven questions relating to transition. Demographic data (gender only) was included in the survey as well. The survey was open for responses for a 4 month period.

Over the period of 4 months, weekly reminders were emailed to recipients to increase participation. The total number of surveys returned out of 57 surveys distributed was 20, reflecting a 35.1% response rate (Table II). All participants completed the survey in full. There were 26 (46%) male participants and 31 (54%) female participants (Table I).

Survey Results

- Question (Q) 1: Thirteen (65%) participants were able to have visits with their pediatric endocrinologist without their parent or guardian before transitioning out of the clinic (independent visits). Five (25%) participants did not have independent visits with their pediatric endocrinologist. The remaining 2 (10%) participants responded “maybe” indicating that they were not sure if they had independent visits with their endocrinologist.
- Q2: The vast majority, 19 (95%) participants stated that they were given a recommendation for a specific provider with whom to follow-up. Only 1 (5%) participant stated that they were not given a specific recommendation for a provider with whom to follow-up.

- Q3: Again, the majority, 19 (95%) participants stated that they were given specific and adequate contact information for the recommended provider. Only 1 (5%) participant responded that they were not given contact information for a recommended provider.
- Q4: In regards to having a specific conversation about transitioning to an adult clinic, 16 (80%) participants responded that they did have a visit addressing this topic. Four (20%) participants stated that they did not have a visit that specifically addressed transition.
- Q5: Participants were asked if they were given written materials about the transition process or expectations for transition. Twelve (60%) of participants responded that they were given written materials, 6 (30%) responded that they were not given written materials, and the remaining 2 (10%) were unsure if they were given written materials regarding transition.
- Q6: The majority of respondents, 19 (95%) stated that they did discuss independent management of diabetes with their provider or educator in the clinic. One (5%) participant stated that they did not specifically talk about independent management during clinic visits.
- Q7: The majority of respondents, 19 (95%) stated that they did review and understood screening tests that they would expect in adult diabetes care before transitioning out of the pediatric clinic. One (5%) participant stated that they did not review and understand the screening tests that they would expect in adult diabetes care before leaving the pediatric clinic.

A chart review was completed for each patient (n=57) that met the inclusion criteria for the program evaluation. Success of the transition program was measured by timely (within 6 months) follow-up with an adult provider for young adult patients. Time to transition was calculated based on the last office visit with the pediatric provider and the first office visit to the adult provider. Resources, such as “care everywhere”, were utilized. If a follow-up visit could

not be determined in the EPIC charting system, the clinic to which patients were referred was called and information was requested to determine if follow-up had occurred.

Time to transition (Table III) was divided into 4 time categories: 0-2 months, 3-5 months, > 5 months, and 'lost to follow-up'. Approximately 51 (89.5%) patients were able to complete follow-up with an adult endocrinologist within 6 months. Fifteen (26.3%) patients reached an adult provider in the 0-2 month range. The majority of patients, 26(45.6%) were able to reach an adult provider in the 3-5 month range. The remaining 10 (17.5%) patients were able to reach a provider in 6 months or greater following their last visit with the pediatric endocrinologist. 'Lost to follow-up' indicates that a record of follow-up appointment could not be found. Six (10.5%) patients fell under this category. An appointment gap can be calculated to range from 6 -12 months. This range is based on chart review for patients who transitioned in the preceding 6-12 months.

Outcomes in Relation to the Literature

The ADA (2015) recommends that transition is addressed with patients approaching this time period at least one year before the expected transition date. The majority of the literature speaks to addressing transition in the pediatric clinic as well as gaps in care between visits to the pediatric endocrinologist and the adult endocrinologist. This evaluation shows that the majority of patients in this clinic (80%), although a time period was not specified, were able to discuss the details of transition with their provider. The high percentage of success with beginning a conversation about transition shows that this clinic is moving toward the ADA goal for transition. Given the 6-month follow-up result of 89.5%, this transition program is likely positively affecting the gap in care for transitioning adolescents.

Practice Related Implications and Recommendations

The need for further research associated with transition to adult care for patients with chronic diseases is apparent when reviewing current literature on transition of care. Longitudinal studies that evaluate outcomes associated with formal transition programs are needed (Ladores, 2015). Standardized readiness assessments and needs assessments of patients should be developed in order to have consistent care throughout this vulnerable population. Standardized assessments would also assist in comparing relative effectiveness of programs across studies. There are a variety of assessments for transition but there are not many that have been validated as a standard of care (Ladores, 2015). A standardized approach for education around transition would be useful as well. Common modes of education are classes in clinic as well as handouts and pamphlets. Patients and their families may not see classes and written materials as the most useful way to provide education, although, this is a common mode of delivery (Polfuss, Babler, Bush, & Sawin, 2015). An alternative to in class education could be online modules or video formats in place of the classroom education setting. Multidisciplinary approach for transition including psychology, dietitian, and nurse educators would ensure that all areas are address and needs are met for each individual patient. Group visits are a possibility for peer support and topic review. One aspect of this could be individual and group counseling sessions to help support and develop coping skills and maintain motivation in the patient (Babler & Strickland, 2015). Transition of care is an emerging field and there are many ways that the transition process could be evaluated and improved.

Summary

Transition to adult care is a challenge for many adolescents who are gaining new independence and experiencing the world as an adult. Gaps in care lead to poor glycemic control, complications associated with chronically high blood sugars, and increased hospitalizations (Hilliard et al, 2013). A focused transition program can help bridge the gaps and promote health in patients with chronic diseases. Evaluation of this transition program is important so that improvements can be made to better prepare these young adults for independent management of T1DM and thereby success in the long run as they become adults.

Appendix I

Table I

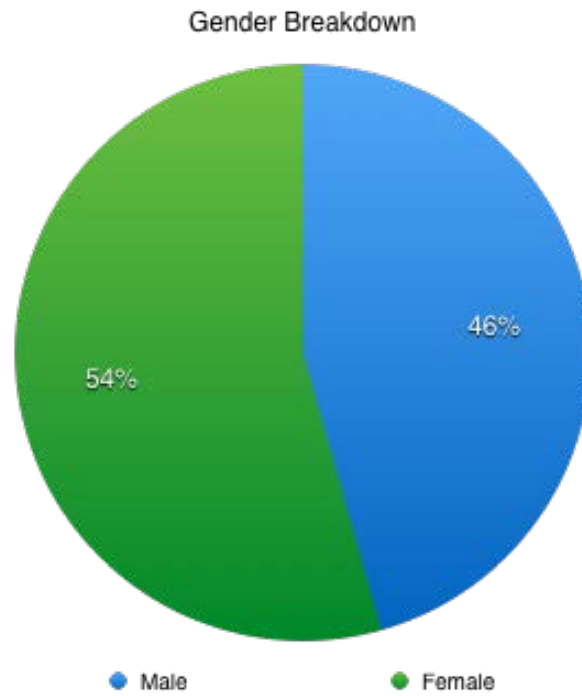


Table II

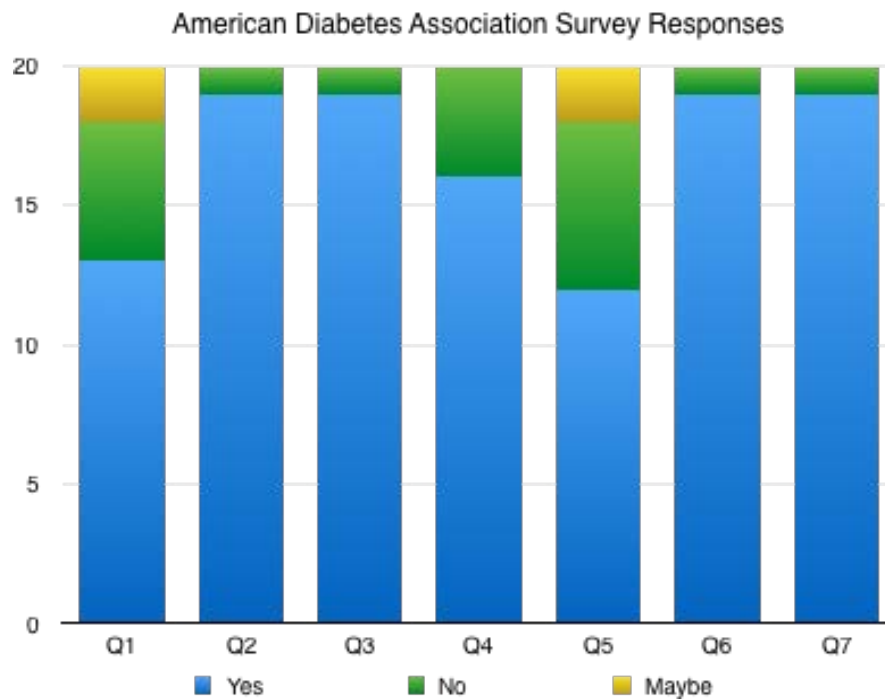
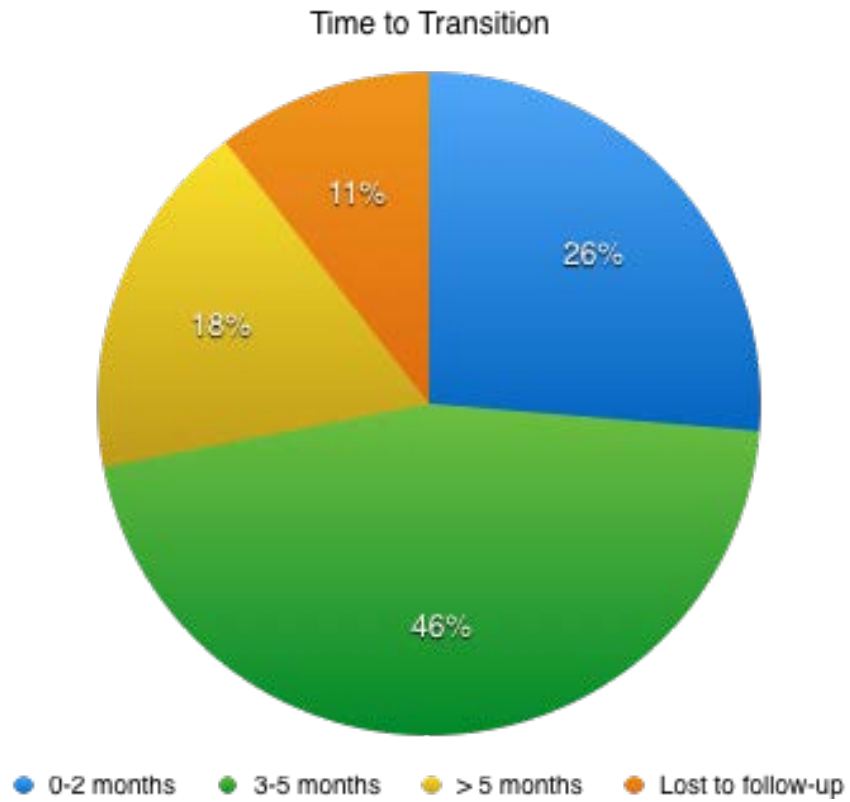


Table III



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