

The Need for a Seamless Healthcare System:
Transition Care for Adolescents with Diabetes

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Abstract

When children with a chronic illness reach adolescence or young adulthood, they have to transition from the pediatric to adult healthcare systems. At this time, adolescents and young adults (AYA) with chronic conditions are at risk for negative health outcomes because they have to manage dynamic changes in their personal lives as well as their illness. However, they have to endure this period without much guidance from their healthcare providers. Timely and seamless transition to adult healthcare is particularly important for AYA with diabetes given the consequences of mismanagement of their condition. Diabetes is a complex illness that may encompass various difficulties including financial, social, psychological and physical burdens. Without a proper guideline through the transition process, AYA with diabetes may feel confused or even fearful at this vulnerable time. This study investigated whether adolescents with diabetes received more or less physician-directed transition guidance when compared with adolescents without special healthcare needs (SHCN) and the influence of age and sex in receiving physician-directed transition guidance. Results illustrated that adolescents with diabetes who are older or in middle adolescence received more physician-guided transition care. Furthermore, the age and sex interaction revealed that male patients with diabetes received less transition guidance during their early adolescence than middle adolescence. More research regarding transition guidance for AYA with diabetes must be done in order to ensure best practices and a seamless healthcare system that will yield positive health outcomes.

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Introduction

Chronic conditions are widespread in our society, impacting more than 75% of Americans (CDC, 2009). In particular, the number of children with chronic conditions is increasing (Price et al., 2013). This is alarming because they are prone to other comorbidities such as hypertension, cardiovascular diseases, depression, and behavioral disorders and therefore vulnerable for worsened health outcomes (Blackman et al., 2011; DiMatteo et al., 2000; Nadeau et al., 2016; Mencin et al., 2015; Bjornstad et al., 2014; Nadeau et al., 2009; Carper et al., 2013; Garrison et al., 2005; Perrin et al., 2017). Adolescents and young adults (AYA) with chronic conditions are especially at risk for negative health outcomes because they have to handle transitions involving their changing social environments, including school or work, in addition to their illness (Peters & Laffel, 2011; Weissberg-Benchell et al., 2007; Garvey et al., 2013; Bryden et al., 2003). When children with and without chronic health conditions reach adolescence and young adulthood, they have to eventually move to an adult healthcare system (Bhawra et al., 2016; Blum, 1991). However, they may be left without much guidance from their healthcare team in their time of transition (Bhawra et al., 2016; Rapley & Davidson, 2010).

AYA with diabetes also have to transition into the adult healthcare system (Garvey et al., 2013). Diabetes is a common chronic illness with various onset reasons; AYA managing diabetes are not only faced with the physiological aspects of the complex mechanisms of diabetes but also are faced with difficulties regarding social, financial, and psychological aspects such as stigma, healthcare cost, depression, and anxiety (Garvey et al., 2013; Arnett, 2000; Nakhla et al., 2009). AYA with chronic conditions could feel abandoned and fearful at this stage of life for the lack of guidance through the transition period and the adult healthcare

system. This gap in healthcare calls for a better transition care system to ensure positive health outcomes at this vulnerable time (Garvey et al., 2013; Markowitz & Laffel, 2012; Peters & Laffel, 2011; Lebrun-Harris et al., 2018). Furthermore, seamless healthcare should be provided for all AYA transitioning to the adult care system, regardless of the presence of any chronic conditions. Social determinants of health such as gender, socioeconomic status, and race affect health outcomes in individuals with diabetes; for this reason, it is important to take social determinants of health into account when considering transition care for AYA with diabetes. This study examined transition care for adolescents with diabetes and adolescents without any special healthcare needs (SHCN). Specifically, the different types of guidance that the adolescents receive during their transition and the relationship between social determinants of health (e.g., sex, age) were investigated.

Literature Review

I. Chronic Illness

According to the Centers for Disease Control and Prevention (2019), chronic illness is broadly defined as a condition that lasts one year or more, involves medical attention, or limits daily activities. Common chronic illnesses include heart disease, stroke, cancer, diabetes, arthritis, respiratory disease, and many more (CDC, 2009). Seven out of 10 deaths in the United States resulted from a chronic condition; 75% of healthcare expenditure in the United States is used by individuals with chronic illnesses (Kung et al., 2008; CDC, 2009). Around 40 million people in the United States have limited daily activities due to a chronic illness, illustrating the heavy impact of persistent health conditions (Adams et al., 2013) on quality of life and mortality.

Specifically, the number of children with chronic illnesses seemed to be steadily increasing over the years: the percentage of children with a chronic illness quadrupled from 1960 to 2006, rising from 1.8% to 7.0% (Price et al., 2013). This rise could be explained by the recent developments in medical research that reclassified illnesses that were marked as fatal to be marked as chronic (e.g., type 1 diabetes before the discovery of insulin treatment); furthermore, early diagnosis or increased survival rates for many children could also explain the rise in the number of children with chronic conditions (Buschur et al., 2017; Viner 1999, McDonagh 2005; Transition Medicine Steering Group, 2008; Vaks et al., 2016; Perrin et al., 2014; Compas et al., 2017; Halfon & Newacheck, 2010). Children and AYA with chronic illnesses tended to have comorbidities, such as anxiety, depression, and learning disabilities (Blackman et al., 2011). Comorbidities, such as depression and anxiety, could be critical to illness management for individuals with chronic illnesses since these conditions are often correlated with noncompliance to medical treatment (DiMatteo et al., 2000). Additionally, emotional, developmental, and behavioral (EDB) difficulties that might come with chronic illnesses may further challenge the quality of the lives of children and AYA with chronic illnesses (Blackman et al., 2011). Because children and AYA with chronic illnesses have a range of EDB difficulties such as acting-out or feeling depressed, it is crucial to offer support, such as chronic illness management programs, that addresses both physical and psychosocial components of the illness in order for them to have a positive health outcome.

II. Adolescents and Young Adults with Chronic Illness

While individuals of all ages with chronic illnesses might have difficulties in caring for their conditions, AYA might especially have a difficult time in illness management. This is due to the fact that they have to also tend to their rapid physical changes, individuation, and

socialization processes in addition to the multitude of tasks related to their physical conditions (Suris et al., 2004). They also have to slowly take initiative in arranging their own conditions as well as pursuing autonomy in medical decisions (Bhawra et al., 2016; Blum, 1991). At this particularly vulnerable period of life, chronic illnesses can be adverse to AYA in the physical mode as well as psychosocial mode (Peters & Laffel, 2011; Weissberg-Benchell et al., 2007; Garvey et al., 2013; Bryden et al., 2003). For these reasons, exploring the vulnerable population of AYA with chronic illnesses is worthwhile.

Adolescence is broadly defined by the time between puberty and the development of social independence (Curtis, 2015; Steinberg, 2014). It is generally defined by the ages between 10 and 18 (Curtis, 2015; APA, 2002). During adolescence, individuals go through distinct, fast, dramatic, and complicated changes in their biology, psychology, and social environments; they also go through changes in their social roles (Suris et al., 2004; Blackman 2011; Sawyer et al., 2012). During this period, individuals develop a sense of body image and self-identity (Suris et al., 2004; Hauser et al., 1983; Rosenthal et al., 1981).

During the adolescence, individuals with chronic illnesses may have challenges with physical growth, puberty, psychosocial development, cognitive growth, education, and relationships with family and friends (Suris et al., 2004). A number of adolescents with chronic illnesses face delayed growth and late onset of puberty (Suris et al., 2004; Power & Manor, 1995). Late onset of puberty could pose a threat to adolescents, especially for boys, for it could proceed to low self-esteem as well as other negative social implications among peers (Suris et al., 2004; Cepeda et al., 2000). Adolescents with chronic illnesses also may encounter problems with psychosocial development; many adolescents displayed internalizing, psychiatric, and behavioral symptoms and disorders compared to their healthy counterparts

(Suris et al., 2004; Suris et al., 1996; LeBlanc et al., 2003). Furthermore, girls are more likely to have emotional challenges regarding their chronic illness compared to boys.

Adolescents with a chronic illness had a lower body satisfaction rate (Suris et al., 2004; Hauser et al., 1983). Manworren (1996) suggested that chronic illnesses that leave physical marks, such as sites for insulin pumps, scars, or stomas, could potentially serve as a reason for the decreased body satisfaction rate. Moreover, many adolescents feared to reveal their chronic condition to members of their school to avoid labels and stigma (Suris et al., 2004; Andrews, 1991). Their condition and treatment may result in frequent absence from school and education, which could potentially impact their academic achievement, especially when they do not reveal their condition to the school (Suris et al., 2004; Sturge et al., 1997). Finally, adolescents may have an interesting relationship with their family and friends. Depending on the severity of their conditions, they could be overly dependent on their parents for illness management or ostracized by their peer groups (Suris et al., 2004; Eiser & Berrenberg, 1995; Manworren, 1996).

Young adulthood occurs approximately between the ages of 18 and 25 (Arnett, 2000; Arnett, 2006; Reifman et al., 2007). This period is represented by individuals who have not yet entered the normative adulthood. Young adulthood is characterized by a high amount of demographic diversity as well as instability: it is a period of transition and exploration. Young adults start to accept responsibility for self and start to make independent decisions. During young adulthood, individuals with chronic illnesses are faced with new developmental milestones (i.e., financial independence, moving for college, seeking a significant other) as well as managing a demanding illness care regimen (Peters & Laffel, 2011; Weissberg-Benchell et al., 2007). Consequently, chronic illness patients in these populations are at risk for

poor health outcomes (Garvey et al., 2013; Bryden et al., 2003). The negative health outcomes of AYA with chronic conditions emphasize the need for better health support in their time of developmental transition.

To summarize, adolescence and young adulthood is a time of autonomy and instability (Curtis, 2015; Steinberg, 2014; Arnett, 2000; Arnett, 2006; Reifman et al., 2007). AYA with chronic illnesses could have a difficult time handling their conditions because of the additional adjustments they have to endure from various physical and social changes at this period of development (Suris et al., 2004). More research and clinical support should be given to adolescents with chronic conditions, as a preventative measure, in order to ensure positive health outcomes in their path towards adulthood. Currently, there is a gap in literature on AYA with chronic illnesses. In particular, there is limited literature discussing the differential support individuals with chronic illnesses receive during young or older adolescence, as well as during young adulthood.

III. Transition Care

IIIa. Transition Care for AYA with Chronic Illness

With recent advancements in research and medical management, an increasing number of children and adolescents with chronic illnesses are surviving into adulthood (Buschur et al., 2017; Viner 1999, McDonagh 2005; Transition Medicine Steering Group, 2008; Vaks et al., 2016; Perrin et al., 2014). Furthermore, early diagnosis allowed for increased survival for children and AYA with previously fatal illnesses (Compas et al., 2017; Halfon & Newacheck, 2010). When individuals with chronic illness are in their childhood years, their parents and guardians will most likely care for their chronic conditions (Cousino & Hazen, 2013). However, at some point, they will have to start considering the transition from pediatric to

adult healthcare systems (Bhawra et al., 2016; Blum, 1991). At this time, families must learn when to eventually ‘let go’ and allow the individuals to figure out and manage their chronic conditions themselves, which many parents find difficult (Rapley & Davidson, 2010; Conway, 2007; Tuchman et al., 2008). This change could be startling for many adolescents, since they are accustomed to the friendly and family oriented pediatric healthcare system; many expressed feelings of anxiety and abandonment during this period (Minicozzi 2000, National Collaborating Centre for Women’s and Children’s Health, 2004). In an interview by Tuchman and colleagues (2008), one adolescent patient said the following, illustrating his ambivalence in moving to the adult healthcare system because of his familiarity with his pediatric physician:

He knows every single thing about me. He knows my whole family. He knows my whole life, and like, I like that he does. But I don’t think with any other doctor I would be comfortable with that, because it would just feel weird. (p. 561)

Currently, there is no set age that determines the time of transfer, leaving individuals with chronic illnesses responsible for the initiation of their transfer to the adult healthcare system without any guidance (Bhawra et al., 2016; Kaufman & Pinzon, 2007; Davis et al., 2014; National Collaborating Centre for Women’s and Children’s Health, 2004; Wedgwood et al., 2007). This disrupts continuous care for AYA with chronic illnesses when the physical and psychosocial burden of their condition could intensify. Some adolescents postpone their transition process until they encounter a crisis with their condition (National Collaborating Centre for Women’s and Children’s Health, 2004; Holmes-Walker et al., 2007; Tuchman et al., 2008). The majority of AYA described their transition period as lacking adequate support and service because of insufficient planning and service arrangements, as well as lacking education

and training from the healthcare team. Many also felt not prepared for the transition (Rapley & Davidson, 2010). The cessation in AYA's care for chronic illness could bring adverse results to their health, such as patient disengagement, inadequate treatment adherence, and elevated incidents of hospitalization (Bhawra et al., 2016; Okumura et al., 2008). Even when AYA successfully transition into the adult healthcare system, the adult care system is generally unprepared to meet their demands, because of the different philosophies of the pediatric and adult healthcare systems (Rapley & Davidson, 2010). Pediatric care includes family-focused approach to health whereas adult healthcare includes an individualized and independent self-care approach. Although these differences of philosophies could currently be changing with the Affordable Care Act and consequently the promotion of shared decision-making policies, it is still early to determine if the policies have been well adjusted specifically to pediatric care (Wallace & Sommers, 2015; Elwyn et al., 2013).

In order for AYA to successfully manage their chronic illnesses, it is crucial for healthcare service providers to work together to provide a "seamless, coordinated, developmentally appropriate, psychologically sound and comprehensive" (Blum et al., 1993, p.570) care experience throughout their adolescent years (Bhawra et al., 2016; Farre et al., 2016; Britto, 2006; Sadun et al., 2019). One of the ideal transition modes included a three-stage model that consisted of preparation in the pediatric healthcare setting and engagement in the transition procedure followed by a period of assessment for a minimum of two years (National Collaborating Centre for Women's and Children's Health, 2004; Wedgwood et al., 2008). For a seamless transition care experience, placing more interventions and trainings for the healthcare team could help enhance the experience of transition for AYA. Rosen and

colleagues (2003) suggested that having a trained transition coordinator might improve adolescents' health outcomes.

Since there is a growing number of AYA with chronic illnesses, it is imperative to address the transition from the pediatric to the adult healthcare system for a healthy management of their conditions (Buschur et al., 2017; Viner 1999, McDonagh 2005; Transition Medicine Steering Group, 2008; Vaks et al., 2016; Perrin et al., 2014; Bhawra et al., 2016; Blum, 1991). This process can be intimidating for many AYA, as there are differences and a lack of communication in the two care systems, as well as a lack of an unified age of transition (Bhawra et al., 2016; Kaufman & Pinzon, 2007; Davis et al., 2014; National Collaborating Centre for Women's and Children's Health, 2004; Wedgwood et al., 2008; Tuchman et al., 2008). In order to advocate for a positive health outcome for AYA with chronic illnesses, the healthcare team should strive to collaborate to provide continuous care during healthcare transition (Blum et al., 1993, Bhawra et al., 2016; Farre et al., 2016; Britto, 2006; Sadun et al, 2019).

IIIb. Transition Care for AYA Without Any Chronic Illnesses

Although there was a limited number of literature on the topic of healthcare transition for individuals without any chronic illnesses, a small number of literature strongly suggested that AYA without any chronic conditions must also eventually transition to the adult healthcare system from the pediatric healthcare system (Davidson et al., 2017; White et al., 2018; Lebrun-Harris et al., 2018; Eaton et al., 2017). Individuals without chronic illnesses or any special healthcare needs were less likely to take care of necessary routine medical tasks as compared to individuals with chronic illnesses (Davidson et al., 2017; Eaton et al., 2017; Weller et al., 2003). Furthermore, healthcare professionals were less likely to discuss transition in care and

future goals with individuals without chronic illnesses when compared to individuals with chronic illnesses.

To sum up, although AYA without any special healthcare needs must also ultimately transition into the adult healthcare system, they were less likely to get any support in this process (Davidson et al., 2017; Eaton et al., 2017; Weller et al., 2003; White et al., 2018; Lebrun-Harris et al., 2018). Regardless of one's special healthcare needs, the healthcare system should offer research and clinical support for adolescents in a time of transition. In terms of gaps in literature, as mentioned previously, there was only a small number of studies that explored the healthcare transition experiences for individuals, and particularly AYA, without any health conditions. Eaton and colleagues (2017), in their literature search on transition care of individuals with and without special health needs, found limited scholarship on the change of health-related responsibilities between AYA and parents. Particularly, their findings did not include a comparison between AYA with chronic illnesses with their healthy counterparts. Comparing how much support individuals with chronic conditions receive regarding transition care with individuals without any chronic conditions could reveal interesting trends in the healthcare transition realm.

IV. Diabetes

IVa. Type 1 Diabetes

According to the International Diabetes Federation (2015), 10-15% of the population have type 1 diabetes (T1D); approximately 500,000 children are currently living with T1D around the world (Katsarou et al., 2017). Number of individuals diagnosed with T1D is escalating each year and it is predicted that approximately 90,000 children are diagnosed each year around the world (Diaz-Valencia et al., 2015).

T1D is a chronic autoimmune disease that is identified by high blood glucose levels, or hyperglycemia (Katsarou et al., 2017). Hyperglycemia is caused by insulin deficiency from lack of insulin producing pancreatic islet β cells (Gepts, 1965; DiMeglio et al., 2018). Insulin allows the body to use or store glucose from carbohydrate intake from our diet (Chauhan, 2018). In the liver, insulin works to convert glucose into the “storage” form of glucose, glycogen, by a process called gluconeogenesis. Furthermore, insulin signals the muscle and fat cells to utilize glucose from the bloodstream through the GLUT4 transporter. Most of the individuals with T1D lose their β cells due to an autoimmune occurrence, in which their own immune system attacks their β cells (Katsarou et al., 2017; American Diabetes Association, 2016). The onset of T1D is assumed to be a combination between genetics and environment, in which different environmental elements could serve as a trigger to start the autoimmune response against the β cells.

Management of T1D call for meticulous cooperation between physicians, diabetes educators, nurses, dieticians, psychologists, social workers, family, school and the patient (Katsarou et al., 2017; American Diabetes Association, 2016). Everyone in the healthcare and support systems is driving towards a healthy range in glycemic control to avoid cases of hyperglycemia, hypoglycemia, as well as diabetic ketoacidosis (DKA). In managing T1D, it is important to target Hemoglobin A1c (HbA1c), or glycated hemoglobin level, and blood glucose level for HbA1c is an important indicator of long-term glycemic control (WHO, 2011; Lachin et al., 2008). In order to keep both HbA1c and blood glucose in range, it is essential to take frequent measures of both at various time frames, such as before eating meals or going to bed.

AYA with T1D are not only at risk for physical complications, but also at risk for having mental health disorders (Khandelwal et al., 2016; Kovacs et al., 1997; Buschur et al., 2017). Adolescents who had T1D for an average period of 10 years had higher rates of psychiatric illness, as high as 47%, when compared to adolescents without T1D. In particular, major depressive disorder was the most commonly reported disorder. Furthermore, AYA with T1D were more prone to having disordered eating and insulin restriction, in which individuals purposely withheld from insulin injection as a form of purging and weight control. Around $\frac{1}{3}$ of females and $\frac{1}{4}$ of males with T1D mentioned deliberate restriction of insulin in order to lose weight (Bachle et al., 2016). As seen by the many different symptoms and comorbidities, T1D is a complex disorder that involves all domains of health (i.e., social, physical and psychological domains). Therefore, patients, family and healthcare professionals should all work together for illness management.

IVb. Type 2 Diabetes

Type 2 Diabetes (T2D) is the prevailing form of diabetes, accounting for 90-95% of all diabetes patients (ADA, 2016; Katsarou et al., 2017). Merely 30 years ago, T2D was considered a rare diagnosis for children and AYA (Reinehr, 2013). However, with the recent rise of childhood obesity, the number of children and AYA with T2D is also rapidly increasing with the annual relative increase for T2D being 4.8% (Copeland et al., 2013; Temneanu et al., 2016; Springer et al., 2013; CDC, 2017). Approximately 193,000 children and adolescents under the age of 20 are currently diagnosed with T2D in the United States (CDC, 2017; CDC, 2017).

T2D is a metabolic illness that has many different causes involving social, behavioral, and environmental factors working with genetic predisposition (Reinehr, 2013; Kiess et al.,

2003). Lifestyles involving unhealthy diet or sedentary habits for individuals with first-degree relatives with T2D have shown a high correlation with the diagnosis of T2D in children and AYA (Temneanu et al., 2016). Puberty and increased growth hormone also seemed to take a role in the onset of T2D; individuals in puberty often have heightened levels of insulin resistance (Reinehr, 2013; Arslanian, 2000). Individuals with T2D have impaired glucose metabolism and homeostasis, or the balance between insulin secretion by the β cells and glucose (Reinehr, 2013). Patients with T2D are often resistant to insulin and have inadequate secretion of insulin from their β cells to control their blood glucose level (Reinehr, 2013; Temneanu et al., 2016; ADA, 2000). Patients of T2D are also at risk for comorbidities such as hypertension, hyperlipidemia, non-alcoholic fatty liver disease, cardiovascular dysfunction, and kidney disease (Nadeau et al., 2016; Mencin et al., 2015; Bjornstad et al., 2014; Nadeau et al., 2009).

For illness management of T2D, patients should also work towards an optimal HbA1c range (ADA, 2000; Willett et al., 1999). Children and AYA with T2D should also thoroughly learn how to self-manage their treatment regimen, as well as how to self-monitor their blood glucose levels. Involving the family for diabetes education was also very important for positive health outcomes for younger children with T2D (Temneanu et al., 2016; Copeland et al., 2013). Routine blood glucose and HbA1c checks were highly encouraged in order to monitor patients' glycemic control. A referral to a dietitian was also recommended as nutritional management is a big part of diabetes management. Increasing physical activity could also be very beneficial since exercise reduces insulin resistance and obesity.

T2D also brings upon psychological comorbidities such as depression, diabetes or emotional distress, internalizing disorders, externalizing disorders, emotional disorders, and

behavioral disorders (Carper et al., 2013; Garrison et al., 2005; Perrin et al., 2017). Carper and colleagues (2013) found that quality of life among individuals with T2D (ages 18-80) was associated with severity of depression and diabetes distress in a study that involved the Quality of Life Inventory (QOLI). This was presumably because of the complex physical and psychological components of T2D illness management (Walders-Abramson, 2013; Carper et al., 2013). Furthermore, individuals with T2D had a higher chance of developing eating disorders, often because they were dissatisfied with their body image, illustrated by the 53% of the sample population being diagnosed with binge-eating disorder in a study by Gangnon, and colleagues (2016) (Herpertz et al., 2001). For individuals with T2D and an eating disorder, restrictive-eating and binge-eating could become a pattern that results in weight gain (Gagnon et al., 2016; Mannucci et al., 2002; Rodin & Daneman, 1992). T2D often led to hardships in terms of self-control, illness management, and stigma; individuals with T2D should be fully supported by family and the healthcare team throughout their journey of navigating through T2D management to ensure positive health outcomes (Browne et al., 2013; ADA, 2000; Willett et al., 1999).

It is important to address AYA with diabetes as the number of individuals diagnosed with T1D or T2D has increased and is projected to continue to increase over time (Diaz-Valencia et al., 2015; Copeland et al., 2013; Temneanu et al., 2016; Springer et al., 2013; CDC, 2017). Diabetes is a complicated condition in terms of illness management and onset reasons; however, it is even more complicated as it could involve stigma, guilt, and shame (Suris et al., 2004; Perrin et al., 2017; Pouwer, 2009; Adriaanse et al., 2008). It is crucial to offer support, such as guidance in transition for adult care, in their psychosocial and physical management of diabetes (Garvey et al., 2013).

V. Transition Care for Diabetes

Like many other AYA with chronic illnesses, AYA with diabetes are advised to eventually transition to the adult healthcare system from the pediatric healthcare system within a reasonable time (Garvey et al., 2013). Diabetes is a chronic condition that requires complicated daily glycemic management and medical decisions. During adolescence and young adulthood, individuals are faced with difficulties with academic, social, and emotional aspects of life in addition to their illness management (Garvey et al., 2013; Arnett, 2000). Many encounter changes in this period for various reasons, such as attending college, moving away from home, and searching for jobs (Markowitz & Laffel, 2012). When AYA encounter problems with transition in care, they are at risk for discontinuation of healthcare as well as negative health outcomes, such as poor glycemic control, acute health problems, and even early mortality (Laing et al., 2005; Wills et al., 2003). Successful transition care, illustrated by steady continuance of clinic attendance, decreased rates of diabetic ketoacidosis and hospitalization, for patients with diabetes is absolutely essential as young adults with T1D in their twenties are four times more likely to pass away than their healthy counterparts. This was most likely due to the compilation of difficulties they faced during young adulthood (Rapley & Davison, 2010; Health Canada 2003; Garvey et al., 2013).

Furthermore, Weissberg-Benchell and colleagues (1995) found that although adolescents in general were prone to mismanaging their diabetes, older adolescents were more likely to mismanage their condition than younger adolescents. A study done by Hilliard and colleagues (2013) further conveyed the vulnerability of older adolescents, as 60% of their sample composed of older adolescent did not meet the diabetes control and management recommendation from the American Diabetic Association (ADA). This was presumably so

because adolescents, with their growing autonomy, were granted more responsibility for their medical adherence: however, reduced parental involvement in diabetic management was correlated with increased hospitalization and worsened blood glucose levels, which ultimately placed older adolescents at risk for adverse diabetic outcomes (Anderson et al., 1997; Anderson & Coyne, 1991; McConnell et al., 2001; La Greca et al., 1988; Wysocki et al., 1996; Palmer et al., 2004).

The current field of transition care illustrated that although there are some guidelines for an “ideal” three step procedure (preparation, engagement, and follow-up) for transition care, as mentioned in the transition care section above, these procedures were mostly without significant empirical evidence and left many AYA to potentially feel anxious and fearful of transition (Garvey et al., 2013; Markowitz & Laffel, 2012; Peters & Laffel, 2011). Feelings of anxiety and fear could stem from the fact that there is a dissonance between the two care settings (Buschur et al., 2017). The management of diabetes in a pediatric setting involves a more supportive environment with the supervision of a parent or guardian and the diabetes team working together to help the patient. In contrast, adult care settings depend more on patient independence and autonomy. When Sadun and colleagues (2019) surveyed practitioners from both pediatrics and adult care, they found out that many of their participants did not receive education regarding transition of care and were left with different expectations and views of the process (Nakhla et al., 2017; Sonneveld et al., 2012). Specifically, 53% of the pediatric practitioners and 69% of the non-pediatric practitioners (i.e., adult healthcare practitioners) revealed that they had not received training nor role modeling of transition care in terms of communicating with providers in other healthcare systems. Furthermore, 56% of pediatric practitioners and 73% of non-pediatric practitioners claimed that they did not receive

training nor role modeling of discussing healthcare transition with patients and family. In line with these findings, some practitioners also expressed that they felt “not at all prepared” to help children transition. Perhaps these results could be explained by the fact that transition skills are not currently taught in most of the medical schools (Nazarian et al., 2010).

Garvey and colleagues (2013) noted that AYA considered receiving specific provider referral names as an important aspect of transition care, but less than half received them from their pediatricians; this could be from the lack of education and communication between the pediatric and adult healthcare systems (Bhawra et al., 2016; Blum, 1991; Okumura et al., 2008; Peter et al., 2009; Patel & O’Hare, 2010). Only 62-63% of the AYA with diabetes reported feelings of complete readiness for transition to adult care and satisfaction regarding the process (Garvey et al., 2012). In a post-transitional survey, 34% of the young adults with diabetes expressed that they experienced a gap in healthcare that was longer than 6 months. However, this number significantly decreased when they received strong transition preparation. To establish a seamless care and to reduce negative health outcomes, the transition in care must be meticulously coordinated by the pediatric and adult healthcare systems (Garvey et al., 2012; Rosen et al., 2003). Coordinated support in healthcare transition will reduce preventable health emergencies, such as hospitalization for diabetic ketoacidosis, for AYA with diabetes (Rapley & Davison, 2010; Health Canada 2003; Garvey et al., 2013; Bhawra et al., 2016).

AYA with diabetes have to eventually transition into the adult care system (Garvey et al., 2013). However, life changes in midst of this period accompanied by difficulties presented by diabetes management could make AYA with diabetes especially susceptible to disruptions in their diabetes care (Garvey et al., 2013; Arnett, 2000; Laing et al., 2005; Wills et al., 2003). In order for AYA to have a stable transition experience, coordinated care between the pediatric

and adult healthcare systems was recommended (Rapley & Davison, 2010; Health Canada 2003; Garvey et al., 2013; Bhawra et al., 2016). The current literature lacked specific comparisons with AYA with diabetes and their healthy counterparts in their experiences in transition care guidance, as well as exploring which age range of AYA receive the most help during their transition to the adult healthcare system.

VI. Implications of Sex Differences for Patients with Diabetes

Although the majority of the literature on diabetes did not discuss the different experiences of diabetes for females and males, significant differences were present between the two sexes (Enzlin et al., 2002; Legato et al., 2006). Illness management of diabetes became a challenging task during adolescence and young adulthood and, consequently, both sexes illustrated a decrease in diabetes management (Williams, 1999; Pound et al., 1996). However, girls with diabetes in their adolescent years had a harder time with glycemic control as well as treatment adherence than boys with diabetes as sex hormones have different influences in body metabolism; furthermore, adolescent girls and women had poorer glycemic control most likely due to higher psychological stress with diabetes management (Korbel et al., 2007; Shim et al., 1999; Tylleskar et al., 2001; Kautzky-Willer et al., 2016; Lloyd et al., 1999; Kelly & Ismail, 2015). Girls may have a harder time with managing diabetes because of increased resistance to insulin during their puberty as well as heightened concerns regarding their weight and body shape (Shim et al., 1999; Daneman et al., 2002; Austin et al., 2011). Furthermore, girls were more prone to getting an earlier onset of T2D (Temneanu et al., 2016). There were also cases of early adrenarche in girls with T2D, for example early development of pubic hair as early as age eight, which could potentially have social implications for girls (Temneanu et al., 2016; Hanson & Gluckman, 2014).

Moreover, teenage girls tended to set higher goals in glycemic control than teenage boys; when their goals were not met, many of them internalized their own failure in controlling their blood glucose level (Korbel et al., 2007; Lavigne et al., 1982; Pomerantz & Eaton, 2001). Perhaps for these reasons, girls with diabetes reported more instances of depression than boys with diabetes; between the ages of 10 and 15, girls with diabetes were twice as likely to express feelings of depression than boys (Korbel et al., 2007; Anderson et al., 2001; Nolen-Hoeksema, 1990; Nolen-Hoeksema & Girgus, 1994). In terms of protective factors regarding diabetes and gender, Charmaz (1994) suggested that men with diabetes perhaps benefited from their active and problem-solving disposition (Williams, 1999). Additionally, girls with diabetes were twice as likely to have an eating disorder or disordered eating habits that further exacerbated their condition and glycemic control (Daneman et al., 2002).

Charmaz (1994) found that women with diabetes illustrated more adaptability in their diagnosis and accepted their conditions as part of their lives, more so than men. Concerning differing meaning and identity-making of the diabetic condition, Williams (1999) interviewed ten girls and ten boys with diabetes between the ages 15 and 18 going through transition care. In her study, she found that all of the girls in her sample had fully incorporated diabetes as their identity. Below is a statement from one of the girls that portrayed her embracement of diabetes as part of her identity:

Everyone should know [that I have diabetes] because then they can help if something happens. It's not a question of minding or not, it's my health, you know. People, everyone should know so that in case something happens, even if they don't know what to do they can tell someone (Williams, 1999, p.1162).

However, Williams (1999) found out that nine out of ten boys she had interviewed tried to minimize their diabetic condition, especially to everyone outside of their family (Williams, 1999). One of the boys said, “That’s your business if you’re diabetic sort of thing” (Williams, 1999, p.1162), illustrating that boys might not want to talk about their diabetic condition, even with their close friends since they considered diabetes to be more of a private matter.

Another interesting finding from Williams (1999) was that most of the girls in her sample had full responsibility of their diabetic conditions whereas mothers had more involvement in their son’s diabetes. Higher expectations of self-management and independence in illness management were not only enforced by girls themselves, but also from mothers and healthcare professionals (Williams, 1999; Korbel et al., 2007; Lavigne et al., 1982; Pomerantz & Eaton, 2001). The higher expectations and responsibilities for diabetes management could come from societal gender norms since a systematic review by Lenroot and Giedd (2009) and another study by Overman (2004) illustrated that there were no significant differences regarding biological brain development nor cognitive abilities between AYA girls and boys. In terms of gender socialization impact on diabetes management, girls were granted more autonomy when making decisions for they are socially perceived to “typically mature earlier than boys,” and were given earlier autonomy over their condition (Endendijk et al., 2016; Bumpus et al., 2001). Thus, mothers had more control over boys’ diabetes management, which led boys to have better adherence outcomes than girls (Williams, 1999). Because the bulk of the responsibility of girls’ own conditions laid upon their shoulders, they felt blamed more for their failures in diabetes management and were hesitant to ask for help, which consequently could have led girls to hide their non-adherence to their insulin regimen (Williams, 1999). As there are clear sex differences in the management of diabetes, it is important to control for the

sex variable when conducting a study regarding diabetes. Additionally, exploring different levels of guidance in the transition process for AYA girls and boys with diabetes could be worthwhile.

VII. Implications of Socioeconomic Status Differences for Patients with Diabetes

Socioeconomic Status (SES) is inversely correlated with various chronic illnesses, illustrating an unfortunate inequity in the healthcare system (Secrest et al., 2011; Blaxter, 1987; Gonzalez et al., 1998; Kaplan & Keil, 1993). Even in countries like Canada, where universal healthcare is offered, there were inequalities in the social aspect, such as healthy food, blood glucose monitoring supplies, or transportation to hospitals (Houle et al., 2016; Weaver et al., 2014). Thus, SES is also a powerful predictor in the outcome of diabetes illness management (Gallegos-Macias et al., 2003). In particular, considering SES differences during adolescence and young adulthood is valuable because diabetes management during this period could easily be staggered by financial burdens (Peters & Laffel, 2011). In the lower SES groups, more health complications were present, such as cardiovascular diseases, hypertension, renal disorders, blindness, and amputation (Secrest et al., 2011; Muhlhauser et al., 2000). Additionally, patients (age 8 to 17) with diabetes at a lower SES were prone to having poor glycemic control, depression, insufficient knowledge regarding diabetes management, as well as lower self-empowerment than those of higher SES (Hassan et al., 2006). Patients of higher SES were more disposed to receiving comprehensive insulin care, such as insulin pump as well as continuous glucose monitors (Hassan et al., 2006; Rodbard, 2019; Paris et al., 2009). As SES is a crucial factor in health outcomes for individuals with diabetes, the SES variable should be controlled when investigating a population with diabetes.

VIII. Implications of Race Differences for Patients with Diabetes

Although there have been great efforts to bring equality and equity to different races in healthcare systems, inequities in healthcare still exist among racial and ethnic minorities in the United States (Berry et al., 2010; Willi et al., 2015). Minority populations in terms of race and ethnicity with diabetes could be at risk for poor health outcomes (Redondo et al., 2018). In particular, African American children with diabetes seemed to be at the greatest risk out of all the minority groups and Caucasian children seemed to be at the greatest privilege; researchers hypothesized that this could be from the fact that many African American children come from lower SES families, ultimately leading to different insurance programs that yielded different diabetes management plans (Chalew et al., 2000; Willi et al., 2015; Redondo et al., 2018). Children of color, especially African American, American Indian, and Alaska Native children, had higher rates of diabetes diagnosis and considered diabetes as a bigger burden (Walker et al., 2016). This could be due to people of color potentially having insufficient “self-management skills” (Walker et al., 2016; CDC, 2014; AHRQ, 2001; Kirk et al., 2006). African American children with diabetes tended to have worse glycemic control, higher HbA1c levels, more frequent cases of diabetic ketoacidosis, hypertension, neuropathy and retinopathy, when compared to Caucasian children with diabetes (Chalew et al., 2000; Redondo et al., 2018; Walker et al., 2016; CDC, 2014). Redondo and colleagues (2018) explained that these negative health outcomes could stem from differing health insurance statuses, basic β cell function, and SES factors; Chalew and colleagues (2000) suggested that these differences could be from reduced sensitivity of insulin for African American children with diabetes.

Even when SES was controlled, fewer African American children were using insulin pumps instead of injections, compared to Caucasian children (Willi et al., 2015). In fact, even

African American children in the highest SES group were less likely to have an insulin pump compared to the Caucasian children in the lowest SES group. The annual income was at least \$100,000 for African American children to have an insulin pump, whereas the annual income was less than \$50,000 for Caucasian children to have an insulin pump. Considering that fewer African American children with private insurance get prescribed insulin pump therapy compared to Caucasian children without private insurance, this difference could perhaps come from disparities in treatment plans. This puts African American children in every SES in a vulnerable position. To further support this finding, Valenzuela and colleagues (2011) found that African American children, along with Hispanic children, received a less intense insulin regimen than Caucasian children.

Although Hispanic children with diabetes had better health outcomes than African American children, they still had worse outcomes compared to Caucasian children (Redondo et al., 2018). Hispanic children were prone to severe hypoglycemia compared to Caucasian children; they were also more likely to develop other comorbidities associated with diabetes, such as hypertension and thyroid disease. They also had higher HbA1c levels and episodes of diabetic ketoacidosis, although not as severe as observed in African American children. Because the disparities of diabetes care and severity in different races are evident, it is crucial to incorporate race as a control variable in diabetes research.

The Current Study

AYA with chronic illnesses are particularly vulnerable for negative health outcomes during a period of dynamic change, encompassing physical, social, and psychological changes on top of illness management (Suris et al., 2004). AYA find this period especially intimidating since there is not much guidance in the transition process from the pediatric care to the adult

healthcare system (Minicozzi 2000, National Collaborating Centre for Women's and Children's Health 2004; Rapley & Davidson, 2010). There is limited literature on young adults with chronic illnesses and the differing degree and types of transition guidance they receive. Individuals without any chronic conditions also have to eventually transition to the adult healthcare system, however few studies discuss the transition to adult care system for AYA without any special health needs (Davidson et al., 2017; Eaton et al., 2017; Weller et al., 2003; White et al., 2018; Lebrun-Harris et al., 2018; Eaton et al., 2017). There was also a lack of literature that compared the amount of transition guidance that AYA with diabetes received to AYA without any special health needs. Because diabetes is a complex disorder that affects many different domains of health, transition guidance must be offered to AYA with diabetes for positive health outcomes (Katsarou et al., 2017; American Diabetes Association, 2016; Khandelwal et al., 2016; Kovacs et al., 1997; Buschur et al., 2017; Willi et al., 2015; Garvey et al., 2013). The intricacies of diabetes are further illustrated by the distinct implications of differing social determinants of health such as sex, race and SES (Enzlin et al., 2002; Legato et al., 2006; Gallegos-Macias et al., 2003; Redondo et al., 2018).

This study will investigate the different types of guidance that adolescents with diabetes receive in comparison to adolescents without any special health concerns. This study will further examine differing types of guidance in the transition process by age and sex of adolescents with diabetes.

Primary Question:

1. Is there a difference in parent- or guardian-reported transition care guidance given by the physician between adolescents with diabetes and adolescents without any special healthcare needs (SHCN)? If so, to what extent?

Hypothesis: Given that a wide array of literature suggests that there are more adverse health outcomes related to disruptions in care for adolescents with diabetes, I hypothesize that doctors or healthcare providers will offer more transition guidance to adolescents with diabetes than adolescents without any special healthcare needs by discussing when to see other providers who treat adults and actively working with adolescents to understand changes in healthcare that happen at age 18.

Secondary Question:

2. Is there a difference in parent- or guardian-reported transition care guidance given by the physician by sex and age of adolescents? Specifically, does guidance vary for boys and girls and does this differ when boys and girls are younger adolescents (ages 12-14) versus older adolescents (ages 15-17)? If so, to what extent?

Hypothesis: Dynamic changes often occur after high school (e.g., going to college, getting a job) that might encourage seeking for a new healthcare provider, which consequently could lead to negative health outcomes associated with an interruption of diabetes care. Furthermore, given the poor diabetes outcome for girls due to factors such as gender socialization and increased insulin resistance during puberty, I hypothesize that doctors or healthcare providers will offer more transition guidance to older adolescent and male adolescent populations with diabetes when compared to the younger adolescent and female adolescent populations with diabetes, respectively, by discussing when to see providers who treat adults and actively working to educate changes in healthcare that happen at age 18.

Method

The research questions addressed above were explored with secondary data. The quantitative data for analysis was provided by The National Survey of Children's Health from

the Data Resource Center on Child and Adolescent Health, with the Child and Adolescent Health Measurement Initiative from 2016 to 2017. The survey was devised to assess the intersections of health of individuals aged zero to 17, on a national and state level. The survey was completed by parents or guardians, if there was a child in the household.

Procedure

The National Survey of Children's Health (NSCH) is a self-administered questionnaire, completed either on an online platform or a mail-out/mail-back paper platform. For the households that were more likely to answer via paper platform or 'High Paper' group (roughly 30% of the addresses), they were first mailed the screener questionnaire and the web-based survey. For the households that were more likely to answer via the online platform or 'High Web' group (roughly 70% of the addresses), the invitation to participate in the online survey was sent. When the 'High Web' group did not respond, they were sent a paper version of the survey for a follow-up. The 'High Paper' and 'High Web' groups were determined by the results from the American Community Survey (ACS); respondents of ACS could choose to answer by the online platform and the paper platform. For the 2016-2017 NSCH, Census created the paper-response probability index based on the ACS response mode behavior and geographic tendencies to determine which group of residents would most likely answer by paper or web-based survey.

For data collection, a screener questionnaire was placed to determine the presence of children in the household. If the household did have children, the parents or guardians were instructed to create a list of their children regarding age, demographics, special health needs, and many more. After the screener questionnaire, one child was randomly chosen for an age

specific topical survey, per household. The age specific topical survey included T1 for ages 0 to 5, T2 for ages 6 to 11, or T3 for ages 12 to 17.

Incentives are a crucial and cost-effective way to collect survey responses while reducing nonresponse bias (Brick et al., 2011). The abundance of such research results drove NSCH to include incentives in their administrations of the survey. There were two different incentive conditions in which the survey was carried in: screener incentive and topical incentive group. In the screener incentive group, around 90% of the respondents were provided with \$2 while 10% of the respondents received \$0 as a control group. The screener incentive revealed that providing incentive aided in the response rate. NSCH also included a topical incentive group, in which 80% of the households that replied that they had a child in the screener survey would receive \$2 incentive, while 20% of them did not. The \$2 incentive increased the chances of the survey response by 51%.

Furthermore, there were the web group and the infographic group in order to further increase the response rate of the questionnaires. As described above, the web group consisted of the 'High Paper' group (30%) and 'High Web' group (70%). For the infographic group, a very colorful infographic paper was sent with the initial materials in order to elicit interests in responding to the questionnaire. 50% of the addresses received a one-page infographic and the other 50% did not. Infographic was not helpful in increasing the response rate as it slightly reduced the response rate from 37.3% to 36.8%.

Population

A combined data set for the surveys from 2016 and 2017 was used for analyzing the research questions. A total of 71,811 surveys were completed for the 2016 and 2017 questionnaires; 50,212 surveys in 2016 and 21,599 in 2017. The questionnaires were sent to

different households, in 50 states and the District of Columbia. The range of addresses per state was 2,014 (Minnesota) to 9,490 (Alaska). The sample was categorized by state and child presence indicator, which granted the Census Bureau to distribute the NSCH to households that had a higher chance of having children. The child presence indicator was created by many different sources of administrative data by the Census Bureau's Center for Administrative Records Research and Applications. The 2016 and 2017 combined data set contained approximately 1,400 surveys per state (state range: 1,070 to 1,784). The response rate was 40.7% and 37.4%, for 2016 and 2017 surveys, respectively. The survey oversampled for households that were more likely to have more children, children with special healthcare needs (80%), and young children aged 0 to 5 years old (60%).

Selection

The T3 survey for adolescents aged 12-17 was used for analyzing the research questions. The T3 survey regarding the topic of transition care only involved adolescents aged 12-17 for this age range was the only relevant population in investigating healthcare transition care experiences: younger children would still be in pediatric care and older adults would have already transitioned into the adult healthcare system. In particular, survey responses regarding individuals with diabetes and individuals without any chronic health conditions were used for answering the research questions. The selected sample for this specific study was comprised of 233 individuals (ages 12-17) who were diagnosed with diabetes in the United States. The selected sample population (n=233) was 0.79% of the total T3 survey population (n=29,617), comprised of individuals aged 12 to 17 ($M_{age}=15$, 50.4% female).

The primary question compared the transition experiences between adolescents with diabetes and adolescents without any chronic health conditions. In order to compare 233

individuals with diabetes, 233 individuals without any special healthcare needs (pre-defined by NSCH) between the ages 12 and 17 were randomly chosen for data analysis by the random selection function on SPSS. In order to ensure that the two groups were compared only by transition care experiences and not by other social determinants of health, race, sex and SES variables served as control variables in the statistical analysis. The individuals without any special health conditions were identified by asking the parents or guardians five questions regarding health in the screener questionnaire. The five questions involved currently prescribed medication, medical care or extra services, ability, need of special therapy and EDB problem, respectively. Additionally, all of the five questions ask a follow-up question that asked if the condition has lasted or expected to last more than 12 months. The secondary question only used the data from adolescents with diabetes (n=233) and looked at the differential transition experiences by age (continuous variable and categorical variable between early (ages 12-14) and middle adolescence (ages 15-17), sex, as well as the interaction of age and sex.

Measures

I. Diabetes Diagnosis

The child's diagnosis of diabetes, race, and gender were all self-reported measures from the parent or guardian. For the diagnosis of diabetes, they had an option to answer "Yes" or "No" on the survey question that said, "Has a doctor or other health care provider ever told you that this child has diabetes?" and "If yes, does this child currently have the condition." Then, they were asked, "If yes, is it: mild, moderate, severe."

II. Demographics: Age, Sex, Race

For the determination of ethnicity, they were first asked, "Is this child of Hispanic, Latino or Spanish origin?" and they had the option to say "no" (not of Hispanic, Latino, or

Spanish origin) or “yes” (Mexican, Mexican American, Chicano; Puerto Rican; Cuban; another Hispanic, Latino, or Spanish origin). Then, they were asked, “What is this child’s race?” and given the option to mark one or more boxes. The options were: White, Black or African American, American Indian or Alaska Native, Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Other Asian, Native Hawaiian, Guamanian or Chamorro, Samoan, Other Pacific Islander or Some other race. Race was only used for control variable throughout data analysis; the categories were condensed to “Hispanic” (Mexican, Mexican American, Chicano; Puerto Rican; Cuban; another Hispanic, Latino, or Spanish origin), “White” (non-Hispanic), “Black” (non-Hispanic) (African American), and “Other/Multi-racial” (included non-Hispanic American Indian or Alaska Native, Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Other Asian, Native Hawaiian, Guamanian or Chamorro, Samoan, Other Pacific Islander or Some other race). For the child’s age, they were asked, “How old is this child?” They could answer in years or months. Given that transition of healthcare occurs during adolescence, only questionnaires from parents and guardians with adolescents between age 12 and 17 were used in data analysis. For the child’s sex, they were asked, “What is this child’s sex?” and given two choices: male and female.

III. Socioeconomic Status

For the economic status, in the section of household information, parents and guardians were first asked, “How many people are living or staying at this address?” and “How many of these people in your household are family members?” Then, they are asked, “Income in the last calendar year” and asked specifics about their income. Finally, they are asked about their total combined family income in the last calendar year for all members of the family. Then, they

were put in four different categories of 0-99% of family poverty ratio, or federal poverty line (FPL), 100-199% of FPL, 200-399% of FPL or 400% of FPL or more.

For the educational status, the primary caregivers were asked for their highest grade or level of school they have completed, and given the following options: 8th grade or less, 9th-12th grade with no diploma, high school graduate or General Education Development (GED) completion, vocational, trade, or business school completion, some college credit without a degree, associate degree (AA, AS), bachelor's degree (BA, BS, AB), master's degree (MA, MS, MSW, MBA), or a doctoral degree (PhD, EdD) or professional degree (MD, DDS, DVM, JD). Then, they were put in four different categories of less than high school education, high school education or GED, some college or technical school or college degree or higher. Finally, the less than high school education population was combined with the high school education or GED group due to small sample size. SES was used as a control variable throughout the data analysis process.

IV. Transition Care Experience

Two questions related to transition care were explored for the transition care experience. The first question (transition to adult care) involved two parts: the first part asked, "Do any of [your] child's doctors or other health care providers treat only children?" and the second part asked, "If yes, have they talked with you about when [your] child will need to see doctors or other health providers who treat adults?" Response options were "Yes" or "No." The second question (anticipatory guidance for changes in healthcare) asked, "Has [your] child's doctor or other healthcare provider actively worked with this child to understand the changes in healthcare that happen at age 18?" Response options were "Yes," "No," or "Don't Know." The

33 participants with adolescents with diabetes who responded “Don’t Know” were excluded from the analysis.

Data Cleaning

The National Survey of Children’s Health includes a large data set that also involves many parts that are unnecessary for the proposed research questions. In order to clean the data and create the file that is needed with the specific sample population, Statistical Package for the Social Sciences (SPSS) software was used to only leave rows and columns for individuals with diabetes currently, individuals with no special healthcare needs, age, transition care questions, education status, income level, race and sex.

The file was then split into two: the first file included adolescents with diabetes for the secondary question and the second file included adolescents without any special healthcare needs (SHCN) to prepare for the random selection of 223 adolescents from the total sample of 29,617 adolescents. After picking the random sample by a randomization process, a third file was made just for the randomly selected sample. For the primary question, the first and third file was merged.

Data Analysis

Descriptive statistics were conducted for all of the relevant variables. Chi-square analysis and independent samples t-test were done in order to investigate any differences in the demographic variables between the two selected sample populations (adolescents with diabetes and adolescents without SHCN). The research questions involved a categorical variable (e.g., transition guidance from physician) for the dependent variable and a categorical variable (e.g., diagnosis of diabetes, younger or older adolescence, sex) for the independent variable. In order to assess the correlation between the two categorical variables while taking control variables

(e.g., SES, sex, ethnicity) into account, binomial logistic regression analyses for the research questions were conducted. First, the regression was done separately for the adolescents with diabetes and adolescents without SHCN. Then, the two populations were combined to see the effects of having diabetes in transition guidance. To ensure that only the difference in the guidance of transition care was investigated, SES (parent education, FPL), age, sex, and ethnicity were controlled for the first research question. For the second research question, hierarchical regressions were computed. The first block included race/ethnicity, parent education, and FPL as these were the control variables. The second block included age and sex to explore the main effect of these variables after accounting for variance explained by the control variables. The third block included the age and sex interaction variable. Two outcomes were assessed for each of the research questions in order to assess transition guidance from physicians to adolescents in this study. The first outcome was seeing doctors who treat adults (transition to adult care), and the second outcome was teaching changes that occur at age 18 in healthcare systems (anticipatory guidance for changes in healthcare). All of the regressions involving age were ran twice, with one regression accounting for age as a categorical variable (age group) and another accounting for age as a continuous variable. Confidence interval of 95%, or $p < 0.05$, was used to assess all significant findings.

Regression equations

Binomial logistic regression to assess the difference in reported transition care guidance given by the physician between adolescents with diabetes and adolescents without any special healthcare needs (Tables 2-5):

1. y (transition to adult care) = B_0 (constant) + B_1 (ethnicity) + B_2 (sex) + B_3 (parent education) + B_4 (FPL) + B_5 (age or age group) (Tables 2-3)

2. y (anticipatory guidance for changes in healthcare) = B_0 (constant) + B_1 (ethnicity) + B_2 (sex) + B_3 (parent education) + B_4 (FPL) + B_5 (age or age group) (Tables 4-5)
3. y (transition to adult care) = B_0 (constant) + B_1 (ethnicity) + B_2 (sex) + B_3 (parent education) + B_4 (FPL) + B_5 (age or age group) + B_6 (diabetes status) (Tables 2-3)
4. y (anticipatory guidance for changes in healthcare) = B_0 (constant) + B_1 (ethnicity) + B_2 (sex) + B_3 (parent education) + B_4 (FPL) + B_5 (age or age group) + B_6 (diabetes status) (Tables 4-5)

Hierarchical Regression #1 to assess the difference in reported transition to adult care given by the physician by sex and age of adolescents (Tables 6-7):

$$\text{Step 1: } y \text{ (transition to adult care)} = B_0 \text{ (constant)} + B_1 \text{ (ethnicity)} + B_2 \text{ (parent education)} + B_3 \text{ (FPL)}$$

$$\text{Step 2: } y \text{ (transition to adult care)} = B_0 \text{ (constant)} + B_1 \text{ (ethnicity)} + B_2 \text{ (parent education)} + B_3 \text{ (FPL)} + B_4 \text{ (sex)} + B_5 \text{ (age or age group)}$$

$$\text{Step 3: } y \text{ (transition to adult care)} = B_0 \text{ (constant)} + B_1 \text{ (ethnicity)} + B_2 \text{ (parent education)} + B_3 \text{ (FPL)} + B_4 \text{ (sex)} + B_5 \text{ (age or age group)} + B_6 \text{ (age x sex)}$$

Hierarchical Regression #2 to assess the difference in reported anticipatory guidance for changes in healthcare given by the physician by sex and age of adolescents (Tables 8-9):

$$\text{Step 1: } y \text{ (anticipatory guidance for changes in healthcare)} = B_0 \text{ (constant)} + B_1 \text{ (ethnicity)} + B_2 \text{ (parent education)} + B_3 \text{ (FPL)}$$

$$\text{Step 2: } y \text{ (anticipatory guidance for changes in healthcare)} = B_0 \text{ (constant)} + B_1 \text{ (ethnicity)} + B_2 \text{ (parent education)} + B_3 \text{ (FPL)} + B_4 \text{ (sex)} + B_5 \text{ (age or age group)}$$

$$\text{Step 3: } y \text{ (anticipatory guidance for changes in healthcare)} = B_0 \text{ (constant)} + B_1 \text{ (ethnicity)} + B_2 \text{ (parent education)} + B_3 \text{ (FPL)} + B_4 \text{ (sex)} + B_5 \text{ (age or age group)} + B_6 \text{ (age x sex)}$$

Results

I. Descriptive Statistics

When caregivers of adolescents with diabetes were asked about transition to adult care, 48.9% (n=109) said “yes” and 51.1% (n=114) said “no” (Table 1). When parents or guardians of a subsample of adolescent without SHCN were asked about transition to adult care, 52.9% (n=105) said “yes” and 47.1% said “no” ($\chi^2(1)=0.1437$, $p=0.705$) (Table 1). Chi-Square results showed that the frequencies of “yes” and “no” to the transition to adult care question were not significantly different between the two groups. When caregivers of adolescents with diabetes were asked a question regarding anticipatory guidance for changes in healthcare, 92.8% (n=206) said “yes” and 7.2% (n=16) said “no”, illustrating that most physicians of adolescents with diabetes provide anticipatory guidance for changes in healthcare (Table 1). When parents or guardians of adolescents without SHCN were asked about anticipatory guidance for changes in healthcare, 57.0% (n=127) said “yes” and 43.0% (n=96) said “no” ($\chi^2(1)=75.8827$, $p<0.001$) (Table 1). Chi-Square results suggested significant group differences in anticipatory guidance for changes in healthcare.

The sample population comprised of adolescents with diabetes and adolescents without SHCN whose mean ages were 14.97 (SD: 1.686) and 14.37 (SD: 1.781), respectively ($F=3.218$, $p<0.001$) (Table 1). Although an independent samples t-test revealed that the mean ages were significantly different, the mean ages were merely 0.6 years apart. In both populations, there were slightly more male adolescents than female adolescents, with males comprising 51.6% (n=115) of the adolescents with diabetes population and comprising 50.7% (n=113) of the adolescents without SHCN population ($\chi^2(1)=0.0359$, $p=0.850$) (Table 1). Chi-square results showed that the sex distribution was not significantly different between the two

groups. The majority of the sample population, 72.6% (n=162) of adolescents with diabetes and 76.2% (n=170) of adolescents without SHCN, was composed of individuals who have identified themselves as “White, non-Hispanic” ($\chi^2(3)=7.6732$, $p=0.053$) (Table 1). The majority of both samples were at or above 400% of the FPL ($\chi^2(3)=7.4341$, $p=0.059$) and had parents who received a college degree or higher ($\chi^2(2)=3.9772$, $p=0.137$) (Table 1). Chi-square results depicted that ethnicity and SES distributions were not significantly different between the two groups.

II. Research Question 1: Parent- or guardian- reported transition care guidance given by the physician between adolescents with diabetes and adolescents without SHCN

Ila. Transition Guidance Question #1: Discussion of seeing doctors who treat adults

Results of the binomial regressions predicting transition to adult care are presented in Tables 2 and 3. The regression was significant for the combined sample (labeled “Both Populations” in the table), when age was entered as a continuous variable (Nagelkerke $R^2=0.129$, $\chi^2(8)=45.408$, $p < 0.001$) and when age was entered as a categorical variable (Nagelkerke $R^2=0.090$, $\chi^2(8)=31.028$, $p < 0.001$). Age (OR=1.45, $p < 0.001$) was positively related to transition to adult care such that for each year increase in age, the likelihood of receiving guidance in transition to adult care increased by 45% (see Table 2). Age was also significant when entered as a categorical variable (OR=2.784, $p < 0.001$) such that individuals who were in middle adolescence were 2.78 times more likely to receive guidance on transition to adult care than those who were in early adolescence (see Table 3). Diabetes status (OR=0.947, $p=0.787$) and other demographic variables were not significantly related to transition to adult care.

The regression was significant for adolescents with diabetes when age was entered as a continuous variable (Nagelkerke $R^2=0.132$, $\chi^2(7)=23.295$, $p=0.002$) and not significant when age was entered as a categorical variable (Nagelkerke $R^2=0.077$, $\chi^2(7)=13.217$, $p=0.067$). Age (OR=1.433, $p<0.001$) was positively related to transition to adult care such that for each year increase in age, the likelihood of receiving guidance in transition to adult care increased by 43% (see Table 2). Other demographic variables were not significantly related to transition to adult care.

The regression was significant for adolescents without SHCN when age was entered as a continuous variable (Nagelkerke $R^2=0.177$, $\chi^2(7)=31.639$, $p<0.001$) and when age was entered as a categorical variable (Nagelkerke $R^2=0.166$, $\chi^2(7)=29.541$, $p<0.001$). When age (OR=1.444, $p<0.001$) was entered as a continuous variable, it was positively related to transition to adult care such that for each year increase in age, the likelihood of receiving guidance in transition to adult care increased by 44% (see Table 2). Age was also significant when entered as a categorical variable (OR=3.346, $p<0.001$) such that individuals who were in middle adolescence were 3.35 times more likely to receive guidance in transition to adult care than those who were in early adolescence (see Table 3). Furthermore, identifying as being “Other/Multi-racial” was also significant when age was entered as a categorical variable (OR=0.346, $p=0.038$) (Table 3). This finding illustrated that the likelihood of receiving guidance in transition to adult care for individuals identifying as “Other/Multi-racial” decreased by 65.4%. Other demographic variables were not significantly related to transition to adult care.

Iib. Transition Guidance Question #2: Anticipatory guidance for changes in healthcare that occur at age 18

Results of the binomial regressions regarding anticipatory guidance for changes in healthcare are presented in Tables 4 and 5. The regression was significant for the combined sample (labeled “Both Populations” in the table) when age was entered as a continuous variable (Nagelkerke $R^2=0.280$, $\chi^2(8)=93.622$, $p < 0.001$) and when age was entered as a categorical variable (Nagelkerke $R^2=0.276$, $\chi^2(8)=92.213$, $p < 0.001$). Unlike results from transition to adult care, age (OR = 1.136, $p=0.070$) and age group (OR=1.406, $p=0.169$) were not significant (Tables 4 and 5). However, diabetes diagnosis (labeled “Health Condition”) (OR=9.559, $p < 0.001$) was significant when age was entered as a continuous variable such that adolescents with diabetes were 9.56 times more likely receive anticipatory guidance for changes in healthcare than adolescents without SHCN (Tables 4 and 5). Diabetes diagnosis (OR=9.759, $p < 0.001$) was also significant when age was entered as a categorical variable such that adolescents with diabetes were 9.76 times more likely to receive anticipatory guidance for changes in healthcare than adolescents without SHCN (Tables 4 and 5). Other demographic variables were not significantly related to anticipatory guidance for changes in healthcare.

The regressions were not significant for adolescents with diabetes (Tables 4 and 5) when age was entered as a continuous variable (Nagelkerke $R^2=0.046$, $\chi^2(7)=4.163$, $p=0.761$) and when age was entered as a categorical variable (Nagelkerke $R^2=0.046$, $\chi^2(7)=4.164$, $p=0.761$). The regressions were not significant for adolescents without SHCN (Tables 4 and 5) when age was entered as a continuous variable (Nagelkerke $R^2=0.076$, $\chi^2(7)=12.994$, $p=0.07$) and when age was entered as a categorical variable (Nagelkerke $R^2=0.064$, $\chi^2(7)=10.919$, $p=0.142$).

III. Research Question 2: Parent- or guardian-reported transition guidance given by the physician by sex and age of adolescents with diabetes

IIIa. Transition Guidance Question #1: Transition to adult care

Results of the hierarchical regressions assessing the relationship between sex, age, and transition to adult care for adolescents with diabetes are presented in Tables 6 and 7. In the regression using age as a continuous variable, none of the control variables in “Block 1” (Nagelkerke $R^2=0.024$, $\chi^2(5)=3.994$, $p=0.550$) were significant. In “Block 2” (Δ Nagelkerke $R^2=0.108$, $\chi^2(7)=23.295$, $p=0.002$), adolescents who were older were more likely to receive guidance in transition to adult care (OR=1.433, $p<0.001$) while transition to adult care did not significantly differ by sex (OR=1.285, $p=0.378$). The interaction of age and sex was not significant in “Block 3” (Δ Nagelkerke $R^2=0.004$, $\chi^2(8)=24.072$, $p=0.002$, OR=0.856).

In the regression in which age was grouped into early and middle adolescence, none of the control variables in “Block 1” (Nagelkerke $R^2=0.024$, $\chi^2(5)=3.994$, $p=0.550$) were significant. In “Block 2” (Δ Nagelkerke $R^2=0.053$, $\chi^2(7)=13.217$, $p=0.067$), individuals in middle adolescence were more likely to receive guidance in transition to adult care (OR=2.200, $p=0.007$) while discussion of transition to adult care did not significantly differ by sex (OR=1.322, $p=0.317$). The interaction between age group and sex was significant in “Block 3” (Δ Nagelkerke $R^2=0.036$, $\chi^2(8)=19.782$, $p=0.011$, OR=2.200). A post-hoc chi-square analysis revealed that while physician directed guidance of transition to adult care was not significantly different between early and middle adolescent girls ($\chi^2(1)=2.7262$, $p=0.99$), it differed significantly between early and middle adolescent boys ($\chi^2(1)=6.0919$, $p=0.014$) (Figures 1 and 2).

IIIb. Transition Guidance Question #2: Anticipatory guidance for changes in healthcare that occur at age 18

Adolescents with diabetes depicted no significant results ($p > 0.05$) regarding any of the variables related to the transition guidance question regarding anticipatory guidance for changes in healthcare. The hierarchical regression yielded in no significant results (“Block 1” Nagelkerke $R^2 = 0.042$; “Block 2” Nagelkerke $R^2 = 0.046$ (Age Range); 0.046 (Age); “Block 3” Nagelkerke $R^2 = 0.037$ (Age Range); 0.049 (Age)).

Discussion

The primary research question inquired about the difference in parent- or guardian-reported transition care guidance offered by the physician between adolescents with diabetes and adolescents without SHCN. I hypothesized that the healthcare provider would offer more transition guidance to adolescents with diabetes as they are more vulnerable to poor health outcomes (Laing et al., 2005; Wills et al., 2003). This hypothesis was supported; this study found that adolescents with diabetes received more guidance for transition to adult care when compared to adolescents without SHCN. The secondary research question investigated the difference in parent- or guardian-reported transition care guidance offered by the physician by the sex and age of adolescents with diabetes, particularly exploring the interaction between sex and age. I hypothesized that healthcare providers would offer more transition guidance to older adolescents and adolescent boys. They would provide more guidance to older adolescents because of the dynamic changes that many go through that prompt interruptions in diabetes care (Garvey et al., 2013; Arnett, 2000); providers would also give more guidance to adolescent boys, which in part could account for the poor diabetes outcomes seen in adolescent girls (Shim et al., 1999; Daneman et al., 2002; Austin et al., 2011). This hypothesis was

partially supported as results showed that adolescents who were older received significantly more transition guidance and revealed that there was a relationship between age and sex.

However, results did not support the sex differences hypothesis in receiving transition care.

I. Research Question 1: Parent- or guardian-reported transition care guidance given by the physician between adolescents with diabetes and adolescents without SHCN

Results for the first research question illustrated that anticipatory guidance for changes in healthcare differed between groups. Adolescents with diabetes were significantly more likely to receive anticipatory guidance for changes in healthcare when compared to adolescents without SHCN, as hypothesized. This may be because adolescents without SHCN may have fewer medical check-ups compared to their counterparts with a chronic condition (Davidson et al., 2017; Eaton et al., 2017; Weller et al., 2003). Healthcare providers are perhaps less likely to discuss future goals with regards to adolescents without SHCN because of their lack of a chronic condition, which was consistent with the results found by this study. Although this finding is reassuring for adolescents with diabetes as their medical needs are more complex and a lapse in care could be fatal, adolescents without SHCN still need guidance for transitioning into the adult healthcare system. Pediatric healthcare providers could perhaps address this lapse in guidance by referring their adolescent patients to a provider in the adult healthcare system or by helping adolescent patients to plan specific strategies for transition. Comparison between adolescents with diabetes and without SHCN were nonsignificant for transition to adult care. This could suggest that, although adolescents with diabetes get more help for anticipatory guidance for changes in healthcare, they do not get more help than adolescents without SHCN for transition to adult care. Alternatively, this finding may be indicative of health literacy expectations providers have of parents or guardians regarding

transition to adult care. Adolescents with diabetes are particularly vulnerable to adverse health outcomes because of the complexity of its health implications, and consequently necessitates informed knowledge about adult care (Garvey et al., 2013; Arnett, 2000; Nakhla et al., 2009). More effort should be placed by physicians to educate and inform patients about changes they will face once they enter the adult healthcare system, from insurance policy changes to the difference of philosophies between the two care systems (supportive vs. independent; Buschur et al., 2017). The lack of education regarding the changes that adolescents will experience in adult healthcare systems could be from the lack of formal training in the medical school curricula (Nakhla et al., 2017; Sonneveld et al., 2012) and the lack of an uniform age to transition to the adult healthcare setting (Bhawra et al., 2016; Kaufman & Pinzon, 2007; Davis et al., 2014; Nazarian et al., 2010). This could be improved by placing a formal medical school curriculum change with a unit including transition care for physicians in both care systems (pediatric and adult) and setting guidelines around a central and uniform (but flexible per situation) age to transition (Bhawra et al., 2016; National Collaborating Centre for Women's and Children's Health, 2004; Wedgwood et al., 2008) to decrease dissonance and difference of views between physicians of different care systems (Sadun et al., 2019; Nakhla et al., 2017; Sonneveld et al., 2012).

It was also notable that age and age group were significant in both populations regarding transition to adult care. In both populations, older adolescents and individuals in middle adolescence were more likely to receive transition to adult care than younger adolescents or individuals in early adolescence, respectively, as hypothesized. This finding is plausible as older adolescents have a higher chance of mismanaging their diabetes, are closer to the time of transition, and may consequently need more guidance during their journey towards

the adult healthcare system (Weissberg-Benchell et al., 1995; Hilliard et al., 2013). However, in reality, older adolescents and individuals in middle adolescence may actually receive more guidance in transition to adult care than the results of this study indicate, as minor consent laws allow older adolescents to receive transition guidance directly from their healthcare providers without parent or guardian consent; further investigations must be done to confirm the exact degree and type of guidance adolescents receive from their healthcare providers (Field & Behrman, 2004). Regardless, it could be beneficial to start discussions about transitioning to the adult care system during early adolescence as prior research has found that some adolescents describe their period of transition to be lacking proper support and services due to poor planning of health service arrangements (National Collaborating Centre for Women's and Children's Health 2004; Holmes-Walker et al., 2007; Tuchman et al., 2008). Starting the discussion about transitioning to the adult healthcare system earlier could allow more time for adolescents to plan their transition and may consequently result in more support in receiving related services. As some adolescents have voiced that knowing specific provider names was useful, it could also be worthwhile to discuss various provider options from early adolescence (Garvey et al., 2013). Moreover, pediatricians could help by explaining the differences in philosophies between the two care systems (family-focused approach vs. self-care approach) to adolescents so that they are not taken aback when they transition to the adult healthcare system (Rapley & Davidson, 2010). Furthermore, providing transition guidance resources and making them readily accessible on the AMA (American Medical Association) website could be beneficial for families and physicians planning for transition.

For other findings between adolescents with diabetes and adolescents without SHCN, the "Other/Multi-racial" group for adolescents without SHCN was significantly less likely to

receive guidance regarding transition to adult care. The “Other/Multi-racial” group was a combination of many different racial and ethnic groups, including non-Hispanic American Indian or Alaska Native, Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Other Asian, Native Hawaiian, Guamanian or Chamorro, Samoan, Other Pacific Islander or Some other race. Given the heterogeneity of the individuals included in this category, further investigations must be done to interpret this result. However, literature suggests that people of color may consider diabetes management as a greater burden and admit to having insufficient self-management skills (Walker et al., 2016; CDC, 2014; AHRQ, 2001; Kirk et al., 2006). This could also potentially lead people of color to receive less transition guidance from physicians for having less self-advocacy or health literacy during adolescence. Given the gap in the literature regarding transition care for adolescents of color with diabetes and the diversity of the “Other/Multi-racial” group, studies with sufficient samples to explore each group individually should be done to make any further conclusions.

II. Research Question 2: Parent- or guardian-reported transition guidance given by the physician by sex and age of adolescents with diabetes

Results for the second research question, which investigated the sex and age variables for adolescents with diabetes, conveyed several significant results for the question about transition to adult care, but yielded no significant results for the question about anticipatory guidance for changes in healthcare. As aforementioned, age and age group were significant and adolescents who were older or in middle adolescence, respectively, were more likely to receive guidance in transition to adult care, as hypothesized. Older adolescents and individuals in middle adolescence would have received more guidance since they were closer to the age of transition than younger adolescents or those in early adolescence, who were still largely under

parental control for diabetes management. Since older adolescents or individuals in middle adolescence may have more autonomy in their management of diabetes, physicians could talk to them more about their diabetes management plan, compared to younger adolescents who receive more help from parents and guardians for their management of diabetes (Weissberg-Benchell et al., 1995; Hilliard et al., 2013). Older adolescents may also advocate for their health more, resulting in physicians' discussion about transition care, potentially depicting a reciprocal relationship in receiving more care when adolescents are older, when they self-advocate.

The hierarchical regression revealed intriguing significant results. The second block showed that age and age group were significant factors in transition guidance; adolescents who were older or in middle adolescence were more likely to receive guidance in transition than adolescents who were younger or in early adolescence, respectively, consistent with previous results. The third block (age and sex interaction) of the regression with age group as a predictor revealed a significant age group by sex interaction. Post-hoc analysis revealed that transition to adult care was significantly different between early and middle adolescence for boys but not for girls. Boys in early adolescence received less guidance in transition to adult care than boys in middle adolescence. Perhaps this is because boys tend to be more reliant on their mothers for their management of diabetes; physicians could have talked to the parent or guardian more about transition to adult care rather than the male patients in their early adolescence (Endendijk et al., 2016; Bumpus et al., 2001; Williams, 1999).

These results illustrate inconsistencies and the lack of a proper guideline regarding transition guidance for adolescents with diabetes. Moreover, these results delineate the need for further research regarding transition care for adolescents with diabetes and a research-based

guideline to be taught to physicians, healthcare providers, families and adolescent patients. Individuals with diabetes are especially vulnerable for poor health outcomes during adolescence and young adulthood and therefore should be supported through a seamless healthcare plan (Blum et al., 1993; Garvey et al., 2013; Markowitz & Laffel, 2012; Peters & Laffel, 2011; Lebrun-Harris et al., 2018). Instead of being left alone to figure out the currently inconsistent world of transition care, healthcare providers should be aware of different social determinants (sex, ethnicity, SES) that may put some groups in particular dangers of poor diabetes outcome and tailor the transition guidance for their needs (Enzlin et al., 2002; Legato et al., 2006; Redondo et al., 2018; Gallegos-Macias et al., 2003). It would also be helpful for healthcare providers to attend seminars on being mindful about differential distributions of medical services to certain groups (e.g., individuals who identify as “Other/Multi-racial” or “White”, older adolescents, adolescent boys) regarding transition care guidance. Healthcare providers must also take patient’s developmental stage into account and consider integrating mental health services in planning for transition to the adult healthcare setting to account for the psychological comorbidities (Lloyd et al., 1999; Anderson et al., 2001; Nolen-Hoeksema, 1990; Nolen-Hoeksema & Girgus, 1994). Lastly, starting transition guidance earlier, instead of waiting until patients reach older adolescence, could provide more time for adolescents and their families to prepare for the transition and, consequently, positive health outcomes.

Limitations and Future Directions

Because this study was a secondary data analysis, there were limitations in the measures beyond the author’s control. The sample size was not large enough to explore transition guidance differences between groups based on social determinants of health (e.g., race, ethnicity, SES). It was not ideal to assess transition guidance with merely two questions,

as there are many other measures such as receiving specific adult healthcare provider referral names, which some adolescents with diabetes considered as important (Garvey et al., 2013). The questionnaire did not collect which doctor (pediatric or adult health providers) provided the transition guidance. The questions were answered by the parents or guardians, not the adolescents themselves, excluding the adolescents' perspective of discussion and education about transition care; minor consent laws, which allow adolescents (age determined by individual states) to see healthcare providers without parental consent, could have also prohibited the parents or guardians to be aware of the full scope of the transition care guidance received by the adolescents (Field & Behrman, 2004). The research outcomes questions resulted in a binary answer, yes or no, which could exclude many different or nuanced cases, such as a limited discussion of anticipatory guidance that merely covered insurance plan changes but not the difference of philosophies or the degree of help that they received. Furthermore, the diabetes diagnosis did not separate the diagnosis to T1D or T2D, which have different health implications. The results could have been further strengthened by including qualitative (e.g., views and expectations about adult healthcare system) and quantitative results from all members (adolescents with diabetes, family members, pediatricians, physicians) who are associated with the transition process.

In a perfect world, this study would have been a longitudinal study involving a large population of adolescents, young adults, emerging adults and adults of diverse ages (ages 12-35) with diabetes and related members, such as pediatricians, adult healthcare providers, nurses, diabetes educators, as well as parents and guardians. This population would have a sufficient number of individuals associated with many different racial and ethnic groups. It would explore the ideal way to provide transition care as well as investigating the age range

that would result in the best diabetes outcome to ultimately develop a guideline. Diabetes group would be separated by T1D and T2D, as they have different implications. The experimental population of individuals with diabetes would be SES, gender, and age matched with a control population without any SHCN. Transition guidance would be assessed by a multitude of questions, based on research and need voiced by the individuals with diabetes and related members. It would also include blood glucose and hemoglobin A1c levels to indicate glycemic control. The survey would entail both qualitative and quantitative sections to reveal significant relationships, as well as views and expectations that different individuals might have about the transition process.

For future studies, it could be interesting to further investigate social determinants that hinder the transition process from the pediatric to adult healthcare systems. It would also be intriguing to use other markers of developmental level than age, such as autonomy and risk perception. Expansion of age range to include young adults could also be interesting as well. It may be also worthwhile to explore what guidance given at what stage in adolescence may yield the best health outcomes for adolescents with diabetes during the transition process.

Conclusion

This study found that older adolescents with diabetes receive more guidance in transition to the adult healthcare system than younger adolescents with diabetes or adolescents without SHCN. Furthermore, results suggest that age matters in receiving more transition guidance as boys grow older. Adolescents with diabetes during a time of healthcare transition may be at risk for a poor diabetes outcome because of the lack of communication between the pediatric and adult healthcare systems as well as the lack of proper guidance by either system (Garvey et al., 2013; Markowitz & Laffel, 2012; Peters & Laffel, 2011; Lebrun-Harris et al.,

2018). With an absence of appropriate guidance for transitioning individuals, adolescents with diabetes report feelings of fear and abandonment during their transition period (Garvey et al., 2013; Arnett, 2000; Nakhla et al., 2009). This study demonstrated trends in the transition guidance field showed that mostly older adolescents and individuals with diabetes receive more support in transition guidance, as well as older adolescent boys, revealing differential distributions of guidance for certain groups. In order to create a seamless healthcare system that ensures a smooth transition, transition guidance should start earlier so that adolescents, family, and their healthcare provider can fully prepare for the transition and result in a positive health outcome. Moreover, a central guideline, developed based on research and evidence, could be immensely helpful in decreasing the confusion and fear surrounding transition care for adolescents with diabetes. Furthermore, this central guideline could be included in medical school curricula so that pediatricians and adult healthcare givers could learn the same content and ultimately yield in better communication between the two care systems. Lastly, it would be immensely important to continue research regarding adolescents with diabetes during a vulnerable time to ensure a seamless and smooth healthcare system and to ensure positive health outcomes for all adolescent diabetes patients.

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Tables

Descriptive Statistics

Table 1. Frequencies of Yes/No Answers to Transition Guidance Questions Regarding Two Age Groups (Early Adolescence and Middle Adolescence) and Frequencies of Sex, Race, and SES (Federal Poverty Line, Parent Education) of Adolescents with Diabetes, Subsample of Adolescents without SHCN and the Total Sample Populations

Topic	Categories	Adolescents with Diabetes (n=223)	Subsample of Adolescents without SHCN (n=223)	Total Sample (n=446)
Questions	Discussion of seeing a doctor who treats adults	Yes 48.9% (n=109) No 51.1% (n=114)	Yes 52.9% (n=105) No 47.1% (n=118)	Yes 48.0% (n=214) No 52.0% (n=232)
	Teaching changings that happen at age 18 in health care	Yes 92.8% (n=207) No 7.2% (n=16)	Yes 57.0% (n=127) No 43.0% (n=96)	Yes 74.9% (n=334) No 25.1% (n=112)
Age Groups	Early Adolescent Population (ages 12-14)	38.5% (n=86)	52.5% (n=117)	45.5% (n=203)
	Middle Adolescent Population (ages 15-17)	61.4% (n=137)	47.5% (n=106)	54.5% (n=243)
	Mean, SD	Mean: 14.97 SD: 1.686	Mean: 14.37 SD: 1.781	Mean: 14.67 SD: 1.758
Sex	Female	48.4% (n=108)	49.3% (n=110)	49.7% (n=225)
	Male	51.6% (n=115)	50.7% (n=113)	48.8% (n=221)
Race	Hispanic	8.5% (n=19)	8.1% (n=18)	8.2% (n=37)
	White, non-Hispanic	72.6% (n=162)	76.2% (n=170)	73.3% (n=332)
	Black, non-Hispanic	12.1% (n=27)	5.4% (n=12)	8.6% (n=39)
	Other/Multi-racial, non-Hispanic	6.7% (n=15)	10.3% (n=23)	8.4% (n=38)

FPL	0-99% FPL	11.7 % (n=26)	5.4% (n=12)	8.4% (n=38)
	100-199%	19.7 % (n=44)	16.1% (n=36)	17.7% (n=80)
	200-399%	27.4 % (n=61)	31.4% (n=70)	28.9% (n=131)
	400% FPL or greater	41.3 % (n=92)	47.1% (n=105)	43.5% (n=197)
Parent Education	Less than high school, or High school or GED	20.1% (n=45)	14.8% (n=33)	17.2% (n=78)
	Some college or technical school	26% (n=58)	22.4% (n=50)	23.8% (n=108)
	College degree or higher	53.8% (n=120)	62.8% (n=140)	57.4% (n=260)

Regression Statistics

Table 2: Binomial Logistic Regression of Transition to Adult Care with Age as a Continuous Variable

Population	Adolescents with Diabetes			Adolescents without SHCN			Both Populations		
Variables	B	Odds ratio	p	B	Odds ratio	p	B	Odds ratio	p
Adult Education	0.154	1.166	0.271	-0.252	0.778	0.104	-0.033	0.957	0.739
Age	0.360	1.433	0.000	0.367	1.444	0.000	0.372	1.45	0.000
Black*	-0.288	0.750	0.537	-0.509	0.601	0.456	-0.411	0.663	0.277
Hispanic*	0.340	1.405	0.512	0.121	1.129	0.825	0.153	1.165	0.681
Other*	0.541	1.717	0.357	-0.951	0.386	0.059	-0.341	0.711	0.350
Poverty Level	-0.084	0.920	0.588	0.356	1.427	0.063	0.092	1.096	0.434
Sex	0.251	1.285	0.378	-0.069	0.934	0.814	0.134	1.144	0.503
Health Condition	N/A	N/A	N/A	N/A	N/A	N/A	-0.129	0.879	0.532

*Compared with White

Table 3: Binomial Logistic Regression of Transition to Adult Care with Age as a Categorical Variable

	Adolescents with Diabetes			Adolescents without SHCN			Both Populations		
	B	Odds ratio	p	B	Odds ratio	p	B	Odds ratio	p
Adult Education	0.174	1.190	0.199	-0.260	0.771	0.088	-0.033	0.967	0.732
Age Group	0.789	2.200	0.007	1.208	3.346	0.000	1.024	2.784	0.000
Black*	-0.136	0.873	0.765	-0.357	0.7	0.598	-0.263	0.769	0.477
Hispanic*	0.343	1.409	0.505	0.183	1.201	0.738	0.168	1.183	0.648
Other*	0.465	1.592	0.411	-1.062	0.346	0.038	-0.387	0.679	0.283
Poverty Level	-0.065	0.937	0.665	0.365	1.441	0.054	0.103	1.108	0.373
Sex	0.279	1.322	0.317	-0.166	0.847	0.569	0.96	1.100	0.628
Health Condition	N/A	N/A	N/A	N/A	N/A	N/A	-0.54	0.947	0.787

*Compared with White

Table 4. Binomial Logistic Regression of Anticipatory Guidance for Changes in Healthcare with Age as a Continuous Variable

	Adolescents with Diabetes			Adolescents without SHCN			Both Populations		
	B	Odds ratio	p	B	Odds ratio	p	B	Odds ratio	p
Adult Education	-0.238	0.788	0.389	0.033	1.034	0.817	-0.048	0.953	0.700
Age	-0.042	0.959	0.788	0.182	1.200	0.025	0.128	1.136	0.070
Black*	0.952	2.590	0.390	0.498	1.646	0.450	0.669	1.951	0.232
Hispanic*	0.397	1.487	0.716	0.570	1.768	0.298	0.594	1.811	0.226
Other*	-0.610	0.544	0.463	1.178	3.247	0.028	0.835	2.304	0.073
Poverty Level	0.398	1.488	0.136	0.010	1.010	0.957	0.132	1.141	0.378
Sex	0.317	1.373	0.553	0.184	1.201	0.516	0.162	1.176	0.510
Health Condition	N/A	N/A	N/A	N/A	N/A	N/A	2.257	9.559	0.000

*Compared with White

Table 5: Binomial Logistic Regression of Anticipatory Guidance for Changes in Healthcare with Age as a Categorical Variable

	Adolescents with Diabetes			Adolescents without SHCN			Both Populations		
	B	Odds ratio	p	B	Odds ratio	p	B	Odds ratio	p
Adult Education	-0.240	0.787	0.385	0.014	1.014	0.920	-0.055	0.947	0.654
Age Group	-0.150	0.860	0.786	0.497	1.645	0.080	0.341	1.406	0.169
Black*	0.945	2.572	0.392	0.581	1.789	0.374	0.721	2.057	0.194
Hispanic*	0.408	1.505	0.709	0.604	1.829	0.267	0.612	1.845	0.211
Other*	-0.599	0.549	0.471	1.146	3.144	0.033	0.815	2.259	0.081
Poverty Level	0.400	1.492	0.135	0.031	1.031	0.863	0.142	1.153	0.340
Sex	0.318	1.375	0.552	0.142	1.153	0.612	0.142	1.152	0.563
Health Condition	N/A	N/A	N/A	N/A	N/A	N/A	2.278	9.759	0.000

*Compared with White

Table 6: Hierarchical Regression of Transition to Adult Care with Age as a Continuous Variable

	B	Odds ratio	p
Block 1 (Nagelkerke $R^2=0.024$, $\chi^2(5)=3.994$, $p=0.550$)			
Adult Education	0.192	1.211	0.146
Poverty level	-0.25	0.976	0.868
Other*	0.523	1.688	0.344
Black*	0.012	1.012	0.978
Hispanic*	0.517	1.677	0.203
Block 2 (Nagelkerke $R^2=0.132$, $\chi^2(7)=23.295$, $p=0.002$)			
Sex	0.251	1.285	0.378
Age	0.360	1.433	0.000
Block 3 (Nagelkerke $R^2=0.136$, $\chi^2(8)=24.072$, $p=0.002$)			
Age x sex	-0.156	0.856	0.378

*Compared with White

Table 7. Hierarchical Regression of Transition to Adult Care with Age as a Categorical Variable

	B	Odds ratio	p
Block 1 (Nagelkerke $R^2=0.024$, $\chi^2(5)=3.994$, $p=0.550$)			
Adult Education	0.192	1.211	0.146
Poverty level	-0.25	0.976	0.868
Other*	0.523	1.688	0.344
Black*	0.012	1.012	0.978
Hispanic*	0.517	1.677	0.203
Block 2 (Nagelkerke $R^2=0.077$, $\chi^2(7)=13.217$, $p=0.067$)			
Sex	0.279	1.322	0.317
Age Group	0.789	2.200	0.007
Block 3 (Nagelkerke $R^2=0.113$, $\chi^2(8)=19.782$, $p=0.011$)			
Age group x sex	0.263	1.301	0.013

*Compared with White

Table 8: Hierarchical Regression of Anticipatory Guidance for Changes with Age as a Continuous Variable

	B	Odds ratio	p
Block 1 (Nagelkerke $R^2=0.042$, $\chi^2(5)=3.769$, $p=0.583$)			
Adult Education	-0.258	0.773	0.353
Poverty level	0.396	1.486	0.138
Other*	-0.595	0.552	0.474
Black*	0.945	2.572	0.391
Hispanic*	0.414	1.512	0.703
Block 2 (Nagelkerke $R^2=0.046$, $\chi^2(7)=4.163$, $p=0.761$)			
Sex	0.317	1.373	0.553
Age	-0.042	0.959	0.788
Block 3 (Nagelkerke $R^2=0.049$, $\chi^2(8)=4.423$, $p=0.817$)			
Age x sex	0.163	1.177	0.609

*Compared with White

Table 9: Hierarchical Regression Anticipatory Guidance for Changes with Age as a Categorical Variable

	B	Odds ratio	p
Block 1 (Nagelkerke $R^2=0.042$, $\chi^2(5)=3.769$, $p=0.583$)			
Adult Education	-0.258	0.773	0.353
Poverty level	0.396	1.486	0.138
Other*	-0.595	0.552	0.474
Black*	0.945	2.572	0.391
Hispanic*	0.414	1.512	0.703
Block 2 (Nagelkerke $R^2=0.046$, $\chi^2(7)=4.164$, $p=0.761$)			
Sex	0.318	1.375	0.552
Age Group	-0.15	0.787	0.385
Block 3 (Nagelkerke $R^2=0.037$, $\chi^2(8)=4.235$, $p=0.835$)			
Age group x sex	0.052	1.053	0.791

*Compared with White

Figures

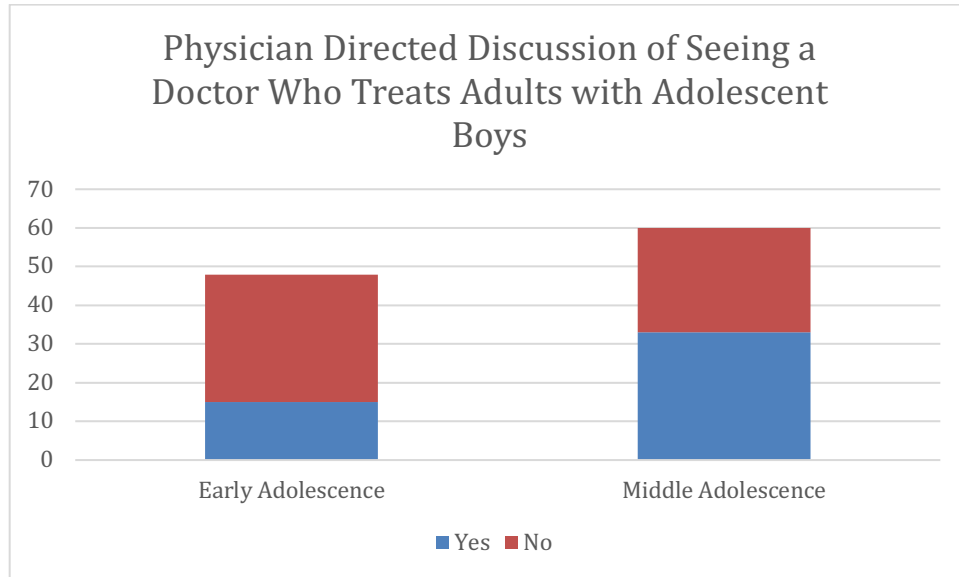


Figure 1. Transition to Adult Care with Adolescent Boys $\chi^2(1)=6.0919$, $p=0.14$

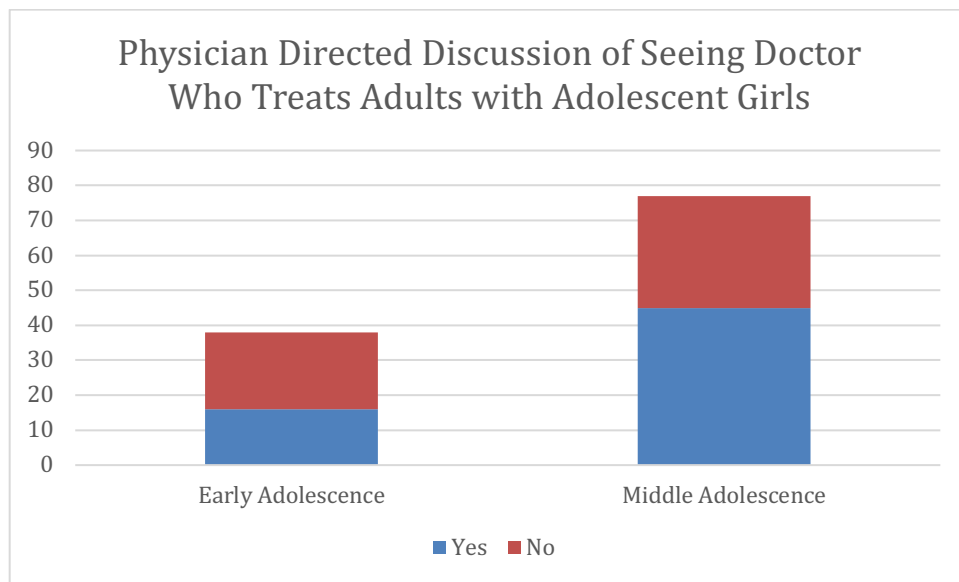


Figure 2. Transition to Adult Care with Adolescent Girls $\chi^2(1)=2.7262$, $p=0.99$