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Type 1 Diabetes in Young Adulthood

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Abstract: Type 1 diabetes has traditionally been studied as a chronic illness of childhood. However, young adulthood is a critical time for the development and integration of lifelong diabetes management skills, and research is starting to identify unique challenges faced by youth with diabetes as they age into adulthood. Most young adults experience multiple transitions during this unstable developmental period, including changes in lifestyle (*e.g.*, education, occupation, living situation), changes in health care, and shifting relationships with family members, friends, and intimate others. Young adults with type 1 diabetes must navigate these transitions while also assuming increasing responsibility for their diabetes care and overall health. Despite these critical health and psychosocial concerns, there is a notable lack of evidence-based clinical services and supports for young adults with type 1 diabetes. We review relevant evolving concerns for young adults with type 1 diabetes, including lifestyle considerations, health care transitions, psychosocial needs, and changes in supportive networks, and how type 1 diabetes impacts and is impacted by these key developmental considerations. Specific avenues for intervention and future research are offered.

Keywords: Adherence, glycemic control, support systems, transition to adult medical care, type 1 diabetes, young adulthood.

1. INTRODUCTION

Current estimates suggest that up to 3 million youth and adults in the United States are living with type 1 diabetes. Although primarily thought of as a disease of childhood, adults represent 85% of the total population with type 1 diabetes [1]. The vast majority of research addresses the needs of youth and has failed to focus on or follow youth into adulthood. As this review will highlight, management of type 1 diabetes in young adulthood brings a unique set of challenges and considerations that require further study.

Young adulthood represents a critical period of risk for those with type 1 diabetes. Only 17% of early young adults (ages 18-25) and 30% of late young adults (ages 26-30) with type 1 diabetes meet current recommendations for glycemic control (*i.e.* HbA1c $\leq$7.0%) [2]. Longitudinal studies suggest that up to 50% of young adults with type 1 diabetes develop diabetes-related complications in their 20s [3], including retinopathy, neuropathy, and hypertension. Young adults with type 1 diabetes are also at disproportionate risk for overweight or obesity, which poses additional health risks [4-6]. Women generally report a higher rate of complications than men [7]. Young adults with type 1 diabetes, particularly those diagnosed in early childhood and with a history of significant hypoglycemia or hyperglycemia, are at a slightly increased risk for difficulties with working memory and attention [8]. Risks during this period are magnified by inconsistent engagement with the health care system. Young adults are less likely than any other age group to maintain a usual source of medical care [9]; this problem is likely exacerbated by the need for young adults to transfer from pediatric to adult medical care systems. Relatively high rates of emergency department use among young adults with and without chronic illness suggest decreased engagement in preventive care and increased engagement in risky behaviors that may negatively impact health [10-12]. It is important to systematically identify risk and protective factors and evaluate spheres of influence for young adults with type 1 diabetes in order to develop targeted services, interventions, and supports that can be executed during young adulthood.

The goal of this review is to highlight the unique considerations associated with managing type 1 diabetes during young adulthood. For the purposes of this review, young adults are defined as adults between the ages of 18- 30 to capture Arnett's developmental period of emerging adulthood, defined as the late teens through the 20s, and to best align with the 2011 Position Statement from the American Diabetes Association on Diabetes Care for Emerging Adults [13-15]. We reviewed current literature, focusing on the most recent 5 years (2009-2014) when possible, to identify normative developmental challenges associated with young adulthood and the impact of type 1 diabetes on these key areas of growth and change. The review will broadly focus on: 1) developmental challenges, including lifestyle considerations; 2) health care system challenges, including transition to adult care and care continuity; 3) evolving psychosocial concerns, including identity development, depression, stress, and risky behaviors; and 4) roles of supportive networks, including parents, peers, and intimate others. Areas for future research and implications for intervention will be discussed.

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2. YOUNG ADULTHOOD AND LIFESTYLE CONSIDERATIONS

Young adulthood is a critical period for health and well-being [16]. Arnett refers to the early period of young adulthood as “emerging” from adolescence into adulthood to better recognize the instability inherent in early adulthood [15]. Young adults are faced with multiple opportunities for growth, exploration, and change. During this stage, many young adults move away from the family home, assume financial independence from parents and guardians, enter into the workforce, and seek intimate relationships with romantic partners [14]. These milestones may be achieved close to home or far flung from prior sources of support or anywhere in between. There is a large – and growing – literature on the many transitions that occur across young adulthood, and there are limited data to suggest that young adults with diabetes are likely to experience similar challenges in addition to coping with management of a chronic disease. It is essential that young adults meet developmental milestones associated with adulthood and disease management to initiate a life-long trajectory of health and well-being [17]. We briefly highlight key developmental tasks of young adulthood that may influence, and be influenced by, diabetes management, including education, living situation, and employment.

2.1. Education

Many students enter higher education after graduating from high school, and there are likely dozens of students with type 1 diabetes on most college campuses. Typical college challenges for all students include managing new schedules and inconsistent routines, changes in diet and physical activity, evolving relationships with peers and parents, and peer pressure to engage in risky behaviors such as using alcohol [18-20]. However, these challenges may be of greater consequence for students with diabetes, and students often report difficulty adapting diabetes management routines on a college campus [18]. Lack of access to healthy foods and decreased physical activity can worsen glycemic control, and inconsistent scheduling can disrupt routines for blood glucose monitoring and insulin administration. Students may also lack support for medical management of diabetes on campus, as recent survey results suggest that only 51% of four year universities in the U.S. reporting having the resources for diabetes care [21]. The recent increase of targeted supports on campus, such as the resources available through the College Diabetes Network and other advocacy groups, may promote adjustment and adaptation in students with type 1 diabetes.

Less research has evaluated the impact of diabetes on attendance and achievement in higher education, and findings are mixed. Some research suggests that students with diabetes have relatively lower completion rates as compared to peers and achieve slightly lower final grades, particularly if diagnosed at a very early age [22-24]. A recent study using data from the National Longitudinal Study of Adolescent Health found that young adults with diabetes were 6% more likely to drop out of high school and, after controlling for related factors, completed .25 fewer years of schooling than healthy peers; however, the authors did not distinguish between type 1 or type 2 diabetes [25]. When examining samples of young adults with type 1 diabetes only, Jacobson *et al.* [26] found similar rates of high school graduation and post-high school education when comparing those with diabetes to a comparison group. Palladino *et al.* compared the life courses pursued after high school by early young adults and also found that those with type 1 diabetes were equally likely to attend college as those without type 1 diabetes [27]. Thus, it appears that young adults pursue higher education at similar rates, but more nuanced research evaluating the day-to-day impact of type 1 diabetes management on attendance and achievement is needed.

2.2. Living Situation

Diabetes status may influence decisions about timing and process of moving out of the family home; however, recent research suggests that diabetes does not influence living situation [27, 28]. Increasing young adults’ confidence in their abilities to manage diabetes and gradually shifting responsibility for diabetes management from family-based management to primarily individual management are important considerations when preparing for independent living situations [28, 29]. Living situation may also influence or hasten transition to adult medical care, and young adults must quickly engage in local health services for diabetes care when they move to a new location [30, 31].

2.3. Employment

Type 1 diabetes should not preclude young adults from pursuing most careers, with the exception of participating in some branches of the U.S. military and serving as a commercial airline pilot. In fact, young adults with type 1 diabetes may have increased pressure to secure full-time employment to maintain health insurance for ongoing medical care for chronic illness [32]. Palladino and colleagues found that young adults with type 1 diabetes were equally likely to be employed as young adults without diabetes [27]. In comparison, one international population-based study found lower rates of employment, higher use of sick leave, and increased participation in disability programs at age 29 for young adults with type 1 diabetes [23]. As a group, young adults with diabetes report slightly lower earnings than peers [25], though the reason for this discrepancy is not well defined.

Young adults with type 1 diabetes report a number of normative challenges associated with employment, including fitting diabetes management in to inconsistent schedules, coping with work-related time pressures, and securing privacy for completion of diabetes-related tasks and storage space for diabetes-related supplies [30, 33, 34]. However, the very limited research available suggests that diabetes is likely just one small factor when evaluating pursuit of employment and overall job satisfaction. Increased awareness of type 1 diabetes demands can improve workplaces for all, and recent shifts in employer cultures to promote employee wellness and health may also benefit young adults with type 1 diabetes.

3. TRANSITION TO ADULT HEALTH CARE

As young adults experience changes in education, living situation, occupation, and health insurance status, it is likely that they need to establish new medical care that better meets their developmental needs. Young adults typically leave the pediatric health care system in their late teens to early 20s and transfer their medical care into the adult health care system. Continuity of medical care is essential for appropriate disease management and, as such, a number of recent reviews have focused on the challenges of transitioning to adult diabetes care [35-38]. In 2011, the American Diabetes Association released a position statement highlighting the specialized needs of young adults during this transition [13]. This position statement offered many important suggestions to optimize care of young adults with type 1 diabetes, including: preparing for adult medical care at least one year prior to transfer, if not sooner; promoting appropriate assumption of independent diabetes care responsibilities in adolescence and young adulthood; assisting young adults with compiling a comprehensive written medical history to bring to adult care providers; increasing young adults' knowledge about the adult health care system; facilitating referrals to adult medical care; and recognizing the challenges associated with diabetes care in young adults, including gaps in medical care, competing lifestyle and psychosocial concerns, and risky behaviors such as disordered eating and poor adherence to prescribed medical regimens [13]. As the topic of transition to adult medical care has been extensively reviewed, a comprehensive discussion of transition-related issues is beyond the scope of this article. Rather, we will focus on factors in young adulthood that may influence health care transition-related outcomes.

Young adults with type 1 diabetes may be cared for in a variety of settings, including pediatric specialty clinics, adult specialty clinics, primary care, family medicine, or in targeted young adult clinics with providers who have joint adolescent/adult medical training (*e.g.* Med-Peds trained endocrinologists), though the latter is less common [31, 39, 40]. The majority of youth transfer to an adult medical care provider between ages 18-22, with a median age of 19.5 - 20 years [41, 42]. More than 25% of young adults report a significant gap in medical care (>6 months) during the transition to adult medical care [31, 43]. Gaps in medical care in young adulthood may be related to psychosocial concerns such as stressful life circumstances or competing life priorities, health care system issues such as inadequate health insurance and difficulty getting appointments, or lack of preparation for adult medical care [11, 44]. A recent study by Garvey and colleagues surveyed 258 young adults who had transferred to adult care and found that young adults who identified at least one significant barrier to transition to adult care experienced a nearly 5-fold increase in risk for gaps in medical care [44]. Another study by Garvey and colleagues surveyed 65 young adults with type 1 diabetes and found that seeing a general practitioner for routine diabetes care rather than an adult endocrinologist was associated with less frequent diabetes care visits [31]. Consistent engagement in diabetes care across young adulthood is an important component of self-care and providing specific referrals for adult endocrinology may decrease gaps in care.

Research is not conclusive on the influence of transition to adult medical care on glycemic control. A review by Lyons, Becker, and Helgeson suggests that young adults maintain stable or even improved glycemic control after the transfer to adult medical care [45]. However, other studies have demonstrated that premature transition to adult medical care is associated with poorer glycemic control [46] and that youth who remain in pediatric care early in young adulthood demonstrate better glycemic control as compared to young adults who transfer to adult care [47]. These data should be interpreted cautiously, as information about glycemic control in young adulthood may represent a biased sample of patients who present for medical care and have appropriate labs drawn. If a young adult does not have regular, ongoing contact with a physician who specializes in diabetes care, information on glycemic control may not be available. Thus, for young adults, clinic attendance, rather than specific indicators of diabetes control, may represent a critical outcome to track [40, 45]. Young adults at risk for poor glycemic control or low rates of clinic attendance post-transfer to adult medical care may have lower income, live in areas with relatively low physician supply, or have a history of poor glycemic control [12, 46]. Assessing readiness for adult medical care and matching the transfer time with perceived readiness, when possible, may enhance outcomes in adult care. It is particularly important to engage young adults who may be at risk for disengagement from adult medical care.

Young adults have identified characteristics of health care transition programs that may facilitate successful engagement in adult medical care, including provision of names of recommended adult health care providers, increased communication and preparation for adult medical care, assistance with making appointments, direct communication between pediatric and adult care providers, and familiarity or continuity with clinic staff across pediatric and adult medical care [40, 43, 48-50]. Research evaluating models of transition care support continuity of care in a specialized young adult clinic either within the same hospital or with a mix of pediatric and adult care providers [51]. If patients must move directly to the adult care system, use of a patient navigator or care coordinator may contribute to improved outcomes in adult care [52]. Some aspects of the adult medical care system may also hinder young adults' participation, including difficulty accessing diabetes technology, lack of integrated diabetes services, long wait times for appointments, and brief or disjointed appointments with little continuity of care [53, 54].

Transition to adult medical care is often accompanied by a decrease or loss of parental involvement in structured medical interactions; however, it is more appropriate to view parents as ongoing "consultants" for diabetes care throughout young adulthood. It is important that providers working with young adults recognize this support role. Families prefer to participate in medical appointments for longer than some clinics mandate [55], and parents tend to be more active support providers when young adults remain in pediatric care rather than transitioning to adult care [46]. Ritholz and colleagues' qualitative findings with young adults with type 1 diabetes support this research, as young adults encouraged providers to foster autonomy while also recognizing the continued role of parental support – even in early adulthood [56].

The quality of engagement in diabetes care throughout young adulthood influences health and quality of life outcomes in young adults' care, including recognizing unique psychosocial needs and changing patterns of relationships with parents, peers, and significant others. The next section reviews the evolving psychosocial needs of young adults with type 1 diabetes.

4. PSYCHOSOCIAL NEEDS

4.1. Identity Development and Self-Esteem

Identity development is an important life task of adolescence, but identity exploration and achievement clearly extend into young adulthood. Early young adulthood is defined by exploration in a variety of life domains, including education, work, family, and love [15]. As young adults make decisions in these areas, they are creating an adult identity and often seeking increased consistency and stability. A diagnosis of type 1 diabetes likely plays a role in identity development. It is possible that diabetes management demands and potential for prolonged parental involvement may interfere with identity development. Alternately, type 1 diabetes demands may accelerate self-reliance and maturation, as young adults are tasked with responsibilities that exceed those of peers.

Only a few studies with young adults with type 1 diabetes have examined identity development and self-concept. One older study compared young adults with type 1 diabetes to an acute illness control group when they were ages 19-26 and then 10 years later [26]. Those with type 1 diabetes scored lower on perceived competence, including global self-worth, than the comparison group at the 10-year follow up. In a more recent study, the self-esteem of young adults with and without type 1 diabetes was examined as part of a resilience or cognitive adaptation index that included self-esteem, mastery, and optimism [57]. Across the three annual assessments, those with type 1 diabetes scored lower on the resilience index than those without type 1 diabetes. By contrast, other studies have found no differences between young adults with and without type 1 diabetes on self-esteem and self-concept variables. Pacaud *et al.*, for example, found no differences between young adults ages 18-25 with and without type 1 diabetes on responsibility, independence, or social maturation [58]. In a large study using the Belgian registry, the self-esteem of 341 young adults ages 18-35 with type 1 diabetes was compared to 341 health controls, matched on sex and age [59]. No group differences in self-esteem were detected.

One study of young adults ages 18-30 with and without type 1 diabetes examined a variety of dimensions of identity exploration and achievement and showed that those with diabetes scored lower on proactive identity exploration than those without diabetes, indicating a reduced likelihood of searching for alternatives before committing [60]. However, the two groups did not differ on other dimensions of identity achievement, including identification with commitment and ruminative exploration, leading the authors to conclude that there were more similarities than differences in identity development. A longitudinal study of young adults with and without diabetes examined life purpose as a potential outcome of identity exploration [27]. Youth with and without type 1 diabetes were examined in their senior year of high school and followed for three years. Group differences in sense of life purpose emerged with time. There were no group differences in life purpose senior year of high school, but life purpose increased over time for those without diabetes but remained the same for those with diabetes [27]. By contrast, another study asked early young adults with and without type 1 diabetes whether they would classify themselves as adults. Those with type 1 diabetes were more likely to self-classify as adults than those without type 1 diabetes (57% vs. 42%). The authors suggested that the demands of taking care of diabetes could increase independence and self-sufficiency [61].

Taken collectively, the research is not clear on whether there are differences in identity achievement between young adults with and without type 1 diabetes. It may depend on the aspect of identity achievement that is evaluated. The research reviewed above suggests that those with type 1 diabetes may struggle a bit more with figuring out their life path, but view themselves as adults at an earlier point in development. Future research should explore the different facets of identity exploration and achievement in greater depth as well as potential mechanisms that might explain any group differences

Research is beginning to explore the contributions of identity development and self-esteem to diabetes care. A cross-sectional study showed that a stronger sense of identity was linked to fewer diabetes-related problems, fewer depressive symptoms and better coping [60]. Another study found cross-sectional relations of a positive self-concept to better self-care [62]. Classification of the self as an adult has been linked to better coping strategies and better glycemic control [61]. Longitudinal data also have linked a positive self-concept to good glycemic control. In a study that spanned 11 years, Luyckx and Seiffge-Krenke examined the glycemic control of children with type 1 diabetes over adolescence and young adulthood. They identified three trajectories of glycemic control (optimal, moderate, deteriorating) and examined whether psychosocial variables could distinguish the groups. During young adulthood, a positive self-concept was the psychosocial variable most likely to distinguish the trajectories. Specifically, the group with the deteriorating glycemic control was most likely to be characterized by a low score on positive self-concept [63]. In a longitudinal study of young adults with and without type 1 diabetes, a resilience index predicted an array of positive young adulthood outcomes, including enhanced psychological health, better relationship functioning, reduced risk behavior, and positive vocational outcomes [57]. In some cases, the links were stronger for those with than without type 1 diabetes. Thus, there are clear indications that a positive self-concept is related to a broad array of well-being indices among emerging adults with type 1 diabetes.

4.2. Depression, Distress and Anxiety

Young adults with type 1 diabetes must address the emotional demands of managing a serious illness while navigating the many developmental life challenges posed by emerging adulthood. In the general population, late adolescence and young adulthood appear to be a time of particular vulnerability to the development of depression. Rao and colleagues followed a non-clinical sample of female high school seniors (*i.e.*, the sample was not selected for diabetes or depression), conducting diagnostic interviews to assess for major depressive disorder annually for five years. Almost 50%

met diagnostic criterion for major depression across the five year period, with the highest risk (30%) occurring between ages 18 and 20 years [64]. This finding is consistent with other longitudinal studies of individuals without chronic illness suggesting that depression, anxiety and distress increase across adolescence, reaching a peak in late adolescence and young adulthood, and then declining across adulthood [65-67]. These risks are greater for females and for those who have a history of psychiatric difficulties in childhood and adolescence. Thus, young adults with type 1 diabetes are most vulnerable to emotional difficulties at the same time that they face the challenges of managing a chronic illness during young adulthood.

The challenges of living with type 1 diabetes may exacerbate this vulnerability to emotional distress during young adulthood [53]. Multiple measures have been used to examine psychological distress in young adults with diabetes, varying in the assessment of general versus diabetes-specific distress, the evaluation of diagnostic criteria for psychiatric disorders versus assessment of symptoms along a continuum, and the type of emotional difficulty experienced (*e.g.*, anxiety or depression). We use the term that was assessed in reported studies, and the term “psychological distress” in summary statements regarding findings across multiple measures. Reviews comparing rates of psychological distress among those with versus without type 1 diabetes report higher distress among children and adolescents with diabetes [68] and among adults with diabetes [69, 70]. Some caveats should be noted about these reviews. First, Reynolds and Helgeson found the heightened risk for adolescents with type 1 diabetes was smaller in more recent studies, potentially because newer treatment regimens and technologies facilitate a smoother integration of diabetes into daily life [68]. In a more recent review, Johnson and colleagues found the evidence inconclusive that youth with type 1 diabetes have higher depressive symptoms than non-diabetes controls or population norms [71]. Second, few studies have examined the young adult developmental period per se. Recent research with participants in the young adult age range suggests young adults with diabetes have higher rates of treatment for mental health problems than their healthy peers [22, 72], but do not differ on self-report measures of psychological distress [22, 27].

Regardless of whether diabetes poses increased risk for emotional maladjustment, young adults with diabetes have significant psychosocial needs [73]. Young adults have relatively high rates of antidepressant use [72], and 37% report using mental health services in the past year [22]. In samples including young adults with type 1 diabetes, 7-35% report elevated levels of depressive symptoms, 21-30% report elevated levels of anxiety, and 40% report elevated diabetes distress [71, 74-76]; rates vary as a function of the measure and criteria used to indicate emotional maladjustment and the age range included in the sample. It is notable that longitudinal studies extending from adolescence into young adulthood reveal stability in depressive symptoms across this transition and that depression in adolescence predicts depression in young adulthood [27, 77, 78]. Such data suggest that emotional concerns for young adults with diabetes are prevalent and enduring.

Elevated psychological distress among young adults with type 1 diabetes raises serious concerns because such difficulties are associated with poorer diabetes management and outcomes. Reviews of adults with diabetes indicate depression is associated with poor glycemic control [79], poorer adherence [80], and more diabetes complications [81], and reviews of adolescents with type 1 diabetes suggest depressive symptoms are associated with poorer diabetes management [71, 73]. Recent research suggests similar associations are likely during young adulthood. In samples including at least some participants in the young adult age range, heightened psychological distress is associated with poorer glycemic control [7, 22, 71, 75], more hypoglycemic episodes [75], more diabetes complications [72], and lower satisfaction with care [76].

Given the prevalence and adverse consequences of psychological distress, clinical care for young adults with diabetes should routinely monitor psychosocial adjustment, screen for depression, and refer to appropriate mental health resources as needed [73, 82]. Although young adults find it challenging to discuss psychosocial concerns with their adult care provider, particularly given the brevity of visits and not having an extended relationship with their adult provider, they report that such discussions are helpful and should be a standard part of diabetes care [53].

4.3. Stress

It is generally assumed that the risks of young adulthood for those with type 1 diabetes reflect the stress of managing a demanding illness while experiencing multiple life transitions. In the general (non-diabetes) population, perceived stress reaches its height during young adulthood, and then steadily declines [83]. Recent research has begun to document how diabetes may exacerbate this high stress time of development. Balfe *et al.* [53] conducted a qualitative study with 23 to 30 year olds to identify the specific stressors facing young adults managing type 1 diabetes. The most common diabetes-specific stressors included: feeling self-conscious about diabetes and its management (worrying about how others perceive them because of diabetes and the public aspects of diabetes management); day-to-day management issues (the emotional toll and ongoing burden of daily management and a perception that diabetes management interferes with their ability to engage fully in normal life); struggles with the health care system; and fears about future complications and pregnancy. In another qualitative study, young adults described treatment burden, fatigue, and burnout as contributors to non-adherence [32]. Thus, although young adults are knowledgeable and generally comfortable with the tasks required to manage their diabetes, they struggle with how to integrate diabetes management into their day-to-day lives [53, 84].

Young adults describe both adaptive and maladaptive efforts to cope with these diabetes stressors. These include avoiding management tasks that could draw public attention to diabetes, but also actively working to improve control over their diabetes (*e.g.*, through diabetes education), and seeking support from parents, peers, and providers [53]. Maladaptive coping strategies may also include engagement in risky behaviors.

4.4. Engagement in Risky Behaviors

4.4.1. Substance Use

As noted earlier, young adulthood represents a time of exploration and young adults with and without chronic illness may increase engagement in risky behaviors during this period. Substance use generally increases throughout adolescence and early young adulthood and then declines through the mid- to late-20s [85]. Youth with type 1 diabetes are not immune to the risky behaviors present in many young adults, reporting similar levels of substance use and abuse as those without diabetes. Helgeson and colleagues surveyed young adults with and without diabetes one year post-high school. Young adults with type 1 diabetes reported comparable rates of substance use as the control population, including alcohol use (47.0%), binge drinking (29.9%), and smoking (34.7%) [27]. Early young adulthood may be a particularly risky time for alcohol use, as Hanna and colleagues found that approximately 1/3 of high school graduates reported increased intake of alcohol over the one year period after high school graduation, even though alcohol use at this age is illegal in the U.S. [86].

Substance use has specific implications for diabetes management and can place young adults at risk for complications [87]. Alcohol use increases the risk for acute hypoglycemia, and many young adults are unaware of how to adjust insulin for alcohol use [88]. Tobacco use is associated with poorer glycemic control, lower self-reported rates of physical activity, and increased risk for chronic complications [89]. Lee and colleagues found that 10 out of 19 young adult patients (ages 17-24) who presented in diabetic ketoacidosis reported using illegal drugs in the 48 hours prior to arriving at the emergency department [90]. Health care providers working with young adults should be aware of the potential impact of substance use on management of type 1 diabetes, particularly as young adults with type 1 diabetes engage in similar levels of risky behavior as the general young adult population. It is critical to routinely include substance use questions when evaluating diabetes self-care, and provide all young adult patients with targeted education on how to safely manage diabetes when using substances.

4.4.2. Disordered Eating

Increased awareness of body image and physical appearance is prevalent throughout late adolescence and young adulthood. Management of type 1 diabetes requires young adults to pay increased attention to food intake and quality, as counting carbohydrates is one of the cornerstones of diabetes self-care [91]. Thus, it is not surprising that young adults with type 1 diabetes may be at greater risk for development of disordered eating as compared to the general population [92], including manipulating insulin related to food intake, binge eating, or restricted eating. Disordered eating is particularly risky for young adults with type 1 diabetes and has been associated with increased risk for complications, including microvascular damage, poor glycemic control, and mortality [93, 94].

Qualitative data suggest that disordered eating behaviors commonly begin in mid to late adolescence and are maintained across young adulthood [95]. Bryden and colleagues followed a cohort of 76 patients with type 1 diabetes into young adulthood and found that the percentage of overweight young adults significantly increased from 21% to 54% in women and 2% to 28% in men [96]. Disordered eating was common among women in this sample, with 21% reporting a history of purging behaviors or laxative use and 37% reporting insulin misuse to control weight [3]. Other studies with young adults with type 1 diabetes have found similar results, with 20-35% of reporting disordered eating and 13% reporting reducing insulin for weight control. [74, 97]. Longitudinal studies suggest that the risk for disordered eating does not decline after early young adulthood, and insulin misuse and other eating disordered behaviors continue throughout young adulthood and into the mid 30s [94].

Health care providers working with young adults should screen for potential eating concerns. Using a diabetes-specific eating questionnaire may provide more specific information about eating concerns among young adults with type 1 diabetes as general screening questionnaires may overestimate eating concerns due to the increased focus of dietary management as part of diabetes self-care [98].

5. RELATIONSHIPS WITH FAMILY, FRIENDS, AND INTIMATE PARTNERS

Young adulthood is a period of growth and change in personal relationships, including relationships with parents/caregivers, friends, and romantic partners. Developmentally-appropriate evolution in these relationships can promote optimal diabetes management, such as the gradual shift in diabetes care responsibility from parents to young adults or increasing emotional support from a romantic partner. In comparison, abrupt changes in support or increased conflict in relationships with significant others may hinder diabetes care. There is little consensus on appropriate timing for shifting of responsibility for diabetes care, and this process is often tailored for each individual based on life circumstances, skill, maturity, and other factors. However, all adults continue to require support from significant others to maintain health and high quality of life, and relevant research findings are presented.

5.1. Family Relationships

The many transitions of young adulthood necessitate that young adults assume independent responsibility for the daily tasks of managing diabetes. Recent longitudinal data demonstrate a steady transfer of responsibility for diabetes management from parent to child across the adolescent years, such that late adolescents are primarily – but not solely – responsible for diabetes management by their entry into young adulthood [99]. Both qualitative interviews and quantitative data across the transition out of high school reveal that this transfer of responsibility continues into adulthood, with responsibility for daily diabetes management increasingly under the purview of the young adult [29, 50, 55, 100, 101]. However, parents often continue to share responsibility for nondaily tasks (*e.g.*, ordering supplies; making appointments) and, while independence is valued, families balance the assumption of independence with other developmental considerations [55, 100]. Not surprisingly, young adults who live independently report greater independence for daily diabetes care than those living at home [29, 101], suggesting changes in living situation may spur increasing independence in the young adult.

Despite increased independence in daily diabetes management, young adults maintain close relationships with parents and view parents as important sources of support, advice, and tangible aid. Qualitative research with young adults and parents suggests the parental role shifts from direct involvement to monitoring and providing backup support during young adulthood [50, 53, 55]. In the first year after high school, young adults reported low levels of conflict and shared diabetes responsibilities with parents, but moderate levels of tangible aid [100], suggesting they are independent but continue to rely on parents for ongoing support. Detailed interviews with young adults who had transitioned to adult care revealed that parents remain a consistent and trusted source of support for diabetes management, often more than peers or partners; parents were sought for advice, emergency support, and reminders about maintaining good diabetes management [101]. Such findings suggest it is most accurate to view young adulthood as a time of interdependence and shifting relationships with parents and family as the young adult assumes responsibility for managing the day-to-day demands of diabetes [55].

Parental and family support play an important role in facilitating diabetes management and psychosocial adjustment during young adulthood. Longitudinal studies reveal that aspects of family structure and support measured during adolescence predict psychosocial well-being and glycemic control during the young adult years [22, 63, 102]. Furthermore, families perceive that parental support *during* young adulthood also facilitates diabetes management [32, 103], and there is some empirical support for these perceptions [104]. Helgeson *et al.* [105] found that higher parental support in the year after high school was associated with better adherence, and lower depression and risk behaviors, and buffered the adverse association between peer conflict and poor glycemic control among young adults with diabetes. Thus, at a time when young adults are facing many transitions, parents appear to be an important social support resource.

Although continued support from parents appears important for diabetes management during young adulthood, this needs to be balanced with the young adults' ongoing efforts to establish independence and their adult identity. Families of young adults with diabetes describe the difficulties of balancing parental support for diabetes with autonomy support, particularly when the young adult is still living at home or is not managing diabetes well [32, 50, 53, 55, 101]. In a study of young adults without diabetes, Nelson and colleagues [106] found that approximately one-fifth of 18 to 26 year olds described their parents as intrusive and controlling, and these perceptions were associated with poorer psychosocial adjustment. Helgeson *et al.* [105] found perceptions of parental control were similarly associated with higher depression among young adults with diabetes, but that parental control may have less adverse associations with psychological well-being among those with than without diabetes.

5.2. Peer Relationships

Despite the fact that friendships are central to the lives of young adults and relationships are critical to good diabetes self-care, there are few studies of friendship among young adults with type 1 diabetes. One study reported that young adults with type 1 diabetes had fewer friends than the control group [107]. A more recent study did not examine number of friends but compared the levels of friend support and friend conflict among young adults with and without type 1 diabetes and found that those with diabetes reported less friend support than those without diabetes across three annual waves of assessment [108]. However, there were no group differences in friend conflict.

A handful of studies have examined the implications of peer relationships for well-being among young adults, with some finding peer relationships are helpful and others finding peer relationships are harmful for diabetes-related outcomes. An older study of 18 to 22-year-olds showed that those who were less satisfied with support from their overall network had a higher risk of diabetic nephropathy [109]. By contrast, those who reported larger support networks had poorer diabetes control. A longitudinal study examined the links of peer relationships to outcomes one year post high school graduation [105]. Peer conflict was a more potent predictor of changes in health behavior and psychological well-being than peer support. That is, peer conflict was associated with increased alcohol usage, increased binge drinking, and increased depressive symptoms and perceived stress one year later. There was also some evidence of cross-domain buffering between peer relationships and parent relationships, meaning that the supportive aspects of one domain buffered persons from conflict in the other domain. For example, parent controlling behavior was related to increased alcohol usage when friend support was low but unrelated to alcohol usage when friend support was high. Similarly, friend conflict was associated with poorer glycemic control when parent support was low but better glycemic control when parent support was high.

One study examined peer relationships during adolescence as predictors of outcomes in early young adulthood [102]. Friend conflict at age 12 predicted poorer self-care behavior 9 years later and friend support at age 12 predicted poorer glycemic control 9 years later. The latter finding may be surprising at first, but it is consistent with previous research on these same participants during adolescence in which friend support was linked to poor glycemic control [110]. It is also somewhat consistent with the finding reported in the previous paragraph in which larger support networks were linked to poorer diabetes control. One possibility for these unexpected relations of friend support to poor health outcomes is that more friend support or a larger network size is a marker of sociability or immersion in peer relationships, which subsequently detracts from self-care and glycemic control.

Thus, there are few studies in the area of peer relationships to draw firm conclusions about whether young adults with type 1 diabetes differ from their nondiabetes counterparts in the quantity or quality of peer relationships. The one study that examined peer conflict found no group differences, which is fortunate because problematic aspects of peer relationships are linked to an array of poor health outcomes. Although one study suggested peer support is related to fewer complications, other studies showed that more peer support is related to poor diabetes outcomes, a finding that is not unique to young adulthood but a topic that is worthy of future investigation.

5.3. Online Support

In addition to parent and peer support, many young adults find support for diabetes management in online communities. While some young adults may not have friends with type 1 diabetes in their immediate communities, it is often easier to find a diabetes "peer" online who can offer support, confirmation, and shared diabetes experiences [101]. Use of websites, discussion boards, blogs, and other online resources can augment support from family or friends and enhance engagement in diabetes care [30]. Young adults also use the internet to seek information and education about type 1 diabetes. A recent survey of 150 young adults with type 1 diabetes in Australia found that 81% of young adults consulted diabetes organization websites and 30% used online chat rooms and blogs for information and support related to diabetes management [111].

5.4. Romantic Relationships

Relationships that become prominent during young adulthood are romantic relationships. Marriage takes place during the latter phase of young adulthood, as the average age of marriage is 28.7 among men and 26.5 among women (Pew Research Center, 2011). Thus, young adulthood is a prime period of development to study the evolution and course of romantic relationships. However, there is a dearth of literature on the romantic relationships of young adults with type 1 diabetes. Little is known about how diabetes is communicated or the content of that communication in the context of romantic relationships. Young adults with diabetes may be concerned about how potential partners will react to their disease and the associated self-management behaviors. Young adults also have to decide how or if to involve their partner in the management of diabetes. Partners clearly need to know enough about diabetes to help with symptoms of hypoglycemic and hyperglycemia, but young adults may worry about burdening potential partners with these responsibilities.

First, we examine the mere existence of romantic relationships among young adults with type 1 diabetes. One study showed that young adults with type 1 diabetes were equally likely to have a romantic partner as those without diabetes [107]. However, those with diabetes reported less trust and less sense of friendship in their romantic relationships compared to peers, leading the authors to conclude that those with diabetes might be more cautious in romantic relationships. A focus group of 13 young adults with type 1 diabetes revealed that parents rather than romantic partners are still viewed as the guiding agents in regard to diabetes [101]. Young adults reported that romantic partners are viewed as concerned but not necessarily competent to assist with diabetes self-care.

Second, we examine the implications of romantic relationships for well-being among young adults with type 1 diabetes. In a recent study that examined support from and conflict with romantic partners one and two years after high school graduation, conflict with romantic partners predicted greater psychological distress for those with and without type 1 diabetes and greater disturbed eating behavior only for those with type 1 diabetes [108]. Conflict with romantic partners also predicted poor self-care behavior. By contrast, support from romantic partners revealed mixed relations to outcomes and was often moderated by whether the person had diabetes or not. For those with type 1 diabetes, romantic support was unrelated to life satisfaction and related to higher psychological distress and disturbed eating behavior. The authors concluded that those with diabetes were more adversely affected by romantic conflict and less able to take advantage of support from romantic partners compared to peers without diabetes.

Clearly, romantic relationships and their influence on the health and well-being of young adults with type 1 diabetes is an important avenue for future research. The importance of family relationships and peer relationships to children and adolescents with type 1 diabetes is well-established, but research on the potential future family relationships of young adults lags behind. Investigators should examine the role that romantic partners play in diabetes and identify ways in which romantic partners can impact diabetes self-care as well as overall psychological well-being. Some of these romantic relationships will evolve into stable family relationships that provide the relational context for adults with diabetes.

6. INTERVENTIONS FOR YOUNG ADULTS WITH TYPE 1 DIABETES

Few behavioral interventions for young adults with type 1 diabetes exist, and even fewer specifically target key developmental issues present during young adulthood such as assuming independent responsibility for diabetes care, promoting wellness and a healthy lifestyle, and reducing risky behaviors. Young adults have expressed a desire for developmentally appropriate education and services, particularly those targeting new technologies, managing physical activity, and providing diabetes re-education for those who were diagnosed at a very young age [111]. Some interventions for this age group take advantage of the pervasiveness of mobile technology among young adults. Louch and colleagues used text messaging to improve consistency with evening insulin administration among young adults with type 1 diabetes [112]. Huang and colleagues evaluated an intensive 2-month internet and text message-delivered intervention designed to promote disease management among 81 adolescents and young adults (ages 12-20) with chronic illness, including 34 participants with type 1 diabetes. Participants in the intervention group demonstrated increased disease self-efficacy, improved disease self-management skills, and more frequent patient-initiated contacts with health care providers as compared to participants in an education-only control group [113]. Another randomized clinical trial (RCT) evaluated the impact of real-time feedback and online graphical representation of blood glucose values with or without specific, structured contact with a diabetes specialist nurse. A1c decreased for both the intervention and control groups after the 9-month intervention, but a greater proportion of intervention than control participants reduced their A1c by $\geq$0.7% [114]. Enhancing peer support is another potential area for intervention. Markowitz and Laffel [84] recently piloted a peer support group for young adults with diabetes to problem-solve and provide support for dealing with diabetes specific stressors. Although not a controlled trial, young adults displayed improvements in glycemic control and diabetes distress across the course of the intervention.

As moving to adult medical care is a salient task that most young adults with diabetes face, transition programs and pathways have also been a focus of intervention research, though no rigorous randomized controlled trials (RCTs) exist [52, 115]. Van Walleghem and colleagues found increased attendance in adult medical care and decreased morbidity and mortality with the use of a comprehensive transition program that included a patient navigator, targeted education, and social activities for young adult patients with type 1 diabetes [52]. There is also a growing body of literature on promoting change at the health care system level by applying broad policies, such as the six core elements of health care transition detailed by Got Transition? [116]; however, these core elements have not been systematically evaluated in a type 1 diabetes population.

There is much work to be done in developing and evaluating interventions for young adults with type 1 diabetes. It is likely that successful interventions will incorporate many features of the interventions presented here, including technology, targeted education, and peer and parent support, with the goal of assisting young adults with being autonomous in a supportive context. However, it is premature to draw conclusions on effective components of intervention at this time, and a more robust knowledge base of risk and protective factors unique to this age group is needed. It is also important that interventions move beyond change at the health care system level and address the larger developmental context of young adulthood.

7. FUTURE DIRECTIONS

As reviewed in this article, young adulthood is a time of opportunity and risk for everyone and the demands of type 1 diabetes management may exacerbate risk during this developmental period. There remains a paucity of quantitative, developmentally-focused research with this key demographic. Much of the quantitative data discussed included young adults as part of a larger sample of adolescents or adults but failed to focus on the unique challenges of the targeted young adult period, here defined as ages 18-30. Research is often falsely dichotomized as “pediatric” or “adult” and very few studies have been able to follow a cohort of adolescents into young adulthood to evaluate changes over time. The few examples, such as the work by Helgeson and colleagues, have identified key adolescent precursors to health in young adulthood, such as parental involvement and peer conflict [102]. This research has also been able to systematically evaluate developmental milestones in young adults with and without type 1 diabetes, finding few differences in educational and occupational achievement [27].

Research on young adults with type 1 diabetes is scarce, in part, due to practical concerns, as this age group is highly mobile and can be difficult to recruit and retain in ongoing studies. Current research may overestimate functioning in this group, as researchers are often unable to identify or access the most at-risk young adults who may be temporarily disengaged from the medical care system or absorbed into general care instead of specialty endocrinology care. Longitudinal research tracking youth from adolescence into young adulthood is one way to access a more representative sample of young adults with type 1 diabetes. Greater attention should also be paid to novel ways to better engage young adults in the specialty health care system, including specialty clinics for young adults, greater communication during the health care transition process, and moving away from the standard outpatient model to include more flexible clinic times or increased use of technology.

It is critical to translate qualitative findings into developmentally-appropriate services for young adults. A number of studies have directly queried young adults on their specific needs, and this research can be utilized to develop and evaluate educational resources, clinical services, and interventions for this age group. For example, young adults express interest in harnessing new technologies for diabetes management and recognize the importance of including parents and significant others in supportive networks while also enhancing their autonomy. Future research should focus on rigorous trial designs, such as RCTs or other innovative designs, to systematically evaluate the impact of such interventions on young adult health and related outcomes.

8. CONCLUSION

Young adulthood represents a high risk period for type 1 diabetes management, and diabetes care behaviors during this developmental period have significant implications for long-term health and well-being. Descriptive and qualitative research are beginning to identify key factors that influence – and are influenced by – diabetes management during young adulthood but research has not yet advanced to translate these findings into innovative, developmentally-targeted programs and services for young adults with type 1 diabetes. There also remains a critical need to cast a wider net to reach young adults who may move away from traditional health care delivery systems. Evidence-based interventions and supports are needed to reduce the risk of long-term complications, facilitate incorporation of diabetes care into changing lifestyles, address psychosocial and health care needs, and promote healthy support systems among young adults with type 1 diabetes.

CONFLICT OF INTEREST

Authors have no conflicts of interest to declare. All three authors made substantial and meaningful contributions throughout the entire manuscript process, including conceptualization, writing, and editing of the manuscript.

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