

Health Care Experience of Young Adults Diagnosed With Type 1 Diabetes

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ABSTRACT

Young adulthood, defined as 17 to 25 years, is a critical period of development. For young adults newly diagnosed with type 1 diabetes, effective communication from a health care provider is critical. This qualitative study used an electronic interview questionnaire focused on health care professional interactions and course of diagnosis for 12 young adults in college who were diagnosed between ages 17 and 25 years. Three themes emerged: 1) a lack of health information specific for the young adult with type 1 diabetes, 2) emotional turbulence with forward thinking, and 3) needs/concerns of the group. Health care providers need to work to limit barriers in communication and provide a holistic plan of care.

Keywords: communication barriers, type 1 diabetes, young adults

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Young adulthood, defined as ages 18 to 26 years, is a critical period of development, with long-lasting implications for a person's health, well-being, and economic security.¹ Young adulthood is a time of transition and involves major individual changes in every domain of life. Most young adults experience multiple transitions during this unstable developmental period including changes in lifestyle (eg, education, occupation, and living situation); changes in health care; and shifting relationships with family members, friends, and intimate others.²⁻⁴ Additionally, behaviors during this developmental period, such as poor dietary patterns, inadequate sleep, and tobacco or drug use, may result in immediate or long-term consequences on health.⁵

For young adults recently diagnosed with type 1 diabetes (T1DM), not only do they need to navigate age-appropriate transitions but also navigate while assuming increasing responsibility for their diabetes care and overall health.⁴ Recent estimates suggest that up to 3 million youth and adults in the United States are living with type 1 diabetes.⁵ Of that number, young adults and adults represent 85% of the total population with T1DM.^{5,6} A large study by Dabelea et al⁷ of over 1,700 adolescents and young adults with T1DM diagnosed before the age of 20 (average age = 17.9 years) in the US found that 32% had evidence of at least 1 early diabetes-related

complication or comorbidity, including nephropathy, retinopathy, arterial stiffness, neuropathy, hypertension, and cardiovascular autonomic neuropathy.⁷ Multiple studies have shown that young adults with T1DM are at risk for gaps in medical care, premature mortality and morbidity, and poor health outcomes during and after the transition from pediatric to adult health care.^{5,8-11}

Therefore, it is important for the health care provider to teach young adults the importance of managing their care because recently diagnosed illness or disease can be avoided or managed better if they engage in wellness practices.^{1,3} Also, health care providers can have honest discussions with young adults regarding risk-taking behavior that is common during these years and how that behavior can impact lifelong functioning. Effective communication with this group is paramount.^{1,4} Young adulthood potentially represents a critical period of risk for those with T1DM because of independence coupled with exposure to new people and new environments.⁴ Only 17% of early young adults (ages 18-25) and 30% of late young adults (ages 26-30) with T1DM meet the current recommendations for glycemic control (ie, hemoglobin A1c \leq 7.5%).^{8,12} The provider needs to recognize, especially in young adults with a recent diagnosis of T1DM, the importance of education that

will increase young adults' confidence in their abilities to manage diabetes.⁴

It has also been suggested that for young adults with T1DM, greater attention should also be paid to novel ways to better engage them in the specialty health care system. The health care provider also needs to allow for opportunities for greater communication at every appointment, discussing the health care transition process in concert with college and career. The health care provider can engage the young adult outside the examination room with T1DM with social media supplement or streamline the care provided.³ Also, for this tech-savvy population, greater educational resources directed specifically at the young adult need to be available online. Additionally, moving away from the standard outpatient model to include online scheduling with more flexible clinic times is appealing to this young population.⁴

Monaghan et al⁴ pointed to the need for greater descriptive and qualitative research to not only identify key factors that influence diabetes management during young adulthood but also research to translate these findings into innovative, developmentally targeted programs and services for young adults with T1DM. Given how little is known regarding newly diagnosed young adults, we propose that in order to develop those innovative, age-specific interventions, it is important to understand how those with T1DM perceive their providers' communication and success with navigation of the health care system. The purpose of this research study was to explore the health care experiences of young adults diagnosed with T1DM between 17 and 25 years of age.

METHODS

Design

This qualitative research design used an electronic interview questionnaire that included both closed and open-ended questions. The interview questions focused on health care professional interactions and the course of diagnosis for young adults in college who were diagnosed between 17 and 25 years of age. The University of Delaware Institutional Review Board approved this qualitative research study.

Participants

A purposeful sample of 12 participants was recruited from the College Diabetes Network (CDN) weekend retreat for this specific age group. CDN is a 501c3 non-profit organization whose mission is to provide innovative peer based programs which connect and empower students and young professionals to thrive with diabetes. The inclusion criteria were as follows: male and female, all races/ethnicities, T1DM diagnosis between 17 and 25 years old and currently ≥ 18 years old, enrolled in college or a recent graduate within the last year, able to read and write English, and have Internet access. The participants attended universities/colleges across the country in every region except for states in the Southwest region. Participants received a \$15 electronic Amazon gift card for their study participation. The researchers recruited both male and female participants.

Procedures

Enrollment. CDN staff e-mailed potential participants in February 2017 who were attending the upcoming retreat weekend, informing them of this study opportunity. The primary researcher, who is not on the CDN staff, met with potential research participants during the retreat to explain the study and review the informed consent. Informed consent was obtained before enrollment in the study, and participants were made aware that participation in this study was voluntary and would not change any relationships with the CDN.

Data Collection

Researchers created the interview questionnaire based on the current literature and input from an advisory committee comprised of a sophomore college student diagnosed 17 weeks before college, a senior college student diagnosed at age 10, an adult/pediatric nurse practitioner, and 2 CDN staff members. The interview questionnaire included both open-ended (Table) and closed-ended questions to capture not only the lived experience but also demographics and variables of interest. The researchers used Research Electronic Data Capture (REDCap) to create the questionnaire. REDCap (Vanderbilt University, Nashville, Tenn) is a secure

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